



Opinion of adults escorting children on an outpatient chemotherapy service about a “Chemo-teca” in a municipality of Sao Paulo*

Opinião de acompanhantes de crianças em quimioterapia ambulatorial sobre uma quimioteca no Município de São Paulo

Opinión de acompañantes de niños sometidos a quimioterapia en ambulatorio sobre una quimioteca en el municipio de Sao Paulo

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ABSTRACT

Objective: To know the opinion of adults escorting children, from 2 to 12 years, undergoing chemotherapy about the Orsa Foundation “Chemo-teca”. **Methods:** This is a descriptive quantitative study. Were conducted semi-structured interviews with 54 children’s escorting companions during an outpatient chemotherapy treatment. **Results:** In the opinion of those escorting companions, the colorful environment, the toys and the leisure activities, offered during the administration of chemotherapy, has positive influence on the quality of treatment and the state of child welfare. Despite the very positive evaluation of the service, were mentioned areas requiring improvement, particularly in relation to the attention care. **Conclusion:** The companions escorting the children perceived that the happy environment collaborated on the wellbeing of children in treatment. The “Chemo-teca” is an innovative experience that can serve as an example for the development of creative technologies to care for children with cancer and their families, contributing to the improvement of care assistance to this clientele. **Keywords:** Child; Humanization of Assistance; Drug therapy; Play and Playthings

RESUMO

Objetivo: Conhecer a opinião dos acompanhantes de crianças de 2 a 12 anos de idade em tratamento quimioterápico sobre a Quimioteca Fundação Orsa. **Métodos:** Trata-se de um estudo quantitativo descritivo. Realizaram-se entrevistas semi-estruturadas com 54 acompanhantes de crianças em tratamento quimioterápico ambulatorial. **Resultados:** Na opinião desses acompanhantes, o ambiente colorido e cheio de brinquedos e a oferta de atividades lúdicas, durante a administração de quimioterápicos, têm influência positiva na qualidade do tratamento e no estado de bem-estar da criança. Apesar da avaliação extremamente positiva sobre o serviço, foram apontados aspectos que necessitam ser aprimorados, principalmente em relação ao atendimento. **Conclusão:** Os acompanhantes percebiam que o ambiente e o brincar colaboravam no bem estar das crianças em tratamento. A Quimioteca é uma experiência inovadora que pode servir de exemplo para o desenvolvimento de tecnologias criativas de cuidado às crianças com câncer e suas famílias, contribuindo para a melhoria da assistência a essa clientela. **Descritores:** Criança; Humanização da assistência; Quimioterapia; Jogos e Brinquedos

RESUMEN

Objetivo: Conocer la opinión, de los acompañantes de niños de 2 a 12 años de edad sometidos a tratamiento de quimioterapia, sobre la Quimioteca Fundación Orsa. **Métodos:** Se trata de un estudio cuantitativo descriptivo. Se realizaron entrevistas semi-estructuradas con 54 acompañantes de niños en tratamiento de quimioterapia en ambulatorio. **Resultados:** En la opinión de esos acompañantes, el ambiente colorido lleno de juguetes y la oferta de actividades lúdicas, durante la administración de la quimioterapia, tiene influencia positiva en la calidad del tratamiento y en el estado de bienestar del niño. A pesar de la evaluación muy positiva sobre el servicio, fueron apuntados aspectos que necesitan ser mejorados, principalmente en relación a la atención. **Conclusión:** Los acompañantes percibían que el ambiente y el jugar colaboraban en el bienestar de los niños en tratamiento. La Quimioteca es una experiencia innovadora que puede servir de ejemplo para el desarrollo de tecnologías creativas de cuidado a niños con cáncer y a sus familias, contribuyendo para la mejoría de la asistencia a esa clientela. **Descritores:** Niño; Humanización de la atención; Quimioterapia; Juego e Implementos de juego

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INTRODUCTION

In 2004, the Ministry of Health put in practice the National Humanization Policy (PNH in Portuguese) of the Unique Health System (SUS in Portuguese), as the cross shaft to consolidate health care in Brazil. Among its premises, humanization is highlighted as a practice that should value different participants in the system – users, workers and managers – and the various component dimensions of health practices – subjective, cultural, social and clinical⁽¹⁾. It also emphasizes the need to guarantee comprehensive care to the population, through strategies that broaden the exercise of individual and group rights.

The PNH departs from a principle aimed at the reorganization of health work processes, through transformations in the social relations between workers and managers in service organization and management, as well as transformations in the ways services are produced and delivered to the population. Another issue is that it aims to provoke transformations in the interaction that is to be established between professionals and users⁽²⁾.

A humanized practice represents a set of initiatives that permit health care delivery capable of joining the best technology available with welcoming and ethical and cultural respect for the people receiving care, as well as work environments that favor good technical practice and workers and user satisfaction⁽³⁾. In this sense, care humanization projects like Humanized Care for Low Birth Weight Infants – Kangaroo Care Method, Humanization of Prenatal Care, Delivery and Birth, Baby-Friendly Hospital Initiative, among others, are marked by actions aimed at turning hospitalization or outpatient care experiences less painful, stressing or traumatic, such as free visiting hours, the presence of companions, physical improvements in care and hospitalization areas, professionals' accountability and bonding with users and play activities, including the idealization of playrooms⁽³⁻⁶⁾.

Specifically with regard to care delivery to sick children who are hospitalized or receive outpatient care, one of the countless ways to humanize this care is by promoting and offering something any child likes, does and needs to do, which is playing. Literature strongly emphasizes the importance of playing for children's intellectual and social development and to help them deal with the disease, hospitalization and pain⁽⁷⁻¹⁰⁾. According to some authors⁽¹¹⁾, when children play in hospital, the environment changes and gets closer to their daily reality, entailing positive effects for hospitalization. This turns playing into a viable and adequate resource for children to face their condition. These authors also underline that "free and disinterest recreation entails a therapeutic effect, with therapeutic being considered everything that helps to promote the child's wellbeing". Indirectly, playing also influences the sick child's parents as, by watching the child play, they may feel less anguished and more confident in treatment, as play represent a sign of health, mainly in the parents' perspective⁽¹²⁾.

During chemotherapy, including games and play is also indicated as a part of health care delivery to sick children, aimed at

making them relax and permitting some control over the situation they need to cope with, as hospitalized children with cancer also want and need to play⁽¹¹⁾. In this perspective, a new outpatient chemotherapy treatment proposal was elaborated for children and adolescents, through a partnership between the Federal University of São Paulo, the Support Groups for Adolescents and Children with Cancer, companies, foundations and the community for putting in practice the Pediatric Oncology Institute in São Paulo City, whose pediatric oncology outpatient clinic is also called *Quimioteca Fundação Orsa*.

With the main goal of humanizing chemotherapy treatment, the *Quimioteca Fundação Orsa* was restructured based on a creative architectural project, in combination with the use of pedagogical and play-therapeutic strategies to help children, adolescents and their relatives face the discomfort of this treatment.

Based on the premise that more humanized health care demands the incorporation of new practices and re-adaptation of health service routines, the researchers attempted to explore the reformulation carried out at *Quimioteca Fundação Orsa* from the perspective of the subjects/actors in this process, in this case the parents or companions of children undergoing chemotherapy treatment. Hence, the research objective was to get to know the opinion about *Quimioteca Fundação Orsa* among companions of children between 2 and 12 years of age undergoing chemotherapy treatment.

METHODS

A descriptive and quantitative research was carried out at *Quimioteca Fundação Orsa*, which is part of the Pediatric Oncology Institute (IOP in Portuguese), a philanthropic non-for-profit institution inaugurated in 1998. It is located in the state capital of São Paulo, in a construction of 4,200 m², with nine floors and two basements; care is delivered to children and adolescents with cancer from São Paulo City, neighboring cities and other states.

The *Quimioteca* itself occupies 300 m² on the second floor of the IOP. It comprises 28 chemotherapy places, procedure room, test collection, nursing station, kitchen, cleanroom and four bathrooms. On the average, 785 chemotherapy sessions are performed per month. Its physical space was totally reformed, turning it into a welcoming and colored area, full of toys, games, books and cd-players.

Games and play activities are offered in the same place where the children are receiving the medication, respecting their interests, possibilities, limitations and availability. Play activities involve a pedagogue, trained volunteers and partners from other NGOs that develop planned activities, including a matchstick workshop, storytelling, music, origami, balloons, visual arts, jokes with clowns, games, toys and different books. The experience of setting up this chemotherapy playroom has been described earlier⁽¹³⁾.

To select the participants, the following inclusion criteria were established: companions of children undergoing chemotherapy

on the day of the research; companions present at the IOP the whole day and not just half a day; companions aged 18 or older; companions responsible for children older than two years and undergoing chemotherapy at the IOP for more than one month, due to the fact that they interact more with the environment and have already adapted to the *Quimioteca's* routine.

Data were collected on January 2nd – 31st 2006, on Tuesdays and Thursdays, during the entire day. All companions present on those days were invited to participate, within the established criteria. Companions of children who were present to collect tests and undergo other procedures only were not invited to participate in the research. Nobody refused to participate.

A pretested and semistructured questionnaire was used to interview 54 companions. The closed questions first addressed the children and their companions' sociodemographic characteristics and, next, the companions' opinions about the influence of the physical environment and play on treatment quality, on the decrease in the child's stress, on the child's feeling of rejection with regard to treatment and on the child's wellbeing. The following alternative answers were permitted: "nothing", "little", "average" or "a lot". With regard to the open questions, the companions were asked about what they would change in the play activities, physical environment and professional care offered at the *Quimioteca*.

While the children received the chemotherapy, the companions were invited to participate in the study voluntarily, after receiving explanations about the research goals and question contents. If they accepted, the Free and Informed Consent Term was read and, after clarifying doubts, the questionnaire was read to the parents of the children who had agreed to take part in the research. The estimated duration of each interview was between 10 and 15 minutes.

Guidelines for research involving human beings were fully complied with. Approval for the project was obtained from the Research Ethics Committee at the University of São Paulo School of Public Health in 2005 (Protocol No 1368), and the IOP authorized the accomplishment of the research. Data were processed and analyzed in Epiinfo 6.0 software, and results are

described as absolute figures and proportions. Answers to open questions were joined in categories that were further elaborated and quantified.

RESULTS

The mean age of the 54 companions of children undergoing chemotherapy was 31.4 years (sd=7.5) and they were predominantly female (92.6%). Mothers were a majority (49), but four fathers and one aunt were also interviewed. Education levels were quite diverse, ranging from unfinished primary (23) to higher education (5). Practically half came from São Paulo City (53.7%) or the Metropolitan Region of São Paulo (18.5%), while six (11.1%) came from the interior of São Paulo State and nine (16.7%) from other States.

The children's mean age was 6.2 years (sd=2.9) and 36 (66.7%) were male. Little more than half of the children (59.3%) were coming to the *Quimioteca* for less than one year and 15.1% for more than two years.

The companions' opinion about the influence of the play activities offered to the children and the colored physical environment full of toys revealed that these aspects exert a positive influence on the quality of the treatment and on the child's wellbeing during chemotherapy, to a greater or lesser extent, considering the children's discomfort and their rejection of treatment, as shown in Table 1.

Table 1 also demonstrates that many interviewees reported that they found it very important to have a specific professional to play with the children.

Through a specific question, the interviewees were stimulated to report on how the colored physical environment and the offering of play activities facilitated the children's chemotherapy treatment. Table 2 shows that these aspects mainly contribute for the children to forget the pain and hospitalization, to encourage treatment and to make time go by faster. Only one mother had not observed any kind of positive contribution to treatment, probably, according to her, because her daughter was still at the start of treatment.

Table 1 – Companions' distribution according to their opinion about the influence of the physical environment at *Quimioteca Fundação Orsa*. São Paulo, 2006.

Opinion	Little or nothing		Average		A lot	
	N	%	N	%	N	%
The environment influences the quality of treatment.	6	11.1	5	9.3	43	79.6
Play activities influence the quality of treatment.	-	-	4	7.4	40	92.6
Play activities decrease the child's stress.	1	1.9	10	18.5	43	79.6
Play activities decrease the child's discomfort.	9	16.7	14	25.9	31	57.4
Play activities contribute to make time go by faster.	2	3.8	8	14.8	44	81.5
Play activities decrease the child's rejection to come and do the chemotherapy.	11	20.4	15	27.8	28	51.9
Playing helps the child to feel better during the chemotherapy.	1	1.9	9	16.7	44	81.5
The colored space with toys contributes to make the environment more pleasant.	1	1.9	5	9.3	48	88.9
The colored space with toys helps in wellbeing itself.	7	13.0	11	20.4	36	66.7
It is important to have a specific professional to play with the child.	-	-	4	7.4	50	92.6
The colored space with toys facilitates treatment.	-	-	10	18.5	44	81.5

The interviewees were also stimulated to indicate aspects they would modify at the *Quimioteca*, related to the play activities offered (Table 3) and the physical environment (Table 4). The majority considered there was nothing to be modified or improved, but the need was mentioned to increase the number and frequency of play activities and to decrease noise at the *Quimioteca*.

Although more than half of the companions mentioned there was nothing to be improved in care at the *Quimioteca*, some suggestions were made to speed up care, increase the number of employees, improve the relationship with users and advise companions adequately, without contradictions. It was also suggested to offer lunch instead of snacks to those staying at the *Quimioteca* all day for treatment, mainly when coming from other cities.

Table 2 – Distribution of companions according to their opinion about how the colored environment with toys facilitates treatment. São Paulo, 2006.

Opinion	N	%
Distracts: forgets the procedure and the hospital.	27	50.0
Influences the child's mood: calms down, tranquilizes, stops crying, makes happy, decreases stress, enjoys.	20	37.0
Mitigates suffering: forgets the pain and the disease.	9	16.7
Time goes by faster: occupies the child.	8	14.8
Works as a treatment stimulus: the child likes to go to the <i>Quimioteca</i> .	6	11.1
Is different from a hospital: the environment is not happy, as it is adapted to children.	6	11.1
Accepts the treatment.	2	3.7
Occupies the child.	2	3.7
Decreases the child's fear.	2	3.7

Table 3 – Companions' suggestions about what they would change in the play activities offered at *Quimioteca Fundação Orsa*. São Paulo, 2006.

Suggestions for changes in play activities	N	%
None	36	66.7
Increase in quantity and frequency of activities	9	16.7
Diversification of activities through new games, videogame, cable TV and educative activities	8	14.8
Play more music	2	3.7

Table 4 - Companions' suggestions about what they would change in the physical environment at *Quimioteca Fundação Orsa*. São Paulo, 2006.

Suggestions for changes in physical environment	N	%
None	42	77.8
Increase space	5	9.3
Offer more comfortable chairs to companions	5	9.3
Decrease noise	2	3.7
Decrease flow of people not undergoing chemotherapy	1	1.9
Remove test collection room from the <i>Quimioteca</i>	1	1.9

The ten companions who knew and came to the chemotherapy outpatient clinic before the current reform were asked to score (from 1 to 10) the *Quimioteca* before and after the reform. The mean score was 5.4. for the clinic before the reform and 10.0 afterwards.

DISCUSSION

Playing can help children to expand their relations with the outside world, establishing a connection between their own and the hospital world⁽⁴⁾. While playing, the children transform the environment they are inserted in, positively facing the situation experienced at that time. Brazilian and international literature^(4,14-19) has already demonstrated different experiences that used playing during hospitalization and outpatient treatment, with results that valued the children's development process and wellbeing. In that sense, this research collaborates with findings in this research area, valuing the play resource in a new hospital space, which is the *Quimioteca*.

The *Quimioteca Fundação Orsa* mixes recreation, usually developed in playrooms and waiting rooms, in children's chemotherapy room. The positive results of this research demonstrate that this innovative experience responds to the guidelines of the SUS⁽¹⁾ National Humanization Policy and, thus, can serve as an example for other hospitals.

According to the companions, the play activities, the physical environment adequate for the child world and the availability of toys at the *Quimioteca* positively influenced the quality of the treatment offered and on the wellbeing of the children with cancer during chemotherapy. In the interviewees' opinions, these aspects mainly collaborated to forget the pain and hospitalization, to encourage treatment and to support the time they stayed at the *Quimioteca*. These results are in line with literature^(4,11,15,20).

Although most of these findings were positive, negative assessments were also observed. Some companions' reports revealed little or no effect of the play activities on the children's discomfort or rejection to undergo chemotherapy. These reports may demonstrate that playing can serve as a great facilitator during chemotherapy treatment, but that the discomfort experienced may be intense and demand other resources for relief. This may be the case mainly for children who started treatment recently, an opinion shared by one of the interviewed mothers.

With a view to improving current activities, the interviewees were also stimulated to share their viewpoints about changes to be made at the *Quimioteca*. A large majority mentioned there was nothing to modify or improve, but some considerations were made about the need to increase the quantity and frequency of the play activities, as well as to offer more comfort to the companions themselves and to decrease noise. These aspects demonstrate that attention should be paid for the activities to comply with their role of humanizing the environment and treatment, so that the physical and emotional exhaustion the children and companions experience can be mitigated and do not interfere in their willingness, as observed earlier⁽⁴⁾.

Many users travel a lot to reach the *Quimioteca* and wait long to start and/or finish the treatment. Hence, as some interviews revealed, initiatives like providing lunch instead of snacks to those who stay for treatment all day and more comfortable seats can collaborate with the humanization of care delivery, which should not only focus on the patient undergoing treatment, but also on companions, generally the parents, as the disease and the long treatment potentially cause exhaustion for the entire family group⁽²¹⁾.

Other considerations referred to improvements in professionals' care, showing that changes are needed not only in the physical structure, but also in the relations and interactions between workers and users. Nevertheless, the score attributed by companions who knew and came to the chemotherapy clinic before and after the reform shows how important and influential the transformation in the environment and the play activities were for the companions.

Playing in this new space, the *Quimioteca*, could offer the sick children moments of joy and wellbeing during treatment, making them and their companions feel more cheerful and encouraged to continue fighting against cancer. Through play, the context surrounding the children can be transformed, offering them an opportunity for comprehensive development. This kind of

initiatives should be increasingly structured and put in practice in different hospitalization contexts. In addition, knowledge production about the role of playing in the daily reality of children undergoing outpatient treatment is essential, as it can offer scientific support to encourage people directly involved with these children to practice this behavior and provide an environment in which playing occurs in a more enriching way⁽²²⁾.

At the *Quimioteca*, the play activities and the colored and beautiful environment are part of the children's daily reality and, moreover, show that chemotherapy treatment can be joined with games and other activities typical of childhood.

CONCLUSION

The positive and innovative experience of the *Quimioteca Fundação Orsa*, in which children with cancer are stimulated to play during their outpatient chemotherapy treatment, can serve as an example and stimulus to construct new creative strategies in care delivery to children with cancer, their relatives and companions. Moreover, offering this group a space to promote wellbeing contributes to a comprehensive approach in childcare, emphasizing care humanization.

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