Occupational therapy and pediatric oncology: characterization of professionals from reference health centers in the State of São Paulo

Terapia ocupacional e oncologia pediátrica: caracterização dos profissionais em centros de referência no Estado de São Paulo

Regina Helena Vitale Torkomian Joaquim[1], Fernanda Brioschi Soares[2], Mirela de Oliveira Figueiredo[3], Cristiane Miryam Drumond de Brito[4]

ORIGINAL ARTICLE

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ABSTRACT: Occupational therapists help patients and their families to confront and understand the body and psychic process that children may go through when they receive the diagnosis of cancer. In daily life, it aims to improve the quality of the life of children through rehabilitation, prevention of sequelae, maintenance of activities inherent to the age group, in addition to providing the (re)discovery of abilities and skills. This study aimed to characterize the occupational therapists who work with pediatric oncology in the state of São Paulo in Brazil. This is a cross-sectional descriptive research with quantitative-qualitative approach. The sample consisted of 11 professionals who work at oncology institutions. Data collection occurred via Internet, through a semi-structured questionnaire with closed and open questions about the professional's training and practice. The professionals who took part in the research were all female, with prevalent age range from 25 to 35, and graduation conclusion with the highest prevalence was between 1980 and 2008. The predominant occupational therapy approach of these professionals was based on Dynamic Occupational Therapy. The interventions of the professionals preconize multi-professional work, use toy libraries as places of intervention and work with a number of different materials in different types of activities. The number of occupational therapists has been reduced, although there are 101 institutions offering oncological treatment. The type of action described by the occupational therapists responds to precepts of the health policy in integral and expanded care.

KEYWORDS: Medical oncology; Neoplasms; Child, Occupational therapy.

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RESUMO: O terapeuta ocupacional auxilia o paciente e a família a enfrentar e compreender o processo corporal e psíquico que a criança poderá passar a partir do momento que recebe o diagnóstico do câncer. No dia a dia visa melhorar a qualidade de vida da criança por meio de reabilitação, prevenção de sequelas, manutenção das atividades inerentes a faixa etária, além de proporcionar a (re) descoberta de capacidades e habilidades. O presente estudo teve por objetivo caracterizar os terapeutas ocupacionais que atuam na oncologia pediátrica do Estado de São Paulo. Trata-se de uma pesquisa descritiva, transversal e com abordagem quanti-qualitativa. A amostra se constituiu por 11 profissionais que atuam em instituições oncológicas. A coleta de dados ocorreu via *internet*, por questionário semiestruturado com questões fechadas e abertas sobre a formação e prática do profissional. Os profissionais participantes da pesquisa foram todos do sexo feminino, a faixa etária prevalente foi dos 25 aos 35 anos e a conclusão da graduação com maior incidência foi nos anos de 1980 e 2008. A abordagem terapêutica ocupacional predominante entre os profissionais teve como base o referencial da Terapia Ocupacional Dinâmica. As intervenções dos profissionais preconizam o trabalho multiprofissional, utilizam as brinquedotecas como local de intervenção e trabalham com uma diversidade de materiais em diferentes tipos de atividades. O quantitativo de terapeutas ocupacionais foi reduzido apesar de existirem 101 instituições que oferecem o tratamento oncológico. O tipo de atuação descrita pelos terapeutas ocupacionais denota responder aos preceitos da política de saúde no cuidado integral e ampliado.

DESCRITORES: Oncologia; Neoplasias; Criança; Terapia ocupacional.

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1. Lecturer in the Department of Occupational Therapy, Graduate Program in Occupational Therapy and Graduate Program in Clinical Management, Universidade Federal de São Carlos. Email: joaquimrhvt@gmail.com.
2. Undergraduate degree in Occupational Therapy by Universidade Federal de São Carlos. Graduate degree in Occupational Therapy applied to Neurology by Hospital Israelita Albert Einstein. Multi-professional Resident in Emergency Health and Trauma at PUC – Pontífica Universidade Católica, Campinas, SP. Email: fernandabris@yahoo.com.br.
3. Lecturer in the Department of Occupational Therapy, Universidade Federal de São Carlos. Email: mirelafigueiredo@gmail.com.
4. Lecturer in the Department of Occupational Therapy, Universidade Federal de São Carlos. Email: cdrumonddebrito@gmail.com.

Corresponding address: Departamento de Terapia Ocupacional, UFSCar. Rod. Washington Luís, Km 235 - SP-310. São Carlos, SP. CEP: 13565-905.

INTRODUCTION

Child cancer, which affects children and teenagers aged from 0 to 18, is considered a rare disease that occurs in 1 to 3% of most populations. In developing countries, death by neoplasia occurs in about 1% of cases. The main types of cancer in children are leukemia, tumors of the central nervous system and lymphomas[1]. Expectations for treatment and cure are 70% when diagnosed early. Clinical treatment includes surgery, chemotherapy and radiotherapy, and some side effects may arise according to the treatment adopted[2].

During childhood, hospitalization has a negative impact, because children are separated from family, friends and school, which almost always happens suddenly. In this situation, children lose their affective and social references, have to deal with stress, fear, insecurity and traumas, in addition to going through painful and invasive treatments such as chemotherapy, radiotherapy and surgeries[3].

Childhood is an extreme important period for human development regarding physical, motor, social, psychological and emotional aspects. In addition, human growth depends on biological maturation associated with stimulation provided by the environment since the early years of life[4]. It is essential that the treatment of children and teenagers with cancer occurs with the help of a multi-professional team based on interdisciplinarity, being the occupational therapist one of the members of this team[5].

An occupational therapist is able to analyze and evaluate child development and has a fundamental role in interventions with children in the hospital context[6]. The objectives of these interventions with children with cancer are to maintain, stimulate and rehabilitate components of occupational, sensory-motor, cognitive and psychosocial performances, preventing disability and promoting the functionality of children. These interventions also preconize the use of strategies to decrease pain, conserve energy, prevent disabilities and deformities and adapt to changes brought by the illness in daily life, leisure and instrumental basic activities, thus avoiding situations of disability. With the children, their family and a multi-professional team, the occupational therapist aims to help in the confrontation of the disease, to overcome possible complications, to help with the grief experienced by patients and their families as a result of various losses inherent to the disease and the treatment. This professional also aims to recover the self-esteem and emotional balance of the patient, in addition to guide and support families and caregivers[5].

Playful and creative activities at this stage of development are used in occupational therapeutic interventions, since they are resources that promote the continuity of global development, the mental health of children at the hospital, the reorganization of daily life, the expression of pain, sadness or desolation and favors the bond between patient, therapist and family[7]. This professional also indicates accessibility devices such as wheelchairs, walkers, bath chairs and offers training to patients on how to use them. In addition, they also manufacture or indicate adjustments to objects used in daily life to compensate for limitations that can be caused by the treatment or by the disease itself[8-9].

Together with other professionals of the team, the occupational therapist works with the patient's family, because once the child's diagnosis happens and treatment starts, the family dynamics suffers disorganization in their routine and daily life. Thus, as part of inter-professional and multi-professional actions in the context of pediatric oncology, the occupational therapist can: offer guidance to the family so they feel safer regarding treatment procedures; optimize support networks and their communication; offer a space for thinking through individual follow-up or in groups with mothers and caregivers; offer exchanges and qualified listening; receive demands; recover significant activities and when necessary, carry out the arrival of death and after-death follow-up[3].

Current discussions about treatment and health care, in order to respond beyond the doctor-centered view regarding the cure of the disease, require interventions based on integrality. The consolidation of the Unified Health System (SUS) has been allowing the construction of new paradigms about the health-disease process, with repercussions on the organization of health services, on health promotion concepts and on the prevention of diseases and treatment. Therefore, integrality in health care is one of the fundamental principles of the SUS and guides policies and programmatic actions that respond to demands and needs of the population in the access to the health care network, considering complexity and particularities of different approaches of the health-disease process as well as the biological, cultural and social dimensions of the assisted individual[10].

In this sense, occupational therapy aims to meet the needs of the complex and singular current life,

in its different paths. It aims to offer integral care to individuals considering life contexts and their material and subjective relations. This knowledge field acts as part of the team and aims to respond to the concept of integrality defended by Mattos[11], which is built on the praxis of professionals of health services and in the different ways of meeting of these professionals with the service and in the service.

This research aimed to characterize the profile of occupational therapists inserted in the context of pediatric oncology health care. This profile was characterized regarding demographic and educational characteristics of each professional, therefore, age, education time, among other aspects, as well as regarding theoretical references and/or approaches they use in their care practices with families and patients, also considering their insertion in multi-professional teams in the hospitalization health units.

METHODOLOGY

This is a descriptive and cross-sectional study[12] with quantitative and qualitative approach[13].

We studied eleven occupational therapists who work in the pediatric oncology context in the state of São Paulo in Brazil. Identification of these professionals happened through the listing of institutions aimed at cancer treatment available at the Brazilian Lymphoma and Leukemia Association (ABRALE), the Brazilian National Cancer Institute (INCA) and institutions referred by both, at the end of 2012 and early 2013.

This investigation adopted the following inclusion criteria: occupational therapists must work in institutions aimed at the treatment of cancer of children and young people; have online access to the internet in order to receive the questionnaire; agree and sign the informed consent form.

Procedures and instrument for collecting

Data collection occurred under approval of the Human Research Ethics Committee of the Universidade Federal de São Carlos, under the protocol number 231/2012.

After identification and contact with participants, an invitation for participation was sent by e-mail, which contained a link that directed to the research tool. This tool consisted of an online, semi-structured and self-applied questionnaire prepared by the researchers along with the Junior Company of Statistics of the Universidade Federal de São Carlos.

The questionnaire consisted of 60 closed questions, prefixed by the researcher and that required affirmative, negative and/or quantitative responses referring to sociodemographic data of the occupational therapists (age, sex, year of graduation, type of educational institution, postgraduate attendance, position in the institution);profile of activity (types of practices, theoretical references adopted, materials and spaces used, individual or group care, with patient and family, action as a team, average number and duration of sessions held weekly in the institution); characterization of patients assisted by these professionals (age, sex, type of cancer). Besides closed questions, the questionnaire also included two open questions in which respondents had the possibility to talk about actions developed along with other professionals and describe a service that marked their professional careers.

The answers of closed questions were analyzed through simple statistical analysis of frequency and mean, and results were presented in the form of graphs and charts[12]. Answers to open questions were analyzed qualitatively through a categorical analysis technique with emphasis on cores of thematic meaning which presence or frequency of appearing provided responses to the research analytical objective. In addition, excerpts of speeches of the participants were presented to illustrate experiences in the work field[13].

RESULTS

In the listing of institutions aimed at cancer treatment, 25 occupational therapists were found in the pediatric oncology area of the state of São Paulo. These professionals were linked to 17 out of 101 institutions initially identified. However, from the 25 professionals listed, only 11 occupational therapists, all female, participated in the research by answering the collecting tool and forming the sample of this study, which had the following characteristics listed on Table 1.

Scope of practice of occupational therapists in panoramic terms was delimited through their theoretical references, methods of occupational therapy care and types of services. These data are described on Tables 2 and 3.

We highlight that one of the participants work in the three types of services aforementioned.

In relation to the profile of the population assisted, seven participants said that they assist an equivalent number of children of both sexes. The remaining ones (n=4) did not know how to respond whether there was a prevalence of genders in the assisted population.

Table 1 – Sociodemographic characteristics of the participants of the research

Age group	n	Year of graduation	n	Graduation institution	n	Postgraduate course	n
		1980	2				
		1998	1				
		2000	1			Doctoral degree	1
25 a 35 anos	7	2002	1	Public	3	Master's degree	3
35 a 45 anos	2	2004	1	Private	8	Graduate specialization	3
45 a 55 anos	2	2006	1			Refresher course	8
		2008	3				
		2011	1				

Table 2 – Location of postgraduate course and theoretical reference used

		Theoretical reference(s) used					
		Hospital occupational therapy	Theories of child development	Sensory integration	Dynamic occupational therapy method	Did not answer; did not specify	Total
Graduate specialization institution	FMRP-USP	1	1	1	0	0	3
	CETO	0	0	0	4	0	4
	Faculdade Salesianas – Lins, SP	0	0	0	0	1	1
	FCMSCSP	0	0	0	0	1	1
	USP	0	0	0	1	1	2
	Total	1	1	1	5	3	11

Table 3 – Level of care/ Types of services /Theoretical references and therapeutic approaches

Level of care/types of service	n	Theoretical references and therapeutic approach	n
Tertiary health care service (general, presurgical, postsurgical)	8	Dynamic Occupational Therapy Method (DOTM) with training in the Center of Studies in Occupational Therapy (CETO)*	4
		Sensory integration	1
Secondary health care service (outpatient clinic, home visit)	2	Hospital occupational therapy	1
Group homes	3	Did not specify	3

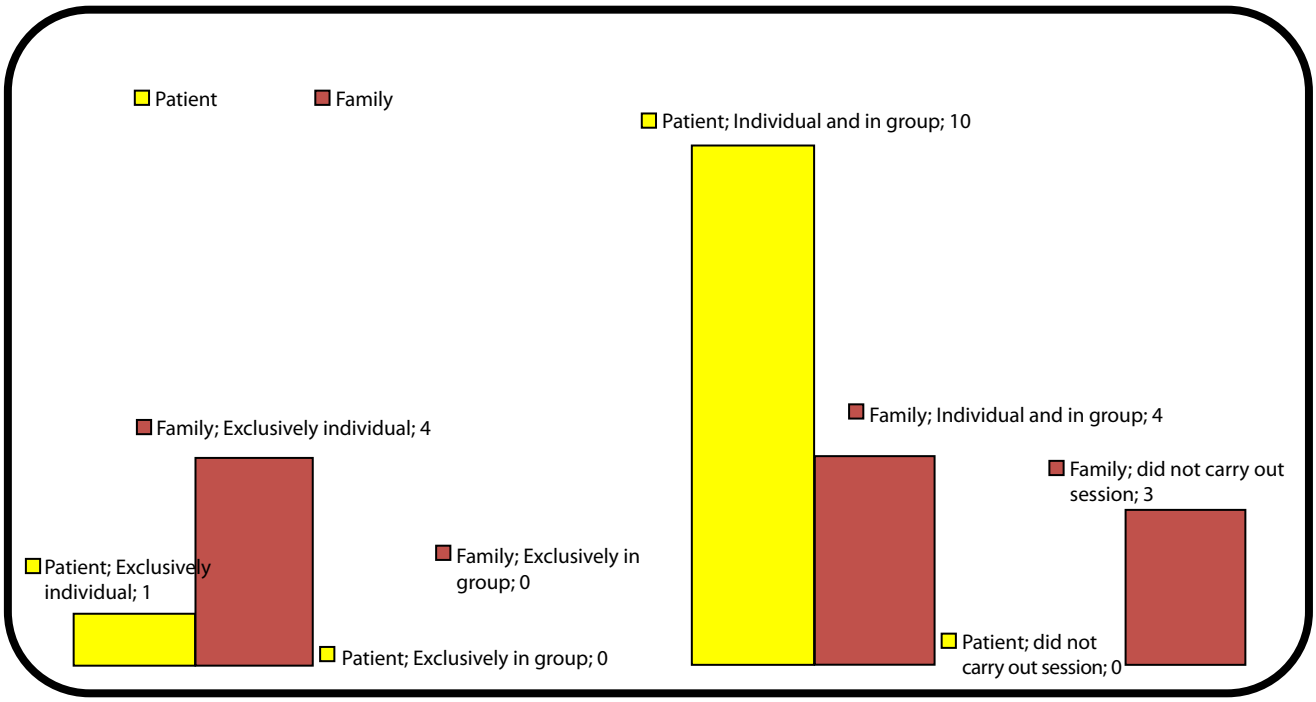
Caption: *CETO and DOTM were founded by Benetton, and DOTM constitutes a method of assistance in occupational therapy based on two fundamental presuppositions. The first is that practice is always an investigation process and the second is that the proposition of using activities as a therapeutic project is clearly presented through theoretical and technical presuppositions to base this use. More information can be found on the website CETO http://www.ceto.pro.br/atividades/index.php/inicio.

The population assisted was the 1 to 15 age group. Seven participants reported to assist the population under 1 year old; nine participants assisted the 1 to 4 age group; nine mentioned that they assisted the 5 to 9 age group; nine reported that they assisted the 10 to 15 age group.

The diagnostics of the users of services where the participants of the research worked were: leukemia (81.82%), lymphomas (63.64%) and tumors of the central nervous system (27.27%). Other diagnoses mentioned were: osteosarcoma, Ewing's sarcoma, retinoblastoma, neuroblastoma, liver, kidney, muscles, testicles and ovaries cancers, and bone marrow transplant.

Regarding the type of care, we verified that both the individual and the group care are performed with children and teenager clients and their respective families, as demonstrated on Graph 1.

Graph 1 – Type of service offered to patients and family



Regarding quantity of care services for patients and family members held daily at institutions where the occupational therapists who are the target of this research work, the number of care services were organized in: one to five sessions, between five and ten, between ten and fifteen and more than fifteen sessions, as illustrated on Graph 2.

We observed that both for patients and for family, the highest frequency is one to five occupational therapy sessions per day. The mean duration of sessions carried out by occupational therapists, with both patients and families, are mostly from thirty minutes up to one hour per session.

Concerning the activity use as a therapeutic resource, the participants mentioned the main materials used during the sessions, which were classified and grouped into graphic materials, games, toys, handicraft materials, media and electronic resources.

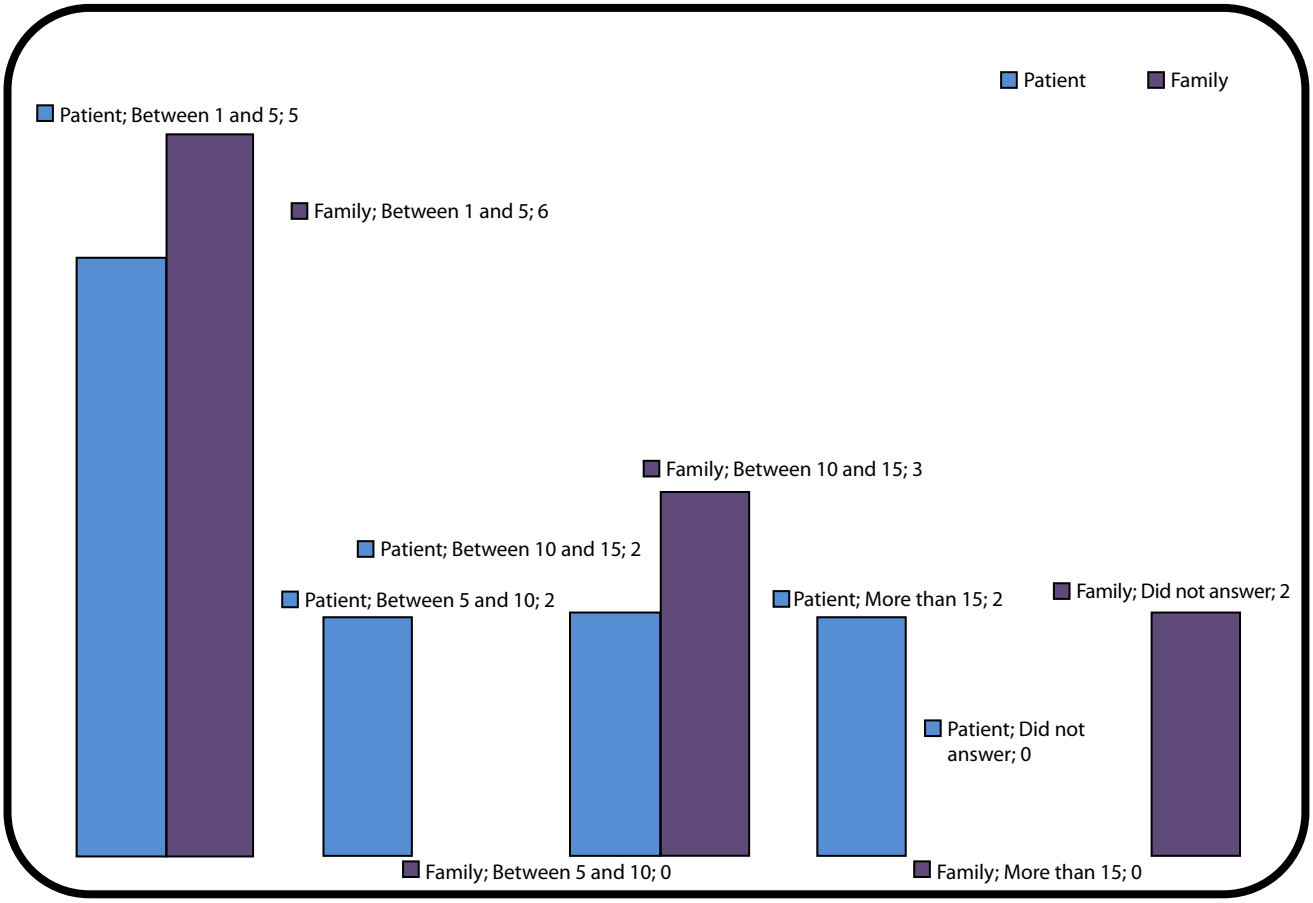
Materials used by the majority of participants were the handicraft ones and the graphic materials (n=5 for each of these materials). Use of toys was mentioned by four participants, while use of games, media and electronic resources, each one was mentioned by three participants. It should be noted that one participant did not answer the question.

Most occupational therapists (n=8) reported they use the toy library as a healthcare service place, two participants said they do not use this place and one said there is no place like this at the institution.

The participants reported they receive help from other members of the multi-professional team during the sessions. One of them receives help from one professional, five of them receive help from two professionals and three of them receive help from more than two professionals. It is important to highlight that two participants provide service by themselves. The participants mention more than one professional category as helpers in the service of an occupational therapist, being psychologists the most mentioned category (n=7), followed by doctors (n=6) and social work assistants (n=5). Physical therapists and nurses were also mentioned by four participants each. Phonoaudiologists were reported by two participants while nutritionists, pharmacists and toy library volunteers were referred to by one participant each. Something important to emphasize is that two participants reported they do not receive any help and three did not answer this question.

Regarding the quantity of professionals who help versus the number of patients seen, the occupational therapist who received help from a professional assisted one to five families of patients. The ones who had help from two people mostly assisted one to five families, and only one of them assisted ten to fifteen families. Concerning participants who had more than two people helping them,

Graph 2 – Type of service offered to patients and family



two of them assisted ten to fifteen families and one of them assisted one to five families.

Considering actions developed along with other professionals, the following were pointed out: team meetings (for study of clinical cases and/or for permanent education); nutrition education group; guidance (hospitalization, hospital discharge, caregivers and family members);healthcare services (multi-professional, groups, to guests, early intervention along with psychologists, palliative care and pain, to solve a specific issue or "inter-appointment", that is, another professional of the team refer the patient to another specialist; celebrations (birthday and theme parties); anticipatory mourning group; waiting list group; humanization group; death support and planned activities with patients and their parents and caregivers. We observed that there is a variety of categories of actions carried out with other professionals of the team, being the team meeting the most pointed out by the participants (n=5).

Multi-professional team meeting was considered an important tool to discuss cases and help for the occupational therapy sessions, according to the following statement:

> *The weekly team meeting for discussion of all cases of patients who are currently hospitalized [...] I believe that help happens through discussions of case, for better understanding of patients and their families, which helps indirectly in occupational therapy sessions. (Participant 1)*

About detailed description of a service carried out by the participants that had marked their lives, it became evident the polarization between the patient description based on the biomedical model and other descriptions based on biopsychosocial aspects. While a model valued technical-scientific reason and prioritization of diagnosis, the other valued subjective aspects and context. Two narratives exemplify that polarization:

Teenage male diagnosed with sarcoma, with pulmonary metastasis and in different bones, hospitalized for pain and respiratory discomfort. (Participant 10)

[...] self-image has changed, influencing self-esteem and social participation, which requires restructuring the way to perform daily life activities and practical life activities from the beginning, followed by activities related to education and leisure. (Participant 1)

Therapeutic resources used as described in the narratives, has different forms, being some of them simple materials such as cardboard and candles. Impact of occupational therapy intervention is to use dynamic resources, based on the context and wishes of patients, as well as to involve families. Playful and fun elements are part of occupational therapy care.

After surgeries and sequelae due to the treatment, he said he wanted to be an airplane pilot [...] Then, we built a cardboard airplane and after lots of time and investment from everybody on its building, finally the flight was scheduled. In the backyard of the group home, the flight happened in the evening and we lighted sparklers (birthday candles) to characterize the turbines. It was a remarkable experience, he had a great time, laughed a lot and flew with his mother, too. (Participant 4)

Pediatric oncology occupational therapy works directly with families of the children and/or teenagers, especially with mothers who are the caregivers most of the time.

This situation marked me first for reflecting care and affection needs that these mothers and caregivers have as much as their children who are sick. Besides, having this affection of their children was even more significant. (Participant 9)

The participants recognize the teamwork and receive a proactive attitude of other professionals.

Thus, I looked for the doctor and the nurse in charge, we discussed the case and I went over all guidelines in detail for the patient and the mother, highlighting the possibilities, not the restrictions. (Participant 1)

Occupational therapy in oncology has an important role in the lives of children, teenagers and families. Professionals receive dreams and wishes of those involved in the process, seek autonomy and independence of children and teenagers and have direct influence on their quality of life. Besides, they provide contextualized and humanized service.

Anyway, through occupational therapy, we can achieve dreams, and wishes and help with independence and autonomy the individual wishes to make them come true. All the way they can perform, on their own time and according to their limitations. The relationship among patient, therapist and activity is indeed the core for occupational therapy. (Participant 4)

Therefore, we understood that the occupational therapist job is constituted by a triple relation, formed by an occupational therapist, by an individual who presents any kind of reason, need and will to be there for occupational therapy, and by activities that enable therapeutic action.

DISCUSSION

The discussion proposed in this research has a descriptive character, since the topic is still insufficient in Brazilian scientific literature and there is the need to know more about the role of Brazilian occupational therapists who work with pediatric oncology.

The data presented that refer to sociodemographic characteristics of occupational therapists (gender, age, education time and type of educational institution) are similar to those found in the study by Lima and Almohalha[15], in which they attempted to understand the role of six occupational therapists in the pediatric oncology field in hospital contexts. This very similarity is confirmed in the studies by Sime et al.[16] and Garcia-Schinzari et al.[8].

This study intended to go beyond sociodemographic data and aimed to characterize the theoretical approaches that support clinical practice of occupational therapists. Concerning the approaches used, within the sample of eleven participants, we observed that 27% did not specify the model used on their interventions and 36% focused on dynamic occupational therapy. Studies of professional dynamic occupational therapists[17] point out that these professionals value the experience that people have with the disease, physical and material, as well as subjective and symbolic. This experience makes sense in the process of occupational therapy care, as it is potentially able to redefine life meaning and daily life from the experience with the disease. Thus, it is possible to infer that the choice of the occupational therapy method for oncologic patients can be related to human processes of

approximation with the death topic. There is an apparent contradiction to which death invites us: we have more intense relations with life. Occupational therapy resources aim to the construction of daily life from the impact generated by the disease. Meaning and wishes are primordial elements in the reasoning of occupational therapy, which are triggered to develop stories capable of transporting people in complex conditions in the health-disease process to their daily life from the triple relationship[17], that is, from the patient, therapist and activities relationship.

Materials used in occupational therapeutic interventions had a diversity of these simple elements of daily life such as cardboard, glue, pencils, paper and even high temperature thermoplastic materials to make orthoses, for example. Those materials are part of the diverse activities proposed by occupational therapists to their clients. According to Bartalotti and De Carlo[18] these activities allow individuals to be recognized by their tasks, (re)discover their potential and interests, acquire new knowledge, new life experiences, transform their routine, modify social interactions and enable cultural inclusion. Thus, by carrying out activities and using many materials, occupational therapists can (re)discover creative potential of patients, increase their self-esteem, stimulate motivation and help them express their feelings[19].

In agreement with Santos et al.[6], the results of this study demonstrated that most occupational therapists use the toy library as a service location to assist children and teenagers with cancer diagnosis. According to Santos et al. 6, the toy library is as a resource that can be used by occupational therapists as well as by other professionals who work in healthcare contexts for humanization of hospitals. This space can ease effects of treatment and be used as a therapeutic setting. In these environments, the playful offers support to ease disruption with daily life, play privation, removal from family context, traumas, fear and anxiety due to medical procedures. In addition, the toy library is a space where children interact with each other, in which they can perform their main occupational role, which is playing. Santos et al.[6] reported that despite the existence of a legislation (Brazilian Law 11.104 from 2005) that makes mandatory the installation of toy libraries in health units that offer pediatric care on a hospitalization basis, this research showed that one of the workplaces had no toy library in its facilities.

The answers evidence that the role of occupational therapists in pediatric oncology involves interventions with both child and family. The literature justifies such intervention by defining that illness and hospitalization of a child or teenager affect patients and their families and modify their daily lives. Therefore, in the job carried out by the occupational therapist, it is necessary to include family or relatives (grandparents, uncles and aunts) and friends with the child, since everyone can help with the care and the hospitalization process[20-21]. This intervention can occur through a therapeutic listening, providing information or strategies to improve quality of life[8,20].

The team meeting, as one of the actions developed by occupational therapists along with other professionals, was also pointed out in the study by Costa et al.[22] who reaffirmed the importance of team meetings as a space for dialogue, exchange of ideas, experiences, discussion and reflection about matters related to daily practice of health professionals, being a way to strengthen the team. In addition, the authors claim that these meetings should not be held only to demand fulfillment of routines and standards of the healthcare unit, or only to criticize what is wrong, but must be held to, from the identification of problems, raise suggestions in order to reach more concrete solutions. Also, they must be carried out to praise when the team performs its job with quality. Therefore, in the field of oncology, the multi-professional team work must be prioritized, since the patient is not considered as just another case, in a holistic and humanized approach. Such professionals must generate not only health, but especially life[8,22].

In this sense, the occupational therapist of the team presents results obtained from their relationship with the service user, in the occurrence dynamics of the three terms of the triple relationship: patient – therapist –activities[23].

Concerning patients' descriptions carried out by the participants of this study based on the biomedical model, Mattingly's article[23] corroborates them by pointing that professionals have conducted formal and biomedical presentations of cases, focusing attention on pathology and addressing key symptoms, main typical physical issues and elementary needs. However, some participants also described patients considering biopsychosocial aspects. Mattingly[23] also referred to the existence of professionals who present cases based on the individual and experiences that this one faces regarding pathology and how it affects them in their entirety, that is, in different aspects of the subject.

FINAL CONSIDERATIONS

This study presented a small number of occupational therapists (n=11) although there are 101 institutions that offer oncologic treatment in the state of São Paulo. With this in mind, we highlight limitations of the study considering the small size of the sample of

participants and the need to continue scientific production in this field, since after a literature review in academic journals, we have not found diversity of scientific papers that cover this topic.

The profile of professionals currently working in the field was: female, aged 25 to 35, finished graduation in occupational therapy mostly between 1980 and 2008, most of them have an undergraduate degree from a private institutions of higher education and completed graduate specialization in CETO, using the DOTM as theoretical reference.

Most participants carried out individual and/or group sessions with patients and/or family members, being one to five sessions performed per day with average duration ranging from thirty minutes to one hour. The occupational therapists reported that they received help during sessions from other professionals, especially psychologists and doctors. They consider the multi-professional team meetings as an important tool for the discussion of cases. They pointed out as useful materials games, playful activities and the potential that such activities can have in the patients' lives. The type of performance described by occupational therapists on pediatric oncology involved aspects such as multi-professional team work; case discussion; focus on the subject and the family which meets Brazilian health policy principles, in particular the humanization policy, such as reception actions, extended clinic and ambience.

All participants reported a service that marked their lives and described patients, in such a way that some of them presented a narrative focused on biopsychosocial aspects of patients and some of them emphasized patients' pathology and functional disorders.

Reports of participants allowed verifying actions taken by occupational therapists that meet needs of intervention with clients of the pediatric oncologic field, to the extent they are skilled to perform evaluations and elaborate intervention programs that meet needs presented by children and/or teenagers and their respective families, as well as by the work team. Therefore, we conclude that occupational therapy contributes to care integrality along with a group of necessary specific professionals to provide healthcare service in the pediatric oncology field.

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