

The frevo step improving the rehabilitation of children with Congenital Zika Virus Syndrome

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Abstract: Introduction: Occupational therapy understands that the context is constituted by elements that permeate the life of the client exerting influence on their occupational performance. Objective: To present a cultural context activity as a resource in the rehabilitation of children with Congenital Zika Virus Syndrome (SCZV). Method: Report of experience during the occupational therapy stage, in rehabilitation service for children with SCZV in Recife/PE. Through information in the medical records, field diary and supervision meetings, the possible therapeutic strategies used were analyzed and a carnival cultural activity was proposed, valuing the context for the rehabilitation. The outpatient clinic was decorated in advance, requesting that the children come dressed on the day of the activity, when they were stimulated and photographed in different functional postures, with benefits highlighted by the team. Results: The relaxed cultural activity facilitated orientations, clarification of doubts and benefits of social participation. It was observed that the family members interacted, comparing the development, advances in the rehabilitation and experiences of care in the home, besides exchange of personal contacts and photos of the children in the social networks. The activity enabled contacts between children and new look beyond the problems of SCZV and its most evident clinical sign is microcephaly. It was emphasized by the relatives that the diagnosis is not an impediment to participation, as expressed in the statements “my son is in the carnival” and “she can also”. Conclusion: Including a cultural activity has brought gains to the clientele. The environment, fantasies and photographs facilitated the interaction and understanding of therapeutic orientations, defusing intervention only in development and favoring social belonging. It is ratified that adopting elements of the cultural context is an important resource for the occupational therapist.

Keywords: *Occupational Therapy, Microcephaly, Rehabilitation.*

O passo do frevo potencializando a reabilitação de crianças com Síndrome Congênita do Zika Vírus

Resumo: Introdução: A terapia ocupacional compreende que o contexto é constituído por elementos que perpassam a vida do cliente, exercendo influência em seu desempenho ocupacional. Objetivo: Apresentar uma atividade cultural como recurso na reabilitação de crianças com Síndrome Congênita do Zika Vírus (SCZV). Método: Relato de experiência durante estágio de terapia ocupacional, em serviço de Reabilitação para crianças com SCZV em Recife/PE. Através de informações nos prontuários, diário de campo e reuniões de supervisão, analisou-se as possíveis estratégias terapêuticas já utilizadas e foi proposta uma atividade cultural carnavalesca, valorizando

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o contexto no momento para a reabilitação. Antecipadamente decorou-se o ambulatório, solicitando-se que as crianças viessem fantasiadas no dia da atividade, quando foram estimuladas e fotografadas em diferentes posturas funcionais, com benefícios destacados pela equipe. Resultados: A atividade cultural descontraída facilitou orientações, esclarecimento de dúvidas e benefícios de participação social. Observou-se que os familiares interagiram, comparando o desenvolvimento, avanços na reabilitação e experiências de cuidado no domicílio, além de troca de contatos pessoais e fotos das crianças nas redes sociais. A atividade possibilitou contatos entre as crianças e novo olhar para além dos problemas da SCZV e seu sinal clínico mais evidente que é a microcefalia. Foi destacado pelos familiares que o diagnóstico não é impedimento para participação social, como expresso nas declarações “meu filho está no carnaval” e “ela também pode”. Conclusão: Incluir uma atividade cultural trouxe ganhos à clientela. O ambiente, fantasias e fotografias facilitaram a interação e compreensão de orientações terapêuticas, desfocando a intervenção apenas no desenvolvimento e favorecendo o pertencimento social. Ratifica-se que adotar elementos do contexto cultural é um importante recurso que pode ser usado pelo terapeuta ocupacional.

Palavras-chave: *Terapia Ocupacional, Microcefalia, Reabilitação.*

1 Open the Wings I Want to Pass Through...

Gestation involves family and social group expectations, from the creation of the name to the characteristics that the baby will inherit. Also, the health condition of the baby expected with a pattern of perfection is relevant. Thus, the frustration when the child is born with health problems or deficiency is understandable (OLIVEIRA; POLETTO, 2015; CHACON, 2011; PICCININI et al., 2009; FALKENBACH; DREXSLER; WERLER, 2008).

The recent outbreak of children with microcephaly associated with the Zika virus infection in Brazil was increased with frustration; fear of the lack of knowledge about the causes of the malformation, a consequence of the extent of damage in the neuropsychomotor development (NPMD) and the precariousness of the support network (HENRIQUES; DUARTE; GARCIA, 2016; BRASIL, 2015).

Research in microcephaly in babies and other alterations of the Congenital Zika Virus Syndrome (SCZV). has generated additional pressure for families to attend exams and therapies to follow up problems and minimize sequels. In some families, members needed to abandon their routine to take on the role of primary caregivers. Thus, the representation of the child with SCZV has negative and ambiguous feelings of dedication and overload, which can be exacerbated by greater social vulnerability and paternal abandonment (ORGANIZAÇÃO..., 2016; OLIVEIRA; POLETTO, 2015; BRASIL, 2015).

Protocols and early stimulation services were established with multi-professional teams, in which the occupational therapist is a participant, to follow up on children and families who are subject to psychosocial pressures and disorders resulting from

anguish and uncertainties about the future of the child and the lack of family capacity to deal with this new situation (ORGANIZAÇÃO..., 2016; VILLELA, 2016; BRASIL, 2015).

In these services, the role of occupational therapy is to stimulate and rehabilitate the child and also to host the family, respecting their values and contexts, enhancing care (BRASIL, 2015). For the occupational therapist, the context is composed of elements that permeate the patient's life, influencing his occupational performance. It involves the environment and cultural, virtual and temporal aspects (AMERICAN..., 2015). It is up to this professional to use elements of daily life as therapeutic resources, re-meaning stories, and experiences in the process of rehabilitation. According to Kondo (2004), the choice of the resource by the occupational therapist has a meaning within cultural practices, values, beliefs of a particular social group.

Thus, this report is justified considering the contexts in the occupational therapeutic process and recognizing their relevance, which aims to present activity of the cultural context as a resource in the rehabilitation of children with SCZV in the city of Recife/PE. In this city, carnival is a multicultural event, deeply rooted in the collective imagination, with music, dance, use of costumes and props, permeating the life of generations in a significant way, even for people who do not get directly involved in the festival.

2 Between Confetti and Streamers

The compulsory internships with 30 hours/week was experienced by students of the Occupational Therapy Course of the Federal University of Pernambuco (UFPE), between February and June/2017, in a

rehabilitation service of a public hospital, reference for SCZV in Recife/PE, where ambulatory care of occupational therapy, physiotherapy, speech therapy and the back-up of medical appointments, psychology, and social services are offered, as well as hospital admission, when necessary. The service began in November/2015 with a focus on the triage of cases and guidelines on NPMD and the rehabilitation outpatient clinics started in August/2016.

During the compulsory internship, 30 children with Congenital Zika Virus Syndrome (SCZV) were assisted, aged between 9 and 18 months old, coming from all the State of Pernambuco. Initially, analyzing their records, recording in the field diary and meeting of supervision, case discussion and the dynamics of the attendances, the therapeutic strategies already used were discussed. The advisors of the internship requested that the trainees innovate, including an activity other than those performed. Thus, considering the period of the year, the trainees proposed a carnival activity, valuing the cultural context for rehabilitation, the inclusion of children and caregivers and interaction with the staff and other relatives.

The team jointly planned the activity to reinforce the guidelines for positioning and cultural and social contextualization of the children in the carnival period. Reports of service changes and traffic were also elaborated, minimizing the exhaustive routine in the displacement for the therapies, aggravated by alteration of the bus route and the reduction of service hours.

To approximate with the reality, the need to use costumes was highlighted, the photographic registration and the provision of a snack, as is typical of the festivities, were planned, which was provided by the team and supported by the caregivers of the children. For a warm and in tune environment with the local context, the team provided the Clinic decoration in advance and as the children and families reached the therapies, they were informed about the activity that would occur in the last attendances of the pre-carnival week. At that time, it was also encouraged that the children came dressed up, reinforcing the identity of the carnival in the city and obtaining the families' consent for the activity and the use of photographs. Other information from the routine altered because of the carnival, were also part of the conversation and previous orientations.

The carnival activity had an average duration of two hours, on different days to allow the participation of other people, such as the siblings and other relatives of the children assisted, engaging them in the treatment.

Predicting that some family members could not provide the costumes, they were available by the team during the activity, carnival props like *frevo* umbrellas, masks, and colored bands. At the first moment of the activity, the therapists placed the routines of the outpatient clinic, highlighting the attendance to the children, the importance of assiduity in the evolution and the waiting list dynamics that have children with SCZV still waiting for places for rehabilitation.

Then, in front of a decorated panel, the costumed children were photographed in different functional positions, and their benefits were highlighted by therapists and trainees. Thus, guidelines for routine care were reinforced, suggesting new stimuli for reproduction at home and the participation of children in situations of their social context.

Finally, there was an exchange of experiences between the family members, who began to highlight solutions and difficulties related to the care, progress of children's neuropsychomotor development and the fact that they were participating in a carnival party, together with other children and different people, possibility previously not provided by family members. A snack was also offered as a propitious moment for valuing the sensory information of foods as flavor and temperature and other stimuli such as the texture and colors of the props, the movement with rhythm, among others. After that, the activity was ended with the reports of family members and their expectations for other activities such as this one, as well as exchanging contacts and sharing photos on social networks such as Facebook and WhatsApp, which caused the activity repercussions for several days and reach other people who did not participate.

3 Just Came to Say It... and with Satisfaction

The human actions occurring in different social groups describe the positions of individuals and groups according to the accumulation and composition of experiences during life (BRITTO; JOAQUIM, 2013). Thus, with the carnival cultural activity used as a resource for occupational therapy, a multidimensional social space was accessed, since subjective, family and community aspects were considered in the planning, during and after the activity.

Therapeutic planning is also more assertive when considering the cultural context of the patients. Therefore, there is a cultural identity of the individuals, which can be transformed through

experiences that the environment can influence and that will consequently influence the formation of these individuals (ALCANTARA; GOMES, 2011; MAGALHÃES; SILVA; OLIVEIRA, 2014). The willingness of families to participate in the activity and to bring their children dressed up as valued by the people of Pernambuco enabled the belonging and engagement of children in real life. For us, it has reinforced some of the skills of the occupational therapist that is to promote the social and cultural insertion of his patients and the family.

The family is the first social structure in which the child is inserted. This interpersonal relationship area throughout childhood development shows the role of parents as mediators of relationships, favoring an increase in information and an increasingly functional and autonomous social organization. Thus, identity is not acquired at birth; it is accepted, built and incorporated into our lives from experiences. That is, inserting cultural elements from childhood and optimizing the partnership with the family in the rehabilitation process is very positive (HALL, 2011).

As the activity was built as a team, and it was a cohesive one, it met with demands, difficulties of family members with children with SCZV, especially those with more severe sequels, favoring changes in beneficial attitudes to the triad of patient-therapist-family care. The possible evolution in the treatment happens when the family engages in the process since it stays longer with the child at home than in the therapies, which has very restricted moments (GUERRA et al., 2015; PINTANEL; GOMES; XAVIER, 2013). The exchanges, doubts, and comparisons of procedures were mediated by the “party”, relaxation with the costumes and positions for the photos, making the reinforcement of learning and participation lighter.

The occupational therapist prioritizes everyday activities, understanding that they are not in themselves beneficial, but instruments to achieve a meaningful goal or ability for the patient’s occupational performance (TOWNSEND; MARVAL, 2013). The situations generated by the carnival activity worked as a bridge to the understanding of children’s needs and perception of the stimuli offered. For the photos, when the children were placed in functional positions, the mothers compared the advances that their children obtained during the rehabilitation process, in phrases such as: “*I am impressed by how well he is*”; “*He’s holding his head*”; “*I always seat my child, she is already used to*

it”; “*She has evolved a lot*”; “*Thank you for the party and for my son to participate*”.

As a team, we also captured what the children demonstrated and reinforced the guidelines, identifying that the children who were more stimulated at home responded better to postures and manipulations in the activity, showing interaction with what happened around them. Through the reports of the mothers/caregivers, it was clear that the cultural manifestation provided a light moment of learning about the placements and how to observe the gains of the child recognizing their needs and ways of attending them.

Naturally, an enthusiasm was generated in the family, since the children could participate in a party with other children, without a focus on the diagnosis. They were seen as children participating in a carnival party, regardless of having the SCZV. Therefore, it is possible to take advantage of social situations and stimulate them outside the therapeutic and home environment, with walks and participation in other environments, parts of the cultural and community context.

The mothers experienced moments of affection with their children and experiences with other caregivers, seeking possibilities together, overcoming barriers imposed by stereotypes that children with problems cannot participate in festivities, or that SCZV only causes problems and impossibilities (MEDEIROS; SALOMÃO, 2012).

4 Saying Goodbye to Their People...

One of the skills of the occupational therapist is to consider the different contexts in the intervention, where significant experiences can be a link for the assimilation of therapeutic recommendations and better occupational performance. Therefore, the relevance of the cultural and social context for children with Congenital Syndrome of the Zika Virus is highlighted, since the celebration of the carnival has become a facilitator to stimulate abilities such as sitting and staying face down which assists in cervical control and postural changes, besides the interaction with the real, contextual and interpersonal life.

The experience provided social participation and identity to the participants, through the use of costumes, greater interaction, and sharing of experiences and the exchange of photographs and comments by social networks. Listening to statements such as “*My son is participating in the carnival*”, “*She*

can too”, made us believe that the reinforcement of socio-cultural identity was positive, in the implication of care, in a different perspective mediated by the light and relaxed environment, even in the hospital. The important thing was not the diagnosis but the possibility that they were children experiencing a party. The availability of the families was motivating and instigated new possibilities of activities to be developed by the trainees and staff.

Including a cultural activity improved the rehabilitation of children with Congenital Syndrome of the Zika Virus. The environment, costumes, and photographs facilitated the interaction and understanding of therapeutic guidelines, favoring social belonging and ratifying that adopting elements of the cultural context is an important resource that can be used by the occupational therapist.

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Author's Contributions

Yone Regina de Oliveira Silva was responsible for the design, writing, and review of the manuscript. Bárbara Botelho Arrais was responsible for the clinical supervision. Marília de Arruda Santos was responsible for planning the activity. Mayara Francelle Oliveira Barata and Ilka Veras Falcão were responsible for guiding the planning of the text and contributed to the drafting and review of the final version. All authors approved the final version of the text.