RevisbraTO
Revista Interinstitucional Brasileira de Terapia Ocupacional
Interinstitutional Brazilian Journal of Occupational Therapy

Original Article

THE IMPACT OF ASSISTIVE TECHNOLOGY ON THE LIVES CHILDREN WITH CEREBRAL PALSY: MATERNAL PERSPECTIVES

Impacto da tecnologia assistiva na vida de crianças com paralisia cerebral: perspectivas maternas

El impacto de la tecnología asistiva en la vida de niños con parálisis cerebral: perspectivas maternas

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Abstract: Introduction: Assistive Technology resources are commonly prescribed for children with cerebral palsy, aiming at functionality and social participation. However, there is a lack of studies that evaluate the impact of these resources from the perspective of users. **Objectives:** To identify the target activity for prescribing Assistive Technology resources and understand their effectiveness in the lives of children with cerebral palsy, from the perspective of mothers who interact with technology and with the child daily. **Methods:** Longitudinal study carried out with three mothers of children with cerebral palsy treated at an Occupational Therapy service. The Canadian Occupational Performance Measure and the Brazilian version of the Quebec User Evaluation of Satisfaction with Assistive Technology were applied to the mothers at three moments: pre, 15 and 30 days after intervention with the resource. A descriptive and comparative analysis of the performance and satisfaction data in the selected activity was carried out, satisfaction with the assistive resource and with the Assistive Technology service. **Results:** The implementation of the resources demonstrated effectiveness in improving performance and increasing satisfaction with the evaluated activity. **Discussion:** The results suggest that the implemented resources were adequate to meet the mothers' needs and expectations. The increase in performance and satisfaction scores suggests that the intervention was successful. **Conclusion:** This study guides the development of intervention strategies in occupational therapy in the area of Assistive Technology, covering aspects pertinent to procedures, data collection instruments and methods to evaluate the impact of the use of these resources.

Keywords: Assistive Technology. Occupational Therapy. Cerebral Palsy. Mothers.

Resumo: Introdução: Recursos de Tecnologia Assistiva são comumente prescritos para crianças com paralisia cerebral, visando à funcionalidade e à participação social delas. Contudo, há escassez de estudos que avaliem o impacto de tais recursos sob a perspectiva dos usuários. **Objetivos:** Identificar a atividade-alvo para prescrição de recursos de Tecnologia Assistiva e compreender a eficácia deles na vida de crianças com paralisia cerebral, na perspectiva das mães que interagem com a tecnologia e com a criança diariamente. **Métodos:** Estudo longitudinal realizado com três mães de crianças com paralisia cerebral atendidas em um serviço de Terapia Ocupacional. Utilizou-se a medida canadense de desempenho ocupacional e a versão brasileira do Quebec user evaluation of satisfaction with Assistive Technology, aplicados com as mães em três momentos: pré, 15 e 30 dias após intervenção com o recurso. Realizou-se análise descritiva e comparativa dos dados de desempenho e satisfação na atividade selecionada, além da satisfação com o recurso assistivo e o serviço de Tecnologia Assistiva. **Resultados:** A implementação dos recursos demonstrou eficácia no aprimoramento do desempenho e no aumento da satisfação com a atividade avaliada. **Discussão:** Os resultados sugerem que os recursos implementados foram adequados para atender às necessidades e às expectativas das mães. O aumento nos escores de desempenho e satisfação sugere que a intervenção foi bem-sucedida. **Conclusão:** Este estudo orienta a elaboração de estratégias de intervenção em terapia ocupacional na área da Tecnologia Assistiva, abrangendo aspectos pertinentes aos procedimentos, aos instrumentos de coleta de dados e aos métodos para avaliar o impacto do uso desses recursos.

Palavras-chave: Tecnologia Assistiva. Terapia Ocupacional. Paralisia Cerebral. Mães.

Resumen: Introducción: Se prescriben recursos de Tecnología de Asistencia para niños con parálisis cerebral con el objetivo de funcionalidad y participación social. Sin embargo, faltan estudios que evalúen el impacto de estos recursos desde la perspectiva de los usuarios. **Objetivos:** Identificar la actividad objetivo para la prescripción de recursos de Tecnología de Asistencia y comprender su efectividad en la vida de los niños con parálisis cerebral, desde la perspectiva de las madres que interactúan con la tecnología y el niño. **Métodos:** Estudio longitudinal realizado con tres madres de niños con parálisis cerebral atendidos en un servicio de Terapia Ocupacional. Se utilizó la Medida de Desempeño Ocupacional Canadiense y la versión brasileña de la Evaluación de Satisfacción del Usuario de Quebec con Tecnología de Asistencia, aplicados a las madres en los siguientes momentos: pre, 15 y 30 días después de la intervención con el recurso, con análisis descriptivo y comparativo de los datos de desempeño y satisfacción en la

actividad seleccionada, con el recurso y servicio de Tecnología Asistiva. **Resultados:** La implementación de los recursos demostró ser eficaz para mejorar el rendimiento y aumentar la satisfacción con la actividad evaluada. **Discusión:** Los resultados sugieren que los recursos implementados fueron adecuados para satisfacer las necesidades y expectativas de las madres. El aumento en las puntuaciones de rendimiento y satisfacción sugiere que la intervención fue exitosa.**Conclusión:** Es importante desarrollar estrategias de intervención en terapia ocupacional utilizando Tecnología de Asistencia, que abarquen procedimientos, instrumentos de recolección de datos y métodos para evaluar el impacto del uso de estos recursos.

Palabras-clave: Dispositivos de Autoayuda. Terapia Ocupacional. Parálisis Cerebral. Madres.

How to cite:

Silva, A. L. S; Palacio, R. M.; Ribeiro, I. R.; Stroppa-Marques, A. E. Z.; Baleotti, L. R. (2025). The impact of assistive technology on the lives of children with cerebral palsy: maternal perspectives. Rev. Interinst. Bras. Ter. Ocup. 9(4): 3585-3595. DOI: 10.47222/2526-3544.rbto68651

Introduction

Cerebral palsy (CP) results in a variety of functional levels that impact the ability to perform coordinated and refined movements, interfering with child development and restricting their participation in daily activities (Gondim et al., 2009; Mello et al., 2012). Therefore, interventions are needed to reduce or eliminate the discrepancy between the functional skills required for the activity and the child's ability to perform (Baleotti et al., 2014). Assistive Technology (AT) represents part of all therapeutic interventions offered and can contribute to improving the participation and performance of children with CP in their activities.

However, while the rapid growth of technological options available to people with CP is a positive development, numerous challenges remain for successfully implementing assistive solutions (Taherian & Davies, 2017). One such challenge is related to users' perspectives, expectations, and predispositions toward AT, which can be decisive for the success or failure of technological engagement (Martin et al., 2010).

Disregarding the needs of users and their families can lead to inappropriate use and, consequently, abandonment of the AT resource (da Costa et al., 2015). On the other hand, understanding user demands and preferences is a fundamental aspect that can positively influence usability (Siqueira & Bandini, 2021). Therefore, it is clear that this is just one of many variables that must be evaluated and considered during the implementation process of an assistive solution.

Regarding children with CP, it is known that most parents play the role of primary caregiver and provider of care and support for their children (King et al., 2004). Furthermore, they have significant influence on health-related decision-making (Magill-Evans et al., 2005) and their children's engagement in daily activities, such as self-care, household chores, social activities, and mobility within community spaces (Murphy et al., 2011; Nguyen et al., 2016). Thus, involving the family in AT services is essential to provide appropriate assistive resources and support the child's performance in various settings, such as school and home (Chmiliar, 2007; Cockerill et al., 2014).

It is crucial to listen to the family's needs and demands in the child's daily care and in the use of the different resources prescribed, as well as to understand the meaning of technologies for them (Barbosa et al., 2020). In this sense, it is known that AT can have an impact on the performance of activities of

daily living (ADLs), reducing the need for assistance to perform them in order to compensate for functional difficulties and improve the child's autonomy (Lino et al., 2020).

However, the literature still lacks studies regarding family involvement and analyzing the impact of AT on children's daily lives. Rocha & Castiglioni (2005) state that assistive resources should be aligned with the satisfaction and personal fulfillment of individuals and their social groups. Therefore, the present study aims to identify the target activity for prescribing Assistive Technology resources and understand their effectiveness in the lives of children with cerebral palsy from the perspective of mothers who interact with technology and their children in their daily environment.

Methods

This longitudinal study was approved by the Research Ethics Committee of the local university, under opinion No. 3,550,293. This research complies with Resolution No. 466/2012, adhering to the ethical principles for research involving human subjects.

Three mothers of children with CP participated. They met the following inclusion criteria: caregivers of children with CP who did not use assistive devices for performing ADLs but had difficulty performing them, and who were receiving Occupational Therapy services. Those whose children with CP already used AT for performing ADLs were excluded. The study was conducted at a Specialized Rehabilitation Center affiliated with a public university in the interior of São Paulo state, which offers outpatient care in the areas of physical therapy, speech therapy, and occupational therapy for people with various health conditions. Before this study began, participants were informed of the objectives and procedures, and their personal data were guaranteed confidentiality. They subsequently signed an informed consent form confirming their participation. Only those who agreed by signing the informed consent form participated.

Two instruments were used to collect data, which are described below.

1- Brazilian version of the Canadian Occupational Performance Measure (COPM) (Magalhães et al., 2009): The COPM was developed to investigate individuals' self-perception of their occupational performance. It is used as an outcome measure to support the implementation of an occupational therapy intervention program, according to the client's established priorities (Magalhães et al., 2009). In recent years, the COPM has been used in the field of AT and has proven useful for identifying and prescribing assistive resources (Souza et al., 2018; Baleotti et al., 2024), as well as for monitoring client performance and satisfaction with the activity they perform using the assistive resource (Baleotti et al., 2024). The COPM is administered through an interview and encourages the patient to reflect on their daily activities, categorized as self-care, productivity, and leisure. The patient rates the importance of each activity on a 10-point scale. Afterwards, select the five most relevant activities and evaluate your performance and your satisfaction with that performance, also on 10-point scales.
2- Brazilian version of the Quebec User Evaluation of Satisfaction with Assistive Technology – QUEST (Carvalho et al., 2014): QUEST assesses user satisfaction with the resource and the AT service through twelve items, scored from 1 (dissatisfied) to 5 (completely satisfied). Additionally, the user selects the three items considered most relevant to their satisfaction. The total resource score is calculated by adding the scores for items 1 to 8 divided by the number of valid items. The total service score (items 9 to 12)

is obtained in a similar manner. The final QUEST score represents the average of the scores for all valid items on both scales.

The instruments were administered individually to the three mothers of children with CP. Initially, the COPM was administered. After the mothers rated their performance and satisfaction with the activities investigated, they were asked to choose an activity that, in their opinion, could benefit their child with the use of an assistive device. The activity should be meaningful and relevant to daily life. Subsequently, each child's performance in the selected activity was assessed by analyzing the relationship between structural demands and bodily functions, activity demands, and context, based on the Human Activity Assistive Technology (HAAT) model proposed by Cook & Polgar (2020).

This analysis enabled the prescription and development of prototypes of assistive devices for daily use. It should be noted that these tools were developed using 3D printing technology. After the device was delivered, usability training sessions were conducted with each child individually, twice a week, one in a clinical setting and the other at home, over four weeks, totaling eight sessions. Additionally, the sessions facilitated observation of the child's performance in the activity, enabling adjustments to the assistive device. The COPM was reapplied to the mothers after 15 and 30 days of continuous use of the assistive device to facilitate evaluation through experimentation with the device in daily activities.

QUEST was administered to mothers, along with the COPM, in the final two stages of data collection. Data collection procedures, development of assistive devices, and usability training were conducted from June to September 2023. The data were initially organized in a Microsoft Office Excel 2016 spreadsheet, and the analysis involved a descriptive and comparative approach, aiming to investigate variations in the COPM and QUEST instrument scores.

This analysis focused on performance and satisfaction related to the selected activity, as well as satisfaction with the assistive device and the service, pre- and post-intervention. Regarding the COPM, performance and satisfaction are quantified using a scale of 1 to 10, where 1 represents the inability to perform the activity or dissatisfaction with performance, and 10 indicates maximum ability or satisfaction. Therefore, higher scores reflect better performance and greater satisfaction. Regarding the QUEST, three main scores were considered: the total assistive resource score (calculated by adding the scores for questions 1 to 8 divided by the number of valid items), the total service score (calculated similarly for questions 9 to 12), and the final QUEST score (obtained by adding all scores divided by the total number of valid items). Similar to the COPM, higher QUEST averages indicate greater user satisfaction. The variation between the pre- and post-intervention periods was described by calculating the delta percentage, represented by the formula $\%\Delta = (post - pre) \times 100/pre$.

Results

Three mothers, aged 43 to 48, of children clinically diagnosed with CP participated in the study. The children, all 8 years old, presented with different CP classifications: one with diparesis (C1) and two with quadriplegia (C2 and C3). Only C1 had verbal communication; C2 and C3 did not have oral language and did not use alternative communication strategies.

The results of the first application of the COPM for the target activity of the AT intervention are presented in Table 1. Figure 1 illustrates the initial assistive solutions, manufactured using three-dimensional (3D) printing.

Table 1: COPM – Activity listed by mothers as a priority and initial scores

Mother (M)	M1	M2	M3
Activity	Tying your shoelaces	Opening screw-top bottles	Bring food to your mouth
Importance	10	9	8
Performance	1	1	6
Satisfaction	1	4	7

Source: Elaborated by the authors

Figure 1: Assistive Resources
Source: Thingiverse Platform (https://www.thingiverse.com/).

During usability testing, the resources demonstrated effectiveness in the activity performance for two children (C2 and C3). However, C1 had difficulty in bimanual manipulation of the resource, which led to the adoption of an alternative assistive solution: a commercially purchased elastic shoelace (Figure 2).

Figure 2: Elastic Shoelaces
Source: Research Laboratory in Neuropediatrics, Technology and Inclusion (LINTI)

The child's adherence to the second assistive device implemented proved unsatisfactory. A preference was observed for the original assistive solution, produced by 3D printing, which played a motivating role in the use of AT. This preference is illustrated by the following excerpt from the child (C1) and his mother (M1): "...I want the other one made with that machine, I think it's different and cool..." (C1); "There's no way, he doesn't want to use that shoelace" (M1). Given this scenario, it was decided to intensify the usability training with the initially prescribed 3D device, extending it for an additional 15 days.

The results obtained by applying the COPM at the three data collection points and the variation results (Δ) are summarized in Table 2.

Table 2: Absolute values of the COPM performance (D) and satisfaction (S) scale and % variation (Δ) at post-15 (%Δ post-15), post-30 (%Δ post-30) compared to the pre-condition, and the percentage of variation between post-15 and post-30.

Mother (M)	M1		M2		M3	
	D	S	D	S	D	S
Pre	1	1	1	4	6	7
Post 15	3	3	8	8	9	10
%Δ Post 15	200	200	700	100	50	42,86
Post 30	9	10	8	8	9	10
%Δ Post 30	800	900	700	100	50	42,86
%Δ Post 30-15	200	233,33	0	0	0	0

Source: Elaborated by the authors.

In order to assess satisfaction with the assistance resource and related services, the QUEST instrument was applied concomitantly with the COPM at moments 1 and 2. The results obtained in the COPM and the percentage of variation (%Δ) between the moments after 15 and after 30 days will be presented below.

Table 3: Average values of resources, services and total score of the QUEST instrument and percentage of variation (%Δ) between the moments after 15 and after 30 days.

Mother (M)	M1			M2			M3		
	Resource	Service	Total	Resource	Service	Total	Resource	Service	Total
Post 15	2,62	5	3,42	4,25	5	4,5	4	5	4,33
Post 30	4,87	5	4,92	4,87	5	4,92	4,75	5	4,83
%Δ	85,71	0	43,91	14,71	0	9,24	18,75	0	11,54

Source: Elabrated by the authors

Discussion

This study sought to identify the target activity for prescribing AT resources and understand their effectiveness in the lives of children with cerebral palsy, from the perspective of their mothers. The results indicate that mothers play a crucial role in AT. Their role as partners is essential both in identifying the activities considered priorities for their children's performance in the home environment and in monitoring the effectiveness and usability of the prescribed AT resources. This active collaboration from

mothers offers valuable insights for personalizing and optimizing the AT intervention, maximizing its positive impact on the quality of life of children with CP.

Based on the results presented in Table 2, a significant improvement in activity performance is observed for all three participants. In the 15-day post-intervention condition, C1 showed a 200% (%Δ) increase in performance. Despite this considerable improvement, the absolute value of the COPM remained unsatisfactory.

In contrast, by resuming the previous adaptation preferred by C1 and intensifying usability training, an 800% improvement in performance was observed after 30 days of intervention, accompanied by an increase in the absolute COPM value. This result highlights the importance of an individualized approach to the intervention process, considering the specific preferences and needs of each child to optimize therapeutic results and adherence to the assistive resource. Understanding and considering individual preferences, needs, and predispositions, as well as family lifestyle and daily routines, is essential for successful AT use (Siqueira & Bandini, 2021).

Regarding C2 and C3, mothers observed a significant improvement in performance after 15 days of intervention, progressing from an unfavorable initial condition to a level considered satisfactory. This gain represented a 700% increase (%Δ) between the pre-intervention assessment and the assessment conducted 15 days after the start of the intervention, with progress maintained after 30 days. The improvement in performance appears to have positively influenced mothers' satisfaction, evidenced by the increase in both the absolute COPM value and the percentage change (%Δ).

The effectiveness of AT service delivery depends on a collaborative environment involving multiple stakeholders. The client, including family members and caregivers, plays a fundamental role in this partnership, acting as the primary user of the technology (Cook & Polgar, 2020). Furthermore, the inclusion of the user or caregiver empowers professionals to design solutions aligned with their real needs and demands, potentially positively impacting the usability of these resources. Such usability, in turn, contributes substantially to the individual's independence and autonomy. This principle, as highlighted by Lino et al. (2020) and Baleotti et al. (2020), highlights the importance of collaboration between professionals, users, and caregivers in optimizing therapeutic interventions in AT.

Regarding QUEST results, there was an increase in maternal satisfaction with the prescribed resource between the 15-day and 30-day periods after intervention. A substantial increase in the percentage of satisfaction observed in the M1 assessment (85.71%) suggests that this variation is consistent with the resumption of use of the initially prescribed resource. Additionally, maternal involvement in the development, adaptation, and monitoring of the resource proved crucial to ensuring its adequacy to the child's needs. Considering that the family maintains constant contact with the child, it is essential that they also be the target of interventions, especially regarding the provision of information about the needs and contexts experienced (Biancolli, 2020). This approach necessarily includes assessing the impacts of AT resources on daily activities.

Regarding the services provided, the average satisfaction score (5.0) remained constant in both QUEST questionnaire applications, demonstrating the mothers' overall satisfaction with the prescription, assessment, and monitoring of AT use. These results reinforce the relevance of AT services and the need

for professionals in the field to be aware of the implications of their interventions for the child and family caregiver.

In this context, family participation and recognition of the effectiveness of assistive technology in the home environment are motivating factors for usability, as demonstrated by Kruger et al. (2011) and corroborated by the results of this study. Accordingly, the international guideline for good clinical intervention practices in children and young people with cerebral palsy recommends that the preferences of the child and the family guide the selection of interventions (Jackman et al., 2022).

In this study, mothers were recognized as indirect participants in the use of assistive technology, due to their fundamental role in the decision-making processes. This influence stems from daily interaction with the child and the device in the home environment. This makes maternal support a central factor in the success of the proposed intervention.

Maternal perceptions of the child's performance and satisfaction data guided the AT usability training. Overall, the data demonstrate that as the child's performance improves, there is a corresponding increase in maternal satisfaction with the assistive device and the service provided. This increase in satisfaction may indicate recognition of the child's potential to perform tasks previously considered unfeasible or too difficult, thus fostering greater independence and autonomy, as suggested by previous studies (Meneses et al., 2014).

Despite the limitations of this study, especially regarding the number of participants, the results obtained were relevant and reinforce the importance of including family members in the prescription of assistive devices. To provide a more comprehensive understanding of the topic, future research is recommended to investigate the impact of collaborative interventions between occupational therapists and primary caregivers and longitudinal monitoring of the effects of the assistive device and the service on the quality of life of both the child and their family members.

Conclusion

More intensive training strategies, detailed monitoring with the user's preferred device, and valuing the maternal perspective proved effective, promoting positive impacts on both children's performance and reported satisfaction. The data, measured by the COPM and QUEST instruments, demonstrated considerable benefits in these aspects. These results provide relevant clinical guidance for occupational therapy. Therefore, it is essential to systematically integrate mothers (or other primary caregivers) into the therapeutic process, from planning to implementation of assistive resources. Valuing their perceptions, offering personalized training, and promoting collaboration and communication are strategies that enhance the effectiveness of assistive devices and increase satisfaction with the service provided. This family-centered approach strengthens the child's autonomy and contributes to more humane and efficient practices in occupational therapy focused on assistive technology.

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Authors' contributions: A. L. S. S.: Preparation, data collection, formatting, data analysis, text review. R. M. P.: Data collection, data analysis, discussion. I. R. R.: Discussion, text review. A. E. Z. S.: Data analysis, text review. L. R. B.: Work supervision, data analysis, data discussion, text review.

Source of fouding: Programa Institucional de Bolsas de Iniciação Científica, Conselho Nacional de Desenvolvimento Científico e Tecnológico (PIBIC, CNPq). Coordenação de Aperfeiçoamento de Pessoal de Nível Superior-Brasil (CAPES)-Código de Financiamento 001.

Received: June 4, 2025

Accepted: August 13, 2025

Published: October 31, 2025

Editor: Andreza Aparecida Polia