Benefits of TREINI on functional goals of children with myelomeningocele

Benefícios do TREINI nas metas funcionais de crianças com mielomeningocele

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Abstract

Introduction: Children with myelomeningocele (MMC) often experience limitations that affect their daily activities and family routines. Understanding parental priorities and applying effective interventions is essential to optimize functionality and promote the overall development of these children. **Objective:** To characterize the functional goals of children with MMC, organize them according to the F-words framework, and evaluate the effects of the TREINI Program on the improvement in these functional goals. **Methods:** A non-randomized pilot study was conducted involving 26 children (ages 2-14) with MMC. The Canadian Occupational Performance Measure (COPM) was used to characterize functional goals and evaluate the benefits of the TREINI program. The protocol consisted of training functional goals in a naturalistic environment combined with the use of a flexible therapeutic suit, over three months, five times a week, for 3-4 hours per day. Descriptive statistics were used to provide the profile of priorities. Pre- and post-intervention data were analyzed using the paired t-test. **Results:** A total of 130 goals were established by parents, among which activities of daily living (ADLs), such as functional mobility, dressing, and personal hygiene, were the most frequently set goals. More goals were associated with the terms "function" (45.8%) and "fitness" (37.5%). The TREINI program resulted in significant improvements in performance and satisfaction for most functional priorities ($p < 0.05$). **Conclusion:** For parents of children with MMC, ADLs were identified as the main treatment priorities. The TREINI program resulted in significant improvements in the performance of functional goals and increased parental satisfaction.

Keywords: Myelomeningocele. Children. Adolescents. Rehabilitation.

Resumo

Introdução: *Crianças com mielomeningocele (MMC) frequentemente apresentam limitações que impactam suas atividades diárias e rotina familiar. Compreender as prioridades parentais e aplicar intervenções eficazes é essencial otimizar a funcionalidade e favorecer o desenvolvimento global dessas crianças.* ***Objetivo:*** *Caracterizar os objetivos funcionais de crianças com MMC, organizá-los de acordo com o referencial* F-words *e avaliar os efeitos do programa TREINI namelhoria desses objetivos funcionais.* ***Métodos:*** *Realizou-se um estudo piloto não randomizado envolvendo 26 crianças (2 a 14 anos) com MMC. A Medida Canadense de Desempenho Ocupacional (COPM) foi utilizada para caracterizar os objetivos funcionais e avaliar os benefícios do programa TREINI. O protocolo consistiu no treino de objetivos funcionais em ambiente naturalista, combinado com o uso de uma veste terapêutica flexível, durante três meses, cinco vezes por semana, de 3 a 4 horas por dia. Estatísticas descritivas foram aplicadas para descrever o perfil das prioridades. Dados pré e pós-intervenção foram analisados pelo teste t pareado.* ***Resultados****: Um total de 121 metas foi estabelecido pelos pais, sendo as atividades de vida diária (AVDs), como mobilidade funcional, vestir-se e higiene pessoal, as metas mais frequentes. A maioria dos objetivos esteve associada aos domínios "função" (45,8%) e "capacidade física" (37,5%). O programa TREINI resultou em melhorias significativas no desempenho e na satisfação para a maioria das prioridades funcionais (p < 0,05).* ***Conclusão:*** *Para os pais de crianças com MMC, as AVDs foram identificadas como as principais prioridades terapêuticas. O programa TREINI promoveu melhorias significativas no desempenho dos objetivos funcionais e aumentou a satisfação dos pais.*

Palavras-chave: *Mielomeningocele. Crianças. Adolescentes. Reabilitação.*

Introduction

Myelomeningocele (MMC) is one of the most common congenital defects among children and is characterized by the incomplete closure of the neural tube.[1] Children with MMC often present with hydrocephalus and Arnold Chiari malformation, as well as various levels of motor and sensory impairment, which vary depending on the location of the lesion.[2] MMC can also be associated with long-term physical and cognitive disabilities and developmental delays.

These children often require assistance with mobility and self-care activities[3] and exhibit low levels of participation.[4] Thus, children with MMC may experience impairments in all components of functionality as outlined by the International Classification of Functioning, Disability and Health (ICF).[5]

The ICF has played a fundamental role in broadening the understanding of various factors that affect health.[5] However, its practical application still encounters significant obstacles. The F-words have been essential in overcoming these barriers, fostering a deeper awareness of how we should approach, communicate, and interact in the care of children with disabilities.[6-8] The F-words translate the complex framework of the ICF into accessible concepts that facilitate implementation.[8] For example, the F-word "function" corresponds to the activity category in the ICF, encompassing the activities a person can perform, such as daily tasks. The F-word "fitness" relates to body structures and functions, while the F-word "family" represents a vital component of children's environmental factors. The F-words "friends" and "fun" reflect participation and personal factors, respectively. Finally, the F-word "future" was introduced to emphasize how a child's current condition can influence their future life, as development is always oriented toward what is to come.[8,9]

Based on the principles of the F-words and family-centered practice, parents of children with disabilities should be considered essential partners in the healthcare team. Their active participation in the decision-making process and in setting goals for their children's development is fundamental, as they possess in-depth knowledge of their child's needs and preferences.[10,11] This knowledge should be integrated into healthcare services, ensuring that they address family priorities and the established functional goals.[12-14] The involvement of both the child and family in all stages of decision-making is crucial, as it allows them to share their priorities with healthcare professionals.[11] Given that children with MMC face challenges in various areas, goal setting should be carried out collaboratively between the family and professionals, using an integrated approach, rather than treating the objectives in isolation. Therefore, it is essential to offer interdisciplinary interventions, as the complex needs of these children require ongoing collaboration among different healthcare professionals.[14]

The TREINI program, developed for children and adolescents with MMC and other neurodevelopmental disorders, is an interdisciplinary intervention that utilizes

the principles of collaboration between families and professionals, as well as family-centered practice.[15] TREINI is an intensive intervention based on the biopsychosocial model and the ICF. The program employs evidence-based practices within a naturalistic learning environment called the "City of Tomorrow," where children enga-ge in daily activities in simulated contexts, such as the home, school, market, streets, and sports court.[15] The program is complemented by the TREINI exoflex therapeutic garment, which uses the principles of tensegrity and myofascial meridians to provide stability, postural correction, and support to the musculoskeletal system, without restricting movement.[15,16] The entire theoretical foundation of the TREINI program is available in the study by Loffi et al.[15] The TREINI program has been proven to be beneficial for achieving functional goals, balance, mobility, and postural control in children with cerebral palsy.[16,17] However, its effects have not yet been evaluated in children with MMC.

Despite the potential of the TREINI program, there is limited literature demonstrating how therapeutic approaches, including TREINI, integrate parental priorities, particularly for children with MMC.[14-19] This gap is especially relevant when we consider the F-words framework, which emphasizes a holistic view of functionality centered on the child's potential and family priorities. Although the inclusion of parental input in rehabilitation services has been shown to improve engagement, satisfaction, and outcomes,[10] there is a lack of evidence on how family priorities align with the domains of the F-words and how such alignment can enhance therapeutic results. Furthermore, existing studies fail to adequately describe how programs like TREINI address functional goals in ways that are meaningful and specific to the needs of families of children with MMC. Incorporating parental priorities into intervention programs is essential to foster greater acceptance, engagement, and satisfaction among families, which is reflected in more positive outcomes for children and adolescents with disabilities.[11-20] This alignment between family goals and therapeutic approaches promotes family-centered interventions that are more responsive to real-life contexts.[20]

Thus, this study sought to address two critical gaps. First, it aimed to characterize the profile of functional goals for children with MMC, investigating their relationship with participants' functional classifications and the domains of the F-words framework. Second, it sought to evaluate the effectiveness of the TREINI program in improving these goals, particularly focusing on its ability to align with parental priorities and address the holistic needs of children with MMC. By emphasizing family-centered care within an integrated and innovative intervention model, this research aims to bridge significant gaps in the literature and contribute to the development of more personalized and effective therapeutic approaches.

Methods

A single-group, non-randomized pilot study was conducted. The protocol for this study received approval from the local research ethics committee, under number CAEE 72360923.9.0000.5134. Before the assessments were performed, all parents signed an informed consent form. Children and adolescents also signed the informed assent form.

Participants

A total of 26 children and adolescents participated in the study. Participants from both public and private clinics were invited to take part in the study. However, the final sample consisted of participants from private clinics that provide rehabilitation services for children and adolescents. Individuals of both sexes, diagnosed with MMC, aged between 2 and 14 years, were included in the study. Children and adolescents classified at different levels of the Myelomeningocele Functional Classification (MMFC) scale were included.[21] Participants were excluded if they had undergone orthopedic surgical procedures within the six months prior to the start of the study; had associated health conditions that could compromise the safe execution of the intervention (such as cardiorespiratory diseases or uncontrolled seizures); or exhibited cognitive and/or behavioral challenges that either impeded their ability to follow instructions or compromised their safe participation in the proposed intervention.

Instruments

Classification scale: The MMFC was used to assess the functional classification of the participants.[21] The MMFC considers lower limb muscle strength, the type

of external support and orthoses required for ambulation, and walking capacity as measured by the distance traveled. The scale is easy to interpret, has prognostic value in terms of function, and facilitates communication among members of the healthcare team. In the current study, the MMFC was used solely for sample characterization. The MMFC consists of four levels: MMFC1 corresponds to individuals with the greatest dependence and impairment, requiring total reliance on a wheelchair and continuous assistance for daily activities; MMFC2 represents those who need a wheelchair for mobility, but may have limited ability to perform some tasks independently; MMFC3 includes individuals who walk with assistive devices and maintain partial independence; and MMFC4 refers to the most functional group, who walk without assistance. The MMFC has already been translated and cross-culturally adapted for use in Brazil.[21]

Primary outcome measure: The Canadian Occupational Performance Measure (COPM) is an individualized, client-centered tool for establishing therapeutic goals, widely used in pediatric rehabilitation.[22,23] It assists therapists and families in setting intervention priorities, focusing on self-care, productivity, and leisure. Through semi-structured interviews, families identify important activities, by assigning scores from 1 to 10 for performance and satisfaction; 1 indicates low performance or satisfaction and 10 represents high performance or satisfaction. In the current study, the COPM was used to define the profile of participants' functional priorities and to assess changes in performance and satisfaction regarding functional goals following the implementation of the TREINI program. The COPM was proven to be valid and reliable, and effective in detecting changes in performance over time or after interventions.[24]

Secondary outcome measure: A questionnaire was developed by the authors of this study to assess both the collaboration between family and professionals, and parental satisfaction with the TREINI program, adapted from the collaborative practice model by An et al.[25] The instrument consists of seven specific items, with four focused on evaluating collaboration between the family and the professional team, and the remaining three assessing satisfaction with the sessions, therapists, and interventions implemented. Each item is rated on a 5-point Likert scale, where a score of 1 reflects low levels of collaboration or satisfaction, and a score of 5 indicates high levels of collaborative efficiency or strong satisfaction with the program. This instrument has already been used in previous studies.[16,19]

Intervention

The study participants underwent an intensive intervention program using the TREINI program, lasting three months, during which sessions were held 3 to 5 times per week, with a daily workload of 3 to 4 hours. Within the TREINI framework, the initial application of the COPM was conducted together with the families, aiming to identify three to five priority therapeutic goals. The interaction between parents and therapists for the definition of functional goals followed a collaborative approach, centered on the specific needs of the child and family. This process involved open and ongoing communication, allowing parents to share their expectations, concerns, and perceptions regarding the characteristics, strengths, and difficulties of the child or adolescent. In turn, therapists provided their professional input, grounded in scientific evidence, to guide therapeutic choices. Through this collaboration, parents and therapists estab-lished realistic and achievable therapeutic goals, which were integrated cohesively into the family's daily routine.

Subsequently, the interdisciplinary team developed an individualized intervention plan tailored to the specific needs of each child. The selection of the professional specialties involved in the intervention program and activities to be implemented was determined based on the unique characteristics of each participant. The interdisciplinary intervention team consisted of physiotherapists, occupational therapists, psychologists, and speech-language pathologists, whose complementary expertise enabled a holistic and personalized approach to the development and support of the children. The intervention plan encompassed all domains of the ICF that could impact the achievement of the functional goals.

The intervention included the use of the TREINI exoflex therapeutic suit in a naturalistic environment called the "City of Tomorrow." Each professional applied best practices based on the available scientific evidence within their area of expertise: the physiotherapist focused on motor skills training, the occupational therapist imimplemented task-oriented training, the speech-language pathologist adopted socio-communicative strategies, and the psychologist utilized cognitive-behavioral approaches. The team worked collaboratively to achieve the therapeutic goals established jointly with the children and their families, guiding the selection of therapeutic methodologies.

Procedures

Initially, the general characteristics of the participants, such as sex, age, and educational level, were collected. The MMFC classification scale was then administered. The COPM was applied before and immediately after the intervention, by a professional trained in occupational therapy and with experience in using the instrument. The questionnaire on family-professional collaboration and satisfaction was administered by the same occupational therapist after the completion of the 3-month intervention. The TREINI program's interdisciplinary team comprised physiotherapists, occupational therapists, psychologists, and speech therapists. All therapists qualified to deliver interventions using the TREINI program underwent a training process that included both in-person and remote sessions. Additionally, they participated in a certification program and received ongoing guidance from TREINI program specialists, ensuring consistent delivery of therapeutic practices and continual updating of the approaches used.

Categorization of functional goals

The functional goals established by the participants were initially categorized according to the domains described by the American Occupational Therapy Association (AOTA).[26] This framework organizes occupation-related activities into different categories, including activities of daily living (ADLs), instrumental activities of daily living (IADLs), rest and sleep, education, work, leisure, play, and social participation. Each domain encompasses specific subcategories; for example, within the ADL domain, activities such as feeding, dressing, personal hygiene, functional mobility, and bathing are included. Subsequently, the functional goals were also grouped according to the F-words domains, which translate the principles of the ICF into concepts applicable to clinical practice. Two examples of categorization are as follows: the priority "I would like my child to improve balance" was classified as "fitness", and the priority "I want my child to walk with a walker" was classified as "function." The categorization process was independently conducted by two researchers (TKFC and AFBL), with discrepancies resolved by a third researcher (DOS).

Statistical analysis

Statistical analyses were performed using SPSS for Windows, version 22.0. Data were analyzed using descriptive statistics, including measures of central tendency, dispersion, percentages, and frequencies. For organizational purposes, the therapeutic goals established by the participants were grouped according to the F-words framework.[8] The chi-square test was used to analyze the association between the profile of functional goals and participants' functional classification on the MMFC scale. To test the hypothesis that parents' perceptions of their children's performance and satisfaction regarding functional goals would improve following the TREINI program intervention, the percentage changes in COPM scores were evaluated. Additionally, a paired t-test was used to compare mean COPM scores before and after the intervention. Cohen's d was calculated to determine the magnitude of the effects of the TREINI program, adopting the following interpretation criteria: large (d = 0.80), medium (d = 0.50), and small effect (d = 0.20). To investigate the hypothesis that the TREINI program promotes effective collaboration between families and professionals, as well as to assess parental satisfaction with the program, means and confidence intervals were calculated for each item of the collaborative practice and satisfaction questionnaire.

Results

A total of 26 children and adolescents with MMC participated in the study. The age ranged from 2.8 to 14.3 years (mean 7.29 ± 2.94). The majority of participants were female (51.9%). MMCF1 was the most prevalent classification, including 40.7% of the individuals, followed by MMCF2 and MMCF3, comprising 22.1% and 18.2% of the participants, respectively.

Characterization of functional goals

Functional goals, established through interviews with parents or guardians using the COPM, identified and prioritized up to five relevant daily activities of their children. A total of 121 goals were established by the parents/guardians of the children and adolescents with MMC. When all goals were categorized according to to the areas of occupational performance proposed by AOTA,[26] it was found that the majority of functional goals (63.63%) were related to ADLs, with goals concerning functional mobility (19.19%), dressing (14.14%), and personal hygiene (14.14%) being the most frequent.

Among the IADLs, demands related to home management and organization (e.g., tidying the bedroom) accounted for 6.06% of the goals. Regarding goals related to body structures and functions, 6.06% focused on attention and behavior functions. Approximately 5.05% of the goals were related to participation in formal education. Details of the goals established by the participants are presented in Table 1.

Table 1 - Functional goals established by the participants

Activity	n (%)
Activities of daily living	
Functional mobility	19 (19.19)
Dressing	14 (14.14)
Personal hygiene	14 (14.14)
Feeding	10 (10.10)
Use the toilet and perform intimate hygiene	3 (3.03)
Bathing and bathing in the shower	3 (3.03)
Instrumental activities of daily living	
Establishment and management of the home	6 (6.06)
Communication management	1 (1.01)
Mobility in the community	1 (1.01)
Body functions	
Mental functions associated with behavior	6 (6.06)
Neuromusculoskeletal functions	4 (4.04)
Sensory functions	2 (2.02)
Play	
Exploratory or participatory play	3 (3.03)
Social interaction skills	
Social interaction with peers and family	3 (3.03)
Education	
Formal educational participation	5 (5.05)
Motor skills	
Manual and fine motor skills	3 (3.03)
Positioning	3 (3.03)

Chi-square test analyses showed no association between the profile of goals and the functional classification of the children on the MMFC scale. When the functional goals established by the parents of children and adolescents with MMC were grouped into the different F-words, the results showed that 45.8% were associated with the F-word "function", and 37.5% with "fitness"; "fun" and "friends" were less frequently chosen, representing 11.7% and 5%, respectively. No goals were related to the F-words "family" or "future". Figure 1 provides further details on the orga-nization of the goals within the F-words categories.

Effect of the TREINI program on functional goals

Tables 2 and 3 detail the percentages of functional goals that showed changes in the COPM after the intervention with the TREINI program for performance and satisfaction, respectively.

Table 2 - Number of goals (NG) that showed changes in performance after the intervention

IE	NG	CNA	Cumulative %
9	4	4	4.87
8	1	5	6.09
7	3	8	9.75
6	1	9	10.97
5	6	15	18.29
4	5	20	24.39
3	11	31	37.80
2	12	43	52.84
1	7	50	60.97
0	24	74	90.24
< 0	8	-	-

Note: IE = intervention effect (change in Canadian Occupational Performance Measure scores); CNA = cumulative number of activities.

Table 3 - Number of goals (NG) that showed changes in satisfaction after the intervention

IE	NG	CNG	Cumulative %
9	5	5	6.09
8	0	5	6.09
7	3	8	9.75
6	5	13	15.85
5	7	20	24.39
4	8	28	34.14
3	3	31	37.80
2	13	44	53.65
1	6	50	60.97
0	24	74	90.24
< 0	8	0	-

Note: IE = intervention effect (change in Canadian Occupational Performance Measure scores); CNG = cumulative number of goals.

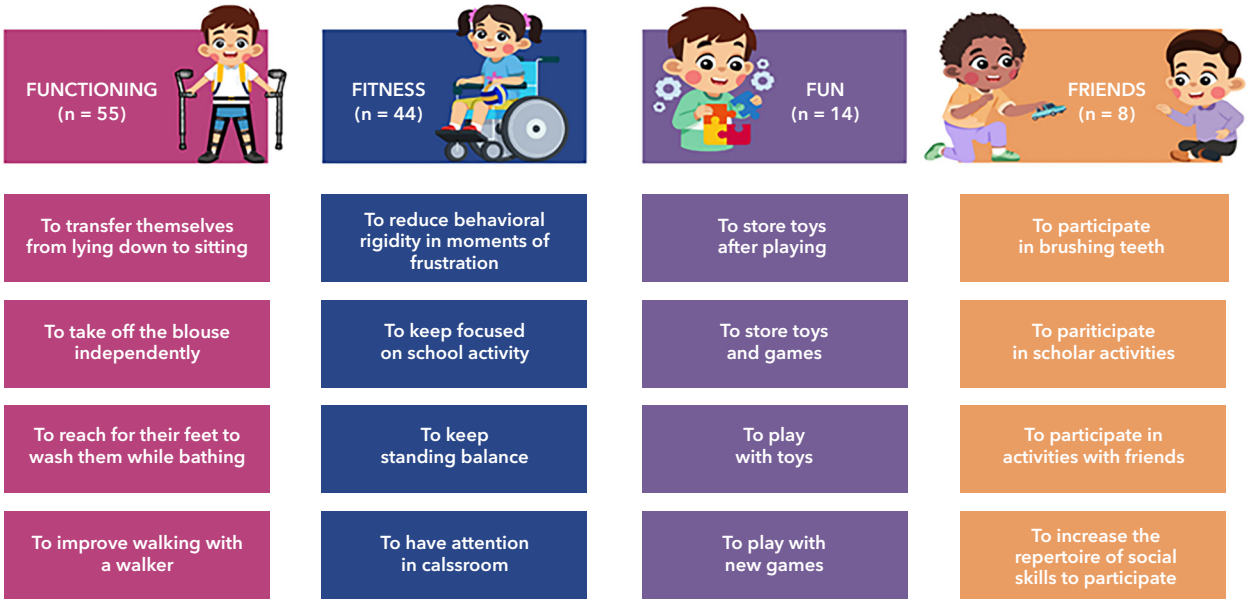

Figure 1 - Organization of the goals within the F-words categories.

According to the parents' perception, the percentage of functional priorities that improved by at least one point in COPM performance was 60.97%. For a small number of goals (29%), no improvement in performance was observed. The value for satisfaction with children's performance in COPM was similar (60.94%). Analyses using the paired-sample Student's t-test revealed significant effects in pre- and post-intervention comparisons, for both performance [$t(25) = 3.704$; $p < 0.002$, $d = 0.98$] and satisfaction [$t(25) = 4.994$; $p < 0.001$, $d = 1.26$].

Table 4 details the results of the questionnaire assessing parents' perceptions of collaboration between families and professionals, as well as their satisfaction with the intervention offered by the TREINI program.

Table 4 - Parent perception about the TREINI program

Questions for parents	Min – Max	Median
1. How encouraged were you by the therapists to share your opinion when setting the goal of your child's therapy?	3 - 5	5
2. To what extent did the therapists encourage you to share your opinion when planning the therapies for your child and family?	1 - 5	5
3. To what extent did the therapists provide guidance and suggestions, encouraging you in activities that your child and family can incorporate into daily routines to reach the goal?	3 - 5	5
4. How many days per week did your child and family engage in activities in your daily routines to achieve the goal?	1 - 4	3
5. What was your level of satisfaction with TREINI regarding the improvement of your child's skills?	4 - 5	5
6. What was your level of satisfaction with how the therapies were conducted?	4 - 5	5
7. Compared to other interventions you have experienced (conventional interventions), how would you evaluate your experience with TREINI?	4 - 5	5

Note: Min = minimum; Max = maximum. Response options for items 1, 2, and 3: very great encouragement = 5; great encouragement = 4; moderate encouragement = 3; small encouragement = 2; no encouragement = 1. Response options for item 4: everyday = 5; 5-6 days = 4; 4-3 days = 3; 2-1 days = 2; never = 1. Response options for items 5 and 6: very satisfied = 5; satisfied = 4; more or less satisfied = 3; unsatisfied = 2; very unsatisfied = 1. Response options for item 7: much better = 5; better = 4; same = 3; worse = 2; much worse = 1.

For the items addressing family-professional collaboration (items 1-4), approximately 88% of parents reported high or very high encouragement from therapists during goal setting, planning interventions, and providing guidance on incorporating activities into daily routines.

Approximately 60% of parents indicated that they practiced activities at home on between 3-4 days/week to achieve the program objectives (item 4). Regarding satisfaction with the intervention program (items 5 and 6), around 99% of parents expressed that they were satisfied or very satisfied with the TREINI program. Furthermore, 94.1% of parents rated the intervention with the TREINI program as significantly superior to conventional therapies.

Discussion

The current study aimed to characterize the functional goals established by families of children and adolescents with MMC. In addition, we evaluated the changes in performance and satisfaction associated with these goals after the application of the TREINI program, an interdisciplinary, family-centered intervention program. ADLs such as functional mobility, dressing, and personal hygiene were identified as the main functional goals, regardless of the participants' functional classification on the MMFC. The results showed that more goals were related to the "function" and "fitness" dimensions of the F-words. Finally, the findings of this study indicated that the TREINI program was perceived as effective for the majority of functional goals for children/adolescents with MMC. Parents believe that the TREINI program fosters family-professional collaboration and were satisfied with the intervention received. These main results will be discussed in the following paragraphs.

The predominance of goals related to functional mobility, set by the parents of children with MMC in the current study, reflects a concern grounded in the functional limitations commonly observed in this population. Children with MMC, especially those classified at MMFC levels 1 and 2, tend to present significant mobility restrictions, which compromise their ability for independent locomotion and directly influence their participation in social, educational, and recreational contexts.[27] Parents' perception of mobility as a central limiting factor is supported by studies that identify mobility as a critical barrier to the participation of children with physical disabilities.[28] Considering that more than 60% of the participants in the current study were classified at MMFC levels 1 and 2, this finding was expected. In this context, mobility is established as an essential component of overall functionality, being closely related to personal autonomy, independence in ADLs, and quality of life, which justifies its prioritization as a therapeutic goal by families.

The results of the current study demonstrate that ADLs are the main functional priorities for the parents of children and adolescents with MMC, regardless of the functional classification assigned by the MMFC system. This finding highlights the centrality of demands related to self-care and functional mobility in parents' perceptions of their children's quality of life and development. This trend is consistent with previous studies conducted with pediatric populations with cerebral palsy[13] and autism spectrum disorder,[14] which also identified ADLs as the primary focus of family expectations regarding therapeutic interventions.

According to Chiarello et al.,[29] a child's ability to meet their basic self-care needs is directly associated with higher levels of social participation and autonomy in adulthood. Furthermore, evidence indicates that, in children with neuromotor dysfunctions, limitations in ADL performance and the resulting participation restrictions negatively impact quality of life.[30,31] As such, the prioritization of ADLs by parents in this and other studies is justified, reinforcing the relevance of these skills as central therapeutic goals in pediatric rehabilitation programs. These findings highlight the need for intervention strategies that, while individualized, are oriented toward practical functionality and the promotion of independence within the family and community context.

The analysis of the functional goals established by parents, based on the F-words, showed a predominance in the categories "function" and "fitness," which correspond to activities and to body structures and functions, according to the ICF.[5] This preference reflects the tendency of parents to prioritize basic motor and functional skills, such as mobility, sphincter control, and self-care, as these are more visible aspects and directly associated with the child's autonomy. In cases of neuromotor impairment, such as MMC, these goals are perceived as more urgent, given the clinical challenges and the desire to promote greater independence. On the other hand, goals related to "family," "friends," and "fun" tend to be seen as less of a priority, or more abstract, especially when therapeutic resources are limited and

expectations are focused on concrete functional gains. This low representation may also reflect the influence of traditional biomedical models, focused on the body and function, to the detriment of approaches geared towards participation and quality of life.[31] In light of this, it is essential to implement awareness strategies that broaden parents' understanding of the multiple aspects of child development. Professionals should adopt a family-centered, interdisciplinary approach, promoting goals that also include social participation, emotional bonds, leisure, and emotional well-being. By valuing all the F-words (function, family, fitness, fun, friends, and future), the development of more comprehensive, meaningful therapeutic plans is promoted, aligned with the real needs and potential of the child.[9,32]

The absence of goals related to the F-word "future" in the definitions presented by parents of children with MMC, as observed in the current study, may reflect both a prioritization of immediate functional demands and a restricted view regarding the long-term developmental potential of these children. As pointed out by Rosenbaum and Gorter,[8] the concept of "future" in the F-words for child development goes beyond defining distant goals; it encompasses the ongoing construction of realistic and positive expectations for the child's trajectory, with emphasis on potential, interests, and progressive autonomy. However, in the face of clinical uncertainties, motor limitations, and the inherent burden of daily care, parents often focus on short-term goals, prioritizing immediate gains and neglecting planning for future stages, such as the transition from childhood to adulthood. This gap highlights the need for health and education professionals to foster, from the early stages of intervention, an active reflection on the future, promoting practices that empower families, broaden their understanding of developmental possibilities, and support the construction of meaningful life projects for the child. This approach includes setting goals related to functional independence, vocational choices, social inclusion, and quality of life in adulthood. Thus, considering the "future" constitutes a fundamental element for promoting child agency, aligning family expectations, and guiding broader, more coherent interventions that prepare children for a full and participatory life course.[32]

City of Tomorrow, an innovative component of the TREINI program, was designed with the aim of fostering the construction of the "future" for children with MMC by offering opportunities to develop independence in an enriched, functional environment that represents everyday life contexts. This approach may have positively influenced the outcomes observed with the implementation of the program in the present study. By integrating playful and contextualized experiences, City of Tomorrow facilitates the acquisition of practical skills and the promotion of autonomy, which are central aspects for the functional progress observed. Similar results have already been reported in previous studies with children with cerebral palsy,[16,17] reinforcing the effectiveness of the TREINI program in different neurological conditions. In line with the principles of family-centered practice, the program values the active involvement of parents and caregivers in the therapeutic process, promoting the collaborative definition of goals together with the interdisciplinary team. These objectives are operationalized through individualized plans, based on the best available scientific evidence.[15] Another innovative resource of the program is the TREINI exoflex therapeutic garment, which plays a fundamental role in enhancing results, by providing targeted postural and proprioceptive stimuli. Its use supports postural correction, biomechanical alignment, and muscle activation, promoting greater engagement of the child during therapeutic activities. The adoption of programs with these characteristics is particularly relevant for children with MMC, considering their clinical profile, which is often marked by motor, sensory, proprioceptive, and urological challenges, that increase the risk of participation restrictions. Thus, interventions that prioritize functionality, autonomy, and engagement are essential to promote overall development, support social inclusion, and improve the quality of life for this population.

In addition to the intensity of practice and the use of the therapeutic suit, it is plausible that the TREINI method promoted changes through mechanisms of neuroplasticity and motor learning. Intensive, goal-directed training in naturalistic environments provides repeated opportunities for active movement generation and problem-solving, conditions that favor activity-dependent synaptic plasticity and the strengthening of motor networks.[33] Repetition of meaningful tasks may enhance cortical reorganization and facilitate the integration of new motor strategies, in line with principles of motor learning such as variability, feedback, and task specificity.[34] Furthermore, the TREINI exoflex therapeutic suit may have supported sensorimotor feedback and alignment of biomechanical chains, thereby increasing

proprioceptive input and optimizing motor control.[15] These mechanisms provide a theoretical rationale for the functional improvements observed, suggesting that TREINI may act not only by compensating impairments but also by stimulating adaptive neuroplastic changes.

The results of the current study should be interpreted in light of some important limitations. Firstly, the small sample size and the predominance of children classified at MMCF1 and MMCF2 levels limit the generalizability of the findings to the entire population of children with MMC, especially those with different levels of functional impairment. Participants were recruited by convenience sampling from specialized rehabilitation clinics, which ensured feasibility and consistency of the intervention, although it limited the generalizability of the results. This strategy is common in exploratory research, reinforcing the relevance of the findings as preliminary evidence. Future studies should broaden recruitment to more diverse contexts to enhance external validity. Additionally, although the COPM was used for goal setting, specific instruments to assess parents' knowledge of the F-words were not employed, which may have affected the accuracy in identifying and classifying these goals. Future studies could incorporate more targeted assessment tools to allow deeper exploration of parents' understanding of the F-words.

Regarding the benefits of the TREINI program, no objective measures were applied to evaluate the direct effects of the program on the children, which limits the quantitative analysis of the program's effectiveness. The questionnaire to assess parental collaboration and satisfaction was developed grounded in family-centered practice and existing literature. While it enabled the capture of relevant aspects of parental involvement, it has not yet undergone formal psychometric validation, which should be pursued in future research. According to this, another limitation of this study is that no specific instrument was used to directly measure functionality, which restricts the possibility of relating the observed improvements to objective performance outcomes. However, the use of the COPM allowed us to sensitively capture families' perceptions of meaningful functional changes, which is consistent with the family-centered nature of the TREINI method and reinforces its potential to promote relevant gains in daily life. The absence of a control group also prevents direct comparisons, making it difficult to associate the observed improvements in goals with the effects of the program. For a more robust and conclusive evaluation, future studies should include controlled clinical trials, larger samples, and long-term follow-up, in order to provide more consistent evidence on the effectiveness of the TREINI program.

Conclusion

The identification of functional goals for children and adolescents with MMC is essential for developing individualized therapeutic interventions that are aligned with the real needs of families. In this study, ADLs emerged as the main functional goals for parents, with most of the F-words goals related to "function" and "fitness," reflecting an emphasis on activities and body functions, while participation, contextual factors, and future projections were less frequently prioritized. These findings provide valuable preliminary insights for health professionals, both to design more targeted interventions and to support families in broadening their perspectives across all domains of child development. The TREINI program demonstrated promising potential in enhancing performance and satisfaction with functional goals within a family-centered, interdisciplinary, and evidence-informed approach. While these results suggest positive effects, further research with larger samples, objective outcome measures, and control groups is necessary to confirm the program's effectiveness and strengthen the evidence base for its use in clinical practice.

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Authors' contributions

TKFC and DOS conceived the study, revised the background, prepared the data collection plan and prepared the draft of the manuscript. AFBL and ACCS participated in the data collection and contributed to drafting the manuscript. RPCN participated in the revision of the background and participated in the data collection. All authors conceived the study, participated in

preparing the data collection plan and prepared the final version of the manuscript, read and approved the final version of the manuscript.

Data availability statement

Research data is not available.

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