Effects of Interdisciplinary Therapy in A Patient with Severe Dystonic Cerebral Palsy: a 12-Year Follow-up Case Report

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ABSTRACT

Dystonic cerebral palsy (CP) presents significant challenges due to its complex movement disorders and associated complications. This case report details a unique 12-year longitudinal observation (from birth to 12 years of age) of a patient with severe dystonic CP, highlighting the benefits of an interdisciplinary, structured therapeutic approach.

The patient exhibited severe dystonia, motor impairment, and a high risk of musculoskeletal and systemic complications. Diagnosis and treatment were guided by the WHO's International Classification of Functioning, Disability, and Health (ICF) framework, incorporating the "F-words" concept and evidence-based recommendations. An interdisciplinary team collaborated to provide comprehensive, long–term care, including a neurologist, orthopaedist, neurosurgeon, physiotherapist, orthoptist, neuro-logopedist, alternative communication specialist, and psychologist.

Over the whole course of treatment, the patient maintained good body structure and function, with no significant pain or respiratory, gastrointestinal, or urinary complications. While the mild range of motion restrictions were observed, the patient achieved independent mobility using assistive technologies and actively participated in school, sports, family activities, and social interactions. However, dystonic movements remained an unresolved challenge.

This case underscores the potential of a structured, interdisciplinary approach to enhance the quality of life for individuals with severe dystonic CP. This approach significantly improved the patients' and their families' quality of life across all ICF domains. Our findings highlight the need for national healthcare systems to adopt comprehensive rehabilitation strategies to improve functional outcomes and promote independence in children with CP.

Keywords: Cerebral Palsy, Dystonia, Interdisciplinary Therapy, Long-term Follow-up

INTRODUCTION

Being aware of the contemporary trends in the holistic management of children with CP and the existing informational gaps, we conducted a 12-year observation (from birth to 12 years of age) of the patient with dystonic form CP. Employing International Classification of Functioning, Health, and Disability (ICF; WHO, 2001), the concept of "F-words" (Rosenbaum & Gorter, 2012) and evidence-based recommendations for the management of patients with CP from several regions of the world (Damiano et al., 2021; Hägglund et al., 2014; NICE, 2016a; NSW Health, 2018), we achieved very encouraging results in several ICF domains that we would like to spread to the broader community.

LITERATURE REVIEW

Cerebral Palsy (CP) is an umbrella term comprising a group of permanent postural and motor disorders that are attributed to non-progressive disturbances occurring in the developing fetal or infant brain. It is the most common source of motor disability in childhood. The impact of CP on patients and their families extends across their lifespans, influencing independence in activities of daily living and participation in education, social, and community.

CP is a heterogeneous condition based on impairments' etiology, type, and severity. Considering the kind of altered muscle tone, we distinguish three forms: spasticity, rigidity, and dystonia (Ganguly et al., 2021). Dystonia is characterized by involuntary contractions of opposing muscles, resulting in deviating movement and/or postures (Zoons et al., 2011). However, non-motor features (e.g., cognitive deficits, pain, fatigue, sleep problems, and psychiatric problems) appear to be an integral component of the phenotype of dystonia. They may contribute even more to the perceived burden of the disorder than motor symptoms (Peall et al., 2015).

The diagnosis and treatment of dystonia are challenging due to its variable presentation. Dystonia may not be evident early in a patient's life before the age of 3 or 4 years and may develop as late as 12 or 13 years of age. Dystonia may also evolve and progress over time (Cerovac et al., 2007). A review of the literature indicates a lack of clear guidelines for the treatment of dystonia. Due to limited evidence, the American Academy's Dystonia Care Pathway (AACPDM, 2024) is based on conditional recommendations. As a result, shared decision-making with families is essential. The recommendations' values and preference statements highlight the need for flexibility and key considerations when selecting a management approach that balances potential benefits and risks while aligning with the family's priorities.

This case report is unique in offering a comprehensive, longitudinal 12-year follow-up of a child with severe dystonic CP, providing rare insights into the real-world challenges and successes of interdisciplinary, patient-centered care. Unlike many studies that focus on short-term outcomes or specific interventions, this report details the long-term evolution of the condition. The findings underscore the urgent need for more structured therapeutic frameworks and reinforce the value of holistic, interdisciplinary approaches. Most importantly, this case illustrates how sustained, personalized care can enable a child with severe dystonia to achieve meaningful participation in life – an objective that should be central to all CP management strategies.

METHODS

All diagnostic and therapeutic procedures were implemented under supervision, with full informed consent and cooperation with the patient's parents. All were conformed with the Declaration of Helsinki as revised in 2013.

Clinical history and current presentation

The pregnancy progressed without complications, and a natural delivery occurred at the 41st week of gestation (birth weight: 3,400 g; length: 53 cm). However, complications arose during delivery, with the infant being born in thick meconium-stained amniotic fluid and displaying signs of moderate birth asphyxia (Apgar score: 4/4/4/5). The child, now a 12-year-old girl, has been diagnosed with the dystonic form of CP and is classified at level V on the Gross Motor Function Classification System (GMFCS).

Diagnostic process

The diagnostic process was structured by the ICF (Rosenbaum & Stewart, 2004) and engaged the interdisciplinary, international (Polish, German, Ukrainian) team of specialists, including neurologist, orthopedist, neurosurgeon, physiotherapist, orthotist, neuro-logopedist, alternative communication specialist and psychologist. The ICF domains include body function and structure, activity and participation, personal and environmental factors. The use of ICF in the management of the patient was based on the notion that "ICF expands our think-

Table 1. **The patient's Diagnostic history from birth to 12 years of age within the four ICF domains.**

ICF domain	Tool	Age	Results
			Laboratory and imaging trials
	Laboratory tests	day 1	MAS with associated respiratory and circulatory failure, persistent pulmonary hypertension, elevated inflammatory parameters and exponents of perinatal hypoxia, abnormal pattern of reflex oral responses
	EEG	4m. and 6y.	Generalized brain abnormalities
	Hip joints X-ray (Kiapekos et al., 2019)	18m. to 7y., twice per y.	• 2.5y – increased, MP <30% (observation) • 7y. – increased MP, <70% (moderate subluxation)
		8y. to 12y., once per y.	Left hip with no changes after osteotomy (observation)
	Spine X-ray (Graham et al., 2016)	2.5, 7 and 12y.	Asymmetry, without features of scoliosis
	Genetic tests	5y.	Exclusion of Angelman and Smith-Lemle-Opitz syndromes
			Clinical trials
Body structure and function	APGAR score	1., 3., 5., 10. min.	4/4/4/5 points
	Functional Motor Ability (HINE) (Haataja et al., 1999)	3m.	Cranial nerves function score (13 points), posture score (2), movements score (1), tone score (7), reflexes and reactions score (1); total result of the study: 24 (age-adjusted norm: 62.5-69)
	Functional Motor Ability (GMFCS) (Palisano et al. 1997)	24m.	Level V – unchanged until now
	Tone (HAT) (Jethwa et al., 2010)	24m.	Mixed tone: dystonia (items 1, 2, 6), rigidity (item 5), spasticity (items 3, 4)
	Range of motion	12y.	Lower extremities – mild to moderate limitations, focal hypermobility; upper extremities – joint hypermobility, limitations due to increased muscle tone (see Table 3)
	Myotonometry	12y.	Mild to moderate increase in muscle tone and stiffness at rest (see Table 3)
	US of the lateral abdominal muscles activity (Gogola et al., 2016, 2018)	8y. to 12y., once per y.	Non-regular reflexive activity present in response to neurodevelopmental traction technique. Significant side-to-side asymmetry
	Pain (FACES) (Garra et al., 2010)	12y.	Occasionally, left biceps and lumbar spine 2-4 per 10
Activity and participation	Speech and language (CFCS) (Hidecker et al., 2011)	36m.	Ability to communicate by eye gaze
	Quality of Life KIDSCREEN 10 (Ravens-Sieberer et al., 2001)	12y.	38 per 50
Environmental factors	School Readiness (SFA) (Sakzewski et al., 2007)	7y.	Patient requires: 1) special classroom, toileting, transfers, 2) AAC, 3) support and assistance at mealtimes, 4) one-on-one academic support, 5) changing positions, 6) adaptive equipment (9)
Personal factors	SB5 (Bain, 2005)	5y.	Severe intellectual disability (evaluation without the use of AAC)
	SB5 (Bain, 2005)	7y.	Moderate intellectual disability (assessment using AAC)

m. – month; y. – year; EEG – electroencephalography; MAS – meconium aspiration syndrome; X-rays – radiographic examination; MP – migration percentage; HINE – Hammersmith Infant Neurological Examination; GMFCS – Gross Motor Function Classification System; HAT – Hypertonia Assessment Tool; US – ultrasounds; FACES – The Wong-Baker Faces Pain Rating Scale; CFCS – The Communication Function Classification System; AAC – Augmentative and Alternative Communication; SFA – School Function Assessment; SB5 – Stanford-Binet Intelligence Scales.

ing beyond fixing on primary impairments to a view that places equal value on promoting functional activity and facilitating the child's full participation in all aspects of life" (Rosenbaum & Stewart, 2004) that strongly influenced our standpoint. In ICF, participation is considered an involvement in life situations. To achieve the ultimate goal through broader participation, we tried to assess and modify various aspects of the body structure and function, activity engagement, and environmental and personal factors influencing the patient's status (Sakzewski et al., 2007). Table 1 summarizes the diagnostic process and findings within the four ICF domains.

Structure of the therapeutic process

The general framework of the therapeutic program was outlined prospectively and based on several preliminary assumptions. The therapeutic interventions were divided into the four domains of the ICF. However, interactions between these domains were always taken into consideration. In many instances, a given intervention could affect more than one ICF domain. We paid particular attention to how interventions in other ICF domains could improve the patient's status in the participation and activity domain. The selection of particular interventions and techniques was based on evidence-based recommendations from Australian (NSW Health, 2018), Nordic (Hägglund et al., 2014), and British (NICE, 2016a). Throughout the observation period, we monitored updates of the aforementioned recommendations, emerging new therapeutic concepts, and scientific evidence in systematic (Jackman et al., 2022; Novak et al., 2013, 2020; NSW Health, 2018; Rosenbaum & Gorter, 2012; te Velde et al., 2022). New solutions were analyzed regarding their usefulness for the patient, and therapeutic plans were modified if necessary.

The therapy plan was presented in detail to the patient's parents, along with the appropriate literature. After further consultations with the program's authors, at 3 months of the child's age, they decided to cooperate with the therapeutic team throughout the developmental period. They agreed to include the child in long-term observation. The interdisciplinary, international Polish-German team guided the therapeutic process involving a physiotherapist and three medical doctors. Due to the amount of in-person contact between the patient and the physiotherapist, the last mentioned played a crucial role in the team, governing all necessary consultations, suggesting clinical centers to be employed, implementing the physiotherapeutic part of the therapy, engaging other specialists, etc. After agreeing to participate in the program, the child's parents became equal therapeutic team members. They participated in making all the decisions, defining their life needs and preferences and their environmental, social, and economic background. They were informed about the possibility of withdrawing from participation at any time without any consequences.

The therapeutic program was always operationalized with consideration of the F-word concept (Rosenbaum & Gorter, 2012). Authors of this concept indicate that in order to achieve a patient's motivation and commencement in therapy, the six F-words should always be considered: function, family, fitness, fun, friends, and future. Our interventions, environments, clinical centers, particular clinicians/specialists, therapy groups, equipment, and how to conduct interventions were always selected so that at least three of the F-words could actively "work." This issue also dictated parents' participation in the therapeutic team.

Therapeutic process

The overall structure of the therapeutic process is presented in Table 2. In this place, we only would like to add some details that could be of special importance.

Thanks to the efficient diagnostic process, the child was quickly admitted to therapy (3 months of age). At the initial stage, it was agreed that the goal of the ICF body structure and function domain would be to maintain musculoskeletal tissue elasticity and achieve head control to effectively use assistive technological devices (AT) in the future. For this purpose, two groups of interventions were constantly present in the treatment program: 1) prevention against musculoskeletal deformity (Table 2, Contracture prevention and management, and tone management), 2) muscle strength and motor control improvement (Table 2, Functional motor ability management). In the first group, we mainly relied on British guidelines (9): low-load passive stretching, 24-hour postural management strategies, orthotic support, and botulinum toxin (BTX-A). No serial casting was implemented due to the low tolerance for this measure in children with dystonia, confirmed by our patient.

Additionally, to reduce muscle tone, the Molli suit therapy (transcutaneous electrical nerve stimulation delivered through a full-body garment aiming to prompt reciprocal inhibition of the spastic muscles (Novak et al., 2020) was implemented at the age of 7 years. Throughout the treatment process, we have not been able to reduce symptoms of dystonia despite the attempts at pharmacological treatment (Table 2, Tone management). Implementation of the methocarbamol reduced dystonic spasms, but in

Table 2. **The patient's Treatment history from birth to 12 years of age within the four ICF domains.**

ICF domain	Diagnostic findings	Age	Solution
Body structure and function			***Early intervention***
	Respiratory and circulatory failure, persistent pulmonary hypertension, elevated inflammatory parameters, perinatal hypoxia, abnormal pattern of reflex oral responses	birth to day 16.	• BVM • intubation • NCPAP per 72 h • broad-spectrum antibiotics • catecholamine infusion • parenteral nutrition, intragastric feeding
	Generalized brain abnormalities	3m. to 3y.	Antiepileptic drugs
			Nutritional management
	Drooling, sucking, swallowing, chewing motor difficulties	birth to 12y.	Oral motor therapy to improve mouth function and control
			Functional motor ability management
	Poor head and body control	3m. to 3y.	Active form of NDT Bobath
	Poor head and body control	3 y. to 12y.	Gait training with the help of AT devices: • NF Walker® (1h every day) • Innowalk® (1-month training, 2-3 times per year) • Levi Active® therapy (suspension system)
			Contracture prevention and management
	Hypertonia, abnormal postures, involuntary, twisting movements	birth to 12y.	• 24-hour postural management strategies (NICE, 2016b) • fascial therapy and low-load passive stretching • orthotics to prevent or delay contractures • botulinum toxin (BTX-A): biceps, pronator teres muscles; hip adductors and gastrocnemius • fasciotomy: biceps brachii and teres major (bilateral)
			Tone management
	Twisting, dystonic movements making usage of AAC devices difficult	1y. to 12y.	Hydrotherapy
		7y. to 12y.	Electrical stimulation (Molli suit)
		11y.	Methocarbamol (unsuccessful – adverse side effects)
			Pain management
	Low back pain (associated with dystonic postures)	7y..	Muscle relaxation methods to attenuate pulling and pain (Jinnah & Factor, 2015)
	Spasms in the biceps brachii	11y.	Stretching exercises against contractures
	Respiratory restrictions	8y.	Chest and diaphragm manual therapy (Rutka et al., 2021)
			Hip surveillance
	MP < 30%; MP index increased more than 10%/y.	29m.	Soft tissue release: APT, obturator nerve neurotomy (left limb), APT (right limb) (Hägglund et al., 2014; NICE, 2016a; NSW Health, 2018)
	MP < 70% (moderate subluxation)	7y.	Hip/femur reconstruction: VDRO combined with pelvic osteotomy (left limb) to restore joint congruency and reduce forces on the hip (Novak et al., 2020; Wagner & Hägglund, 2022)
	post-osteotomy LLD	12y.	Planned epiphysiodesis of the left limb (Novak et al., 2020)
Activity and participation			***Speech/language and oral motor management***
	Motor speech impairment	36m.	Implementation of an eye gaze Tobii Dynavox device with BoardMaker Speaking Dynamically Pro. software
Environmental factors	Full support in the school setting required	7y..	Learning in a special school using AAC and AT (NICE, 2016a), one on one academic support (class for 4 students)
Personal factors	Support of intellectual development	3y. to 12y.	Stimulation of intellectual development using AAC and AT at school and home environment

m. – month; y. – year; BVM – bag valve mask; NCPAP – nasal continuous positive airway pressure; NDT – neurodevelopmental therapy; AT – assistive technological devices; MP – migration percentage; APT – adductor-iliopsoas tenotomy; LLD – leg length discrepancy; VDRO – varus derotation osteotomies of the proximal femur.

parallel, a significant decrease in the neck muscle tone occurred, making the usage of AAC impossible. In addition, the selective dorsal rhizotomy was considered. However, the patient was not qualified, as dystonia constitutes a relative contraindication (Jinnah & Factor, 2015).

In the second group of interventions, we focused on increasing muscle strength (especially in the neck). However, in the early period of life, we had limited opportunities. Unfortunately, there are currently no recommended methods addressing this problem for young children with CP who demonstrate GMFCS level V. Therefore, from the age of 3 months to 3 years, the NDT Bobath method was introduced despite the fact that, in light of current knowledge, it is rather not recommended (Faccioli et al., 2023; Kiapekos et al., 2019; Novak et al., 2020; NSW Health, 2018; te Velde et al., 2022). At the age of 3, AT devices were introduced into therapy, with a special role played by the NF Walker, which the child now regards as an integral part of her body. All interventions implemented in this group shared certain standard features: the practice of real-life activities, using self-generated active movements, high intensity, and directly targeting the goals set by the child/family.

Throughout the therapy, we also performed preventive procedures against hip dislocation following the Swedish model (Elkamil et al., 2011; Hägglund, 2014; Kiapekos et al., 2019). Unfortunately, we were not able to prevent the dislocation, and at the age of 7, the patient underwent the reconstruction of the left hip joint (Table 2, Hip surveillance). A minimally invasive approach was chosen, in which the child was not put in a cast and returned to physical activity just after 4 weeks. As a consequence of the operation, a shortening of the left lower limb occurred (7 cm). Therefore, another operation is currently planned to compensate for the length of the lower limbs – epiphysiodesis within the right extremity (Novak et al., 2020). Considering approaching the end of the growth processes, the right moment for the procedure is currently being determined.

A crucial aspect of the procedure was the neuro-logopedic training (Table 2, Nutritional management) implemented soon after birth and continued until recently. To improve mouth function and mouth control, the tactile and proprioceptive input from the mouth region was therapeutically amplified, food texture was gradually thickened, and a proper positioning program for eating activities was introduced, including support from the AT (NSW Health, 2018).

A significant step was taken at the age of 3 when augmentative and alternative communication (AAC) technology was introduced. Gradually developing communication ability finally allowed the patient to start special school education. (Table 2, Speech/language and oral motor management) (Graham et al., 2016). It is worth emphasizing that the introduction of the eye-controlled AAC between the two intelligence and cognitive abilities examinations (age 5 and 7) led to the change in the qualification of the child's intellectual disability level from severe to moderate, thus enabling school education (Table 2, Personal factors).

So far, there have been no particular interventions in the domain of personal factors in ICF. Periodic psychological consultations were conducted without any evident findings. The knowledge acquired by parents over the years, instructions from a psychologist, close contact, and conversations with the child proved, so far, sufficient.

Most of the interventions mentioned above and in Table 2 are localized within the body structure and function ICF domain, reflecting current global trends (Cans, 2000; Rosenbaum & Gorter, 2012). It must be remembered that in our approach, we constantly "use" the potential of this particular domain to achieve the ultimate goal of improved patient's activity and participation in life situations.

The patient and her family have generally demonstrated good adherence to the therapy, which has been essential for the ongoing progress in all ICF domains. Despite the challenges associated with her condition, she has shown remarkable tolerance for various interventions, including hip surgery, botulinum toxin injections, frequent manual therapy sessions, etc. Although some treatments, such as serial casting, were not well-tolerated due to her dystonic movements, the patient has generally responded well to other modalities. This positive adherence and tolerability have been key factors in achieving the therapeutic goals, particularly regarding mobility and communication. The family's active involvement and the patient's willingness to engage with the treatment plan have contributed significantly to the overall success of the interventions.

RESULTS

From the clinical perspective, the patient currently presents a good overall state of body structure and function. Aside from the left hip joint, which required surgical reconstruction at the age of seven, the musculoskeletal system remains in good condition. The spine and pelvis show relative symmetry; no significant pain symptoms, respiratory issues, gastrointestinal complications, or uri-

nary dysfunction have developed. There are mild range of motion restrictions, more pronounced in the upper limbs than in the lower limbs, along with mild tissue consistency changes (Table 3). Without external assistance, the patient exhibits limited head motor control but complete voluntary eye control. With the aid of assistive technologies (NF Walker), she is able to move independently, covering distances of approximately 800 meters on flat terrain, navigating adapted playgrounds, and responding appropriately to traffic signals and environmental cues. Despite intensive interventions, dystonic movements remain a persistent challenge, affecting overall motor control and fine motor skills. Cognitively and communicatively, the patient has made significant progress. Using AAC, she actively participates in a special education setting, demonstrating good comprehension of everyday and educational communication. She constructs logical, grammatically correct statements, engages in meaningful discussions, and effectively utilizes social media to communicate with peers and professionals, including therapists and medical staff.

Her physical well-being and independence have also positively influenced family dynamics, allowing the family to maintain an active lifestyle, engage in travel, and participate in adapted sports activities. Psychological assessments indicate no signs of emotional distress thus far; however, increasing self-awareness of her condition and emerging existential questions regarding her disability are becoming more frequent, particularly as she approaches puberty.

From the patient's viewpoint, she perceives herself as an active and engaged individual despite her physical limitations. She enjoys participating in school activities, socializing with friends, and expressing her personality through humor and conversation. AAC enables her to articulate thoughts clearly, advocate for her needs, and even challenge others in discussions, demonstrating her growing independence. She finds great joy in music, art, and sports, showing enthusiasm for adapted physical activities despite the constraints of dystonia. She appreciates outings with her family and enjoys exploring new environments, feeling included in shared experiences such as travel and recreational activities. However, as she grows older, she is becoming more aware of her differences and has begun questioning the nature of her disability. She asks thought-provoking questions such as, "Why can't I walk like my cousins?" and "What is the purpose of disability?" This growing self-awareness signals a need for increased psychological support, emotional guidance, and reassurance as she navigates adolescence and its associated challenges.

As far as the prognosis is concerned, several outcomes can be anticipated based on the patient's current condition. From a musculoskeletal perspective, it is expected that potential deformities, such as scoliosis or hip subluxation, may be managed effectively. However, progressive musculoskeletal challenges are always possible as she grows. Given the presence of dystonic movements, further strain on the musculoskeletal system is likely, and ongoing reassessment of orthotic support and potential surgical interventions may be necessary to preserve mobility and prevent secondary complications. Regarding motor function and mobility, the ability to move independently with assistive technologies is a significant achievement and is expected to continue with proper support. Cognitively, the patient has demonstrated strong intellectual engagement, problem-solving abilities, and social awareness. These abilities are expected to develop further, and she will likely continue to gain independence in educational settings. With the ongoing use of AAC, the patient will be able to enhance her capacity for self-expression and decision-making, which will be essential for her independence and integration into society. Psychologically, as the patient matures, her awareness of her condition will likely increase, leading to more questions about her disability, her self-identity, and how she fits into the broader social context. Looking ahead, advances in therapeutic interventions – such as personalized medicine, wearable exoskeletons, and brain-computer interface technology – hold the potential to enhance the patient's mobility and independence further. In addition, new pharmacological treatments and neuromodulation therapies for dystonia may better manage motor symptoms, reducing the impact of dystonic movements. Overall, the patient's prognosis is favorable, with significant progress in physical, cognitive, and social domains. While challenges remain, the holistic approach to care, ongoing interventions, and technological advancements provide a strong foundation for continued improvement.

DISCUSSION

Therapeutic interventions for children and young people with CP have evolved significantly over the past two decades, aligning with the ICF framework. This shift represents a transition from primarily addressing underlying symptoms and impairments to focusing on individually meaningful, real-life activities and task-based training, as well as directly enhancing participation within the community (Damiano et al., 2021; Jackman et al., 2022; WHO, 2001). Given that CP is one of the most

Table 3. **Ranges of passive motion of selected joints and tissue resting tone and stiffness.**

	Joint/dir.	side	1y.	2y.	3y.	4y.	5y.	6y.	7y.	8y.	9y.	10y.	11y.	12y.	ref.
passive range of motion (deg)	ankle/ dorsal flex.	R	50	49	44	44	40	41	45	44	44	43	42	40	*28*
		L	50	49	45	45	45	46	47	46	45	44	43	42	±7
	ankle/ plantar flex.	R	58	60	54	55	55	55	51	50	50	48	49	47	*49*
		L	60	60	58	55	52	55	50	47	45	45	45	43	±5
	knee/ flex.	R	145	148	145	145	145	142	140	138	135	135	135	131	*137*
		L	148	151	150	147	145	145	139	140	140	138	135	135	±9
	knee/ ext.	R	-5	-3	-2	0	1	0	-2	-2	-2	-5	-5	-7	*-2*
		L	-5	-2	-1	-1	-1	-1	-1	-4	-3	-3	-5	-5	±2
	hip/ flex.	R	130	132	135	135	137	132	125	120	117	115	110	110	*115*
		L	133	135	133	135	135	130	120	118	110	110	108	105	±8
	hip/ ext.	R	-5	-5	-3	0	0	2	2	0	0	0	0	0	*11*
		L	-7	-5	-3	0	0	0	0	-3	-1	-5	-5	-5	±4
	hip/ abd.	R	37	39	37	40	40	40	35	37	39	40	40	50	*48*
		L	40	42	43	41	45	45	50	60	70	80	90	90	±9
	shoulder/ flex.	R	172	175	175	178	175	173	175	173	170	173	170	170	*171*
		L	167	170	173	170	175	175	173	175	175	175	173	174	±6
	shoulder/ ext.	R	75	75	78	80	78	80	75	76	75	70	70	70	*62*
		L	79	75	80	80	80	76	75	74	73	70	70	68	±8
	elbow/ flex.	R	142	145	145	145	143	140	140	140	140	137	135	135	*141*
		L	145	145	143	145	145	144	140	138	140	140	142	140	±7
	elbow/ ext.	R	-5	-5	-3	-5	-2	-2	0	0	0	0	2	2	*2*
		L	-7	-5	-5	-5	-3	0	0	0	2	4	5	5	±3
	wrist/ flex.	R	88	85	83	85	83	85	87	85	90	90	90	90	*78*
		L	83	85	80	80	82	80	80	80	83	85	85	84	±5
	wrist/ ext.	R	82	80	80	76	78	76	78	80	80	82	80	80	*72*
		L	89	85	85	82	80	80	80	80	83	85	83	85	±6
	muscle	**side**	**1y.**	**2y.**	**3y.**	**4y.**	**5y.**	**6y.**	**7y.**	**8y.**	**9y.**	**10y.**	**11y.**	**12y.**	**ref.**
myoton – tone (Hz)	triceps surae	R	13.2	13.5	13.6	14.2	14.5	15.2	15.9	16.0	15.5	16.2	16.5	16.1	*15.8*
		L	13.8	14.0	14.2	14.7	14.4	15.4	16.0	15.7	16.1	16.7	16.3	16.9	±1.1
	hamstrings	R	11.9	11.5	12.8	13.5	14.1	15.1	15.5	16.0	16.8	16.0	16.3	16.1	*13.9*
		L	12.0	12.3	13.1	13.3	13.9	15.3	15.1	15.5	16.2	15.6	16.1	15.9	±1.5
	quadriceps femoris	R	12.2	12.8	12.8	13.9	13.7	14.7	15.1	15.5	15.8	16.0	15.4	15.5	*14.7*
		L	12.5	13.0	13.3	14.2	14.0	14.5	14.3	14.7	15.2	15.4	15.5	15.3	±1.5
	biceps brachii	R	12.5	12.8	12.4	13.5	13.2	14.0	14.5	14.0	14.7	14.5	15.3	14.9	*14.0*
		L	13.1	13.2	12.9	13.8	13.5	14.3	14.3	14.5	14.9	14.9	14.8	14.5	±1.0
	wrist flexors	R	12.2	12.0	12.5	14.0	15.6	16.5	17.8	17.5	18.4	18.1	18.3	18.5	*14.8*
		L	11.9	12.4	13.1	14.6	15.9	17.0	18.3	17.9	19.0	18.5	18.9	18.8	±1.3
myoton – stiffness (N/m)	triceps surae	R	181	186	187	205	220	248	261	265	278	281	275	275	*236*
		L	174	182	190	212	234	253	277	269	281	285	288	284	±37
	hamstrings	R	188	202	205	225	240	260	255	268	275	269	275	270	*228*
		L	179	210	215	237	248	258	263	260	268	280	288	279	±26
	quadriceps femoris	R	205	207	205	220	232	241	248	240	251	253	250	245	*231*
		L	198	203	212	215	228	244	256	246	255	248	257	253	±21
	biceps brachii	R	181	175	180	195	207	210	205	220	215	221	225	215	*208*
		L	176	184	190	203	215	222	215	219	220	230	234	230	±19
	wrist flexors	R	201	210	208	225	240	252	258	265	280	290	292	288	*242*
		L	207	215	219	232	256	270	275	271	295	297	290	294	±23

Ranges of motion were evaluated using standard goniometric measurement with periarticular muscles in a relaxed position; tissue resting tone and stiffness were assessed via myotonometric (myoton) measurement. Records were gathered yearly over the 12-year observation period. Reference values at the age of 12 years (mean ± standard deviation; right and left extremities pooled together) in the last column were obtained from 11 gender, age (±1 year), and body mass index (±1 kg/m^2) matched children. Information on myotonometric measurements and interpretation is available on Myoton AS (n.d.).

dir. – movement direction; ref. – reference value; y. – year; R – right; L – left; flex. – flexion; ext. – extension; abd. – abduction (https://www.myoton.com/technology/)

common causes of childhood disability, efforts have been made to standardize diagnostic and management systems for the condition. The WHO Rehabilitation 2030 initiative aims to develop a set of evidence-based interventions drawn from clinical practice guidelines for managing CP (Damiano et al., 2021). However, as of now, no universally accepted guidelines exist. As a result, clinicians must primarily rely on their in-depth analysis of the literature and clinical experience to effectively apply contemporary therapeutic concepts in CP management. Furthermore, long-term observational studies providing robust evidence of the effectiveness of these evolving approaches remain urgently needed.

Considering the severe physical, mental, and social conditions frequently presented by level V GMFCS patients with CP at the age of 12 years, our observations seem significant enough that we want to share them with a broader community and encourage the implementation of similar approaches. We must emphasize the great share of the ICF in our undertaking. It offered a solid framework for diagnosis and treatment, preventing chaos. The visualization of ICF domains and their interconnections allowed us to predict more distant effects of implemented interventions, not limited to the borders of one particular domain. This allowed for maintaining flexibility and a deeper exploration of the patient's potential.

The patient's current condition suggests our long-term approach has been successful thus far. However, it cannot yet be deemed a definitive success, as the developmental period is ongoing, and certain limitations remain permanent. Our key achievements include slowing or limiting unfavorable changes in body structure and function, appropriately adjusting environmental factors, and, most importantly, enabling the patient and her family to achieve the highest possible level of independent participation in social life (see supplementary video material). This holistic approach addresses all modifiable factors influencing patient outcomes and aligns with the "F-words" framework for child development: function, family, fitness, fun, friends, and future (Rosenbaum & Gorter, 2012). While there is a growing emphasis on activity and participation within the ICF model, the majority of interventions – approximately two-thirds – continue to target body structure and function components (Damiano et al., 2021; Rosenbaum & Gorter, 2012). Implementing the F-words concept of fun, family, friends, function, fitness, and future also seems undoubtedly beneficial. In many difficult moments, it increased patient/family motivation and allowed them to stick to the therapeutic regime without making it a form of 'punishment' (Rosenbaum & Gorter, 2012). However, we want to acknowledge a slight modification we introduced to this concept. In place of the F-word function, resembling in its essence activity from ICF and coming into uncomfortable collisions with body function from ICF, we thoughtfully decided to insert freedom. Freedom and independence seem to be equally meaningful qualities.

LIMITATIONS

It cannot be denied that behind our success stands the consistent subordination of the family to the proposed approach. This was, however, possible thanks to ensuring their complete subjectivity and decision-making as equal therapeutic team members. The effect achieved required financial and time expenditures and the involvement of many specialists and clinical centers. We are aware that this is not possible for every patient, but at the same time, it is not impossible, just *per se*. Besides that, we admit that not everything was 100% successful, e.g., our attempts to reduce dystonic spasms have failed; despite continuous control, reconstruction of the left hip was finally needed. Further problems are also to be expected, e.g., the development of pain related to impaired motor functions, psychological problems associated with growing self-awareness, puberty, and developing sexuality. These are significant challenges for the future. Moreover, the reader should consider all methodological limitations associated with case studies and narrow possibilities of generalizing the presented results.

CONCLUSIONS

This case study demonstrates that a structured, interdisciplinary approach has significantly improved the patient's functional abilities, social participation, and overall quality of life as defined by the ICF framework. Despite severe motor impairments, the patient has achieved independent mobility using assistive technologies, effective communication through AAC, and full engagement in educational and social activities. Her good physical condition has also enabled her family to maintain an active lifestyle.

Our encouraging observations may contribute to modifying national healthcare systems for patients with CP, facilitating the implementation of comprehensive approaches similar to ours. It seems that the presented approach is worth recommending. It has the potential to enable more and more individuals with CP to inde-

pendently participate in various aspects of the life of a human being. It also sets a convenient background for future broader studies.

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DECLARATION OF INTEREST STATEMENT

The author reported no potential conflict of interest

ETHIC DECLARATION

The study was conducted in accordance with the Declaration of Helsinki, and the protocol was approved by the Academy of Physical Education in Katowice Ethics Committee (No 1/2013) on 16.12.2013.

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