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CASE REPORT

International Classification of Functioning, Disability and Health (ICF) as an assessment, outcome measure and goal setting tool in spina bifida: a case report

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Background: This case report documents the rehabilitation of a one-year-old male with spina bifida meningomyelocele using the International Classification of Functioning, Disability, and Health (ICF) as a framework for assessment and intervention. The ICF was used to document his rehabilitation and guide therapeutic interventions based on specific physical, functional, and environmental factors.

Case Presentation: The subject had meningomyelocele and Chiari II malformation following a full-term C-section birth and a 40-day neurointensive care unit (NICU) stay. He exhibited significant motor and sensory impairments below the D10 level, including reduced muscle power and absent sensation. Comprehensive assessments were conducted using ICF core sets and additional body function codes, and specific, measurable goals were set.

Intervention and Outcomes: A multidisciplinary team of healthcare professionals pursued interventions, including tactile stimulation, ergometer training, strength training, and therapeutic games. Physical and occupational therapies using assistive technologies improved muscle strength, partially independent transfers, and basic activities. Despite progress, the patient continued to rely on caregivers for complex tasks.

Discussion: The integration of ICF-based documentation tools proved beneficial in providing a structured, holistic approach to the child's care. The report highlights the need for further research into optimizing assistive technology and advanced rehabilitation techniques to improve functional outcomes for children with spina bifida.

Conclusion: The case demonstrates the effectiveness of a structured, individualized approach using the ICF to manage spina bifida, though gaps remain in achieving full autonomy. Future directions should focus on enhancing interventions and support systems to maximize independence and quality of life.

Keywords: International Classification of Functioning, Disability and Health (ICF), Spina Bifida, Outcome measure, Assessment tool, Multidisciplinary Team

Introduction

Neural tube defects (NTDs) are among the leading non-infectious birth defects, with a worldwide prevalence of 1–2 per 1000 live births, causing significant morbidity and mortality (1, 2). Spina bifida is a congenital NTD that affects the spine and spinal cord, leading to various physical and neurological conditions (3). It is classified according to the severity of the infection, from mild (spina bifida occulta) to severe (myelomeningocele) (2). The symptoms include

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mobility impairment, bladder and bowel incontinence, and impaired cognitive function (3). Thus, it necessitates multidisciplinary care toward lifelong rehabilitation. The International Classification of Functioning, Disability, and Health (ICF) is part of a family of classifications developed by the World Health Organization (WHO) (4). It offers a standardized approach for assessing these impacts, focusing on a person's functional abilities and participation in daily life. The ICF provides a standardized framework for assessing and documenting functional status, setting goals, and measuring outcomes in health care. It is used widely in rehabilitation to guide interventions, support treatment planning, and measure outcomes, emphasizing the role of personal and environmental factors in managing conditions such as spina bifida (5). ICF presents a broad framework for understanding spina bifida's effect on the functioning of a person. It helps analyze the physical, psychological, and social domains in care planning and outcomes evaluation in clinical and research settings. The ICF components are divided into several classification units. These can be documented by selecting relevant category codes and assigning qualifiers (numeric codes) that indicate the degree of functioning or disability (6). Qualifiers in the ICF provide information about specific performance levels, indicating how well an individual can execute certain activities or participate in life situations. Qualifiers range from 0 to 4, with the following meanings: "0—No Problem, 1—Mild Problem, 2—Moderate Problem, 3—Severe Problem, and 4—Complete Problem." ICF for Children and Youth (ICF-CY) recommends a biopsychosocial approach to healthcare (7, 8). The absence of a specific ICF core set for spina bifida represents a gap in this complex condition's standardized assessment and management. Developing such a core set would provide a structured, comprehensive, and holistic approach to understanding and addressing the multifaceted challenges faced by individuals with spina bifida. This case study demonstrates the use of ICF in the care of a 1-year-old male child with spina bifida, highlighting its utility in clinical practice.

Patient information

The case presented is a 1-year-old male child born out of a non-consanguineous marriage and conceived naturally. The mother had no complications during pregnancy. He has undergone regular sonography check-ups and took folic acid, calcium supplements, and TT injections throughout the pregnancy. The antenatal scan, performed in the 7th month, was suggestive of inappropriate development of the child's spine. He was delivered via full-term cesarean section, cried immediately after birth, and had a birth weight of 1.4 kg.

Clinical findings

There was swelling in the lumbosacral region, so he was kept in the neurointensive care unit (NICU) for 40 days for further investigations. An magnetic resonance imaging (MRI) on day 4 of his life revealed Arnold-Chiari II malformation with myelomeningocele at the dorso-lumbar level, for which he was operated on immediately. A follow-up MRI after 2 months showed mildly dilated bilateral lateral ventriculomegaly with colpocephaly, partial dysgenesis of the hypoplastic corpus callosum, and periventricular sub-ependymal heterotopia in the left and pineal region. An arachnoid cyst was also noted, with a subtle increase in ventricular and cyst size. At 7 months, a 2D echocardiogram and color doppler imaging (CDI) suggested congenital cyanotic heart disease. At 10 months, uro-cystometry indicated reduced bladder capacity, sensation and compliance, and poor rectal pressure measurement due to a lax anal sphincter. In addition to it, he had recurrent chest infections, for which he was admitted to the hospital for the same. The child suffered from the absence of sensation and reflexes, muscle power, and voluntary control below the D10 level (10th thoracic vertebra in the spine). He also displayed flaccidity below the D10 level. The child has delayed gross motor development; he can hold his neck, roll to either side, push up on his forearms in a prone position, and sit with minimal support. Interestingly, fine motor, language, and social development are age appropriate.

Timeline

The following is the structured timeline of the child (**Table 1**):

TABLE 1 | Chronological summary of prenatal findings, early neuroimaging results, and subsequent clinical and functional assessments during the first year of life.

Age/timeframe	Evaluation and findings
7 months of Gestation	Antenatal scan suggested inappropriate spinal development.
Day 4 after birth	Magnetic resonance imaging (MRI) and physical examination confirmed neurological deficits and spine abnormalities.
First 2 months (follow-up MRI)	Mildly dilated bilateral lateral ventriculomegaly. Colpocephaly. Hypoplastic corpus callosum with partial dysgenesis. Periventricular sub-ependymal heterotopia (left). Pineal region arachnoid cyst.
10th month	Uro-Water Cystometry showed: 1. Reduced bladder capacity, sensation, and compliance. 2. Poor rectal pressure measurement due to a totally lax anal sphincter.
1 year	ICF-based assessment conducted to adapt and reset goals based on patient's evolving needs.

Diagnostic assessment

The clinical assessment of this patient involved several domains of functioning in the ICF-based assessments. The major sensory and neurological evaluation involved an MRI of the spinal cord and an assessment of muscle strength, tone, and sensation below the D10 level. The ICF categories, such as body functions, activities and participation, and environmental factors, were used for the examination. The body functions assessment indicated significant impairments, especially in sensation (b265, b270, and b280) below the D10 level, with an absence of sensations of touch, temperature, and pain. Muscle function assessments indicated decreased power in the lower limbs (b7303) and trunk (b7305), along with spasticity in the muscles of the lower half of the body at (b7353). In the activities and participation category, he had limitations in changing and maintaining body positions (d410–d415), transfers (d420), and mobility (d450). He required support from caregivers with Activities of Daily Living (ADLs) like toileting (d530), and dressing (d540), and needed help to eat and drink (d550). The home environment was adapted to assist his participation and everyday functioning through assistive technology and orthotics (e115). The findings were synthesized using the ICF as a model guiding the formulation of goals in joint mobility (b710), muscle strength (b730), and functional independence.

Here is the **tabular format** with a separate column for ICF codes (**Table 2**).

This layout provides a **clear structure**, making it easier to analyze clinical findings using the **ICF framework**.

TABLE 2 | ICF-based assessment outlining impairments in body functions, activity limitations, participation restrictions, environmental factors, and corresponding ICF codes to guide goal-oriented rehabilitation planning.

ICF domain	Findings	ICF codes
Sensory and Neurological Evaluation	MRI of spinal cord, muscle strength, tone, and sensation assessment below D10 level.	-
Body Functions	Impaired sensation below D10, absence of touch, temperature, and pain sensation.	b265, b270, b280
	Decreased lower limb power.	b7303
	Decreased trunk power.	b7305
	Spasticity in lower body muscles.	b7353
Activities and Participation	Difficulty changing and maintaining body positions.	d410 - d415
	Limited ability in transfers.	d420
	Impaired mobility.	d450
	Required caregiver support for toileting.	d530
	Required assistance for dressing.	d540
	Required help for eating and drinking.	d550
Environmental Factors	Home adapted with assistive technology and orthotics.	e115
Goal Setting	Improve joint mobility.	b710
	Enhance muscle strength.	b730
	Promote functional independence.	-

Therapeutic intervention

A multidisciplinary intervention approach included treatment plans such as physiotherapy (PT), occupational therapy, nursing, and medical teams. The primary purpose of PT is to enable the patient to achieve the greatest range of mobility and strength with exercises to increase joint mobility (b710) and enhance muscle strength in the trunk and lower limbs (b730). Medical management and physical techniques, including the Roods approach, were employed to control and reduce spasticity. Rood's approach is a neurological rehabilitation treatment method involving tapping, brushing, and compression to activate or inhibit a muscle. The occupational therapy session helped the patient to perform ADLs, such as delicate hand use (d440) and arm function (d445). Therapeutic games and repeated transfers encouraged the patient to practice mobility and self-care, emphasizing independence. Other devices involved in the plan were assistive technology like knee-ankle-foot orthoses (KAFO) (c115) and optimized wheelchair training, through which the patient could move more efficiently between different locations and achieve independence (d460). KAFO devices generally stabilize lower limbs and assist patient mobility. These devices promote proper joint alignment and prevent deformities. Ergometer training was implemented to improve cardio-pulmonary endurance (b455). The nursing team and physical therapists managed intermittent catheterization for urological and bowel management to maintain bladder function (b620). Digital stimulation and bowel irrigation were also used to treat neurogenic bowel problems (b525). Short-term treatment plans focused on improving joint mobility, increasing muscle strength, and enhancing fine motor skills, while long-term goals aimed to achieve greater independence in mobility through assistive devices and reducing dependence on caregivers for ADLs.

Follow-up and outcomes

The patient's progress was monitored using ICF-based measures to assess improvement in physical function, increasing levels of independence, and mobilization. A slight improvement was observed in joint mobility and muscle power. Improvement in upper body strength led to independent wheelchair transfers. Fine motor skills (d440) were also improved, allowing the patient to participate in therapeutic activities and simple self-care procedures

with support. The patient's mobility assessments showed improvement in his use of assistive devices. He was proficient in navigating various settings with optimized wheelchairs (d460). However, he still required assistance from caregivers for more complex ADLs, such as dressing up (d540). Overall, the outcome reflected increased muscular strength and cardiovascular endurance, although interventions dealing with muscle tone management reduced spasticity (b7353). An integrated approach of assistive technology plus family support allowed better mobility in his surroundings and increased social participation, which enhanced his quality of life. The structured ICF framework provided an excellent tool for guiding targeted interventions and monitoring measurable progress, thus demonstrating the use of individualized and interdisciplinary care in the management of such complex cases.

Discussion

The management of this patient with spina bifida using the ICF framework facilitated a structured and comprehensive approach that further allowed targeted interventions on specific impairments and activity limitations. The patient had significant impairments in their motor and sensory function below the D10 level, including absence of touch, temperature, and pain sensations, and lower limb and trunk weakness. These results aligned with previous literature, which shows that spina bifida cases involving thoracolumbar spine defects have often been accompanied by motor and sensory deficits (9–11). The ICF-based assessments enabled the researchers to underscore how these impairments influenced mobility, self-care, and social participation, emphasizing the need for specific personalized rehabilitation strategies (4). In this case, interventions such as physical therapy for muscle strengthening, occupational therapy for fine motor skills, and daily living training and activity led to improved muscle strength and functional independence. Recent studies have shown that spina bifida cases would be better addressed through a multidisciplinary approach that combines PT with occupational therapy input to improve outcomes on mobility and quality of life (12, 13). Assistive technologies like wheelchairs and orthotics have enhanced mobility, as indicated in the literature, further promoting a more independent lifestyle in spina bifida patients (14). Despite these gains, they are not entirely independent in their ADLs because they need assistance from the caregivers for dressing and toileting themselves (15). Other reports have noted similar challenges, where the severity of neurological impairments and access to resources often restrict functional gains (16). This underlines the need for a multidisciplinary approach, periodic evaluation of the condition using the ICF framework, and support for the family regarding changing interventions per the patient's changing needs. Further research must optimize intervention strategies with new assistive technologies and advanced rehabilitation methods to achieve maximum independence and quality of life for spina bifida patients.

Conclusion

The ICF-based assessments proved essential in providing a structured and comprehensive approach to managing spina bifida, emphasizing the importance of individualized, interdisciplinary care. However, the patient's limitations in eventually attaining full autonomy indicate a research gap, especially in optimal assistive technology and rehabilitative methods. Future studies focusing on developing advanced and individualized interventions would provide the best possible improvement in independence and quality of life in managing spina bifida. Moreover, establishing an ICF core set for spina bifida patients will provide a general framework to address appropriate issues linked with this condition. This will lead to better individualized treatment planning, better communication among healthcare professionals, and monitoring of functional outcomes in the physical, psychological, and social domains.

Patient perspective (if applicable)

The patient's family expressed satisfaction with the care provided, noting improvements in the child's mobility and independence. They appreciated the education and support they received, which allowed them to participate actively in his care.

Informed consent

Written informed consent was obtained from the patient's legal guardians to publish the case details.

Future research directions

Future research should focus on advancing assistive technologies and refining multidisciplinary rehabilitation approaches to enhance functional independence in children with spinal cord impairments.

1. **Innovations in Assistive Technology (ICF: e115)**
    - Development of adaptive orthotics and exoskeletons to improve mobility (d450) and transfers (d420).
    - Smart sensory feedback devices to compensate for impaired sensation (b265, b270, b280).
    - AI-driven assistive robotics for supporting ADLs like toileting (d530), dressing (d540), and eating (d550).

2. **Multidisciplinary Rehabilitation Approaches**

   - Personalized therapy models integrating neurophysiotherapy, occupational therapy, and speech therapy.
   - Use of neuroplasticity-driven interventions to improve muscle strength (b730) and joint mobility (b710).
   - Exploration of early intervention programs to enhance participation in daily activities (d410–d415).

3. **ICF-Based Functional Assessments**

   - Standardization of ICF-based assessments to track longitudinal functional outcomes.
   - Development of digital assessment tools to monitor changes in body function, activity limitations, and environmental adaptations.

By integrating cutting-edge technology with evidence-based rehabilitation, future research can significantly improve the quality of life and independence of individuals with neurological impairments.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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