NEUROSCIENCE RESEARCH NOTES

OPEN ACCESS | RESEARCH NOTES ISSN: 2576-828X

Assessing Mongolian children with cerebral palsy using the International Classification of Functioning, Disability and Health

Narantsetseg Tsegmid [1], Delgerjargal Dorjbal [2], Battuvshin Lkhagvasuren [3], Suvdmaa Sain-Uchral [4], Gerelmaa Zagd [5], Nyamdavaa Uugandavaa [6], Batchimeg Shirmen [1], Davaasuren Ganbold [1] and Baljinnyam Avirmed [1]*

[1] Department of Rehabilitation Medicine, Mongolian National University of Medical Sciences, Ulaanbaatar, Mongolia.
[2] Department of Rehabilitation Medicine, Fujita Health University, Toyoake, Japan.
[3] Brain and Mind Research Institute, Mongolian Academy of Sciences, Ulaanbaatar, Mongolia.
[4] Rehabilitation development center of children with disability, Ulaanbaatar, Mongolia.
[5] Department of Paediatric Medicine, Mongolian National University of Medical Sciences, Ulaanbaatar, Mongolia.
[6] Department of Radiology, Mongolian National University of Medical Sciences, Ulaanbaatar, Mongolia.
* Correspondence: baljinnyam.a@mnums.edu.mn; Tel.: +976-9912-8860

Received: 29 June 2024; **Accepted:** 7 February 2025; **Published:** 17 May 2025
Edited by: King Hwa Ling (Universiti Putra Malaysia, Malaysia)
Reviewed by: Delgermaa Tsagaankhuu (Mongolian National University of Medical Sciences, Mongolia); Tamis Wai-mun Pin (The Cerebral Palsy Alliance, Australia)
https://doi.org/10.31117/neuroscirn.v8i2.379

Abstract: The functioning and disability of Mongolian children with cerebral palsy were assessed by applying the World Health Organization's Common Brief ICF-CY Core Set for Children and Youth with Cerebral Palsy. The cross-sectional study involved a consecutive sample of 98 children with spastic cerebral palsy (mean age 6.9 years) and their caregivers. They came from both urban and rural areas of Mongolia. The majority (65%) of the participants were spastic diplegic. Body functions, activities, participation, and interaction with the environment differed depending on the type of cerebral palsy. Brain structure did not differ, however. Regarding environmental factors, there was no significant difference between the types of products and technology used for communication, immediate family relationships, or social attitudes. The environment was the key component negatively impacting the lived experience of children with cerebral palsy in Mongolia. Overall, the findings help to identify unmet needs and can improve interventions for such children in Mongolia to meet international standards.

Keywords: Cerebral palsy; International Classification of Functioning, Disability and Health; Mongolia; Rehabilitation

1.0 INTRODUCTION

Assessment is an important first element in the rehabilitation of children with cerebral palsy (CP) (Rauch et al., 2008). CP is a lifelong and complex health condition that results in impairments, limitations and restrictions, and it has manifestations beyond those related to the musculoskeletal system. Cognitive and behavioural difficulties are the possible manifestations (Rosenbaum et al., 2007). Therefore, a methodical, multidisciplinary perspective in assessing this complex health condition is essential for effective rehabilitation. Rehab-Cycle is an approach created primarily for rehabilitation management, and it is one of the main methodologies used for planning and documenting the care and rehabilitation process. The Rehab-Cycle technique involves Assessment, Assignment, Intervention, and Evaluation. It helps clinicians to set appropriate goals and plan suitable interventions (Dorjbal et al., 2016; Rauch et al., 2008).

To standardize and organize the rehabilitation information, the World Health Organization's (WHO's) International Classification of Functioning, Disability and Health (ICF) provides a common language and framework for classifying a variety of health-related information, facilitating communication between various health-related sectors (Klang Ibragimova et al., 2011; Schiariti et al., 2014; WHO, 2002). The ICF also has a child and youth version (the ICF-CY), designed to accurately capture the functional levels of children up to 18 with all types of disabilities (WHO, 2007). The ICF-CY contains 1,685 categories and is further divided into comprehensive and brief core sets, allowing a systematic and thorough description of functional profiles in research and clinical settings (Schiariti et al., 2015). One type of ICF-CY instrument is specific for CP (Schiariti et al., 2018). There are five ICF-CY core sets: a Common Brief Core Set, a Comprehensive Core Set, and three age-specific brief ICF core sets (<6 years, 6-14, and 14-18 years) that provide pertinent functional development information (Schiariti et al., 2014 & 2018).

The Common Brief Core Set for CP aims to describe key domains of functioning and disability in a way that is useful for a single evaluator or an interdisciplinary team relying on minimal data in a clinical setting. To improve the outcomes of rehabilitation care, assessing a child's level of functioning is the first key step in setting rehabilitation goals (Illum et al., 2016; Schiariti et al., 2015). The ICF was created to support more holistic and comprehensive approaches in rehabilitation clinics. Assessment results based on the Common Brief Core Set for CP are crucial to rehabilitation planning and optimizing intervention strategies for children with CP.

This study addressed that process in Mongolia, a middle-income country with a population of 3.4 million, about 32% of whom were below 16 in 2021 (Center for Health Development., 2022). There is no comprehensive data on people living with disabilities in Mongolia (Dorjbal et al., 2020 & 2021; Khan et al., 2018). Indeed, several studies have noted that limited information is available about functioning and disability among children and adolescents with CP in developing economies (Almasri et al., 2018; Chagas et al., 2024; Leite et al., 2022), and Mongolia is no exception (Khan et al., 2018). The main objective of this study was to develop a functional profile of children with CP in Mongolia, assess the functioning and disabilities of children with CP based on their medical admission reports, and apply the Common Brief ICF-CY Core Set for CP. In applying this "common language" approach, the results of this study can better describe the functional profile of children with CP in Mongolia in a way that may help optimize the rehabilitation interventions applied despite the limited resources available.

2.0 MATERIALS AND METHODS

2.1 Data source

This cross-sectional study was conducted at the outpatient rehabilitation centre of the Mongolia-Japan Hospital at the Mongolian National University of Medical Sciences from November 2018 to January 2022. This rehabilitation center is one of the largest among few facilities in Mongolia, providing medical rehabilitation to the whole population, including children with CP. Quantitative and qualitative techniques were applied while collecting and analyzing the data (Schoonenboom et al., 2017).

The study used a consecutive sampling technique until the sample size was reached. To that point, each participant who satisfied the inclusion criteria was included (Bujang et al., 2016). That generated a sample of 315 children with CP whose medical records were then reviewed. Among them, 98 children aged 2-18 years with spastic CP agreed to participate. A few candidates with genetic diseases or degenerative brain diseases were excluded.

2.2 Data collection

The Common Brief ICF-CY Core Set for CP was used to systematically collect information about the participants' functioning. The core set for CP includes 25 categories that describe the most important areas of

functioning (Supplementary Data 1); they constitute a minimal functional data set (Schiariti et al., 2017). The 25 categories comprise of: 1 about body structure, 8 about body functions, 8 about activities and participation, and 8 about environmental factors. All categories were given specific code: b = body functions; s = body structures; d = activities and participation. Each item was graded from 0 to 4. The body structure assessment considered only brain structure as determined by magnetic resonance imaging (MRI). In the images, diffuse brain atrophy, periventricular leukomalacia, and bilateral ischemic changes and infarction were quantified using the ICF's generic scale.

Each participant was assessed with scales that aligned with the content of the Common Brief ICF-CY Core Set for CP. Range of motion (ROM) was measured along with assessments using the Modified Ashworth Scale (MAS), the Gross Motor Functional Classification System (GMFCS), the Manual Ability Classification System (MACS), the Communication Function Classification System (CFCS), and the Eating and Drinking Ability Classification System (EDACS). These scales are all reliable, systematic, and compatible in profiling the functioning of children with CP (Paulson et al., 2017).

To evaluate the items that the scales were unable to measure, parents were asked to complete an open-ended questionnaire (Supplementary Data 2). The questionnaire mainly focused on the environmental factors. For example, the questionnaire asked about a child's relationships with family members, friends, and classmates to measure interpersonal interactions and relationships. It also surveyed what assistive equipment or products each child used daily. Each questionnaire took approximately 30 minutes to complete. The information collected (along with the MRI findings) was added to the participant's medical records.

2.3 Reliability

To ensure the reliability of assessments using the Common Brief ICF-CY Core Set for CP, two of the authors (N.T. and S.S.) performed them independently using the 2nd edition of the "ICF Core Sets – Manual for Clinical Practice" (WHO, 2013). Both are paediatric rehabilitation doctors with 6-20 years of experience, and they had attended two days of face-to-face training on applying the Common Brief ICF-CY Core Set for CP.

A professional translation centre translated the version of the Common Brief ICF-CY Core Set for CP, into Mongolian. To verify its Mongolian version, two of the authors who had been trained in using the ICF (D.D. and B.A.) did a back-translation and then edited the Mongolian version. The Mongolian version was subsequently approved by the Committee for Rehabilitation Medicine of the Mongolian Ministry of Health.

2.4 Data analysis

Frequencies and percentages were calculated for the age, gender, and type of cerebral palsy data, as well as for the variables in body structures, body functions, activities and participation, and environmental factors. The data were presented as mean ± standard deviation (SD). Analysis of variance was used to test for any significant relationships with the three CP types. A test-retest procedure was performed to quantify inter-rater reliability using Cohen's kappa test. All the statistical tests were two-tailed with a p-value of ≤0.05 taken as indicating sufficient confidence. The data were analyzed using version 22.0 of the SPSS software suite.

The answers to the open-ended questionnaire were analyzed qualitatively. Three of the authors (N.T., S.S. and D.D.) applied the principles of qualitative content analysis (Faria-Schützer et al., 2021) together with the linking rules (Cieza et al., 2019; Dorjbal et al., 2016). Such content analysis uses a descriptive approach in coding the data and interpreting quantitative counts of the codes. In that way, it is possible to analyze data qualitatively and, at the same time, quantify it (Vaismoradi et al., 2013). More specifically, a two-step procedure was used to analyze the qualitative content of "the functional profile of children with CP". In the first step, two authors (N.T. and S.S.) independently performed inductive category development (i.e., data-driven coding) to identify category definitions and levels of abstraction from the data. Specifically, words or short phrases of the narratives (i.e. in-vivo codes) were used to assign labels to sub- and main categories. For instance, the narrative "Exercises for muscle strength of non-dominant hand" was assigned to the sub-category "Upper extremity" and the main category "Exercises for body muscle function". In the second step, the same two authors conducted independent deductive category development (i.e. concept-driven coding) using the linking rules (Cieza et al., 2019; Dorjbal et al., 2016) of the codes of the ICF-CY Core Set (WHO, 2007).

In the deductive category development, the ICF's hierarchical structure of domains, chapters and components and their definitions served as coding rules. For example, the narrative "Practices for getting up and down on the floor" was coded to the ICF domain "d410-d429 Changing and maintaining body position"

corresponding to the ICF-chapter "d4 Mobility", which belongs to the ICF's "Activities and participation" component. Following the criteria to enhance the trustworthiness of qualitative investigations (Adler, 2022), the two authors regularly reviewed the analysis, as Graneheim and Lundman (2004) recommended and discussed similarities and differences in their coding. Differences were discussed, and any disparities in the considerations or the coding scheme for data triangulation were resolved by a third author (D.D.)'s review of the development of the inductive and deductive categories.

2.5 Ethical considerations

The Ethics Committee of the Mongolian National University of Medical Sciences in Ulaanbaatar, Mongolia, approved this study (no. 2018/3-16), which adhered to the Declaration of Helsinki. The participants and their guardians were allowed to ask questions, and they received assurances regarding the confidentiality and anonymity of the study's findings. All signed an informed consent form before the data collection.

3.0 RESULTS

3.1 Sociodemographic characteristics

A total of 98 children were studied. Their ages ranged from 2 to 18. The mean age was 6.93±3.58 years. Spastic diplegic CP was the most common type (65.3%), followed by spastic quadriplegic CP (22.4%) and spastic hemiplegic CP (12.3%). Less than half of the participants were from rural areas (**Table 1**).

3.2 Interrater reliability

Table 2 presents the Common Brief ICF-CY Core Set scores for CP and the Cohen's Kappa test for each of the 25 categories. The scale's excellent Interrater Reliability (IRR) was demonstrated by Cohen's kappa test of the scale's 25 categories, which varied from 0.710 to 1.000 (**Table 2**).

Table 1: Characteristics of the study participants (n=98)

Demographics, baseline clinical characteristics		n (%)
Age		6.9±3.6
Genders	Male	59 (60.2)
	Female	39 (39.8)
Types of CP	Hemiplegia	12 (12.3)
	Diplegia	64 (65.3)
	Quadriplegia	22 (22.4)
Living areas	Urban	69 (70.4)
	Rural	29 (29.6)
GMFCS level	I	4 (4.1)
	II	29 (29.6)
	III	49 (50.0)
	IV	8 (8.2)
	V	8 (8.2)
MACS level	I	28 (28.6)
	II	31 (31.6)
	III	25 (25.5)
	IV	10 (10.2)
	V	4 (4.1)
CFCS level	I	48 (49.0)
	II	25 (25.5)
	III	14 (14.3)
	IV	10 (10.2)
	V	1 (1.0)
EDACS level	I	31 (31.6)
	II	29 (29.6)
	III	21 (21.4)
	IV	13 (13.3)
	V	4 (4.1)

CP = Cerebral palsy; GMFCS = Gross motor function classification system; MACS = Manual ability classification system; CFCS = Communication function classification system; EDACS = Eating and drinking ability classification system.

Table 2: Interrater reliability of disability assessing tool based on the Common Brief ICF-CY Core Set for CP (n=21)

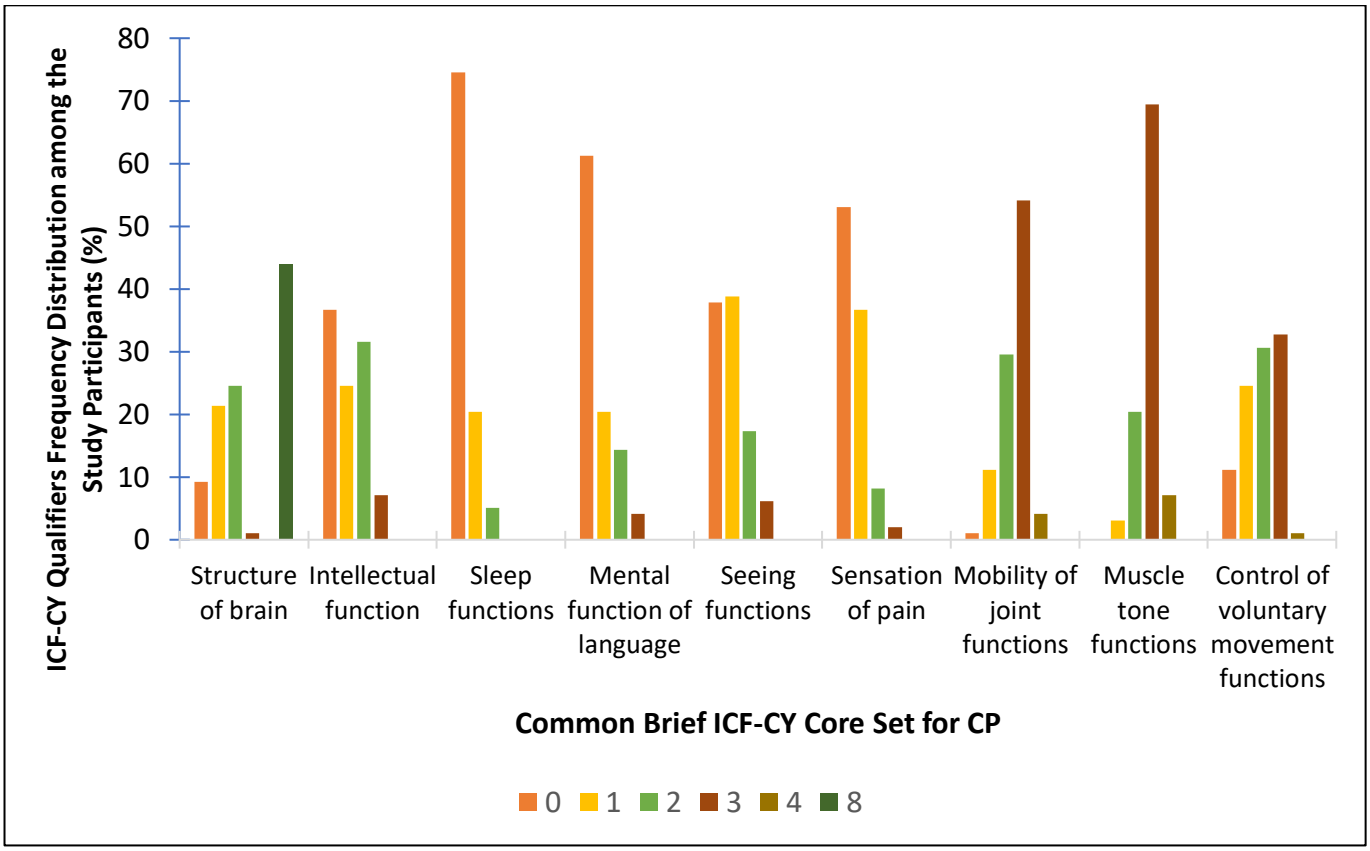
Code	Common Brief ICF-CY Core Set for CP	Cohen's kappa	p-value
S110	Structure of brain	1	<0.001
b117	Intellectual function	1	<0.001
b134	Sleep functions	1	<0.001
b167	Mental function of language	0.930	<0.001
b210	Seeing functions	1	<0.001
b280	Sensation of pain	1	<0.001
b710	Mobility of joint functions	0.829	<0.001
b735	Muscle tone functions	0.710	<0.001
b760	Control of voluntary movement functions	0.928	<0.001
d415	Maintaining the body position	1	<0.001
d440	Fine hand use	0.934	<0.001
d450	Walking	1	<0.001
d460	Moving to different locations	1	<0.001
d530	Toileting	1	<0.001
d550	Eating	1	<0.001
d710	Basic interpersonal interactions	0.937	<0.001
d760	Family relationship	1	<0.001
e115	Product and technology for personal use in daily living	1	<0.001
e120	Product and technology for personal indoor & outdoor mobility and transportation	1	<0.001
e125	Product and technology for communication	1	<0.001
e150	Design, construction and products & technology of building for public use	1	<0.001
e310	Immediate family	1	<0.001
e320	Friends	0.935	<0.001
e460	Social attitude	0.937	<0.001
e580	Health service, systems and policies	1	<0.001

ICF-CY = International Classification of Functioning, Disability and Health for Children and Youth

3.3 Functioning profile of the study participants

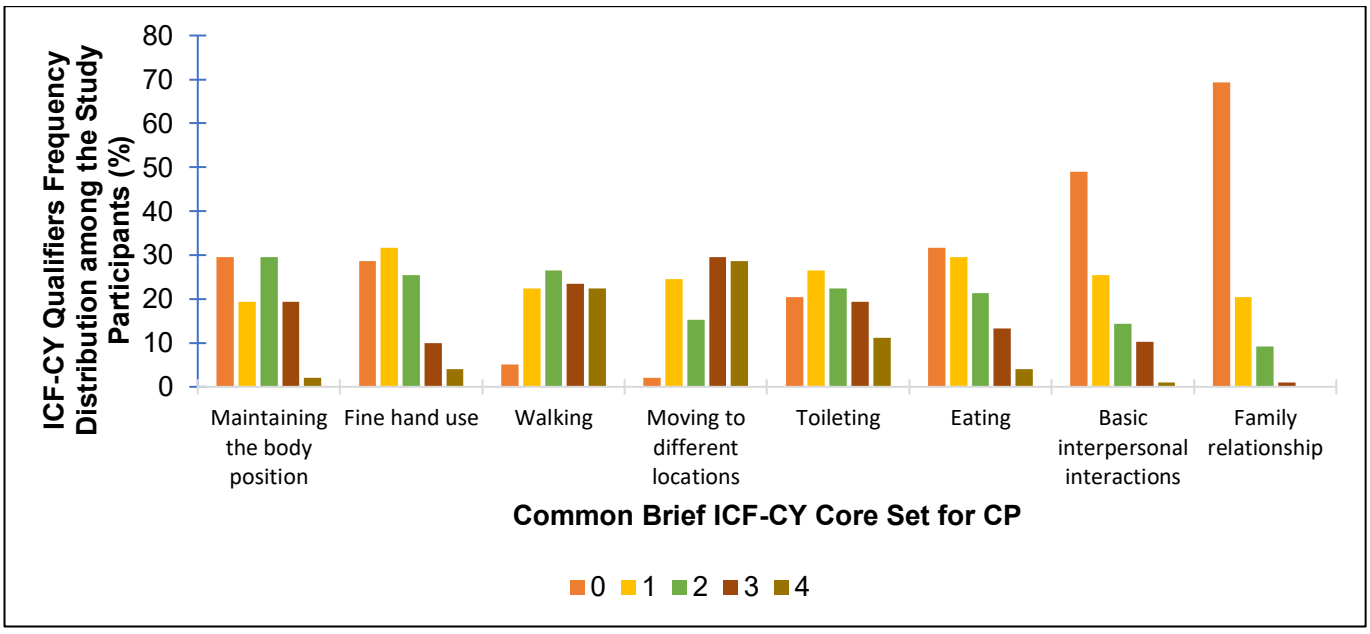
Applying the codes from the Common Brief ICF-CY Core Set for CP, moderate to severe disability was assessed for majority of the body functions, including muscle tone functions (b735), mobility of joint functions (b710), and control of voluntary movement functions (b760). In the body structures component, only the structure of the brain (s110) was assessed by brain imaging. Brain imaging was performed on 55 children, and most showed mild to moderate impairments (**Figure 1**).

Activities and participation information were collected in relation to mobility. In particular, 5 (5.1%) were able to walk independently, while 48 (48.9%) had mild to moderate limitations, and 45 (45.9%) had severe to complete limitations in walking (d450). Severe to complete limitations in moving around different locations (d460) were found in 57 cases (58.2%). Mild to moderate limitations were found in toileting (d530) and eating (d550). In maintaining family relationships (d760), no restrictions were found in 68 (69.4), and mild to moderate restrictions were noted in 20 cases (20.4%). Forty-eight of the children (49%) had no limits in their basic interpersonal interactions (d710), while 39 (39.8%) had mild to moderate restrictions, and 11 (11.2%) had restrictions which were severe to complete (**Figure 2**).



ICF-CY = International Classification of Functioning, Disability and Health for Children and Youth; CP = cerebral palsy; 0 = no problem (0-4%); 1 = mild problem (5-24%); 2 = moderate problem (25-49%); 3 = severe problem (50-95%); 4 = complete problem (96-100%); 8 = not specified

Figure 1: Frequency distribution of body structure and body function ratings (n=98)

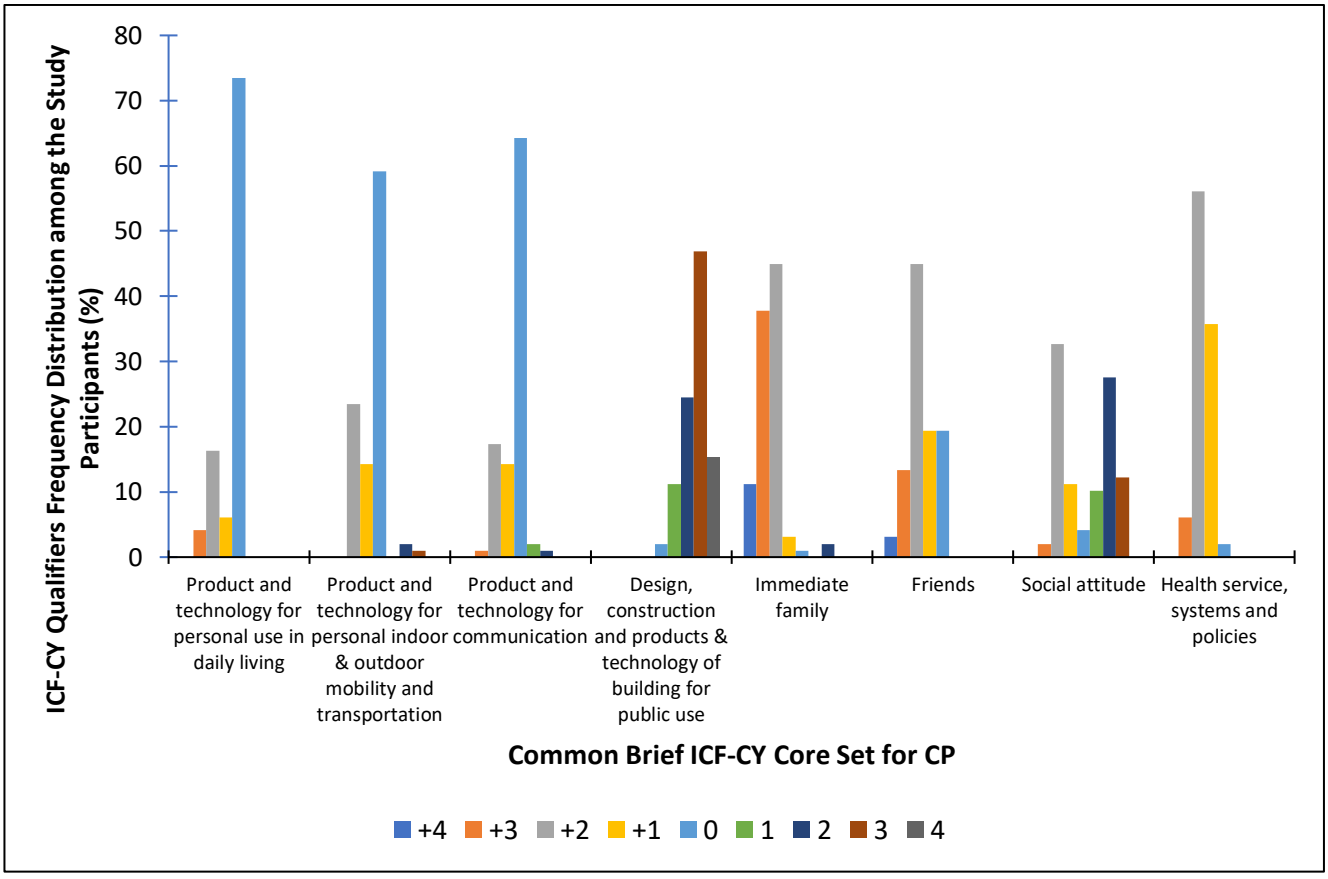


ICF-CY = International Classification of Functioning, Disability and Health for Children and Youth; CP = cerebral palsy; 0 = no problem (0-4%); 1 = mild problem (5-24%); 2 = moderate problem (25-49%); 3 = severe problem (50-95%); 4 = complete problem (96-100%)

Figure 2: Frequency distribution of activity and participation ratings (n=98)

Most of the study's participants described immediate family members (e310) as moderate to complete facilitators, while friends (e320) were noted as mild to moderate facilitators. Most participants reported that health services, systems and policies (e580) serve as a mild to moderate facilitator. Many participants reported no product or technology for personal and daily living (e115), no product or technology for indoor and outdoor mobility and transportation (e120), and no product and technology for communication (e125) as a facilitator. Regarding social attitudes (e460), 32% considered them a moderate facilitator, and 27 (27.6%) had them as a moderate barrier. 86.7% of the participants with spastic CP reported dealing with moderate to complete barriers relating to the design, construction, building products used, and the technology of Mongolia's buildings for public use (e150) (**Figure 3**).

Table 3 shows the functioning profile of all participants sorted by quadriplegia, diplegia and hemiplegia. There was no statistically significant difference in brain structure (S110) among the three types of CP among the 55 participants with MRI reports. However, there were substantial differences in other ICF categories involving body function, activity, and participation. Those with quadriplegic CP tended to have significantly higher scores ($p \leq 0.001$) in those areas. In terms of environmental factors, there were no statistically significant differences among the three CP types in the average scores for: products and technology for communication (e125), immediate family (e310), or social attitudes (e460). However, compared to the participants with diplegic and hemiplegic CP, those with quadriplegic CP described products and technology for personal use in daily living (e115), such as assistive transfer devices and ankle foot orthoses, as mild to moderate facilitators. It was the same for products and technology for personal indoor & outdoor mobility and transportation (e120). However, they reported substantial to complete barriers in the area of design, construction and products & technology of buildings for public use (e150). Friends (e320) and health service, systems and policies (e580) were considered mild to moderate facilitators by such respondents (**Table 3**).



ICF-CY = International Classification of Functioning, Disability and Health for Children and Youth; CP = cerebral palsy; 0 = no barrier/facilitator; +1 = mild facilitator; +2 = moderate facilitator; +3 = substantial facilitator; +4 = complete facilitator; 1 = mild barrier; 2 = moderate barrier; 3 = substantial barrier; 4 = complete barrier

Figure 3: Frequency distribution of environmental factor ratings (n=98)

Table 3: Functioning profile of the study participants by cerebral palsy type (n=98)

Code	Common Brief ICF-CY Core Set for CP	Total	CP type			P value
			Quadriplegia	Diplegia	Hemiplegia	
s110	Structure of brain (n=55)	1.31±0.77	1.44±0.73	1.28±0.77	1.14±0.90	0.672
b117	Intellectual function	1.09±0.99	1.82±0.96	0.95±0.92	0.50±0.67	<0.001
b134	Sleep functions	0.31±0.56	0.77±0.75	0.17±0.42	0.17±0.39	<0.001
b167	Mental function of language	0.61±0.88	1.55±0.91	0.38±0.70	0.17±0.39	<0.001
b210	Seeing functions	0.92±0.89	1.36±1.26	0.84±0.74	0.50±0.52	0.012
b280	Sensation of pain	0.59±0.73	1.36±0.85	0.38±0.52	0.33±0.49	<0.001
b710	Mobility of joint functions	2.49±0.79	2.95±0.65	2.33±0.74	2.50±1.00	0.005
b735	Muscle tone functions	2.81±0.60	3.27±0.55	2.66±0.57	2.75±0.45	<0.001
b760	Control of voluntary movement functions	1.88±1.03	2.36±0.79	1.73±1.06	1.75±1.06	0.040
d415	Maintaining the body position	1.43±1.16	2.27±1.03	1.29±1.10	0.67±0.89	<0.001
d440	Fine hand use	1.30±1.11	2.45±1.14	0.91±0.87	1.25±0.75	<0.001
d450	Walking	2.36±1.20	3.50±0.96	2.14±1.08	1.42±0.67	<0.001
d460	Moving to different locations	2.58±1.20	3.77±0.53	2.38±1.11	1.50±0.90	<0.001
d530	Toileting	1.74±1.29	3.18±0.91	1.44±1.10	0.75±0.75	<0.001
d550	Eating	1.29±1.17	2.64±1.05	0.86±0.89	1.08±0.79	<0.001
d710	Basic interpersonal interactions	0.89±1.06	2.23±0.97	0.52±0.76	0.42±0.51	<0.001
d760	Family relationship	0.42±0.70	0.82±0.85	0.31±0.64	0.25±0.45	0.008
e115	Product and technology for personal use in daily living	0.51±0.91	1.36±0.95	0.31±0.79	0.00±0.00	<0.001
e120	Product and technology for personal indoor & outdoor mobility and transportation	0.54±0.99	0.14±0.77	0.59±1.02	1.00±0.95	0.037
e125	Product and technology for communication	0.48±0.88	0.68±1.04	0.44±0.87	0.33±0.49	0.442
e150	Design, construction and products & technology of building for public use	-2.62±0.95	-3.59±0.59	-2.42±0.75	-1.92±1.16	<0.001
e310	Immediate family	2.47±1.01	2.41±1.10	2.53±1.05	2.25±0.45	0.646
e320	Friends	1.61±1.04	1.14±1.04	1.66±1.03	2.25±0.75	0.009
e460	Social attitude	-0.19±1.98	-0.27±1.86	-0.20±2.03	0.00±2.09	0.928
e580	Health service, systems and policies	1.66±0.62	1.36±0.58	1.77±0.56	1.67±0.89	0.032

ICF-CY = International Classification of Functioning, Disability and Health for Children and Youth; CP = cerebral palsy

4.0 DISCUSSION

This was the first study in Mongolia in which the Common Brief ICF-CY Core Set for CP was used to assess and profile the functioning and disability of children with CP. The findings may help identify unmet needs among such children and improve the relevant interventions in Mongolia. The study has shown that the Common Brief ICF-CY Core Set for CP can be applied to standardize functioning information with a paediatric population experiencing CP in the Mongolian context. Overall, the results show moderate to severe limitations and restrictions in activities and participation covered by aspects of the Common Brief ICF-CY Core Set for CP. The 25 ICF categories capture areas of functioning and disability and important contextual factors relevant to the Mongolian context.

Assessment instruments recommended in the literature for use with children with CP were applied to quantify the impact on the functioning of each of the ICF categories, and the WHO-ICF linking rules were used to classify the assessment measures (Cieza et al., 2019; Schiariti et al., 2018). ROM and the MAS, GMFCS, MACS, CFCS and EDACS instruments are recommended for this purpose (Paulson et al., 2017). As other researchers have done (Hina et al., 2023; Noten et al., 2022), items that were not covered on a specific scale or measure were assessed by asking parents and guardians a series of open-ended questions. A five-point Likert scale was used to quantify their answers based on the ICF's generic scale. Additionally, the age of each participant was considered when assessing the five classification levels (Paulson et al., 2017).

Most of the participants experienced spastic diplegic CP. Concerning body structures, mild to moderate impairments were the most frequent finding in over half of the brain imaging reports. Only some participants received brain imaging examinations due to limited access to health and rehabilitation care services. The study's body function findings (muscle tone, joint mobility, control of voluntary movement) were similar to those of many other studies (de Oliveira et al., 2016; Hina et al., 2023; Trabacca et al., 2012). However, intellectual and language impairments were only moderate among this study's participants.

In activities and participation, some of the findings differed from those of other studies (Hina et al., 2023; Tantilipikorn et al., 2012). For instance, language learning, skills acquisition, toileting and feeding in this study had only mild to moderate restrictions. These findings speculate about the recruitment of our study participants. Specifically, according to the measurement, most participants with I and II levels (i.e., MACS - 60.2%, CFCS - 74.5%, and EDACS - 61.2%) were recruited for the present study. In some other studies, the participants' restrictions were severe to complete (Hina et al., 2023). This could be due to most of the participants here had spastic diplegic CP, particularly GMFCS with II and III levels (79.6%) in the present study.

Severe to complete barriers were identified in the design, construction, building products and technology of Mongolia's buildings for the public. Indeed, as in many developing countries, most public constructions in Mongolia (including hospitals and clinics) lack ramps and elevators for access. The toilets and bathrooms are also not laid out for individuals living with a disability. The findings also highlight limited access to: products and technology for personal and daily living (e115), indoor and outdoor mobility and transportation (e120), and communication (e125). The participants highlighted adapted vehicles, walking aids, wheelchairs, and transfer devices as insufficiently available in Mongolia. Negative social attitudes were also highlighted as a moderate barrier (e.g., discrimination in playgrounds and transportation in rural areas). This has been seen in prior research elsewhere (Menezes et al., 2024).

Many prior studies have documented that low-and middle-income countries face challenges in providing adequate rehabilitation care (e.g., adequate assistive technologies) even for complex health conditions such as CP (Dorjbal et al., 2021; Tangcharoensathien et al., 2018; Visagie et al., 2017). As here, other researchers have highlighted the negative attitudes often confronting persons with complex disabilities in the society of a developing country. For instance, children with CP are still too often isolated and withdrawn from society when it comes to participating in educational and leisure activities (Babik et al., 2021; Devkota et al., 2019; Dorjbal et al., 2020; Hayward et al., 2021).

A key strength of this study was its use of the Common Brief ICF-CY Core Set for CP to assess and profile the functioning and disability of children with CP. However, our study had the following limitations. Firstly, we conducted this study in a single clinical setting, so the results should not be too readily generalized, even to children with CP elsewhere in Mongolia. In addition, 43 of the participants did not receive MRI. As a result, the ICF generic scale for body structure could not be quantified. Secondly, not every rehabilitation professional in Mongolia working with a child with CP has been fully trained on the ICF-CY Core Set.

Professionals working with children CP need to learn more about the ICF-CY and receive proper instruction in using it appropriately.

5.0 CONCLUSIONS

The functioning and disabilities of Mongolian children with CP were successfully quantified using the Common Brief ICF-CY Core Set for CP. The main domains of impairment in the children studied were their body functions, activities, and participation. Environmental factors were the key component that negatively impacted the life experience of children with CP in Mongolia. Overall, this study's results can help identify the unmet needs of children with CP and improve strategies and interventions to meet international standards by applying these core sets, particularly in an economy with limited resources like Mongolia.

Author contributions: N.T., B.A., D.D. and G.Z. developed and designed this study. N.T. and S.S. were involved in the patient selection and data collection. B.S. and D.G. contributed to the data collection. N.T., D.D. and S.S. performed the qualitative data analysis. N.T. and N.U. conducted the statistical data analysis. N.T. and D.D. wrote the paper. B.L. reviewed and edited the paper. All the authors participated in writing the report, and all have approved the final version. This study was performed as part of the first author's PhD work.

Acknowledgements: We would like to acknowledge the time and effort the study participants and their parents provided to this project. The authors are also grateful to Verónica Schiariti for their suggestions in preparing this report.

Conflicts of interest: The authors declare no conflict of interest.

References

Adler, R.H. (2022). Trustworthiness in qualitative research. *Journal of Human Lactation, 38*(4), 598–602. https://doi.org/10.1177/08903344221116620

Almasri, N. A., Saleh, M., Abu-Dahab, S., Malkawi, S. H., & Nordmark, E. (2018). Functional profiles of children with cerebral palsy in Jordan based on the association between gross motor function and manual ability. *BMC Pediatrics, 18*, 1–8. https://doi.org/10.1186/s12887-018-1257-x

Babik, I., & Gardner, E.S. (2021). Factors affecting the perception of disability: A developmental perspective. *Frontiers in Psychology, 12*, 702166. https://doi.org/10.3389/fpsyg.2021.702166

Bujang, M. A., & Sa'at, N. (2016). Application of consecutive sampling technique in a clinical survey for an ordered population: Does it generate accurate statistics? *Philippine Statistician, 71*(1), 87–98.

Chagas, P. S., Lemos, A. G., Ayupe, K. M., Toledo, A. M., Camargos, A. C. R., Longo, E., Rosenbaum, P. (2024). Functioning profile and related impairments of children and adolescents with cerebral palsy: PartiCipa Brazil preliminary results. *BMC Pediatrics, 24*(1), 719. https://doi.org/10.1186/s12887-024-05210-2

Cieza, A., Fayed, N., Bickenbach, J., & Prodinger, B. (2019). Refinements of the ICF linking rules to strengthen their potential for establishing comparability of health information. *Disability and Rehabilitation*, *41*(5), 574–583. https://doi.org/10.3109/09638288.2016.1145258

Center for Health Development. (2022). *Health Indicators 2022*. World Health Organization Representative Office for Mongolia.

de Oliveira, R. P., Caldas, C. A. C. T., & Riberto, M. (2016). Application of the ICF-CY Brief Core Set for cerebral palsy on a school age child. *Jacta Fisiatrica*, *23(*1), 46–50. https://doi.org/10.5935/0104-7795.20160010

Devkota, H. R., Kett, M., Groce, N. (2019). Societal attitude and behaviours towards women with disabilities in rural Nepal: Pregnancy, childbirth and motherhood. *BMC Pregnancy and Childbirth, 19*, 1–13. https://doi.org/10.1186/s12884-019-2171-4

Dorjbal, D., Cieza, A., Gmunder, H. P., Scheel-Sailer, A., Stucki, G., Ustun, T. B., & Prodinger, B. (2016). Strengthening quality of care through standardized reporting based on the World Health Organization's reference classifications. *International Journal for Quality in Health Care*, *28*(5), 626–633. https://doi.org/10.1093/intqhc/mzw078

Dorjbal, D., Prodinger, B., Zanini, C., Avirmed, B., Stucki, G., & Rubinelli, S. (2020). Living with spinal cord injury in Mongolia: A qualitative study on perceived environmental barriers. *Spinal Cord Medicine, 43*(4), 518–531. https://doi.org/10.1080/10790268.2019.1565707

Dorjbal, D., Zanini, C., Tsegmid, N., Stucki, G., & Rubinelli, S. (2021). Toward an optimization of rehabilitation services for persons with spinal cord injury in Mongolia: The perspective of medical doctors. *Disability and Rehabilitation, 43*(15), 2200–2212. https://doi.org/10.1080/09638288.2019.1696415

Faria-Schützer, D. B. d., Surita, F. G., Alves, V. L. P., Bastos, R. A., Campos, C. J. G., Turato, E. R. (2021). Seven steps for qualitative treatment in health research: The clinical-qualitative content analysis. *Ciência & Saúde Coletiva, 26*(1), 265–274. https://doi.org/10.1590/1413-81232020261.07622019

Graneheim, U. H., Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today, 24*(2), 105–112. https://doi.org/10.1016/j.nedt.2003.10.001

Hayward, L., Fragala-Pinkham, M., Schneider, J., Coe, M., Vargas, C., Wassenar, A. et.al., (2021). Examination of the short-term impact of a disability awareness training on attitudes toward people with disabilities: A community-based participatory evaluation approach. *Physiotherapy Theory and Practice, 37*(2), 257–270. https://doi.org/10.1080/09593985.2019.1630879

Hina, A., Maqbool, S., Azhar, H., Fatima, S., Farid, A., & Ullah, E. (2023). Assessment of children with cerebral palsy using common brief core set of International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY). *Pakistan Armed Forces Medical Journal, 73*(1), 159–163. https://doi.org/10.51253/pafmj.v73i1.7023

Illum, N. O., Bonderup, M., & Gradel, K. O. (2016). Environmental needs in childhood disability analyzed by the WHO ICF, child and youth version. *Danish Medical Journal, 63*(6), A5238.

Khan, F., Amatya, B., Avirmed, B., Yi, Y. K., Shirmen, B., Abbott, G., & Galea, M. P. (2018). World Health Organization global disability action plan: The Mongolian perspective. *Journal of Rehabilitation Medicine, 50*(4), 388–366. https://doi.org/10.2340/16501977-2207

Klang Ibragimova, N., Pless, M., Adolfsson, M., Granlund, M., & Björck-Åkesson, E. (2011). Using content analysis to link texts on assessment and intervention to the International Classification of Functioning, Disability and Health - version for Children and Youth (ICF-CY). *Journal of Rehabilitation Medicine*, *43*(8), 728–733. https://doi.org/10.2340/16501977-0831

Leite, H. R., Jindal, P., Malek, S. A., & Rosenbaum, P. (2022). Research on children with cerebral palsy in low-and middle-income countries. *Pediatric Physical Therapy, 34*(4), 551–555. https://doi.org/10.1097/PEP.0000000000000949

Menezes, I., Curi, H. T., & Jurdi, A. P. S. (2024). Environmental barriers and facilitators to the participation of children with cerebral palsy in recreational and leisure activities: An integrative review. *Cadernos Brasileiros de Terapia Ocupacional, 32*, e3623. https://doi.org/10.1590/2526-8910.ctoAR278236232

Noten, S., Selb, M., Troenosemito, L. A., Thorpe, D. E., Rodby-Bousquet, E., van der Slot, W. M., Ballester-Plané, J. (2022). ICF core sets for the assessment of functioning of adults with cerebral palsy. *Developmental Medicine Child Neurology, 64*(5), 569–577. https://doi.org/10.1111/dmcn.15104

Paulson, A., & Vargus-Adams, J. (2017). Overview of four functional classification systems commonly used in cerebral palsy. *Children (Basel*), *4*(4), 30. https://doi.org/10.3390/children4040030

Rauch, A., Cieza, A., & Stucki, G. (2008). How to apply the International Classification of Functioning, Disability and Health (ICF) for rehabilitation management in clinical practice. *European Journal of Physical and Rehabilitation Medicine*, *44*(3), 329–342.

Rosenbaum P, P. N., Leviton A, Goldstein M., Bax M, Damiano D., et al. (2007). The definition and classifcation of cerebral palsy. *Devolepmental Medicine and Child Neurology, 49*(s109), 8–14. https://doi.org/10.1111/j.1469-8749.2007.00001.x

Schiariti, V., Klassen, A. F., Cieza, A., Sauve, K., O'Donnell, M., Armstrong, R., & Mâsse, L. C. (2014). Comparing contents of outcome measures in cerebral palsy using the International Classification of Functioning (ICF-CY): A systematic review. *European Journal of Paediatric Neurology, 18*(1), 1–12. https://doi.org/10.1016/j.ejpn.2013.08.001

Schiariti, V., Longo, E., Shoshmin, A., Kozhushko, L., Besstrashnova, Y., Król, M., Shaba, D. (2018). Implementation of the International Classification of Functioning, Disability, and Health (ICF) core sets for children and youth with cerebral palsy: Global initiatives promoting optimal functioning. *International Journal of Environmental Research Public Health, 15*(9), 1899. https://doi.org/10.3390/ijerph15091899

Schiariti, V., Masse, L. C., Cieza, A., Klassen, A. F., Sauve, K., Armstrong, R., & O'Donnell, M. (2014). Toward the development of the International Classification of Functioning core sets for children with cerebral palsy: A global expert survey. *Journal of Child Neurology, 29*(5), 582–591. https://doi.org/10.1177/088307381347

Schiariti, V., Selb, M., Cieza, A., & O'Donnell, M. (2015). International Classification of Functioning, Disability and Health core sets for children and youth with cerebral palsy: A consensus meeting. *Developmental Medicine Child Neurology, 57*(2), 149–158. https://doi.org/10.1111/dmcn.12551

Schiariti, V., Tatla, S., Sauve, K., & O'Donnell, M. (2017). Toolbox of multiple-item measures aligning with the ICF Core Sets for children and youth with cerebral palsy. *European Journal of Paediatric Neurology, 21*(2), 252--263. https://doi.org/10.1016/j.ejpn.2016.10.007

Schoonenboom, J., & Johnson, R. B. (2017). How to Construct a Mixed Methods Research Design. *Kolner Zeitschrift fur Soziologie und Sozialpsychologie*, *69*(Suppl 2), 107–131. https://doi.org/10.1007/s11577-017-0454-1

Tangcharoensathien, V., Witthayapipopsakul, W., Viriyathorn, S., & Patcharanarumol, W. (2018). Improving access to assistive technologies: Challenges and solutions in low-and middle-income countries. *WHO South-East Asia Journal of Public Health, 7*(2), 84–89. https://doi.org/10.4103/2224-3151.239419

Tantilipikorn, P., Watter, P., & Prasertsukdee, S. (2012). Identifying assessment measures and interventions reported for Thai children with cerebral palsy using the ICF-CY framework. *Disability and Rehabilitation, 34*(14), 1178–1185. https://doi.org/10.3109/09638288.2011.637603

Trabacca, A., Russo, L., Losito, L., Rinaldis, M. D., Moro, G., Cacudi, M., & Gennaro, L. (2012). The ICF-CY perspective on the neurorehabilitation of cerebral palsy: A single case study. *Journal of Child Neurology, 27*(2), 183–190. https://doi.org/10.1177/0883073811415852

Vaismoradi, M., Turunen, H., & Bondas, T. (2013). Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing Health Sciences, 15*(3), 398–405. https://doi.org/10.1111/nhs.12048

Visagie, S., Eide, A. H., Mannan, H., Schneider, M., Swartz, L., Mji, G., et al. (2017). A description of assistive technology sources, services and outcomes of use in a number of African settings. *Disability and Rehabilitation: Assistive Technology, 12*(7), 705–712. https://doi.org/10.1080/17483107.2016.1244293

World Health Organization. (2002). *Towards a common language for functioning, disability and health: ICF*. World Health Organization. https://www.who.int/classification/icf

World Health Organization. (2007). *International classification of functioning, disability and health: Children & youth version: ICF-CY*. World Health Organization. https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health

World Health Organization. (2013). *How to use the ICF: A practical manual for using the International Classification of Functioning, Disability and Health (ICF).* Geneva: World Health Organization.