

# REPORTS OF CASE SERIES OF INSTITUTIONALIZED ADULTS WITH MULTIPLE DISABILITIES: HOW TO ASSESS FUNCTIONALITY?<sup>1</sup>

## RELATOS DE SÉRIES DE CASOS DE ADULTOS INSTITUCIONALIZADOS COM DEFICIÊNCIA MÚLTIPLA: COMO AVALIAR A FUNCIONALIDADE?

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**ABSTRACT:** The objective of this paper is to propose and apply a form of functional neurological classification, based on positioning and transference in institutionalized adults with severe multiple disabilities. The method used was the cross-sectional, descriptive study in a long-stay institution in Curitiba, state of Paraná, Brazil. Participants were filmed at the Gross Motor Function Measure (GMFM), posture transfer and displacement positions. The score from 1 to 5 points was given from the Aquatic Functional Assessment Scale (AFAS), as an adaptation to the floor. The International Classification of Functionality (ICF) was used as a toll to detail the positions regarding qualifiers of facilitators and restrictors for each participant. Five participants with multiple disabilities were evaluated, aged between 21 and 29 years, with a predominance of females (80%). Only one participant had assisted gait and 3 (60%) had stereotyped hands or upper body. Transfers between positions were not performed independently by any participant. The highest score found by AFAS was 14 points and the worst score was 5 points. The results indicate that the ICF was sensitive to perceive the movements or restrictive positions and facilitators for each of the participants and it may be able to help in choosing the best forms of evaluation.

**KEYWORDS:** International Classification of Functionality. Disability and Health. Physical Therapy. Motor Skills.

**RESUMO:** O objetivo deste artigo é propor e aplicar uma forma de classificação neurofuncional, baseada em posicionamentos e transferências em adultos institucionalizados com deficiência múltipla grave. O método utilizado foi o estudo transversal, descritivo, em uma instituição de longa permanência de Curitiba, estado do Paraná. Foi realizada filmagem dos participantes nas posições da escala *Gross Motor Function Measure* (GMFM), transferências de posturas e deslocamento. A pontuação de 1 a 5 pontos foi dada a partir da escala *Aquatic Functional Assessment Scale* (AFAS), como uma adaptação em solo. Utilizou-se a Classificação Internacional da Funcionalidade (CIF) como ferramenta para detalhar as posições quanto aos qualificadores de facilitadores e restritores para cada participante. Foram avaliados cinco participantes com deficiência múltipla, com idades entre 21 e 29 anos, com predomínio do sexo feminino (80%). Apenas um participante tinha a marcha assistida e 3 (60%) apresentaram estereotipia de mãos ou tronco. As transferências entre as posições não foram realizadas de forma independente por nenhum participante. A maior pontuação encontrada pela AFAS foi de 14 pontos e a pior foi de 5 pontos. Os resultados indicam que a CIF foi sensível para perceber os movimentos ou posicionamentos restritores e facilitadores para cada um dos participantes, e ela pode ser capaz de auxiliar na escolha das melhores formas de avaliação.

**PALAVRAS-CHAVE:** Classificação Internacional de Funcionalidade. Incapacidade e Saúde. Fisioterapia. Habilidades motoras.

<sup>1</sup> <http://dx.doi.org/10.1590/S1413-65382519000100004>

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## 1 INTRODUCTION

Life expectancy of people with disabilities (PwD) has increased (Hess, Campagna, & Jensen 2017), accompanying the world panorama of increased life expectancy (Mckenzie, Ouellette-Kuntz, & Martin, 2017), but there are few Brazilian studies (Margre, Reis, Morais, & Ramos, 2011), especially in institutionalized persons with multiple disabilities. Multiple disability is defined as the association of more than one type of disability, with impacts on its functionality (Rocha & Pletsch, 2018).

Over the years, individuals with multiple neurofunctional disorders may present functional decline (Quatman-Yates, Quatman, Meszaros, Paterno, & Hewett, 2012), mainly after 21 years of age and with severe impairment (Hanna et al., 2009). In addition, a prognosis is expected for those individuals who have associated impairments (Voorman, Dallmeijer, Knol, Lankhorst, & Becher, 2007), such as multiple alterations, a fact that may be impacting on functional aspects throughout life (Chaney & Eyman, 2000).

Considering functionality as a health indicator (Stucki & Bickenbach, 2017), the use of the International Classification of Functioning, Disability and Health (ICF) (World Health Organization [WHO], 2015) has been increasing in the field of health care. This form of classification seeks to understand the individual in his/her context, observing his/her functional abilities and constraints. Therefore, individuals with the same diagnosis may have different outcomes when observed by the ICF. In order to carry out this classification, the use of evaluation scales as a form of data systematization (Cieza, Fayed, Bickenbach, & Prodingler, 2016; Silva et al., 2016) is suggested, as well as qualitative observations regarding the individual and his/her environment.

In the biopsychosocial model (WHO, 2015), personal factors such as characteristics and physical-functional sequelae that involve the domains of function and body structure (little change of position and movement and stimuli), activity and participation dimensions (reduced stimulation through physical activity and social involvement), as well as environmental factors (institutionalization and length of stay in each position and environment), added to the lack of knowledge of health professionals about aging, may predispose to a greater functional impairment (Margre et al., 2011). This fact can lead to early comorbidities and mortality (Chaney & Eyman, 2000). Thus, the development of the person with multiple disabilities should be understood in an integrated and context-related manner (Sousa & Franco, 2012), regardless of age, in an attempt to minimize secondary changes to the primary disability.

In the evaluation of PwD, especially in cases of multiple disability, the degree of disability impairment, etiology, gender of the subjects (since women have higher survival rates), the type of residence in which they live and the stimulus received consist of variables to be investigated (Sousa & Franco, 2012). And still today there are several forms of functional evaluation (Castaneda, Castro, & Bahia, 2014) and little discussed about such evaluations in the context of people with adult and institutionalized PwD.

There is lack of standardized functional assessment scales for this population and guidelines on how best to attend and treat each one. To assist in this process, ICF opens new horizons and possibilities for the understanding of human functionality in all its manifestations as an indicator of health (WHO, 2015).

Literature points to controversial results regarding the institutionalization of PwD. Some studies report functional impairment (Quatman-Yates et al., 2012), lower autonomy (WHO, 2015) and greater health problems (Chaney & Eyman, 2000); while other studies are still inconclusive, and do not know exactly if they are institutionalized because the patients have more severe problems, or as they are institutionalized, they end up with more severe limitations (Sousa & Franco, 2012).

Associated with the inconclusive findings about the effect of institutionalization on functionality, there is the very question of the difficulty of evaluation and follow-up of PwD with multiple disabilities in the transition from childhood and adolescence to adult life, in relation to the care of their condition of health and social insertion (Binks, Barden, Burke, & Young, 2007; Haak, Lenski, Hidecker, Li, & Paneth 2009). In this way, how can we think about assessing and monitoring the development of institutionalized adults with multiple disability?

Often, PwD after adulthood shows stagnation and a decline in functional status (Haak et al., 2009), and because there is no specific instrument for functional assessment of adults with multiple disabilities, the Gross Motor Function Measure (GMFM), widely used for cerebral palsy (CP), for children, adolescents and even young adults (Nelson, Owens, Hynan, Iannaccone, & AmSMART Group, 2006; Margre et al., 2011), was selected in this study as a way to measure the motor skills of adults with multiple disabilities.

Selected by the functional positions, GMFM can be a way of monitoring the person with multiple disabilities. And, as a form of scoring, the Aquatic Functional Assessment Scale (AFAS) can be used as a scoring tool for each of these positions, since it looks at the individual skills and not just the functional constraints. Such scale classifies motor components qualitatively/ quantitatively (Israel & Pardo, 2014).

In this sense, in order to propose new ways of observing postural abilities in adult PwD, the objective of this study was to apply a form of neurofunctional classification, based on positioning and transference in institutionalized multiple disability adults, and to present the possible facilitators and restrictors through the ICF in each position.

## 2 METHODS

It is a cross-sectional descriptive study (Abily-Donval et al., 2015), based on the biopsychosocial model of the ICF carried out in a long-stay institution that houses about 200 people with cognitive and/or multiple disability in Curitiba, state of Paraná, Brazil. This institution serves as a home for the residents, with a school education and health service. It is also church-supported and non-profit. The study was approved by the Ethics and Research Committee of the Brazilian Institute of Therapies and Teaching CAAE: 53310116.8.0000.5229, Opinion no. 1,429,717, with clinical record RBR-2st594.

The demand for such research arose from the institution and pedagogical team in order to obtain a form of evaluation and monitoring of functional evolution and learning (Rocha & Pletsch, 2018) of residents with multiple disabilities, considering functionality as an

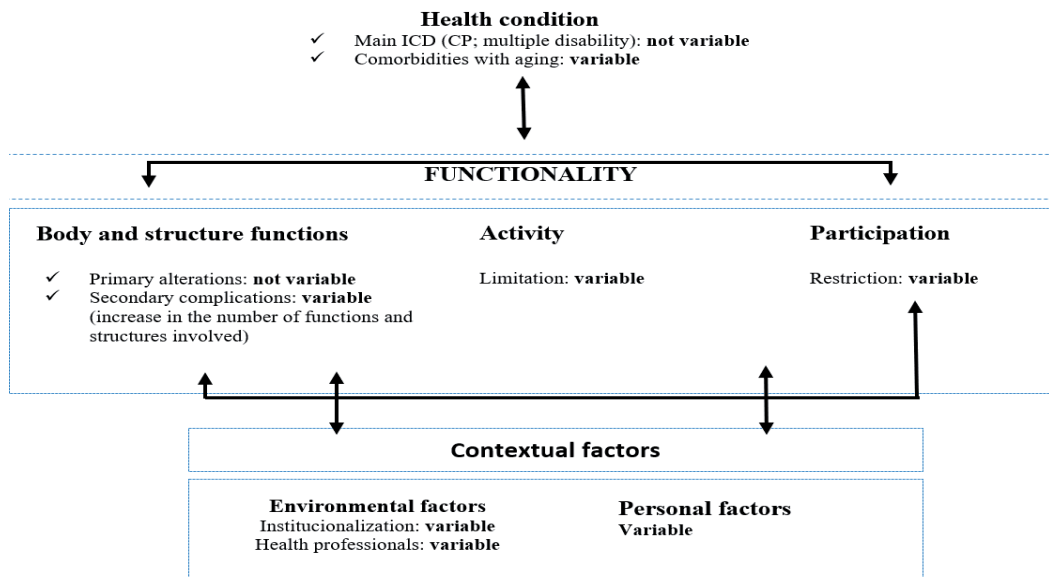
indicator of relevance. However, at that early stage, assessments were made that involved only functional mobility issues.

Residents of a long-stay institution for people with multiple disabilities in Curitiba over 20 years old who could perform physical activities outside the chair and bed were included in the study. Residents with associated psychiatric disorders and elderly were excluded. Five residents of the institution, aged between 21 and 29 years old, predominantly female (80%) and only one (20%) male, took part of the investigation. The data collection through a functional evaluation of the spontaneously observed and/or facilitated motor behaviors happened in the same institution, always in a room equipped with mats, high board, roll and/or balls, and performed by professional physiotherapists in the neurofunctional area.

The entire assessment took place individually, it lasted about an hour and was accompanied by three properly trained physiotherapists. All body positions evaluated in the participants were extracted from GMFM. This evaluation system is divided into five dimensions from A to E, namely: A = lying down and rolling, B = sitting, C = crawling and rolling, D = standing and E = walking, running and jumping. These dimensions add up to 88 items, and the participant can score from 0 to 3, being: 0 = not start, 1 = start, 2 = partially complete and 3 = fully complete (Russell, Rosenbaum, Wright, & Avery, 2002; Mélo, 2011). As a way of classifying and scoring motor skills, within each body position used by GMFM, the AFAS score was used and adapted (Israel & Pardo, 2014).

AFAS ranks functional performance by learning levels in scoring activities ranging from 1 (0%) to 5 (100%), and the higher the score the better the motor ability and independence (Israel & Pardo, 2014). Thus, for each of the positions and transfers in soil, the adaptation and graduation were done as follows: 1 - Does not do it (DN): corresponds to the ability of 0%; 2 - with total help (WTH): more than two points of support, corresponds to the ability of 25%; 3 - with partial help (WPH): 1 or 2 points of support, corresponds to the ability of 50%; 4 - does it without help (DWH): with minor/partial domain, corresponds to the ability of 75%; 5 - fully achieved (FA): with higher/full domain, corresponds to 100% ability.

The biopsychosocial model of the ICF (Figure 1) was used for a better functional understanding in each of these positions and observing, in addition to the position itself, its transference and the context of facilitators (domain of environmental factors) and restrictors (domain of participation). In this perspective, it was observed what each participant could do and what limited him/her in the accomplishment of each posture and transference. It was pointed out which functions and corporal structures were with greater impairment that influenced in the action of the corporal positioning.



**Figure 1.** Proposition of the Integrative Model of the ICF considering the institutionalization of adults with multiple disabilities  
 Source: Elaborated by the authors.

For the evaluation and later score, the participants were filmed in the positions: dorsal, ventral, lateral, transfers to these decubitus, sitting and transfer to the sitting position, quadruped position and kneeling position, orthostatic position and standing with displacement, based on GMFM and AFAS. For this, each evaluated person was initially positioned in their position of better comfort and encouraged with objects and/or verbal command by the evaluators to change their position. Their voluntary and spontaneous motor behaviors were observed and, in their absence, facilitated and guided by the therapists in changes of posture as well as their maintenance.

As complement to the evaluations, the date of birth and the clinical diagnosis of each participant were deleted from the institution’s physical record. A descriptive analysis of the observations made, after video analysis, was carried out and descriptive qualitative information was reported on the factors of facilitators and restrictors of the ICF.

### 3 RESULTS

#### 3.1 EVALUATION FROM GMFM POSTURES

It was possible to notice that only one participant had gait assisted and 3 (60%) had stereotyped hands or trunk. The interaction between therapist and participant was limited in all assessments, and transfers between one body position and another were not performed independently by any participant. All (n=5) required support or encouragement to move from lying down to sitting position, from sitting to quadruped position, from quadruped position to kneeling and standing.

### 3.2 OBSERVATION FROM THE FACILITATORS AND RESTRICTORS OF THE ICF BIOPSYCHOSOCIAL MODEL

Regarding the observation of the facilitators and the restrictors of the ICF, it was possible to perceive that the secondary alterations to the multiple disability itself were often barriers for the accomplishment of the movements. In contrast, as the movement patterns, such as stereotypies and scoliosis have been present for a long time in the participants, in some cases, these are the resources used to perform some movement. These secondary alterations were, at various times, the movement facilitators, as described in Table 1.

Participants	Age	Function and structure of the body		Activity (Postures and transfers)		Participation (Realization of postures and corporal transfers)	
		Clinical diagnosis	AFAS skill completion percentage	Total score AFAS	What facilitates the skill	What restricts the ability	
P1	23	Mild intellectual development disorder and CP	A=50% B=75% C=25% D= 50% E=50%	14	Has reach with the hands. Makes quadruped position with support. Stands up, walks with supervision and support in hand.	Stereotypical hands with self-mutilation. Anterior slope of trunk. Cognitive deficit.	
P2	21	CP, Bronchitis and Seizures	A=25% B=25% C=0% D= 0% E=0%	7	Supports the cervical in prone position and seated. Seeks to interact with the environment (smiles, looks), makes active movements of right knee flexion.	Hip stiffness. Pattern in wrist flexion. Dorsiflexion eversion feet. No trunk control in sitting without support. t Doesn't reach.	
P3	29	CP, Seizures, Hypothyroidism and Severe intellectual development disorder	A=25% B=50% C=0% D= 0% E=0%	8	Thorax without deformities and aligned spine.	Trunk stereotype. It adopts position in trunk flexion when sitting or lying down.	
P4	21	CP, Epilepsy and Intellectual Development Disorder	A=25% B=75% C=0% D=0% E=0%	9	Moves from prone position to seated. Supports cervical in ventral decubitus.	Sits in flexion posture. Has no palmar grasp. Stereotyped hands and lower members. Cognitive deficit.	
P5	24	CP and intellectual development disorder	A=0% B=0% C=0% D= 0% E=0%	5	Is calm and accepts the therapist's positioning.	Hypertonicity in hip, trunk, knees, shoulders that limits transfers. Does not extend in ventral decubitus. Reduction of ROM in knees, ankles and wrists. Tilt the cervical to the left.	

**Table 1.** Classification of participants from the ICF perspective

Source: Elaborated by the authors.

Legend: CP: Cerebral palsy. ROM: range of motion. A= lying down and rolling, B= sitting, C= crawling and rolling, D= standing and E= walking, running and jumping. AFAS Score: 1- DN: does not do it; 2- WTH: with total help (more than two points of support); 3- WPH: with partial help (1 or 2 points of support); 4- DWH: does it without help, with minor/partial domain; 5- FA: fully achieved, with greater/complete domain.

The environment in which the participants spent most of the time was also considered restrictive because, for long periods of the day, all the residents of the institution remain in wheelchairs or beds in shared rooms, leaving these places only in the short period of Physiotherapy. This factor limits the mobility even further and reduces the social relationship of the participants. These aspects end up making them dependent on all day-to-day demands, perhaps leading to greater restrictions and disabilities.

## **4 DISCUSSION**

### **4.1 EVALUATION FROM GMFM POSTURES**

This study sought to apply a form of functional evaluation in adults with multiple disabilities, from adapted instruments, and to perceive through the ICF the restrictors and facilitators of each positioning for each participant. Regarding gender, the study participants had a predominance of females, and this is related to the literature regarding better health conditions, care and female longevity (Sousa & Franco, 2012). However, life expectancy is not always associated with gains in functionality between individuals with multiple disabilities, which ultimately influences mortality rates when limitations and other diseases are added, such as CP and Down Syndrome (Sousa & Franco, 2012). This fact becomes relevant, since the study sample presented here has these characteristics and great functional impairments.

When comparing the aging process of the typical person, a functional decline is also expected in the PwD, and these losses may be higher or lower depending on the environment where they live, type of stimulus received, degree of disability and institutional residence (Sousa & Franco, 2012). Functional difficulties in activity and participation have already been mentioned in a previous study, with children and adolescents in this same long-term institution (Mélo, Yamaguchi, Silva, & Israel, 2017). Thus, it can be noted that functional reduction in adulthood is the result of a process of years of reduction in stimuli and social involvement.

By adapting the GMFM and AFAS scales, we observed low scores related to functional activities in all postures and, mainly, to the performance of transfers. Such observations were justified by the restrictions that the participants presented due to secondary complications, such as deformities, shortenings, contractures and stereotypies, even though this sample was composed of young adults. These musculoskeletal complications are reported in other studies (Binks et al., 2007; Haak et al., 2009), which reinforces the need for care measures for this population.

One of the possible reasons for so many secondary changes in the participants of the present study may be related to the low number of caregivers hired by the institution, who need to care for more than one person at a time and do not always have specific qualifications to care for people with multiple disabilities.

Little social involvement, immobilism, and institutionalization sometimes deepen the functional decline of people with multiple disabilities (Hanna et al., 2009). This leads to premature aging, with greater chances of fragility and dependence, anticipating factors of the aging process and aggravating the condition of these individuals (Mckenzie et al., 2017). People with multiple disabilities end up adopting postures and movement patterns, as evidenced in

this study, which hinder their functionality, jeopardizing their activities and participation. These functional changes impact on activities of daily living, as well as pedagogical processes and adaptation of different functions in different contexts. This includes assistive technology and alternative communication which ultimately require practically individual adaptations, given the constraints and the secondary commitments.

Corroborating with Wanderer and Pedroza (2013), the sample composed of people with multiple disabilities have greater functional limitations than those with only ID, and this greater impairment is more evident in cases of individuals with CP and other aggregate comorbidities (Wanderer & Pedroza, 2013), with emphasis also on the stereotypes that limit the function and were present in more than half of the participants.

The verification of functional changes through the GMFM can be difficult in cases of PwD with multiple alterations, considering that changes from score 1 to score 2 require large gains and are only detected if the evaluated person does so without the evaluator's facilitation. This becomes difficult in people who, in addition to motor difficulties, have associated cognitive limitations. In addition, normative curves and scores for ages above 21 were not identified. In this sense, the use of AFAS seems to allow greater possibilities of identification of such graduations, even in a different environment, such as the floor.

As for the functionality of adults with disabilities, many researches point to different paths, involving professional, sexual life, quality of life and physical-functional mobility. In this perspective, several health areas offer possibilities of assistance with medical, physiotherapeutic, psychological, speech-language interventions with the focus of evaluating and proposing new therapies or possibilities for functional gains in different contexts in which the adult may be inserted (Wanderer & Pedroza, 2013).

#### **4.2 OBSERVATION FROM THE FACILITATORS AND RESTRICTORS OF THE ICF BIOPSYCHOSOCIAL MODEL**

Institutionalization by itself can represent a facilitator with respect to the environmental factor and protection of life, compared to the previous reality of the subject who was probably institutionalized because greater care is needed to maintain his/her life and family difficulties. However, what is seen is a reality of difficult control, because there are many demands that the person with multiple disabilities requires, few physical and human resources and low motor and sensory stimuli.

When observing, from the point of view of the ICF, the restraints and the facilitations highlighted by the ICF, it was possible to notice that the female participants obtained better skills and facilitators when compared with the male participant.

When approaching the ICF of the forms of classification of the PwD, the individual was observed in a multidisciplinary, international context with incorporation of the context of each one, besides seeking to understand the real health status of the subjects, without distinction of age group (Di Nubila & Buchalla, 2008). Thus, from the perspective of the ICF, disability was also observed as limitations in the function or structure of the body, as pointed



out in the restrictions detailed in this study, and the functionality became the functions and performance of actions as tested by GMFM positions.

Based on the observations made by the ICF facilitators and restrictors within each participant's positioning, Physiotherapy could contribute to the maintenance and prevention of new complications in health using methods and techniques such as: Kinesiotherapy, Aquatic Physiotherapy, Equine Therapy, use of orthosis, Snoozelen/multi-sensory environments, Intensive Neuromotor Therapy (INMT), PenguinSuit®, AdeliSuit®, Pedia Suit®, TheraSuit®, and Manual Therapies (Mélo, Ferreira, Yamaguchi, & Israel, 2017).

Often, to measure a disease, the functional impairments caused by it and its limitations in the quality of life are used. According to McKenzie et al. (2017), few strategies for assessing adults with intellectual disabilities and fragility have emerged. In this way, more research is needed for strategy replication and instrument validation.

In this sense, it is important to emphasize that, just as in the study presented here, when talking about assessments of adults with multiple disabilities, involving intellectual disability, there are no standardized scales and there are doubts as to the best form of analysis. However, the diversity of this population often makes standardization of scales unfeasible, since individual descriptions of patterns and postures are required - factors that are only covered in their entirety through qualitative descriptions. Normally, what happens then is the exclusion of these individuals from the research, but they exist in the context of inclusion and their functional aspects need to be discussed (Wanderer & Pedroza, 2013), even because they have lived more and more with functional limitations.

The use of GMFM as a way of analyzing the motor behavior, with AFAS association, is complementary. It may also be an alternative way for rehabilitation and pedagogical staff to monitor and measure functional aspects, considering that functional gains directly impact the possibility of greater autonomy. The lack of assessment tools for adults with multiple disabilities can also be highlighted. In addition, few participants were found for the study due to the functional diversity of institutionalized adults with disabilities.

## 5 CONCLUSIONS

It was possible to apply a form of functional assessment and to perceive the main barriers and facilitators of institutionalized adults with multiple disabilities. There was also a large number of residents with multiple disabilities in long-term institutions without evaluation follow-up and standardized intervention programs.

It was noted the difficulty in finding standardized scales for this population. However, the possibility of qualitative reports of people with disabilities is highlighted. It was perceived that the ICF can be an instrument capable of assisting in the choice of the best forms of classification and later evaluation, in order to understand the functionality of these individuals and to emphasize their capacities and their limitations, guiding, even, therapeutic behaviors.

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Received on: 12/09/2018

Reformulated on: 26/10/2018

Accepted on: 28/10/2018