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Clinical profile and functional classification of people with disabilities in the Marajó Archipelago

Perfil clínico e classificação de funcionalidade de pessoas com deficiência no Arquipélago do Marajó

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ABSTRACT
To analyze the clinical profile and functional classification of the population with physical and/or sensory disabilities in the municipalities of Marajó using the International Classification of Diseases and International Classification of Functioning, Disability, and Health. This descriptive, exploratory study was carried out in all Marajó municipalities. The prevalence of disabilities acquired after birth involving diseases of the nervous system and impairment of the lower and upper extremities of the body was verified. Deficiency in joint mobility, strength, and tonus were the most affected body functions, which impacted mobility and self-care activities, as well as interpersonal relationships with healthcare professionals and immediate family, representing a social barrier. Thus, based on the results found, the influence of social, educational, economic, and geographical contexts on the clinical condition and functional performance of people with disabilities is understood.

Keywords: International Classification of Functioning, Disability, and Health. Mobility Limitation. Disabled Persons.

RESUMO
Analisar o perfil clínico e a classificação de funcionalidade da população com deficiência física e/ou sensorial dos Municípios do Marajó, através do uso da Classificação Internacional de Doenças e Classificação Internacional de Funcionalidade, Incapacidade e Saúde. Pesquisa descritiva e exploratória em todos os Municípios do Marajó. Verificou-se a prevalência de deficiências do tipo adquirida após o nascimento envolvendo doenças do sistema nervoso, comprometimento da extremidade inferior e superior do corpo. A deficiência na mobilidade articular, força e tônus como funções do corpo mais afetadas e impacto nas atividades de mobilidades e autocuidados e nas relações interpessoais por profissionais da saúde e família imediata como barreira social. Dessa forma, a partir dos resultados encontrados, compreende-se a influência do contexto social, educacional, econômico e geográfico na condição clínica e no desempenho funcional de pessoas com deficiência.

Palavras-chave: Classificação Internacional de Funcionalidade, Incapacidade e Saúde. Limitação da Mobilidade. Pessoas com Deficiência.

INTRODUCTION

In many countries, indigenous communities and remote communities, as studied by Dew et al. in Australia, have social determinants that influence access to quality healthcare, especially those who have a disability. These authors argued that identifying their particularities and perspectives must be taken into consideration when exercising health based on a set of local and cultural specificities[1]. From this perspective, Nascimento et al. also emphasized such particularities in the Amazonian scenario with riverside older people who, through traditions, customs, and beliefs, influence health care[2].

The Marajó Archipelago, the largest fluvial-maritime archipelago in the world, is surrounded by the Amazon River and the Atlantic Ocean and has numerous singularities in its complex territory[3]. In this context, the unique hydrographic conditions represent a scenario of social and geographic isolation in addition to the local architectural configuration, which requires differentiated accessibility standards[4].

Under these circumstances, the Populations of the Field, Forest, and Waters, which have connections, above all, with forest and aquatic areas, are inserted in contexts with unique social determinants, where the challenge for health practices must be addressed to understand the logic and form of organization of the territory[5]. Therefore, different groups are inserted in different contexts, such as the Australian and Canadian indigenous populations, based on a more holistic health model. This specificity can be captured by a model more sensitive to the identification of biopsychosocial components, such as the International Classification of Functioning, Disability, and Health (ICF), which covers the social and cultural context of the individual[6]. However, the correlation of the clinical profile with the biopsychosocial components is an aspect poorly addressed in studies in more remote communities.

In this context, people with disabilities who live in the countryside are vulnerable to limitations during their daily lives, as there is less inclusion in this environment, whether in terms of adherence to education, employment, or other forms of social participation[7]. In addition to the care model provided to this community, as investigated among indigenous people with disabilities in Australia, New Zealand, Canada, and the United States, who have a different standard of care, especially related to the integration of care with family care, there is little access of the indigenous population to a model that covers their specificities, as well as little evidence about promising care models for this population[8].

In accordance with Art. 2 of the Statute of Persons with Disabilities (Law 13,146, of July 6, 2015)[9]: "A person with a disability is considered to be someone who has a long-term impairment of a physical, mental, intellectual, or sensory nature. This impairment, when interacting with one or more barriers, may obstruct their full and effective participation in society on equal terms with others".

Regarding the concept and applicability of the term "disability," the World Health Organization (WHO) bases reference classification models to standardize communication between health professionals, such as the International Classification of Diseases (ICD-10), used to codify the causes and consequences of diseases; and the International Classification of Functioning, Disability, and Health (ICF), which encompasses the functions and structures of the body, activities, and participation, indicating the positive aspects of the interaction between an individual with a health condition and their contextual factors, being environmental and personal factors[10,11,12]. Therefore, considering the theme of studies on the clinical profile associated with the limitations of activities of persons with physical and/or sensory disabilities as underdeveloped, the present article sought to analyze the clinical profile and classification of the functionality of the popula-

tion with physical and/or sensory disabilities in the Municipalities of Marajó. This analysis was carried out using the International Classification of Diseases and the International Classification of Functioning, Disability, and Health.

METHODOLOGY

This was a descriptive, cross-sectional, and exploratory study conducted in 16 municipalities of the Marajó Archipelago between July 21 and October 20, 2021.

The study protocol was approved by the Research Ethics Committee (Opinion 4,871,778) and followed the recommendations of the National Research Ethics Council (CONEP), according to Resolution 466/12. The Informed Consent (IC) used in the research was explained verbally to each individual and applied before data collection, and the participant's signature was collected on this form. Participants under guardianship signed the Informed Assent (IA).

STUDY POPULATION

Participants were recruited based on spontaneous demand after disseminating the research in each municipality through prior contact with the health secretariats and the provision of a data collection schedule, which was delivered to the population through managers and community health agents of the units. Collection occurred at the following locations: Dom Ângelo Basic Health Unit, Chaves Municipal Hospital, Oldemar Coelho Citizen Service Center, Santo Antônio Basic Health Unit, Paraíso Family Health Strategy, Maria Alves Cardoso Family Health Unit, Abelardo da Silva Health Unit, Mário de Oliveira Gomes Rehabilitation Center, Nossa Senhora das Graças Family Health Strategy, Raimundo Barbosa Nunes Basic Health Unit, Bosque e Tijuca Family Health Strategy, Joanes Family Health Strategy, Coqueiro Community Family Health Unit, Family Health Strategy Matinha São Pedro, Centro Family Health Unit, Family Health Strategy Jenipapo I, and Pedro Fernandes de Souza Basic Health Unit. As inclusion criteria, individuals of any age, of both genders, with disabilities related to motor skills and/or the presence of sensory deficiencies residing in the Marajó region participated in the study. Individuals who, although they had motor or sensory disabilities, also manifested more severe characteristics and illnesses such as hemodynamic instability and severe cognitive impairment, and people with restrictions regarding their care were excluded from the study, as well as those who refused to participate in the research and did not sign the IC or AC. In total, data were collected from 67 people with some type of physical and/or sensory disability, of which 51 only had physical disabilities.

ASSESSMENT INSTRUMENTS

Two assessment instruments were used: a sociodemographic profile form prepared by the authors and a checklist adapted by the project team based on the International Classification of Functioning[10].

The socio-demographic profile form was applied during an interview with residents of 16 municipalities in Marajó, whether or not they had physical and/or sensory disabilities, which included questions such as gender, age, color/race, religion, education, marital status, and monthly family income. In addition to this information, through this form, it was possible to identify the etiologies and classification of deficiencies, for example, whether acquired or congenital, which were reported by the participants or their guardians. Information on the type of physical and sensory disability was based on the International Classification of Diseases (ICD-10) codes.

The questionnaire, structured based on the ICF Checklist version 2.1a, was adopted to classify the activity level of individuals with and without disabilities across domains of mobility

and personal care related to "activity limitations and participation restrictions." These domains include tasks such as lifting and carrying objects, fine hand motor skills, walking, washing (bathing, drying oneself, washing hands, etc.), caring for body parts (brushing teeth, shaving, etc.), processes of excretion, dressing, eating, drinking, and maintaining own's health. When answering items related to the topics of activity and participation, environmental factors, deficiencies in body structures, and most affected body functions, participants had the following response options, respectively: no disability, some disability, or unspecified (activity and participation); no barriers, barriers or facilitators (environmental factors); no disability, some disability or unspecified/not applicable (body structure deficiencies); no disabilities; some disability; unspecified (body functions most affected).

DATA ANALYSIS

Data were entered into Excel software and presented in tables. Socio-demographic data are listed in Table 1, which contains the relative frequency of participants and their percentage distribution regarding characteristics such as sex, age, color/race, religion, education, marital status, and monthly family income. The clinical conditions, activities and participation, environmental factors, deficiencies in body structures, and body functions most affected in individuals were listed, and the four items from the most prevalent domains are presented in relative frequency and percentage relative to the total in Table 2. For statistical analysis, the chi-square test and the G adherence test were applied using the BioEstat 5.3 software, with a statistically significant difference at $p < 0.05$.

RESULTS

Participants were 67 people with disabilities, with an average age of 41.3 years (SD±17.03). There was a predominance of males (55%), individuals with primary education (57%), mixed race/mulatto ethnicity (63%), Catholics (54%), and single (61%). Regarding family income, 80% of participants receive some type of financial assistance as a form of monthly family income. Additionally, 81% of participants declared an income of 1 to 2 minimum wages (Table 1).

Table 1. Sociodemographic profile and characterization of the sample of people with disabilities from Marajó.

Characteristics	n	%	P
Gender			
Female	30	45%	0.4635
Male	37	55%	
Age (years)			
10-39	27	40,3%	0.0648
40-59	23	34,3%	
60 e +	17	25,4%	
Race or ethnicity			
Mixed race/mulatto ethnicity	43	64%	< 0.0001
Black	18	27%	
White	5	7%	
Indigenous populations	1	1%	
Religion			
Catholic	36	54%	< 0.0001
Protestant	27	40%	
None	4	4%	
Education			
Primary education	38	57%	< 0.0001
High school	12	18%	
Higher education / University	2	3%	
No formal education	15	22%	
Marital status			
Married	26	39%	0.0872
Single	41	61%	
Monthly Family Income			
1 to 2 minimum wages	54	81%	0.3767
3 to 4 minimum wages	7	7%	
Less than one minimum wage	6	6%	

Among the participants in the study sample, 51 people had physical disabilities, of which 37 had acquired disabilities. Additionally, 7 individuals had sensory disabilities, with 4 of them having acquired disabilities. Furthermore, 9 people had both types of disabilities, of whom 8 reported acquired disabilities. Therefore, all participants had some physical condition, congenital or acquired, that compromised and/or affected their performance in daily life occupations.

Based on the characteristics of the physical or sensory disabilities identified during the interview, the nosological diagnosis using ICD-10 was defined, and the five main codes referring to the profile of disabilities are presented in Table 2. Of the 51 people with physical disabilities included in the study, no code could be assigned to four participants, and they were excluded from this analysis.

Table 2. Clinical profile and activity limitations of people with physical and/or sensory disabilities from Marajó.

Variable analyzed	n	%
Clinical condition		
G00 - G99 - Diseases of the nervous system	18	26.87%
S00 - T98 - Injury, poisoning and certain other consequences of external causes	12	17.91%
H00 - H59 - Diseases of the eye and adnexa	10	14.92%
I00 - I99 - Diseases of the circulatory system	7	10.45%
Deficiency of body structures		
s750 - Lower extremity	54	80.60%
s730 - Upper extremity	27	40.30%
s740 - Pelvis	27	40.30%
s120 Spinal cord and peripheral nerves	20	29.85%
Body functions most affected		
B710 - Joint mobility	52	77.61%
B730 - Muscle power	47	70.15%
B735 - Muscle tone	44	65.67%
B280 - Pain	33	49.25%
Activity and participation		
D450 - Walking	48	71.64%
D430 - Lifting and carrying objects	47	70.15%
D570 - Taking care of one's own health	32	47.76%
D540 - Dressing	31	46.27%
Environmental factors (barriers)		
E355 - Health professionals	49	90.74%
E310 - Immediate family	48	88.89%
E360 - Other health-related service providers	44	81.48%
E125 - Products and technology for communication	38	70.37%

In this way, the following five main clinical conditions were identified among participants with disabilities: Nervous system diseases (G00 -G99); Injuries, poisoning, and some other consequences of external causes (S00 - T98), H00 - H59 - Disease of the eye and appendages, Diseases of the circulatory system (I00 - I99), and M00 - M99 - Diseases of the musculoskeletal system and connective tissue.

Regarding deficiencies in body structures, the lower extremity (s750), upper extremity (s730), pelvis (s740), Spinal cord and peripheral nerves(s120), and brain (s110) were the most affected. The most affected body functions are joint mobility (b710), muscle strength (b730), muscle tonus (b735), pain (b280), and vestibular (b235).

To determine the influential barriers in the physical and social environments of the participants' lives, data collected from the adapted ICF checklist were used, based on four qualifiers: none, mild, moderate, and severe or complete. Only 11 individuals with physical disabilities, 1 with sensory disabilities, and 1 with both physical and sensory disabilities were excluded from this analysis regarding environmental factors. This exclusion is because they did not respond to the components of environmental factors assessed when requested by the interviewer.

Participants showed significant difficulty in performing activities such as walking (d450), lifting and carrying objects (d430), taking care of their health (d570), dressing (d540), and washing (d510, including bathing, drying, washing hands, etc.). Furthermore, among the components of environmental factors, barriers were prevalent regarding their relationships with health professionals (e355), immediate family (e310), other professionals who provide health-related services (e360), communication products and technology (e125), and friends (e320) (Table 2).

DISCUSSION

Regarding the socio-demographic profile, in Marajó, there is a distribution of fewer white people than expected for the population in the north of the country, according to data from the Brazilian Institute of Geography and Statistics from 2022, which states that 19.7% of the population residing in the North region declared themselves white and 8.3% declared themselves as black[13]. Furthermore, according to the results, there was a higher tendency for many more evangelicals and fewer people without religion, as well as the level of education with illiteracy rates higher than expected for Brazil, with 5.6% according to the last census, so in Marajó, this population tends to have low education, with only high school or no education at all[14].

Our results indicate that the population with disabilities living in the Marajó region who participated in the study mainly presented physical disabilities acquired after birth involving diseases of the nervous system, impairment of the lower and upper extremities of the body, impaired joint mobility, strength, and tonus as the most affected body functions, which impact mobility and self-care activities and interpersonal relationships with health professionals and immediate family, representing a social barrier.

The results were analyzed according to the following groups: only physical disability, only sensory disability, and both types of disability. Although the number of participants was disproportionate between the groups, the groups were chosen to understand the functionality, disability, and health profiles, considering the specific aspects of each type of disability; however, the objective of the study was not to make comparisons between groups.

To obtain these results, the ICD-10, published by the World Health Organization, was used as a tool that provides standardized information about epidemiological data through the coding of pathologies, facilitating understanding of the local health context[15]. ICF is based on a biopsychosocial concept for health events, in which functionality is a term that encompasses the functions and structures of the body, activities, and

participation through different domains referring to health conditions, as well as a coding system[10].

As this is the first study to address the clinical profile associated with the limitations of Populations of the Field, Forest, and Waters, the complexity and fragility of this topic stand out, requiring further studies like the surveys carried out by the Health Survey in the city of São Paulo, whose reports deal with aspects related to physical, visual, hearing, and intellectual disabilities of the population, aiming precisely at the reflection, elaboration, and improvement of public policies, and despite only addressing the urban area, it is a good government initiative for improvements[15]. In this article, we sought to relate our results to research with social, educational, economic, and geographic contexts like those found in the Marajó region.

The deficiency can be congenital, meaning it is present since birth, or it can be acquired, influenced by numerous external situations such as trauma, infections, and poisoning[16]. Among the participants in this study, approximately 73% acquired a disease after birth because of the influence of habits, living conditions, or the social and work environment in which they were born. A social scenario with insufficient health conditions and an unstructured environment makes the community more vulnerable to developing some disability, especially physical[17]. This was also identified by Nogueira et al. in their study of people with physical disabilities living in Florianópolis, who reported a predominance of disabilities arising from chronic non-communicable diseases (47.48%)[18].

The situational diagnosis of the Marajó Archipelago highlights the low levels of social indicators in the region, revealing deficient sanitation, health, and education systems[19]. This scenario reflects the adversities that impact the quality of life in several aspects, especially for invisible minorities, such as the population with some disability and low income (N= 54), whose monthly family income varies from 1 to 2 minimum wages; and with low education (N= 38), whose formal education only reaches elementary school. Associated with low education, there was also a prevalence of 36.17% of subjects with some physical disability arising from diseases of the nervous system, such as the sequelae of a stroke. In this context, Xiuyun et al. used Mendelian randomization to estimate the causality and association between education and stroke incidence and reported that individuals with higher levels of education have lower rates of total and ischemic stroke but no incidence of hemorrhagic stroke[20]. Furthermore, Che et al. also complement the idea and state that a low level of education is a risk factor for increased mortality from stroke, regardless of the presence or absence of other risk factors, since an insufficient educational situation makes community participation and autonomy in the health-disease process unfeasible[21].

Furthermore, another point to be highlighted is that individuals with diseases affecting the nervous and sensory systems have high morbidity and mortality, and their deficiencies have a varying impact on health, mobility, functionality, and social participation[22]. These changes interfere with the independence of the subjects, especially when performing Activities of Daily Living (ADL), as reported in limitations in the washing and dressing activities of the participants in the study. This is because physiological changes result in disabilities, reducing the individual's performance in ADL[23].

However, the main reasons that compromise higher social integration of these people permeate environmental and socioeconomic barriers and inequality in the provision of services in different regions of the country[19]. Activities can be influenced by interpersonal relationships, especially in the family environment, considering it as the primary socialization context in which individuals are initially inserted. This environment represents a crucial inclusion factor for people

with disabilities. Therefore, an imbalance in these relationships can significantly impact the individual's quality of life and functionality[24]. From this perspective, the family can be understood as a social barrier, promoting experiences of disability, as reported by a high number of participants (N = 49), even though this result contradicts the initial hypothesis of greater prevalence of physical barriers, whether due to environmental changes or products and technologies.

Complementary to this scenario, in 2010, the Ministry of Health of Mexico conducted a National Survey of Disability Perceptions in the Mexican Population for people with disabilities from urban and rural areas related to health and disability and its association with the perception of environmental barriers outside the home[25]. There was an association between factors related to physical limitations and disabilities, which was strongly related to the perception of environmental barriers, considering the individual's physical capacity.

Concerning education, 21% of people with disabilities do not have any level of education, which is well below the indicators for people aged 25 or over in Brazil (6.4%)[26]. This data may be related, above all, to the lack of accessibility in municipal schools, as well as the lack of qualifications of professionals in understanding the particularities of students with some disability, thus creating an unfavorable environment for the inclusion of the individual and favoring school dropouts. Therefore, investments in inclusive education must be made. However, according to Oliveira et al., "for inclusive education to happen in the right way, improvements are necessary in several aspects of a school atmosphere, from infrastructure to the continuous qualification of professionals who work inside and outside the school environment" (p. 286)[27].

Furthermore, the territorial dynamics of the Marajó Archipelago have suffered from several social influences, which led to socioeconomic changes mainly based on livestock and plant extractivity[28]. That said, 28.20% of the study subjects had disabilities due to S00-T98 - injuries, poisoning, and some other consequences of external causes, mostly caused in the workplace. Roggio et al. presented the risk conditions present in agricultural employment through electromyographic analysis, testing muscular activities with a brush cutter, electric saw, and pruning saw, and identified numerous physical disorders in workers[29]. Therefore, in occupations, especially those related to extractive activities, there are numerous situations prone to compromising the worker's integrity. Thus, this employment situation prevalent in Marajó imposes numerous occupational risk factors that, when not checked, threaten the physical dignity of individuals. In this clinical condition, snake bites are prevalent in the municipalities of Marajó and are reported among study participants as the etiology of their disability. Epidemiological data from the Ministry of Health[30] indicate that regions such as Northern Brazil have higher incidences of snake bites, especially in rural areas during hot and rainy periods. In this way, the importance of demanding attention to the topic, given the prognoses of morbidity and mortality from snake bites, such as deformities and amputations in the lower limbs.[31]

Based on this context, Amazonian regions have singularities such as low assistance support due to geographic distance, social and economic inequalities, and other limitations. Therefore, the Marajó Archipelago has unique social phenomena that require particular intervention measures. Within this perspective, Puszka et al.[8] addressed the implications of health services to support the disability of Australian First Nations peoples by identifying barriers to accessing services, including restricted access to telehealth, residences in remote areas, and limitations of interpreters, besides cultural barriers.

Therefore, the development of public policies must highlight the real conditions pres-

ent in municipalities, as well as approaches based on studies conducted in the region. It is noteworthy that regular access to health services enables the practice of health promotion and education, aiming to minimize problems, such as low education and barriers to access to information and adequate sanitation, discussed in the present study.

The strengths of the present study include the originality of the theme addressed in a complex territory of social and geographic isolation, field research based on WHO reference classifications, and providing reference and encouragement for future studies. After completing the field research, accessibility reports were prepared for each municipality visited, which will be delivered to the municipal executive branch to contribute to future interventions.

The main limitation of this study is the scarcity of literature to be used as a basis and comparison parameter, considering that this is an innovative study. Furthermore, the study also included many evaluators responsible for conducting the interviews. Knowing that different evaluators can influence the greater or lesser difficulty of understanding some questions, this variable may have led the interviewee to leave some questions unanswered, although notably, everyone received the same training to apply the instruments.

As reported in this study, the environment in which an individual lives, the level of education, and lifestyle directly impact their health, highlighting the prevalence of physical disabilities acquired after birth. Therefore, the identification of modifiable and influential factors in the field of health is essential to adopt effective measures and avoid risk factors such as toxic agents, chronic non-communicable diseases, and lack of basic sanitation. Moreover, we highlight the implications of the biopsychosocial approach for analyzing biological, psychological, and social factors in the dimensions that constitute the well-being of human beings, which must be understood beyond the biomedical model.

CONCLUSION

Therefore, to the best of our knowledge, this is the first report describing the clinical profile of people with physical and/or sensory disabilities in Marajó using the ICD-10 associated with activity limitations using the ICF checklist. There was a predominance of low education and low monthly family income among those interviewed. Furthermore, regarding the types of disability, the participants mainly presented physical disabilities acquired after birth involving diseases of the nervous system, impairment of the lower and upper extremities of the body, and deficiency in joint mobility, strength, and tonus as body functions most affected, which impacted mobility and self-care activities, especially washing and dressing, and on interpersonal relationships with health professionals and immediate family, representing a social barrier. Based on our findings, the influence of the social, educational, economic, and geographic context on the clinical condition and functional performance of people with disabilities living in the Marajó Archipelago is understood. The coexistence of these scenarios was also identified in studies conducted in similar environments and international territories. Therefore, to plan improvements in the functionality of people with disabilities in regions with geographic singularities, up-to-date information about the profile of the population is required, as well as their activity limitations and factors that constitute barriers.

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