ORIGINAL ARTICLE

Considerations about rehabilitation institutions for children and adolescents with disabilities in the city of Rio de Janeiro

Considerações sobre instituições de reabilitação para crianças e adolescentes com deficiência no município do Rio de Janeiro

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ABSTRACT

Discussion based on data extracted from the research "Study of the offer and analysis of rehabilitation programs for children and adolescents with disabilities in the city of Rio de Janeiro". **Objective:** To increase knowledge about institutions that offer rehabilitation for the population of children and adolescents with disabilities. **Method:** A descriptive questionnaire study, specifically prepared for this purpose. **Results:** The sample was composed of 7 (12.6%) educational institutions, 16 (29.6%) institutions belonging to the Unified Health System (SUS) and 31 (57.41%) representing: 11 non-governmental organizations, 15 philanthropic and 5 private agreements with the SUS and/or the Single Social Assistance System (SUAS), showing that most of the calls do not occur in the public network. This data suggests professional turnover due to lack of stability and consequent treatment discontinuity. Most organizations, outside the public network, have an agreement with SUAS, whose mission is to regulate and organize services, programs and social assistance, which may lead to the lack of technical advances in health. Specialized medical evaluations and features such as eyeglasses, wheelchairs, walkers have not proved easy to obtain. Considerations about rehabilitation difficulties are raised. **Conclusion:** The fact that this population when rehabilitated has expanded its condition for active participation in society, with consequent cost reduction and increase of social capital is a reality. Increasing knowledge about rehabilitation management is becoming increasingly urgent, as scientific and technological advances coupled with constant social achievements make it increasingly possible to insert people who previously would be restricted to a life of social exclusion.

Keywords: Rehabilitation Centers, Rehabilitation Services, Disabled Persons, Child

RESUMO

Discussão a partir de dados extraídos da pesquisa "Estudo da oferta e análise de programas de reabilitação para a população infanto-juvenil com deficiência no Município do Rio de Janeiro". **Objetivo:** Ampliar o conhecimento sobre as instituições que oferecem reabilitação para a população de crianças e adolescentes com deficiência. **Método:** Estudo descritivo tipo inquérito, por questionário, especificamente preparado para este fim. **Resultados:** A amostra composta por 7 (12,6%) instituições de ensino, 16 (29,6%) instituições pertencentes ao Sistema Único de Saúde (SUS) e 31 (57,41%) representam: 11 organizações não governamentais, 15 filantrópicas e 5 privadas conveniadas com o SUS e/ou Sistema único de Assistência Social (SUAS), mostrando que a maior parte dos atendimentos não ocorre na rede pública. Este dado sugere rotatividade de profissionais por falta de estabilidade e consequente descontinuidade de tratamento. Maioria das organizações, fora a rede pública, tem convênio com o SUAS, cuja missão é regular e organizar serviços, programas e benefícios socioassistenciais, o que pode levar ao não aproveitamento de avanços técnicos na área da saúde. Avaliações médicas especializadas e recursos como óculos, cadeira de rodas, andadores, mostraram não ser de fácil obtenção. Considerações sobre dificuldade para reabilitação são levantadas. **Conclusão:** O fato de que esta população quando reabilitada tem ampliada sua condição para participação ativa na sociedade, com consequente redução de custo e aumento do capital social é uma realidade. Ampliar conhecimentos sobre a gestão em reabilitação está se tornando cada vez mais premente, visto que avanços científicos e tecnológicos aliados a constantes conquistas sociais viabilizam, cada vez mais, inserção de pessoas que antes estariam restritas a uma vida de exclusão social.

Palavras-chave: Centros de Reabilitação, Serviços de Reabilitação, Pessoas com Deficiência, Criança

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INTRODUCTION

For the evaluation of the population with disabilities, the 2010 Demographic Census used the self-declaration strategy proposed by the World Health Organization (WHO) in the Classification of Functioning, Disability and Health-ICF.1

This census showed that 23.9% of the Brazilian population reported having - to varying degrees of severity - at least one type of permanent disability, whether visual, auditory or motor, and for mental or intellectual impairment; no specification was required for degrees of severity involvement.[2]

Of this total, 7.5% were children and adolescents from 0 to 14 years old with at least one type of permanent disability. Applying the national proportion of 23.9% in the population of the city of Rio de Janeiro, which at the time was 6,320,446 inhabitants, the estimate is 1,510,587 people with disabilities in this municipality. Considering that 7.5% of this total are children and adolescents, it can be deduced that 113,294 of the city's juvenile population in that year needed special care. From this amount, it can be inferred that the lack of specialized care is huge.

Certainly these numbers are underestimated as the number of people with disabilities is increasing.[3] This change contributes to the change in the pattern of pediatric diseases that have acquired a chronicity profile,[4] which is associated with function or activity limitation, thereby creating special needs conditions.[5] This is a significant number, which leads to the need for health policies aimed at this population.

According to the World Report on Disability,[6] disability is part of the complex human condition and so the interventions needed to overcome the disadvantages are multiples of a multi-professional approach. There is reference in the international literature that children with disabilities wait a long time before being included in rehabilitation programs, even in developed countries such as Canada.[7] For this problem, it is necessary to pay attention not only to the technical-scientific aspects involved in rehabilitation, but also to develop appropriate tools and strategies that fill the gaps pointed out by the research.

The change in morbidity and mortality profiles in Brazil shows a transition from mortality from infectious and parasitic diseases to other diseases of insidious onset and long-term, with progressive reduction of functional capacity.[8] Brazil is experiencing, at the beginning of the century, a health situation that combines an accelerated demographic transition and a unique epidemiological transition expressed in the triple burden of disease: an unsurpassed agenda of infectious diseases and deficiencies, a significant burden of external causes and a strong presence hegemonic of chronic conditions.[9]

The transformation of epidemiological profiles in Brazil has a different character, which does not necessarily fit the model of substitution of infectious and parasitic diseases for chronic, degenerative diseases, accidents and violence.[10] Indicators show that there is still a significant incidence of infectious and parasitic diseases. In pediatrics this is reflected in the need to continue to pay attention to congenital infections, which may have repercussions on the functionality of those affected, while also monitoring the functional deficits of preterm infants, or with genetic or congenital conditions.

Added to these facts is the prolonged survival of those with degenerative diseases, which added to other factors, increasingly increases the population of children and adolescents with disabilities. The study of patients with Duchenne's muscular dystrophy, directed by Strehle, shows that only 13.5% of births in 1960 reached a life expectancy of 25 years, while among those born in 1980 this proportion increased to 49.2%.[11] This is probably due to improved care, as no specific medication for this disease has emerged during this period. In addition, there are the emergence of new disabling diseases, such as the maternal Zika virus infection, which causes sequelae such as microcephaly, when it occurred in the first months of pregnancy,[12] but still with unknown potential damage to the nervous system when pregnant woman is infected during pregnancy.

These changes need to be accompanied by new coping strategies. The challenge for health policies, education of doctors and other health professionals will be to meet, with quality, the growing demand of this surviving population that needs special care. Saving lives is not enough, combating disease should not be synonymous with healing the sick[13] and attention to the quality of life of patients and their families is a premise in rehabilitation.

OBJECTIVE

Increase knowledge about institutions that offer rehabilitation for the population of children and adolescents with disabilities in the city of Rio de Janeiro.

METHOD

This is a descriptive survey-type study using a questionnaire specifically prepared for this purpose. The data used were extracted from the research entitled "Study of the offer and analysis of rehabilitation programs for children and youth with disabilities in the city of Rio de Janeiro", which was conducted through a questionnaire applied in a total of 54 institutions, in the period from 2011 to 2014.

Institutions that serve children and adolescents with motor, sensory, psychocognitive or language disabilities and who are treated in at least two of the following areas were included: physical therapy, occupational therapy, speech therapy and psychology. Institutions providing care for specific, even disabling age-related diseases such as hematological and oncological diseases, and non-governmental clinics unrelated to SUS or SUAS were excluded. Federal, municipal, non-governmental organizations (NGOs), philanthropic and private units with agreements with SUS and/or SUAS and educational institutions participated in the research. No state unit was part of the sample, as there was no service located in the city of Rio de Janeiro, under the direct administration of the Rio de Janeiro State Health Department in the list of institutions provided by it.

The survey of eligible institutions was initially done through consultation with the National Register of Health Facilities (CNES) and telephone calls to each of the institutions or services marked as rehabilitation to verify which were intended for the care of children and adolescents. Noting the inadequacy of the data, we also used a more recent listing of rehabilitation services provided by the Rio de Janeiro Municipal Health Department (SMS-RJ). For the inclusion of non-governmental institutions, we used informal lists in some services such as the Neuropsychomotor Rehabilitation and Development Center (RDN Center) of the Federal University of Rio de Janeiro (UFRJ), the National Trauma Institute-Orthopedics and several others. Informal lists are resources that health professionals commonly use to refer patients who cannot have treatment where they were treated, due to lack of vacancies or living in a remote location or lack of a specific professional to meet the patient's needs.

The completion of the questionnaire was made with information provided, in face-to-face interview, by a member of

the rehabilitation team designated by the institution's director or responsible for the rehabilitation service. The interviewers were 12 students from the undergraduate courses in Medicine, Physiotherapy, Occupational Therapy and Speech Therapy of the UFRJ School of Medicine, participants of an extension project. The training of these students was carried out in simulation dynamics of the application of the questionnaire among them with supervision of the researcher.

The questionnaire was previously tested with pediatricians of the Integral Attention to Development and Rehabilitation Committee of the Rio de Janeiro Pediatric Society (SOPERJ) in order to assess mainly the clarity of the questions and the duration of the interview, which should not be very long. The choice of these professionals for one of the pre-tests was justified by being part of multiprofessional rehabilitation teams of the public health network, which resulted in important contributions.

This questionnaire consists of 4 topics, according to the subject, being the first to collect data about the institution, the second about the patients attended, the third about care and the fourth about support in specialized health care and assistive technology. This paper refers to the first and last topic of the research.

The database was completed by the researcher and collaborators, and for data storage and analysis, the SPSS version 20 program was used and the research was approved by the Ethics and Research Committee of the Martagão Gesteira Institute of Childcare and Pediatrics (IPPMG). of UFRJ number 06/13.

RESULTS

Table 1 shows the distribution of the 54 institutions that participated in the survey, the 10 Planning Areas (PA) of the Municipality of Rio de Janeiro. It is observed that the sample consisted of institutions located in all areas. The largest number of institutions visited were from AP 3.1 areas, which include, among others, the neighborhoods of Bonsucesso, Penha, Ilha do Governador and AP 2.1 which is made up of neighborhoods in the south and surrounding areas.

In Table 2, regarding the type of institution from the administrative point of view, it is found that more than half correspond to NGOs, philanthropic and private institutions affiliated with SUS or SUAS, followed by government institutions, with the predominance of municipalities over federal ones, with less participation from educational institutions.

In Table 3, which is related to type (s) agreement (s) set (s) by non-governmental organizations, charities and private organizations, with SUS, SUAS, with both or neither of them, this occurs the predominance of SUAS.

Table 4 shows the situation found, the accessibility to specialized medical evaluation, according to the perceived need of the professionals, and the number of services that declared not need any of them. The percentages were calculated based on the total number of institutions making the requests.

Table 1. Distribution of institutions by Planning Area

AP	%	AP	%
1.0	11.11	3.3	7.41
2.1	14.81	4.0	3.70
2.2	11.11	5.1	12.96
3.1	14.83	5.2	7.41
3.2	12.96	5.3	3.70

Table 2. Type of institution regarding administrative aspect

Type	%
Teaching	12.96
Federal unit	5.56
Municipal unit	24.07
Private clinic with SUS	9.26
NGO	20.37
Philanthropic Institution	27.78

N=54

Table 5 is relative as to obtain important assistive technology resources to gain functionality and prevention of deformities, but also vital for social life. It also shows the number of institutions that do not request such resources.

DISCUSSION

The data found on the institutions, under the administrative aspect, are compatible with the SUS guidance of decentralization of care to the municipal network.[14] In this sample, the largest percentage consisted of institutions outside the public network. Perhaps this data also corresponds to the worldwide tendency of the role of the public institution to increasingly support the development of policies to support people with disabilities[15] and not necessarily to meet all demand, with managers acting mainly in regulating standards aimed at quality and access to care.

This trend that has emerged since the second half of the twentieth century is seen in the reduction of the direct presence of the state in assistance actions, and this gap has been taken over by the mobilization of civil society through NGOs[16] and philanthropic institutions. There are many successful results in the partnership between the state and NGOs, and the articulation between diverse social sectors is the current way to tackle complex problems.[17] However, the high turnover of health professionals outside the statutory system is a matter of concern, which is observed in some studies.[18]

According to Medeiros, the turnover is due to the lack of stable bond and plan of positions and salaries.[19] The survey on the rotation of professionals was not part of the research, but it was noteworthy that sometimes it was found that the interviewee was no longer part of the rehabilitation team of the NGOs and philanthropic entities visited, after being searched for a short time after the interview, to answer questions regarding information provided by him/her. Turnover causes losses, as it causes discontinuity in rehabilitation work. The main work tool is the professional himself, especially in rehabilitation, since the process depends less on equipment and specific medication and requires more of the professional's direct action with the patient. The service being performed by the same professional or by professionals of the same team facilitates bonding and building trust,[20] which are some indispensable conditions to facilitate treatment adherence and promote better therapeutic performance.[21] Failure to

Table 3. Type of agreement and with SUS or SUAS in NGOs, private and philanthropic clinics

Institution Type	SUS	SUAS	SUS and SUAS	Absent
NGO	0	72.8%	0	27.2%
Philanthropic	26.6%	46.6%	13.3%	13.6%
Toilet	20.0%	80.0%	0	0

N = 31

Table 4. Obtaining specialty medical assessments

Specialty	Request	Yes	Sometimes	No	Do not request
	N				*N*
Ophthalmic	45	12 (27%)	23 (51%)	10 (22%)	9th
Hearing	48	15 (31%)	22 (46%)	11 (23%)	6th
Orthopedic	48	8 (16%)	28 (58%)	12 (25%)	6th
Physiatric	36	8 (22%)	16 (44%)	12 (33%)	18
Neurological	49	10 (20%)	17 (35%)	22 (45%)	5th
Genetics	45	5 (11%)	23 (51%)	17 (38%)	9th

Yes: get most requests. No: rarely get

Table 5. Obtaining Assistive Technology Resources

Resources	Request	Yes	Sometimes	Not	Are request
	N				N
Lower Limb Orthosis	36	11(30%)	17(48%)	8(22%)	18
Upper Limb Orthosis	34	8(23%)	18(53%)	8(23%)	20
Vest	33	5(15%)	18(54%)	10(30%)	21
Insoles	39	14(36%)	17(43%)	8(20%)	15
Walker	37	8(22%)	18(49%)	11(30%)	17
Wheelchair	38	6(16%)	19(50%)	13(34%)	16
Stabilizer	29	1 (34%)	15(52%)	3 (10%)	25
Hearing Aid	36	9(25%)	17(47%)	10(28%)	18
Glasses	37	10(27%)	18(49%)	9(24%)	17

Yes: You get it in most bids No: You rarely get it

adhere to treatment has future individual and social implications, placing children and adolescents at higher risk of developing morbidity, and increased expenditure on delayed treatment.[22]

The representation of educational institutions that care for children and adolescents with disabilities should not pose any difficulties for providing assistance. Its priority task is to staff, and research to generate and develop new knowledge and technologies in the area of rehabilitation. Unlike other institutions, patient care cannot be aimed at productivity or quantity of care that solves the demand, so that they can meet the specific needs related to professional training, with technical mastery and vision of the comprehensiveness of the human being, linked to economic, political and cultural phenomena.[23]

The current training of doctors and other health professionals in undergraduate and continuing education programs requires the development of the ability to value the patient's point of view and their participation as an active agent of their own care. This kind of approach aims at patient adherence to therapeutic proposals, in a participatory way, and not simply in the form of obedience,[24] and certainly the time spent in such teaching has a reduction in the number of patients attended. Particularly in relation to the rehabilitation of the juvenile population, which also includes their families, this professional must be a resilience fostering agent, which is a human predisposition to be developed to resist the potential risk for social exclusion.[25]

In other words, care in these establishments necessarily suffers a reduction in the number of patients to be treated, since the priority is not the dimension of care. Thus, meeting the great demand by educational institutions should be indirect, extending their role, that is, by training and enabling professionals to multiply rehabilitation centers in the network. This has been one of the purposes of the RDN Center of the Institute of Childcare and Pediatrics Martagão Gesteira (IPPMG) of UFRJ, where undergraduate and postgraduate students of medical, physical therapy, occupational therapy, speech therapy and psychology courses. Working in the training of rehabilitation professionals of SMS-RJ and relying on the material resources provided by Rotary International , the RDN Center contributed to the implementation of rehabilitation centers in the municipal network called Interdisciplinary Care Centers for Child Development.26

SUS proposes the financing and decentralization of health actions and SUAS was created to regulate and organize services, programs and social assistance in articulation with civil society. Both systems operate theoretically in an appropriate manner, as it is necessary not only to finance but to set up a rehabilitation network with specific tasks.[27]

Table 3 shows that for most NGOs, private and philanthropic services predominates agreement with SUAS. It is plausible to consider that this is due to the fact that rehabilitation has not been understood for a long time as an activity linked to health. Rehabilitation began with a strong presence in the social area, which may justify SUAS current predominance in financing these institutions, which do not belong to the public network, causing some distancing from the rehabilitation of health actions. The actions developed in the area of health, as in the social, sports and education have as maximum goal the social insertion of the individual, being essential the clarity as to the attributions of each one of them, since the way of operating is differentiated and not substitutable. It is of concern that specific health technical resources are no longer being used in this area because the patient is being treated with a social focus.

The constant increase in demand for rehabilitation implies the need for increasing financial support from the government. The cost of rehabilitation is high and should not depend so much on public funding, so new strategies need to be rethought. The term sustainability, strongly associated with ecology due to scarcity, needs to go beyond this boundary to influence the management of health institutions.[28] Sustainability needs to be considered, although it is a new concept and little discussed in the health area. The three sustainability, financial, environmental and social guidelines applied in management practices seek to increase operational efficiency

and effectiveness[29] and should be part of the organizational policy of the institution.

As alternative sources of income, a rehabilitation center can promote events, market assistive technology, produce orthotics and prosthetics, provide caregiver and vocational training courses, and partner with new sources of income. Recognizing the difficulty of government spheres unilaterally resolving the problem, WHO has published the Community Based Rehabilitation guide. This was elaborated by experts from several countries, who propose to promote access to rehabilitation by maximizing local resources, understanding that disability is a challenge that society as a whole needs to face[15]

The knowledge that children and adolescents with disabilities have greater need for specialized medical care than the general population[30] is behind the inclusion of the topic regarding the accessibility of care in medical specialties. Table 4 shows that access to these assessments, it should be possible to easily and regularly to all children, with or without disabilities, does not occur. Knowing that hearing and visual loss need to be tracked during childhood, it is worrying that 23% of institutions rarely get the required hearing assessment, and that for 22%, the same is true for visual assessment. Most children with congenital hearing loss are identified by neonatal screening; however, hearing loss may be the type of late onset, progressive or acquired.[31] This sensory deficit occurs in about two thirds of children with Down syndrome, and may present as conductive, sensorineural or mixed loss, with prevalence ranging from 60 to 80% for the conductive type.[32]

Table 4 shows also difficulty in obtaining compliance with orthopedist and physiatrist for differentiated assessment of the musculoskeletal system, the orthopedist with a predominantly surgical approach and physiatrist with a vision for more functionality and conduct of clinical resolution. Musculoskeletal problems are secondary to muscle and tendon contractures and can cause pain, functional impotence, joint stiffness, hip dislocation, spinal and limb deformities, and are related to physical growth, spasticity and immobility among other factors.[33]

The intervention of these specialists benefits patients, since reducing spasticity can minimize suffering, promote functional gains, prevent deformities, facilitate the handling of these children by parents and therapists with prescription of specific medication and minimally invasive therapy, such as the application of botulinum toxin, which is already supplied by the government.[34]

In the case of children with epilepsy, often associated with cerebral palsy[35] the neurologist's action is certainly necessary, not only for the control of seizures, without which the rehabilitation work is impaired, but also for the etiological diagnosis of development deviation. Many children in rehabilitation do not have a closed etiological diagnosis, and the geneticist's evaluation may be the differential for this diagnosis, which provides a better understanding of the clinical picture and allows treatment adjustment and family counseling. Vieira mentions that genetic diseases affect 3% to 10% of the population and many affected have chronic health problems and disabilities. In his study with a population of children and adolescents with disabilities, linked to the Family Health Strategy, this researcher found that genetic alterations were responsible for disabilities in 38% of the patients evaluated.[36]

The scenario found regarding medical evaluations needs to be reversed. The presence of a physiatrist or other qualified physician for the disabled person's clinic as a member of the rehabilitation team, as already happens in the RDN Center and other rehabilitation institutions. This specialized approach translates into advantages in reducing some requests for advice, performing specific procedures and prescriptions for this population, providing guidance for home procedures, more promptly resolving questions raised by team members, and acting clinically and manage advice for other specialties when needed. The biopsychosocial view that guides the rehabilitation process receives the technical contribution of a health professional directed to facilitate the social insertion of the patient.

The issue of assistive technology resources is part of the study because they greatly benefit patients' lives and should be easy to obtain because their use can be a decisive factor for hearing, vision, ambulation, risk reduction of body deformities and promotion of social life. Orthotics are therapeutic equipment external to the body prescribed for assistance and functional recovery, prevention of deformities, joint stabilization, reduction of involuntary movements, body support or postural facilitation.37

Failure to obtain a trunk deformity control vest is a concern because it increases the need for surgical correction, making the treatment more painful and much more expensive. In relation to wheelchair, 34% of institutions rarely get this feature, which is indicated not only for patients who do not walk, but also for those who walk with difficulty unable to follow social activities with the family group and community. The stabilizer, which is not available from the government, is a device that enables the orthostatism of patients who, for various reasons, cannot maintain their standing posture. It is indicated for prevention of contractures and musculoskeletal deformities, especially of the lower limbs, but also acts in maintaining muscle and bone trophism and improving bowel function.[38]

The benefit is both physical and emotional, studies show a negative association between time in standing and mortality, indicating the importance of assisted standing,39 thus, the availability of parapodium or stabilizer by SUS needs to be a goal. Hearing aids and eyeglasses are features that reduce disability, facilitate social inclusion and improve school performance should be easy to obtain. However, 28% of institutions stated that they rarely get a hearing aid and 24% reported the same for glasses.

The data obtained in this study reveal an unfavorable picture for full rehabilitation, which probably has a negative impact on the social inclusion of children and adolescents with disabilities in the city of Rio de Janeiro.

FINANCING SOURCE

This research started as part of an extension project called "Contribution to the formation of a cooperative rehabilitation network - Data on child rehabilitation institutions in the city of Rio de Janeiro." This project was approved in 2010 in the University Extension Program (ProExt) of MEC, which aims to support public higher education institutions in the development of extension programs or projects that contribute to the implementation of public policies. With this approval, the project received financial resources, largely in the form of scholarships for 12 students who participated in the survey for the year 2011.

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