

Social profile of children and teens with cerebral palsy in a physical rehabilitation center

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ABSTRACT

It is necessary to understand the changes in the lives of people with Cerebral Palsy (CP) in order to develop rehabilitation programs and health actions for their performance and participation in the various activities of daily living. Cerebral palsy is the most common cause of severe disability in infancy. It affects about two in every thousand live births worldwide, while in developing countries it is estimated at seven in every thousand live births. **Objective:** To get to know the socioeconomic and demographic universes of children with cerebral palsy in São Paulo/SP. **Methodology:** This is a quantitative, qualitative, and descriptive study on patients with a clinical and functional diagnosis of cerebral palsy who were active in rehabilitation programs during the year 2014 in the city of São Paulo/SP, between 0 and 18 years of age, and of both sexes. **Results:** Twenty-five patients participated in the study. The survey revealed that 52% (13) of patients were female, aged 6-15 years. In the economic sphere, 80% (20) of patients were on welfare, which is the main source of income for 40% (10) of the families. Twenty-two of the patients (88%) live in nuclear families formed by couples. The second largest proportion 20% (5) was for single-parent families headed by women. As regards the participation of the father in the treatment, 56% (14) of the cases had parental involvement, of which 91% (22) live with family income under 2 minimum salary a month. In eleven of the families (44%) there is no paternal involvement. Fourteen of these families 57% (14) live with a family income of under 1 minimum salary a month and have different family arrangements. The survey results show that 1 in every 4 patients did not attend school. As for housing, 18 patients (72%) did not have their own home and 80% (20) did not have wheelchair access. **Conclusion:** Getting to know the environment in which people live with disabilities is extremely important, since it can positively or negatively influence the experience of health and disease. The family dynamism and teamwork commitment in the rehabilitation process can contribute favorably to everyone's well-being and the social inclusion of children with CP, as well as assisting in the formulation of public policies.

Keywords: Cerebral Palsy, Children, Health Profile, Social Work

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INTRODUCTION

The role of a Social Worker in health requires considering the objective conditions under which the professional practice develops in dealing with public health services. This requires that health be thought of as a social policy that materializes as a service.¹ Health work is distinct from working in general because it considers patients as co-participants, to the extent that success depends on them. From this perspective, a socioeconomic study brings knowledge of the users' reality with an eye toward comprehension and intervention permeated by principles of equity and social justice and in search of universal access to the goods and services pertaining to social policies and programs.²

It is necessary to understand the changes in the lives of people with disability in order to develop rehabilitation programs and health actions for their performance and participation in the various activities of daily living. The Social Worker in rehabilitation programs seeks to help the patient and their family overcome the difficulties stemming from the onset of the deficiency. This is why analyzing the questions that may contribute to one's adherence to a rehabilitation program, as well as to improving living conditions in terms of personal, intrafamily, and broader social relationships is the foundation of the work in this field.³

Cerebral palsy (CP) is the most common cause of severe physical disability in infancy. Worldwide, it affects two in every thousand live births, while in developing countries it is estimated at seven in every thousand.^{4,5} CP is a chronic infantile encephalopathy characterized by non-progressive motor disorders that appear in a developing brain (before the age of 3) that lead to problems with motor skills, tonus, and posture, and possibly to cognitive disorders.⁵ The present work will contribute to the gathering of socioeconomic and demographic data concerning a disabled person, as well as assisting in the interdisciplinary work of rehabilitating persons affected.

OBJECTIVE

The goal of this work is to get to know the socioeconomic and demographic worlds of a child with cerebral palsy in metropolitan São Paulo/SP.

METHODS

This was a quantitative, qualitative, and descriptive study on patients with clinical diagnosis of cerebral palsy who were active in a

rehabilitation program in São Paulo/SP of both sexes and aged between 0 and 18 years.

After the Research Project's approval by the Ethics Commission for Analysis of Research Projects (CAAE 42663015.5.0000.0068), interviews were done with the child's or teenager's guardian. The data was collected by a questionnaire entitled *Socioeconomic and Demographic Profile of Patients with Cerebral Palsy*. This was made up of 18 questions on gender, age, state of origin, schooling and school inclusion, welfare assistance, family and per capita income, father's participation in the treatment, family dynamic, and living conditions based on the Social Evaluation protocol, inserted into the operational institutional routine. Family arrangements followed the following classifications:⁶

- **Nuclear:** couple with or without children, or single children;
- **Extended:** nuclear family plus one or more relatives in the home;
- **Composite:** nuclear family plus one or more non-related persons;
- **Broadened:** resulting from a marriage plus people separated and/or divorced who combine relatives and descendants from new homes;
- **Single parent:** single woman or man responsible for the home and raising the children.

Those raised by grandparents or aunts and uncles are not included in the arrangements classified in this work. However, this scenario was maintained by the researcher in the tabulation and data analysis. The analysis of school inclusion, shown below in Chart 1, was based on the level of schooling *versus* ideal age for participation and monitoring of activities proposed by the Ministry of Education.⁷

RESULTS

Twenty-five patients participated in this study. The results, in absolute numbers, are shown in Tables 1 and 2. The sequence of social characterization is as follows: gender; age bracket; state of origin; receipt of welfare;⁸ economic profile showing family and per capita income,⁹ including welfare for those who receive it; family composition; paternal involvement in treatment; school profile; and living conditions. Table 2 shows the comparison of income and the family arrangement of those with and without paternal participation; profile of the school situation among those enrolled in the school system; the type of school and the compatibility between grade and age; and finally, the living conditions referring to the type of residence and wheelchair accessibility.

DISCUSSION

This social study, based on family context and social reality, seeks to validate decisions, actions, and observed particularities in the family and relationship context, especially socioeconomic and cultural aspects.¹⁰ It is not possible to comprehend or define health needs without taking into account that they are products of relationships with the social, physical, and cultural environments. Therefore, it is in the social determinants that structure the health-illness process that the work of the professional Social Worker is focused, in such a way as to value the quality of life rather than the absence of the disease.

This research showed that 13 of the patients (52%) were females between the ages

Chart 1. Leven of schooling *versus* Age

Schooling	Ideal Age
1st grade	6 years
2nd grade	7 years
3rd grade	8 years
4th grade	9 years
5th grade	10 years
6th grade	11 years
7th grade	12 years
8th grade	13 years
9th grade	14 years
1st year of high school	15 years
2nd year of high school	16 years
3rd year of high school	17 years

Table 1. Social Profile

Social Indicators n = 25	N	%
Gender		
Male	12	48
Female	13	52
Age Bracket		
6 - 10 Years	9	36
11 - 15 Years	16	64
State of Origin		
São Paulo	23	92
Pernambuco	1	4
Piauí	1	4
Welfare		
Yes	20	80
No	5	20
Income Per Capita		
¼ Min. Salary	3	12
½ Min. Salary	7	28
1 Min. Salary	2	8
1.5 Min. Salary	10	40
2 Min. Salaries	1	4
2.5 to 3 Min. Salaries	2	8
Main Source of Income		
Welfare	12	48
Retirement & Pensions	3	12
BPC	10	40
Family Arrangement		
Nuclear	14	56
Single Parent	5	20
Composite	2	8
Broadened	1	4
Raised by Grandparents	3	12
Nº of People/Family		
2 persons	4	16
3 persons	9	36
4 persons	3	12
5 - 6 persons	9	36
Paternal Participation in Treatment		
Yes	14	56
No	11	44
Living Conditions		
Rented	2	8
Borrowed	6	24
Mortgaged	2	8
Occupied/Invaded	10	40
Own home	5	20
House without stairs	5	20
House with stairs	19	76
Apartment without elevator	1	4
School Inclusion		
Yes	19	76
No	6	24
Public School	2	8
Private School	23	92
Regular	21	84
Special	4	16
Grade/Age Compatibility	7	28
Grade/Age Incompatibility	18	72

of 6 and 15 from the city of São Paulo, with the majority from the southern region.

In the economic ambit, 20 of the patients (80%) were on welfare and this was the main source of income for 10 of the families (40%). As for family income, 21 (84%) survived on less than 2 minimum salaries per month including welfare. According to the age profile, this data corroborates the government IBGE surveys¹¹ in which children aged between 6 and 14 years had a 73.6% chance of living in poverty.

In terms of per capita income, 10 patients (40%) subsisted on between 1/4 to 1/2 per month: five times less than the per capita income in the city of São Paulo according to a socio-demographic survey.¹¹ Such data shows the level of poverty suffered by the families of children with CP, even when inserted into the social protection program. The relationship between disability and poverty was beyond the scope of the analyses, for they centered on work activities focused on the individual. Deeper research is needed for this analysis.

In the family ambit, 22 of the subjects (88%) lived in a nuclear family, formed by couples. The next greatest proportion was for 5 subjects (20%) who lived in single-parent families, headed by women. Under this focus, different family arrangements could be seen for children with CP. The difficulties faced carrying out family social roles are factors that favor new family arrangements, whose vulnerabilities might help explain the frequent marital break-ups in the face of unrealized expectations.¹² On the other hand, families change constantly in an attempt to satisfy the needs imposed by society.² In light of this, the process of rehabilitation sees the family as the caring space, but also has to consider it a field of conflicts and instabilities, whether or not influenced by society.

Regarding the father figure, 14 of the cases (56%) included such participation, of which 22 (91%) lived with a monthly family income of less than 2 minimum salaries. Only 2 families (9%) with paternal participation showed an income over 8 to 10 minimum salaries per month. Both economic configurations are included in the nuclear family context.

There were 11 families (44%) that did not include the father's participation in the treatment. Fourteen (57%) of these families, a majority, survived on a total income of less than R\$880 per month, and in different family arrangements. Thus the father's support is related to the economic situation and the

Table 2. Social Paternal Configuration in the treatment

Paternal involvement in treatment	Yes N = 14	%	No N = 11	%
Family Arrangement				
Nuclear	14	100	5	20
Single Parent	-	-	9	36
Composite	-	-	4	16
Broadened	-	-	2	8
Raised by Grandparents	-	-	5	20
Family Income				
½ Min. Salary	-	-	4	16
1 Min. Salary	2	8	10	40
1.5 Min. Salary	5	20	-	-
2 Min. Salaries	16	64	7	28
2.5 - 3 Min. Salaries	-	-	2	8
8 - 10 Min. Salaries	2	8	2	8

family arrangement of the child with CP. Male authority is based on the mediation the man establishes with society as the family protector, not simply as the breadwinner.¹² Such vision is conceived by a moral order in which the male figure represents authority. In facing the changes and ruptures in conjugal relationships, the family tries to organize itself and seeks support from its network of relatives for help in raising its children.

The results of the research point out that one in every 4 patients does not attend school. The factors that impede attendance to school are socioeconomic issues, over-protection by the family, and attitudinal barriers, all experienced by the subjects in this study.¹³ Of those included in the school system, 23 (92%) are in public schools, and, of those, 4 (16%) are only in special classes. Therefore it was observed that, although the inclusion of people with disabilities is obligatory in regular schools, what was supposed to be a transition stage has become a segregation space.

Another point shown, still regarding education, was the discrepancy between the age and the level of schooling for 17 (70%) of the subjects, with the majority still at the elementary and junior high level.

As for living conditions, 10 (40%) of the subjects lived in irregular housing and 5 (20%), in rented residences. Overall, 18 (72%) do not own a house and 20 (80%) had no wheelchair access. The environment where disabled persons live has a great effect on the prevalence and extension of the disabilities.¹⁴ That said, it was seen that public policies for housing should increase their focus on being inclusive, considering the needs of disabled persons.

CONCLUSIONS

The path taken by this study meant a challenge to the instrumentality and process of the Social Worker in the field of rehabilitation of disabled persons, especially children with cerebral palsy.

Knowing the environment where disabled persons live is extremely relevant, since it can influence the experience of health and illness positively or negatively. In view of that, interpreting the human-social reality is imperative to the success of the treatment. In addition, the participation of the person/family needs to be considered, for the conducts and decisions to be followed during the rehabilitation process will influence them.

The family dynamic and the effort of teamwork in the rehabilitation process may contribute favorably to the well-being of all and to the social inclusion of children with CP and aid in the formulation of public policies.

REFERENCES

1. Laurell AC, Noriega M. Processo de produção e saúde: trabalho e desgaste operário. São Paulo: Hucitec; 1989.
2. Mioto CRT. Cuidados sociais dirigidos à família e segmentos sociais vulneráveis. Brasília: Cadernos CEAD/UNB; 2000.
3. Almeida MC. Saúde e reabilitação de pessoas com deficiência: políticas e modelos assistenciais [tese]. Campinas: Universidade Estadual de Campinas; 2000.
4. Brasil. Ministério da Saúde. Diretrizes de atenção à pessoa com paralisia cerebral. Brasília: Ministério da Saúde; 2013.
5. Fonseca LF, Lellis SSR. Abordagem neurológica da criança com paralisia cerebral: causas e exames complementares. In: Fonseca LF, Lima CLA. Paralisia cerebral: neurologia ortopedia e reabilitação. 2 ed. Rio de Janeiro: MedBook; 2008. p.53-82.
6. Graciano MIG, Santiago MC, Bonfim EO, Galvão KA. Aspectos sociofamiliares constitutivos do estudo social de adolescentes com fissura labiopalatina. Arq. Ciência Saúde. 2015; 22(1):79-84.
7. Brasil. Ministério da Educação. Ensino Fundamental de nove anos: passo a passo do processo de implantação. Brasília: Ministério da Educação; 2009.
8. Brasil. Ministério do Desenvolvimento Social e Combate à Fome. LOAS anotada: Lei Orgânica da Assistência Social. Brasília (DF); Secretaria Nacional de Assistência Social; 2009.
9. Brasil. Presidência da República. Decreto nº 8.381, de 29 de Dezembro de 2014. Regulamenta a Lei nº 12.382 de 25 de Fevereiro de 2014, que dispõe sobre o valor do salário mínimo e a sua política de valorização de longo prazo. Diário Oficial da República Federativa do Brasil, Brasília (DF); 2014 Dez 30; Seção 1:1.
10. Graciano MIG. Estudo socioeconômico: um instrumento técnico-operativo. São Paulo: Veras; 2013.
11. Instituto Brasileiro de Geografia e Estatística - IBGE. Censo demográfico 2010: características gerais da população, religião e pessoas com deficiência. Rio de Janeiro: IBGE; 2010.
12. Sarti CA. Famílias enredadas. In: Acosta AR, Vitale MAF (Orgs). Família: redes, laços e políticas públicas. 3 ed. São Paulo: Cortez; 2007. p.21-36.
13. Sasaki RK. Inclusão: construindo uma sociedade para todos. Rio de Janeiro: WVA; 1997.
14. World Health Organization. Relatório mundial sobre a deficiência. São Paulo: SEDPCD; 2012.