

Social support provided to caregivers of children with cerebral palsy

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Abstract

Objective To describe the perception of caregivers of children with cerebral palsy (CP) concerning social support received and to verify how the characteristics of the children (i.e. type of CP and severity of motor impairment) and those of their caregivers (i.e. age, level of education, occupation, income and number of children) are significantly related to this perception.

Method A total of 50 children with CP aged between 3 and 12 years and their respective caregivers participated in this study. Children were grouped in terms of type of CP and according to the severity of motor impairment through the Gross Motor Function Classification System (GMFCS). The Social Support Questionnaire (SSQ) was used to evaluate the perception of caregivers concerning the social support they receive (number of people offering support – SSQ-N index, and level of satisfaction concerning such support – SSQ-S index).

Results The caregivers reported receiving support from a mean of 1.67 people. Core and extended family members (i.e. husband, mother, siblings) and friends are the most common providers of support. In regard to level of satisfaction, caregivers considered the support they received to be positive, obtaining a mean of 5.52 out of a total of six points. Children's and caregivers' characteristics were not significantly related to the SSQ-N and SSQ-S indexes.

Conclusion Family members are the caregivers' primary source of social support and caregivers reported being satisfied with the support they received.

Introduction

Cerebral palsy (CP) is an important chronic condition affecting childhood. It encompasses a group of permanent disorders affecting one's development of movement and posture, limiting the performance of tasks as a consequence of non-progressive disorders that occur in the foetal development of infant brain. These conditions are often accompanied by sensorial and behavioural disorders, and those affecting perception, cognition

and communication, as well as being associated with epilepsy and secondary muscle dysfunction (Rosenbaum *et al.* 2007).

The severity of gross motor function limitations in children with CP is highly variable. Some children can walk independently with or without auxiliary devices while others use a powered wheelchair or need to be carried by an adult (Tieman *et al.* 2004). The ability to perform daily living activities may be harmed as a consequence of one's motor condition, affecting independent walk, self-care and grooming, and social and

cognitive activities, negatively impacting the child's and family's health and well-being (Liptak & Accardo 2004; Benedict *et al.* 2010).

Meeting the needs of children with CP and providing them care can generate a certain level of stress in parents. Potential stressors include tense family relations and social isolation due to CP children's limited mobility, which can be either minimized or aggravated depending on the family's social, emotional and financial resources (Sipal *et al.* 2010). In this context, researchers seek to understand how families respond to the demands imposed on their routine, family adaptation processes, and the variables that can favour coping with the challenges faced by delivering care to a disabled child (Heiman 2002; Patterson 2002; Butcher *et al.* 2008).

Therefore, we stress the importance of focusing on caregivers of children with CP, expanding care and services provided to the family, through an understanding of how families deal with the demands of having a disabled child (Moore *et al.* 2010) and on what kind of social support they can depend in their daily routine.

Social support can act within the family's adaptation process, triggered in the face of stress associated with the birth of a disabled child and is an important predictor of parental adjustment, as well as a protective factor amid stressful events (Matsukura *et al.* 2007).

Caregivers are the individuals mainly responsible for encouraging the child with CP to become independent in daily living activities. According to Mancini and colleagues (2002), those children with the most severe motor impairment require the greatest level of assistance to perform tasks. Hence, it is possible, considering this context, for many parents to put leisure activities aside and have a more limited number of friends. From this perspective, it is advisable that the health staff acquire improved knowledge concerning how the social support received/perceived by caregivers affects the quality of life of caregivers and that of the children under their care.

This study is an investigation of the perceptions of caregivers of children with CP concerning the social support they receive, the people providing such support and how satisfied caregivers are with it. An investigation of how the type of CP, severity of motor impairment and caregivers' socio-economic factors influence perceived social support is also presented.

Methods

This cross-sectional, non-experimental and quantitative study complied with all ethical guidelines concerning research conducted with human subjects.

Table 1. Characterization of children with cerebral palsy (CP)

Characteristics	<i>n</i> or average
Age	6.6 (variation = 3–10)
Gender	
Male	30
Female	20
Type of CP	
Unilateral	13
Bilateral	37
GMFCS	
I	15
II	4
III	18
IV	5
V	8

GMFCS, Gross Motor Function Classification System.

A total of 50 children with CP, of both genders, aged from 3 to 12 years, participated in this study along with their respective caregivers. Children were selected through a search of those patients receiving outpatient care in the Children's Occupational and Physical Therapy sector and outpatient clinic providing treatment with botulinum toxin in the Neurology sector of a university hospital in the interior of the state of São Paulo, Brazil from September 2008 to December 2009.

In regard to the studied children, most were male with bilateral CP and level III motor impairment. Table 1 presents in detail the demographic characteristics of the children participating in the study.

In regard to the caregivers, 88% were young mothers, 40% had a single child, 38% had completed secondary school, 80% did not have a paid job and 62% had low socio-economic status. Table 2 presents in detail the characteristics of caregivers of children with CP evaluated in this study.

The caregivers received information about the study and were invited to participate signing the free and informed consent forms. After this, the researcher filled out a form recording the caregivers' occupation, income, level of education, number of children and age, and also applied the Sarason's Social Support Questionnaire (SSQ) version, which has been adapted for Brazil (Matsukura *et al.* 2002), through an interview that took a mean of 30–45 min.

The SSQ is intended to verify the number of people providing support as perceived by the respondents and how satisfied they are with such support. The instrument is composed of 27 questions; each question requires a two-part answer. The first part indicates the number of perceived social support sources (SSQ-N) – from none to nine possibilities – and the respondents indicate the degree/type of relationship they have with the mentioned person (i.e. husband, sibling). In the second part, the

Table 2. Demographic characteristics of caregivers of children with cerebral palsy

Characteristics	n (%)
Kinship	
Mother	44 (88)
Grandmother	4 (8)
Aunt	2 (4)
Age (years)	
15–30	26 (52)
31–45	20 (40)
46–60	4 (8)
Marital status	
Married or have stable relationship	43 (86)
Single	7 (14)
Educational level	
Incomplete primary school	13 (26)
Complete primary school	11 (22)
Incomplete secondary school	3 (6)
Complete secondary school	19 (38)
Incomplete college	3 (6)
Bachelor's degree	1 (2)
No. of children	
1	20 (40)
2	12 (24)
3	10 (20)
4	5 (10)
5	3 (6)
Occupation	
Homemaker	40 (80)
Paid job	10 (20)
Income	
Up to 1 times the minimum wage (m.w.)*	9 (18)
Between 1 and 2 times the m.w.	31 (62)
Between 2 and 3 times the m.w.	8 (16)
Between 3 and 4 times the m.w.	2 (4)

*Equivalent to US\$ 345.

respondents report how satisfied they are with the support received (SSQ-S), on a scale of one to six points that ranges from 'very dissatisfied' (score of 1) to 'very satisfied' (score of 6) (Sarason *et al.* 1983).

Children with CP were observed in relation to trunk control, transfers and mobility and classified in relation to gross motor function according to the Gross Motor Function Classification System Expanded & Revised (GMFCS E&R). This instrument has five levels: level I refers to children who walk with limitations and level V refers to children unable to control head and trunk postures in terms of gravity resistance, and require locomotion via a wheelchair (Palisano *et al.* 2008).

The index concerning the number of supportive individuals (SSQ-N) is obtained through the sum of all the individuals mentioned over the 27 questions; it is possible to include up to nine supportive individuals in each question, totalling 243 people.

The level of satisfaction concerning received support (SSQ-S) is achieved through the sum of scores obtained from each

question, which may range from 1 to 6. It is possible to obtain a total raw value of 162, that is, 27 questions multiplied by 6. This sum is divided by 27 (total number of questions) and the SSQ-S is obtained.

Data were analysed to identify the mean and standard deviation of the index concerning the number of supportive people (SSQ-N), the received-support satisfaction index (SSQ-S), and also to identify the individuals most frequently reported by caregivers.

The mean scores concerning the SSQ-N and SSQ-S indexes were analysed in relation to the children's and caregivers' characteristics. The children's characteristics include the type of CP and severity of motor limitations (evaluated through the GMFCS E&R) while the caregivers' characteristics include age, educational level, income, number of children and occupation. The Kruskal–Wallis test, which compares scores of more than two independent groups, was used to identify significant differences between the social support perceived by caregivers (SSQ-N) and satisfaction with support (SSQ-S) in relation to the severity of motor limitations (five levels of GMFCS). The Mann–Whitney test was used to compare the SSQ scores (SSQ-N and SSQ-S) in relation to the types of CP (unilateral or bilateral). The Mann–Whitney test was also used to identify significant differences between social support (SSQ-N and SSQ-S) and the caregivers' occupation (distributed in two groups 'homemaker' and 'paid job'). The Kruskal–Wallis test was used for the remaining variables concerning the caregivers' characteristics [kinship with child (mother, grandmother or aunt), age of caregivers (distributed in 15–30, 31–45 and 46–60), educational level (distributed in incomplete primary school, complete primary school, incomplete secondary school, complete secondary school, incomplete college and bachelor's degree), number of children and income (distributed in up to one times the minimum wage,¹ between one and two times the minimum wage, between two and three times the minimum wage, and between three and four times the minimum wage)]; significance was fixed at $P < 0.05$.

Results

The SSQ was used to identify social support sources perceived by the caregivers, their satisfaction in relation to this support, and to investigate whether such support is influenced by variables related to the children's and/or caregivers' characteristics.

The analysis of how the characteristics of the children influence the perception of caregivers concerning received social

¹ Equivalent to US\$ 345.

Table 3. Relationships among the caregivers' variables and support sources (SSQ-N index) and satisfaction with support (SSQ-S index) (*P*-value)

	SSQ-N index (<i>P</i>)	SSQ-S index (<i>P</i>)
Caregiver's age	0.622	0.519
Income	0.646	0.852
Number of children	0.306	0.644
Occupation	0.297	0.450
Educational level	0.093	0.417

SSQ, Social Support Questionnaire.

Table 4. Average, standard deviations, maximum value of the frequency with which support sources were mentioned

Support sources	Average	Standard deviation	Maximum
Husband	7.9	6.9	26.0
Mother	6.6	7.3	26.0
Brother	6.2	7.1	27.0
Friend	5.1	7.5	23.0
Child (patient's sibling)	4.6	6.2	25.0
Child (patient)	4.2	6.4	16.0
Father	2.2	3.7	14.0
Brother-in-law	2.0	5.4	27.0
Nobody	1.9	2.8	10.0
Father-in-law	1.4	2.6	11.0

support was no significant relationship with the severity of motor impairment (different levels of GMFCS E&R) $P = 0.375$ for SSQ-N index and $P = 0.194$ for SSQ-S index, nor any relation to the type of CP (unilateral and bilateral) $P = 0.565$ for SSQ-N index and $P = 0.609$ for SSQ-S index.

The analysis of how the characteristics of caregivers influence perception concerning received support showed that the number of sources mentioned (SSQ-N index) and satisfaction in relation to support received (SSQ-S) do not significantly differ in relation to the caregiver's age, income, number of children, occupation or educational level. Table 3 shows the *P*-values between social support and caregiver-related variables.

The support sources most frequently mentioned include core family members such as husband, mother and siblings. Friends, an element external to the family, are also frequently mentioned. Table 4 presents the mean, standard deviation and the maximum value assigned by caregivers of the support given by individuals mentioned as sources of support, while the minimum value was not included in the table because it was equal to zero in all the cases. Other social support sources mentioned by the caregivers were not included in Table 4 because they present means below one (nephew, neighbour, psychologist, step mother, grandmother, boyfriend, cousin, daughter-in-law and grandson).

Table 5. Average and standard deviation concerning SSQ-N and SSQ-S indexes

	Average	Standard deviation	Minimum value	Maximum value
SSQ-N index	1.67	0.49	0.96	3.03
SSQ-S index	5.52	0.55	3.80	6.00

SSQ-N index, number of people offering support; SSQ-S index, level of satisfaction concerning such support.

Table 5 presents the means and standard deviations of the SSQ-N and SSQ-S indexes, which refer respectively to the number of people providing social support and the caregivers' level of satisfaction concerning such support.

Discussion

Most studied children present bilateral CP and motor limitations equal or above level III indicating they are dependent on others to perform self-care actions such as feeding, dressing, bathing and walking, demanding, therefore, a greater level of care compared with children with typical development (Raina *et al.* 2005). This dependence remains over time and even though changes may occur as children grow older, the time spent on care and basic aspects of care provided to children with CP are similar (Davis *et al.* 2009).

The influence of the characteristics of the studied children (type of CP and severity of motor limitations) on caregivers' perceived social support (considering number of support sources and satisfaction with received support) was not significant. Apparently quality of life of children with CP and their caregivers is influenced by aspects that are not directly linked to a severity of impairment of child. Care of children with CP affects parent's physical well-being, social well-being, freedom and independence, family well-being and financial stability (Davis *et al.* 2009), but not always the most severely impaired children (in terms of motor functioning or intellectual ability) present poorest quality of life (Arnaud *et al.* 2008) and the caregivers (mother and parents) do not have their quality of life influenced by children motor level.

Most caregivers were young mothers who had completed secondary school, did not have a paid job despite their families' low income. Mothers and women in general tend to assume the responsibility of caring for children with CP, forgoing other occupational roles (Milbrath *et al.* 2008). The functional dependence of children with CP physically and emotionally overloads family members, especially the mothers, who frequently assume the care provided to these children

(White-Koning *et al.* 2008), impeding their inclusion in the job market (Milbrath *et al.* 2008; Davis *et al.* 2009).

An unwillingness of mothers to social relationships associated with decreased mood and problems faced in the social and professional spheres (Ones *et al.* 2005) are factors that may explain the reduced number of individuals providing social support. Such support is mainly provided by those from the core family (husband, mother, siblings, children), the mothers report that the fathers of children with CP (husband) are an important source of support and help (Button *et al.* 2001; Milbrath *et al.* 2008) as well as the mothers' own parents (Milbrath *et al.* 2008).

The fact that some mothers mentioned that their children with CP themselves represent a source of social support is in consonance with the study by Davis and colleagues (2009). These authors also verified that many parents of children with CP find in their own children inspiration to cope with difficulties when they witness their children's examples of courage and resilience.

Having a friend as a source of social support confirms that caregivers usually seek informal social support sources (Almeida & Sampaio 2007). Some studies note that friendships usually originate in relationships established with parents of disabled children in the therapeutic environment (Milbrath *et al.* 2008; Davis *et al.* 2009). Future studies can verify what type of support may be offered and obtained in environments where the children and/or caregivers receive care. For instance, groups of mothers/caregivers of disabled children have been reported as important strategies to provide emotional and informational support and contribute to positive coping strategies adopted by families when facing crises in daily life (Matsukura *et al.* 2000; Dessen & Silva 2004; Matsukura & Sime 2008).

Social support provided by rehabilitation professionals is almost absent in the caregivers' reports, which suggests that the studied mothers do not feel supported by the staff caring for their children; a similar finding is reported by Davis and colleagues (2009). Probably the caregivers considered that health professionals need offer technician support (instrumental/practical) do not considering that in their practice the emotional support is very important too. Even though the SSQ is not an instrument specific to evaluating informational support (instructions and technical guidance, among others), studies indicate that this is the type of support families of disabled children most expect to receive from the health staff (Garwick *et al.* 1998). Even though this instrument mainly focused on emotional/affective and instrumental/practical support, indications of health professionals as support sources

were notably low when compared with other studies addressing similar populations and using the SSQ to evaluate social support received by families (Matsukura *et al.* 2007).

The studied caregivers are quite satisfied with social support received despite the reduced number of individuals providing such support, although other studies report different results. However, a study in Turkey conducted with caregivers of 103 disabled children, of whom 51 were mothers of children with CP, using a personal information form, reported that, specifically to CP, 80.4% have difficulty in caring for the child, 60.8% fell deep sadness, 68.6% reported receive emotional support but only 53.3% said be reasonably sufficient supported with which they were not satisfied (Sen & Yurtsever 2007). Another study conducted in Brazil, using the SSQ, with 75 mothers, of whom 37 were of children with different types of developmental difficulties (MDD), and 38 were of children with typical development (MTD), reported that the number of people to support MTD is higher than the MDD, with significantly differences; but in other hand, do not have significantly differences related to satisfied with social support received between MTD and MDD (Matsukura *et al.* 2007). These results may suggest that caregivers consider more important the quality of support than the number of people whom give this support.

Limitations

The studied caregivers are from different cities in the interior of São Paulo, Brazil. Such a fact could increase the diversity of data; however, data were collected in a single neuropaediatric service from a university hospital in which caregivers with low educational levels and low income predominate. Therefore, further research addressing larger samples with higher socio-economic statuses is needed in Brazil (i.e. studies conducted in other neuropaediatric services located in different Brazilian states).

This study did not associate stress or quality of life measures with social support, which could provide more elements to clarify the role of social support in the routine of caregivers of children with CP.

Conclusion

Children with CP demand care that exceeds the habitual needs of children with typical development, which may cause caregivers to experience physical and emotional overload. Social support networks are a mechanism that may facilitate caregivers' adaptive responses during the entire time they provide care to the affected child.

This study's results show that caregivers are satisfied with social support received, although the sources of such support are restricted to the core family and friends, considered to be informal support. Support provided by the health and educational staff was seldom reported. This finding suggests that neuropaediatric services should be structured so as to provide greater social support to caregivers in addition to the care provided to children with CP. Additionally, interventions directed to these children should include their families and strategies able to encourage the building of the family's social support network.

Key messages

- It is very important that the health staff know the influence of social support received in the quality of life of caregivers and of children who are under their care.
- Family members and friends are the most common providers of support to caregivers of children with CP.
- The caregivers are satisfied with the support they received.
- The severity of motor impairment and the type of CP do not influence the number of perceived social support sources and the level of support received satisfaction by the caregivers.
- The caregiver's age, income, number of children, occupation or educational level do not influence the number of perceived social support sources and the level of support received satisfaction by the caregivers.

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