International Journal of Scientific Engineering and Research (IJSER)
www.ijser.in
ISSN (Online): 2347-3878, Impact Factor (2015): 3.791

Links between Perceived Stress and Social Support for Parents of Children and Teenagers Suffering from Cerebral Palsy

Mustapha Mouilly[1,3], Noureddine Faiz[2,3], Ahmed Omar Touhami Ahami[3]

[1]Mohammed Diouri Health Center, Kenitra, Morocco
[2]SMBA Health Center, Mohammadia, Morocco
[3]Department of Biology, Neurosciences and Nutritional Health/ Ibn Tofail University, Morocco

Abstract: ***The child with cerebral palsy (CP) requires special care; this responsibility becomes heavier at the age of adolescence. Parents during these times through difficult times resulting in a deteriorated physical state and a disturbed mental health expressed a high level of stress. Few studies that seek to study the impact of the disease on the lives of parents and to find out the links between this experience and the support provided to this population. A study protocol consisting of questionnaires, scales were used to measure the impact of cerebral palsy children and adolescents on the stress levels of their parents and to seek the links between perceived stress and the assured social support, 67 relatives (34 mothers and 33 fathers) of children with cerebral palsy participated in this global exploratory study, Most of our results support our hypothesis and confirm the literature in this field little studied in Morocco. Indeed it seems that the parents of children and adolescents with cerebral palsy suffer from high stress levels this suffering seems more pronounced in mothers than in fathers, however, and contrary to what was expected, this suffering is not correlated with social support, which remains in fact a protective factor by one form of esteem. In conclusion, parents, especially mothers, have more need of social support of esteem and psychological support to report a decrease in the level of stress and a state of much better mental health.***

Keywords: Children, Teenagers, Cerebral Palsy, Stress perceived, social support

1. Introduction

Cerebral palsy is the most common physical disability in children and affects 3.6/1,000 children [1]. According to definition, "Cerebral palsy (CP) describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to nonprogressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication, and behavior, by epilepsy, and by secondary musculoskeletal problems"[2].

The management of children with chronic illness has gradually shifted from the hospital to the home where care and monitoring taking responsibilities primarily rest on the shoulders of the family. This is why researchers have started to investigate the child's family background with a chronic disease [3](Walker, Donald & Ford, 1987) .and especially the stress that has successively been conceptualized as a non-specific response of the body to the aggression (biological model Selye) and as a multifactorial process with cognitive, emotional, behavioral and neuro-hormonal, in close interaction with each other (transactional and biopsychosocial models) [4]. However, the peculiarity of the care of a child and teenager with cerebral palsy (CP) and more particularly, the experience of parents facing the illness has been little studied. Furthermore, knowledge of the perceived level of stress experienced by parents and relationship with social support remain unknown. Therefore, the goals of our global study, exploratory, are: (1) identify the level of stress of parents of children and adolescents suffering from CP; (2) highlight the link between perceived stress and social support. (3) Test the existence of gender differences of parent and by the fact that it is a child's parent or teenager's one. Based on data from literature [5] and the experiences of parents, hypotheses postulate that children and teenagers parents report a high level of stress negatively correlated with social support. Similarly, the mother experiences a level worse than the father and that social support with its different forms is the source of adapting the family to face the disease.

2. Methodology

2.1 Recruitment

All parents were recruited through the Moroccan Association for Better Life which manages the Early Medical Social Action Center in Kenitra (CAMSP) and the rehabilitation center for handicapped children. The inclusion criteria were: to have a child aged between 2 and 17 years and know the diagnosis for minimum 1 year.

2.2 Participants

The total sample consisted of 67 parents of children and teenagers suffering from CP. It breaks down as follows: 33 fathers and 34 mothers.

2.3 Measuring instruments

2.3.1 Questionnaire of demographic information

The questionnaire contains some relevant information for research and analysis of results for children with CP such as gender, age, sibling rank, diagnosis age, ownership, associated disorders and autonomy. Parental status was described by the following: gender, age, marital status, socioeconomic status, occupation and number of children.

2.3.2 Questionnaire perceived social support (QPSS)

This scale assesses the type of support received, the resources of this support, the number of people who provide it (or availability) and perceived quality (or satisfaction). It consists of four questions reflecting the main forms of social support: esteem support (comfort, listening in difficult times), material or financial support (direct assistance when necessary), the informational support (advice or suggestions from others), emotional support (reassure, restore confidence) for each type of support, it helps to know how many people providing it, who are these people (family, friends, colleagues, specialists ...) and if the subject is satisfied with this support. So we get two scores for each subject: availability (number of persons involved in the support) and perceived satisfaction (quality of that support). This tool also provides information about the nature of social support perceived by the person. [6]

2.3.3 Perceived Stress Scale (PSS)

This scale assesses the importance with which life situations are perceived as threatening, that is to say, unpredictable, uncontrollable and painful. PSS measuring stress in general and not specifically. [7]

2.4 Statistical analyses

All statistical analyzes were performed using the statistical package for social sciences (SPSS version 20.0). The normality of the distribution variables was tested by the Kolmogorov-Smirnov test. The normally distributed variables are shown as mean ± standard deviation, and those distributed abnormally; median (interquartile range 25 to 75%). The homogeneity of variance was tested using Levene's test, and Welch's correction was used in the case of heterogeneous variances. ANOVA or the Mann-Whitney tests were performed to test for significance between independent samples. The Student t test for independent sample was used. P values less than 0.05 were considered statistically significant. We have used the forcing in the multivariate regression.

3. Results

A total of 67 parents of 34 mothers (50.7%) and 33 fathers (49.3%) participated in the study, the mean age of parents is about (43.0 ± 8.5) .The most were in couples n = 66 (98.5%) and a divorced mother (1.5%), 16.4% of the population has one child. The majority of mothers believe they have that support heavy load, while (11.8%) believe that family responsibilities are equitably distributed. 55 (82.1%) of parents believe that the care of their child is weak and in need of social support, but 12 (17.9%) are satisfied with their care. 65 (97%) of children are not autonomous and depend on adults for all activities of daily living, 2 (3.0%) are autonomous, but all children present disorders associated with their motor disability (table 1).

Table 1: Descriptive statistics of the study population

Characteristic	*N=67 value*
Age (in year) *	43 ± 8,5
Parents **	
Fathers	33 (49,3)
Mothers	34 (50,7)
Marital status **	
divorced	1 (1,5)
couple	66 (98,5)
Socio-economic Level **	
Low	19 (28,4)
Average	40 (59,7)
High	8 (11,9)
Profession of the mothers **	
Without profession	23 (67,6)
Labour Tallies	6(17,6)
average Senior	4(11,8)
staff	1(2,9)
Profession of the fathers **	
Without profession	0 (0)
Labour Tallies	22(66,7)
average Senior	10(30,3)
staff	1(3,0)
Autonomy of the children **	
Not	65(97)
Yes	2 (3)

* Mean ± SD standard deviation, effective ** (%)

From the results shown in Table 2, perceived stress was significantly higher among mothers of children and teenagers suffering from CP than among fathers. Regarding satisfaction score, there is a statistically significant difference (p = 0.004) between the mother's which is higher compared with teenager's father, however there is no statistically significant difference between the scores of mothers and father's children (p = 0.068).

Table2: Description of perceived stress and overall satisfaction score of fathers and mothers of children and teenagers with CP

	Mothers (n=34)	Fathers (n=33)	P value[1]
Child			
PSS Score	32,70(±3, 09)	24,48 (±3,55)	< 0,001
Satisfaction score	11,22 (± 2,69)	13,09 (± 3,96)	0,068
Teenager			
PSS Score	37.55 (±3.80)	25 (±3.59)	< 0,001
Satisfaction score	10,18 (± 1,53)	13,10 (± 2,47)	0,004

[1]p value for independent sample t-test

Table3: Characteristics on the satisfactions of support for parents of children and teenagers with CP.

	Mothers (n=34)	Fathers (n=33)	P value[1]
Satisfaction of esteem	3,0(2,0-3,0)	3,0(2,0-4,0)	0,001
Satisfaction with the material support	2,0(1,8-4,0)	3,0(2,0-4,0)	0,010
Informative satisfaction	3,0(2,8-3,0)	3,0(2,0-4,0)	0,000
Satisfaction with the emotional Support	3,0(2,0-3,0)	4,0(3,0-5,0)	0,002

[1]p-values determined with the Mann-Whitney test.

From the results of our study, it is shown that there is a statistically significant difference in satisfaction of esteem support fathers and mothers (p = 0.001), in satisfaction material support (p = 0.010), in informational support satisfaction (p <0.001) and also in emotional support satisfaction (p = 0.002) .in fact all these forms of satisfaction were higher in mothers than in fathers.

Table 4: Characteristics on the satisfactions of support for parents of children and teenagers with CP

	PSS score	Score of satisfaction
Mothers (child)		
PSS score	1,00	-0,18 (p=0,4)
Score satisfaction	-0,18 (p=0,4)	1,00
Mothers (teenager)		
PSS score	1,00	-0,06 (p=0,8)
Score satisfaction	-0,06 (p=0,8)	1,00
Fathers (child)		
PSS score	1,00	-0,28 (p=0,2)
Score satisfaction	-0,28 (p=0,2)	1,00
Fathers (teenager)		
PSS score	1,00	-0,28 (p=0,4)
Score satisfaction	-0,28 (p=0,4)	1,00

* Significant at 0.05; ** Significant 0.01; *** Significant at 0.001.

According to the results presented in Table 4, it is shown that social satisfaction is associated with a decrease parental stress, the relationships between satisfaction and perceived stress were not significant in children of mothers (r = -0.18; p = 0.4), and in mothers of adolescents see even in children of fathers (r = -0.28; p = 0.2) and fathers of adolescents, ie, when parents perceive that their social network responds support, they do not report lower levels of stress in their relationship with their children.

The multivariate analyzes are intended to check the following exploratory question: the different forms of social support are they associated with a decrease in perceived stress.

Table 5: associated factors to social support with multivariate analysis in mothers

Associated factors	Analyze univarié			Multivariate analysis		
	B	IC 95 %	p	B	IC 95 %	p
Age	0,19	[0,03; 0,35]	**0,02**	0,14	[-0,01; 0,28]	0,06
Support of esteem	0,6	[-1,17; - 0,28]	0,04	-1,41	[- 2,25 ;-0,58]	**0,002**
Material support	-0,6	[-1,81; 1,25]	0,6	1,05	[-1,04 ; 3,15]	0,31
Informative support	0,11	[-0,81; 1,03]	0,81	0,97	[- 0,14; 2,10]	0,08
Emotional support	0,05	[-0,64; 0,74]	0,88	0,63	[-0,13; -0,25]	0,15

Table 6: Associated factors to social support with multivariate analysis in fathers

Associated. factors	Univariate Analysis			Multivariate analysis		
	B	IC 95 %	p	B	IC 95 %	p
Age	0,06	[-0,11; 0,23]	0,49	0,13	[-0,07; 0,34]	0,19
Sup. esteem	0,26	[- 0,42; 0,94]	0,44	-0,23	[-1,57; 1,46]	0,94
Mat. Sup.	-0,29	[-1,81; 1,25]	0,71	-0,17	[-2,81; 1,34]	0,86
Info Sup.	0,62	[- 0,55; 2,15]	0,24	0,60	[-0,77; 3,17]	0,50
Emo Sup.	0,48	[0,49; 0, 78]	< 0,001	0,51	[-1,84; 2,12]	0,6

In multivariate analysis after adjustment for age, support of esteem, material support, informative support and emotional support, only the support of esteem is associated with perceived stress as a protective factor in the mothers. However, no factor is associated with perceived stress among fathers in our study population. (Table 5) and (Table 6).

4. Discussion

Some epidemiological studies on the health of young adults with disabilities show that a well exists on mortality and on-morbidity in this population [8], [9], [10], [11], [12],[13], loss of mobility capabilities and autonomous power supply being predictive of mortality. [8], Life expectancy of patients is related to the severity of the deficiencies [12], [13], [14] The CP children growing up are of particular clinical picture sometimes with scoliosis (complication in 25-65% of patients CP living in institutions) [15] .The risk of progression is even more important that scoliosis is severe [8] Scwartz et al. [16] estimated that 67% of adults with cerebral palsy suffer from chronic pain in the lower limbs [16]. The orthopedic deformities generate pain and contribute to functional alterations [17], [9]. In addition to the sphincter disorders, the CP children suffer from nutritional and digestive disorders [18], the risk of aspiration persists and remains an important factor of respiratory superinfection, sometimes warranting special rehabilitation and education of the patient and his entourage for this reason and for other people in our study composed of 67 parents of children and teenagers CP have a high stress level which corroborates the literature [19], [20], [21] and particularly the mother who takes child care and that primary responsibility for his medical care [22], in this context recall that in our sample almost all the children are dependent on adults for most activities of daily life and they all have several associated disorders and that fathers were much less available, covering among other things occupation, the mother is in a situation where it assumes the heavy charge that will multiply at the age of adolescence. Increase the risk of difficulties must request a special surveillance with his entourage. How can one imagine the quality of life of parents living before this array of complications and sometimes with a major problem of communication that can provide behavioral problems, a lack of understanding can generate cries of even crying attacks, some these disorders are more or less controllable by parents at the age of childhood but become unbearable and disturbs quality of life in adolescence age when the child grows and develops physical strength.

The requirements associated with CP are numerous and expensive and requires a considerable investment of time and energy on the part of parents, they limit the opportunity to enroll simultaneously in secondary activities of distraction or professional occupations in mothers without representing 67.6% of mothers. They also limit the opportunities to maintain social relationship and sometimes create some isolation [23]. The frequency of links with the various forms of support can really decreased the stress level and especially if it is a support of esteem as demonstrated in our study.

However, contrary to what was envisaged, the different forms of social support did not show significant relationship with perceived stress in parents of children and adolescents suffering from CP. The only established relationship only applies to mothers who have a much better satisfaction than fathers.

Furthermore, various studies have shown that psychological distress scores in subjects with high social support are not influenced by the perceived stress scores [24, 25]. In other words, we may well have a high perceived stress score and a low distress score if one enjoys high social support.

In fact, according to Cohen et al. [24, 26], it is appropriate to distinguish conceptually perceived stress of psychological distress. Indeed, the P.S.S. does not assess psychological distress but rather how the subject perceives and interprets external events. So we may well perceive events as painful and stressful without manifest different symptoms of psychological distress (anxiety, depressive affect, somatic complaints, hostility, etc ...). [4]

Finally, the results of this research raise that fathers also report a high level of stress about their situation in the presence of a child with CP, but do not mention social support helping to reduce the stress related to stains they assume.

Given these results, it is appropriate to establish a support system conjugal and to involve as many mothers as fathers, to strengthen their self-esteem, and implement adaptation process related to the presence of a child with CP.

Finally this research has some limitations. If our data have clarified in part the reality of parents, they do not allow us to have a perfect knowledge of the various factors associated with perceived stress. To the extent that the sample size is small and the comparison group is absent statistical possibilities do not allow us to extrapolate and to have the ability to generalize the results.

5. Conclusion

This research demonstrates the existence of a high level of perceived stress among parents of child with CP, however, this suffering is more pronounced in the mother who has the primary responsibility, that among fathers. It was also noted that there is a statistically significant difference in satisfaction scores of various forms of support between the fathers and mothers of adolescents, more pronounced in mothers. In correlational point of view, there is no relationship between the different forms of support and perceived stress among our population; it is a child or adolescent father or mother of child or adolescent with cerebral palsy.

Our study also showed that the support of esteem is the main source of reduction of perceived stress and a determining factor in the adaptation of the mother cope with the disease.

Finally, a similar research is needed on a larger sample and other variables that can be classified as critical in adapting the family including the father to face the disease. The transition in the current Moroccan context demographic, economic and policy should under no circumstances neglect

this population whose needs are precarious and increasingly diversified.

References

[1] Yeargin-Allsop M, Braun KVN, Doernberg NS, Benedict RE, Kirby RS, Durkin MS. Prevalence of cerebral palsy in 8-year-old children in three areas of the United States in 2002: a multisite collaboration. Pediatrics 2008;121:547–554. [PubMed: 18310204]
[2] Rosenbaum P, Paneth N, Leviton A, et al. A report: the definition and classification of CP April 2006. Dev Med Child Neurol Suppl 2007;109:8–14. [PubMed: 17370477]
[3] Walker, L.S., Ford, M.B., & Donald, W.D. (1987). Cystic Fibrosis and Family Stress: Effects of Age and Severity of Illness. Pediatrics, 79(2), 239-246.
[4] Bruno Quintard, "le concept de stress et ses méthodes d'évaluation,"Recherche en soins infirmiers N° 67 - décembre 2001
[5] Mouilly M, Faiz N, Ahami AOT, Abousalah Y « Qualité de vie des parents d'enfants et adolescents souffrants d'infirmité motrice cérébrale ». International Journal of Innovation and Applied Studies ISSN 2028-9324 Vol. 9 No. 4 Dec., pp. 1700-1707, 2014
[6] Bruchon-Schweitzer M., Bruchon-Schweitzer M., Quintard B. Personnalité et maladies. Stress, coping et ajustement.Ed.Dubod:Paris.[Online]Available:(http://www.invs.sante.fr/publications/2005/epidemiologie_catastrophes/module7.pdf), 2001.
[7] Cohen, S., Kamarck, T., & Mermelstein, R. « A global measure of perceived stress ». Journal of Health and Social Behavior, 24(4), 386-396, 1983.
[8] Tiffreau V.Schill A., Popielarz S., Herbau C., Blanchard A., Thevenon A. « La continuité de prise en charge lors de la transition des soins de l'enfant à l'adulte handicapé », Annales de réadaptation et de médecine physique 49,652–658, 2006.
[9] Klingbeil H, Baer HR, Wilson PE. « Aging with a disability ». Arch Phys Med Rehabil;85:S68–73.31, 2004.
[10] Singhal B, Mathew KM. « Factors affecting mortality and morbidity in adult spina bifida ». Eur J PediatrSurg; 9(Suppl 1):31–2, 1999.
[11] Muller T, Arbeiter K, Aufricht C. « Renal function in meningomyelocele: risk factors, chronic renal failure, renal replacement therapy and transplantation ». Curr Opin Urol;12:479–484, 2002.
[12] Hutton JL, Cooke T, Pharoah PO. « Life expectancy in children with cerebral palsy ». BMJ; 309:431–5, 1994.
[13] Strauss D, Cable W, Shavelle R. « Causes of excess mortality in cerebral palsy ». Dev Med Child Neurol;41:580–5, 1999.
[14] Strauss D, Shavelle R. « Life expectancy of adults with cerebral palsy ». Dev Med Child Neurol;40:369–75, 1998.
[15] Majd ME, Muldowny DS, Holt RT. « Natural history of scoliosis in the institutionalized adult cerebral palsy population ». Spine;22:1461–6, 1997.
[16] Schwartz L, Engel JM, Jensen MP. « Pain in persons with cerebral palsy ».ArchPhys Med Rehabil;80:1243–6, 1999.
[17] Murphy KP, Molnar GE, Lankasky K. « Medical and functional status of adults with cerebral palsy ». Dev Med Child Neurol;37:1075–84, 1995.
[18] Mouilly M, Faiz N, Ahami AOT, Abousalah Y « Swallowing disorders and feeding problems in children and teenagers with cerebral palsy ». IOSR Journal of Dental and Medical Sciences (IOSR-JDMS) 15, Issue 7 Ver. IX, PP 115-119, July. 2016
[19] Wintgens A, Hayez JY. « Guidance psychopédagogique des parents d'enfants atteints d'autisme ». Psychiatr Enfant;49(1):207-26, 2006.
[20] Baghdadli, A., Beuzon, S., Bursztjen, C., Constant, J., Desguerre, I., Rogé, B., Squillante, M., Voisin, J. et Aussilloux, C. In B. Rogé, C. Barthélémy et G. Magerotte (dir.), « Améliorer la qualité de vie des personnes autistes » (p. 193-211). Paris : Dunod, 2008.
[21] Cappe E., Marion Wolff, René Bobet, Jean-Louis Adrien « étude de la qualité de vie et des processus d'ajustement des parents d'un enfant ayant un trouble autistique ou un syndrome d'Asperger : effet de plusieurs variables sociobiographiques parentales et caractéristiques liées à l'enfant ».Evolpsychiatr;77(2), 2012.
[22] Quittner, A. L. ,Digirolamo, A., Michel, M. et Eigen,H. « Parental Response to cystic fibrose : A contextual analysis in the diagnosis phase »,.Journal of pédiatrique psychology, 17(6),683-704, 1992.
[23] Carter,B.D ; urey , J.R et Eid, N.S, (1992) the chronically ill child and family stress: family developmental perspective on cystic fibrosis. Review article.Psychsomtics,33(4),397-403.
[24] Cohen, S., Kamarck, T. et Mermelstein, R. A global measure of perceived stress, Journal of Health and Social Behavior, 24, 385-396, 1983
[25] Cohen, S., Sherrod, D.R. et Clark, M.S. Social skills and the stress-protective role of social support, Journal of Personality and Social Psychology, 50, 963 -973, 1986
[26] Cohen, S. et Williamson, G.M. Perceived stress in a probability sample of the United States. In S. Spacapan et S. Oskamp (eds), p. 31-67. The social psychology of health. London : Sage publications. 1988

Author Profile

Mouilly Mustapha received the B.S. and M.S. degrees in biological studies from Ibn Tofail University, Faculty of sciences in 2009 and 2011, respectively. Senior manager at Ministry of Health. He now PhD student in Department of Biology, Neurosciences and Nutritional Health/ Ibnt tofail University Morocco and responsible of Early Medico-social Action Center, Kenitra, Morocco.