



## LIFE QUALITY AMONG MOTHERS OF CHILDREN WITH CEREBRAL PALSY LIVING IN ARMENIA

HAKOBYAN H.H.\*, SABAHOULIAN C.B., MANVELYAN H.M.

Department of Neurology, Yerevan State Medical University, Yerevan, Armenia

Received 07/12/2015; accepted for printing 08/22/2015

### ABSTRACT

*Introduction:* Cerebral palsy is a group of syndromes which is presented as a non-hereditary, multi-etiological damage of developing brain generally occurring with constant deficiency of movement. Motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication and behavior, epilepsy and secondary musculoskeletal abnormalities which lead to the restriction of human ability to take care of himself. It is known that the primary caregivers of children with cerebral palsy are at high risk regarding their physical and psychological health. The impact of a child care process with this pathology doesn't change depending on age; however, the exact mechanisms of interrelation between the health of parents and the severity of child's illness are not clear as well as the causes to why some families cope effectively the psychological burden of a child care with cerebral palsy while others don't.

*Objectives:* The purpose of this research is to study the influence of a child care with cerebral palsy on their parents among ethnic Armenians in Armenia.

*Materials and methods:* Fifty children and adolescents with cerebral palsy aged 3-16 years with varying disability levels and their mothers were examined. Functional levels of children with cerebral palsy were investigated with gross motor function classification system. Depression levels of mothers were assessed with Beck depression inventory – 2 and anxiety levels with Norakidze's modification of Taylor manifest anxiety scale. The information about educational level was gathered.

*Results:* No significant differences were revealed in the average indices of depression in mothers of children with cerebral palsy regardless of the child state severity. The indices of depression and anxiety levels were significantly higher in the group of mothers with secondary or lower education compared to those with incomplete higher or higher education. The correlation between the depression level among mothers and the number of children in family was also investigated, for example, significantly lower levels of depression and anxiety were registered in mothers with 3 children (1 child with cerebral palsy and 2 healthy children).

*Conclusion:* The investigations show that regardless of the child's physical disfiguration level, parents suffer from a high level of anxiety and depression. It was also established that the psychological status, as a rule, is more favorable in parents with multi-child families.

Thereby, the obtained data emphasize the need for further investigations related to the treatment plan of children with cerebral palsy, as well as the physiological and psychological health of caregivers.

**KEYWORDS:** cerebral palsy, motor function, depression, anxiety.

### INTRODUCTION

Cerebral palsy is one of the most prevalent causes of permanently disordered motor function in approximately 2 per thousand newborns [Cans C et al., 2008; O'Shea T, 2008]. Cerebral palsy has a frequency of one to five in every 1000 newborns all over the world [Lee R et al., 2014]. The prevalence of cerebral palsy hasn't increased over the last 17 years, yet the absence of frequency occurrence re-

duction underscores the need in additional resources and support for children with cerebral palsy and their families [Van Naarden Braun K et al., 2016]. Cerebral palsy is a group of syndromes which is presented as a non-hereditary, multi-etiological damage of developing brain generally occurring with constant deficiency of movement [Koman L et al., 2004]. Motor control during walking, grasping, and reaching is disturbed by muscular spasticity, dyskinesia, hyperflexion, excessive co-activation of antagonist muscles, retained developmental reactions and secondary musculoskeletal congenital abnormalities together with paresis and

### ADDRESS FOR CORRESPONDENCE:

"Ararat" Mother's and Child's Health SPA  
18 Shahumyan Street, Jermuk 3701, Armenia  
Tel.: (+374) 93 32-34-31  
E-mail: hhhdoctor@gmail.com

genetical disorders [Richards C, Malouin F, 2013]. Motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication and behavior, epilepsy and secondary musculoskeletal abnormalities [Rosenbaum P et al., 2007] which lead to the restriction of human ability to take care of himself. The therapeutic management of patients with cerebral palsy needs a multi-dimensional approach, which not only means the collaboration of a large group of medical specialists (pediatricians, neurologists, orthopedists, speech and language therapists, physical therapists etc.), but also active participation of caregivers and family members. It has been proved that ecological, geographic, racial, ethnic, religious and socioeconomic disparities in a certain way have an impact on the prevalence and severity of cerebral palsy [Lang T et al., 2012].

It is known that the physical and psychological health of primary caregivers of children with cerebral palsy is at high risk [Parminder R et al., 2005; Bella G et al., 2011] and the impact of a child care with cerebral palsy doesn't change depending on age [Davis E et al., 2010]. However, the exact mechanisms of interrelation between the health of parents and the severity of child's illness are not clear as well as the causes to why some families cope effectively the psychological burden of a child care with cerebral palsy while others don't. It is obvious that the care of children with special needs considerably differs from those without disabilities [Brehaut J et al., 2004; Mugno D et al., 2007]. Mothers, on average, spent 6 hours per day on weekdays and 8 hours on weekends caring for children with cerebral palsy [Sawyer M et al., 2011]. The constant time pressure is strongly associated with maternal depressive syndrome. Therefore, active efforts were made to investigate the family members' state during the last few years, which revealed that parents of children with cerebral palsy are at considerably high risk and they bear a heavy social and financial burden [Guyard A et al., 2012; Majnemer A et al., 2012; Eunson P, 2015]. The main indices of impact on parents with handicapped children are occupational restrictions, social relations, family relations, psychological and physical health, as well as financial burden [Guyard A et al., 2011].

Recent data show strong relationship between IQ level and happiness. Those with lower IQ are less

happy than those with higher IQ. Interventions that are targeted on modifiable variables such as income (e.g. through enhancing education and employment opportunities) and neurotic symptoms (e.g. correct detection of mental health problems) may improve levels of happiness in the lower IQ groups [Ali A et al., 2013]. Although it should be noted that little attention is paid to such aspects as the correlation between educational level and IQ of parents with their life quality, nevertheless the burden of a child care with cerebral palsy can affect and be differently perceived by different parents. Therefore, some efforts should be made to evaluate the specific needs of family members and include the entire family in education, care planning and implementation processes for the promotion of the life quality.

Each family is unique and carries this experience in a different way. Some families are strengthened by this situation and the disabled child serves as a uniting factor, while others fall apart under the pressure. The care of a family member with a chronic disease can result feelings of tension or oppression and even reduce the caregiver's life quality [Prudente C et al., 2010]. The severity of the burden is well understood; nonetheless some investigations are required for the development of appropriate solutions. The unique published investigation on this matter in the Republic of Armenia has been accomplished by our team in 2013. The purpose of this research is to study the influence of a child care with cerebral palsy on their parents among ethnic Armenians in Armenia.

#### MATERIAL AND METHODS

The study was carried out at "Ararat Mother's and Child's Health Center" in Jermuk, where 50 children with cerebral palsy in the age group of 3-16 years and their mothers residing in Armenia included. Mothers didn't have any health problems during general physical examination. The questionnaires were in Armenian as their native language was Armenian. Exclusion criteria: the inhabitation outside Armenia or Kharabakh Republic, psychological disorders, hereditary diseases and disabilities among mothers, mothers' age beyond 65 years (for the avoidance of possible mistakes due to inability to fully grasp the matter or incompletely answer the questionnaire).

The ethical aspect of study was approved by

The Ethics Committee of the Yerevan State Medical University.

Neurological examination of children with cerebral palsy and investigation of medical documents were performed. The children were divided into 5 groups based on the gross motor function classification system. Mothers were investigated with face to face interview, and special questionnaires for collection of data about their age, occupational status, educational level and marital status were filled. Beck depression inventory and Norakidze's modification of Taylor manifest anxiety scale questionnaires were used for the analysis of mothers' psychological health. The gross motor function classification system assesses the severity of movement disorder in children with cerebral palsy. This classification permits measuring skills and limitations, emphasizing the functions of sitting and walking, classifying five levels of cerebral palsy, where I level indicates the lightest and V the most severe form [Morris C, Bartlett D, 2004]. The Beck depression inventory -II was developed in 1996. The 21-item survey can be self-administered and is scored on a scale of 0-3 in a list of four statements arranged in increasing severity according to the severity of depression symptoms unifying the Beck depression inventory - II into alignment with diagnostic and statistical manual - IV criteria. The used test is reduced and differs from the original scale: minimal manifestation of depression 0-13, mild depression 14-19, moderate depression 20-28 and severe depression 29-63. Higher result indicates more severe depression [McDowell I, Newell C, 1996]. Taylor's manifest anxiety scale was originally developed as a device for selecting subjects for inclusion in psychological experiments on stress, motivation and human performance. It has subsequently been used as a general indicator of anxiety like a personality trait. The scale is not intended as a specific measure of anxiety during clinical processes. Items testifying the manifestation of anxiety were selected from the Minnesota multiphasic personality inventory. True-false responses are used for each item; the answers indicating anxiety are counted from 0 to 50 where the higher score represents a higher level of anxiety. It is up to the discretion of psychiatrist to decide whether the person fits to the definition of "expressed anxiety".

## RESULTS

All respondents were parents of children with cerebral palsy. The age of parents ranged from 24 to 56 years (average age 36), the age of children - from 2 to 15 years (average age 7.35), 25 boys and 14 girls.

Initially 50 individuals were participating in the questionnaire but 11 of them were excluded from the investigation as 4 mothers failed to complete the questionnaires in a satisfactory manner, two refused to continue the interview without giving any reason and 5 others were ruled out due to high level (>7) of lie index by Norakidze's modification of Taylor's manifest anxiety scale. Final data included 39 children with cerebral palsy and their mothers. Depression was found in 29 (74%) mothers: 7 (18%) - severe, 9 (23%) - moderate, 13 (33%) - mild. Anxiety

TABLE 1.

Allocation of patients by severity levels according to the classification scale of total motor function assessment

Severity levels	Number of children n=39
I	2 (5 %)
II	10 (26 %)
III	16 (41 %)
IV	10 (26 %)
V	1 (3 %)

TABLE 2.

Percentage ratio of depression and anxiety in mothers according to gross motor function classification system

Severity levels	Depression	Anxiety
I (2)	-	-
II (10)	70 %	90 %
III (16)	87.5 %	93.7 %
IV (10)	70 %	100 %
V (1)	-	-

TABLE 3.

The level of depression and anxiety of mothers due to the number of children in family

Number of children	Depression	Anxiety
One (n=12)	17 (85%)	20 (100%)
Two (n=20)	9 (75%)	12 (100%)
Three (n=7)	4 (57%)	5 (71%)

TABLE 4.

Depression, anxiety and education level				
Psychological state		Educational level		
Type	Severity	School (n=12)	Incomplete higher (n=19)	Higher + degree (n=8)
Beck depression inventory II	High	2	4	1
	Moderate	6	3	2
	Mild	3	6	3
	Minimal	1	6	2
	Total	11 (91.7%)	13 (68.4%)	6 (75%)
Taylor's manifest anxiety scale	Very high	1	2	-
	High	7	11	4
	Moderate	4	4	4
	Mild	-	2	-
	Total	12 (100%)	17 (89.5%)	8 (100%)

indices of various levels were found in 37 (95%) mothers: moderate level – 12, high – 22, very high – 3. Children were divided into 5 groups in concordance with levels (I-V) of gross motor function classification system (Table 1), where the first group corresponded to the minimal restriction of motor function of the present age group, whereas the last one – to the maximal.

The results showing the depression and anxiety levels of mothers in each group are presented in table 2. Mean age of mothers was 36 years (24-56), among them 30 (77%) were married, 7 (18%) were divorced and 1(3%) was widowed.

As part of the study the correlation between the degree of depression in mothers and the number of children in family also was investigated (Table 3). Twelve families had only 1 child with diagnosis of “cerebral palsy”, and the maximum quantity of children in 7 families was 3.

The data about mother's educational level was collected: 8 (21%) mothers with university education and

degree, 19(49%) incomplete higher education and 12 (31%) school education. As table 4 shows, there is a correlation between the severity of depression and educational level. Mothers with school education degree suffered from more severe depression – 11 (91.7%).

#### CONCLUSION

Children with cerebral palsy, regardless of its severity, are considered as a heavy social burden not only for the medical and social workers, but also for the primary caregiver of the child and first of all for mothers. The investigations show that regardless of the child's physical disfiguration level, parents suffer from a high level of depression and anxiety. It was also established that the psychological status, as a rule, is more favorable in parents with multi-child families.

Thereby, the obtained data emphasize the need for further investigations related to the treatment plan of children with cerebral palsy, as well as the physiological and psychological health of caregivers.

#### REFERENCES

1. Ali A, Ambler G, Strydom A, Rai D, Cooper C, McManus S, Weich S, Meltzer H, Dein S, Hassiotis A. The relationship between happiness and intelligent quotient: the contribution of socio-economic and clinical factors. *Psychological Medicine*. 2013; 43(6): 1303-1312.
2. Bella GP, Garcia MC, Spadari-Bratfisch RC. Salivary cortisol, stress and health in primary caregivers (mothers) of children with cerebral palsy. *Psychoneuroendocrinology*. 2011;36(6): 834-842.
3. Brehaut JC, Kohen DE, Garner RE., et al. Health among caregivers of children with

- health problems: findings from a Canadian population-based study. *Am J Public Health*. 2009; 99(7): 1254-1262.
4. *Cans C, De-la-Cruz J, Mermet MA*. Epidemiology of cerebral palsy. *Pediatr Child Health*. 2008; 18(9): 393-398.
  5. *Davis E, Shelly A, Waters E, Boyd R, Cook K, Davern M, Reddihough D*. The impact of caring for a child with cerebral palsy: quality of life for mothers and fathers. *Child Care Health Dev*. 2010; 36(1): 63-73.
  6. *Eunson P*. The long-term health, social, and financial burden of hypoxic-ischemic encephalopathy. *Developmental Medicine & Child Neurology*. 2015; 57(3): 48-50.
  7. *Guyard A, Fauconnier J, Mermet MA, Cans C*. Impact on parents of cerebral palsy in children: a literature review. *Arch Pediatr*. 2011; 18(2): 204-214.
  8. *Guyard A, Michelsen SI, Arnaud C, Lyons A, Cans C, Fauconnier J*. Measuring the concept of impact of childhood disability on parents: validation of a multidimensional measurement in a cerebral palsy population. *Res Dev Disabil*. 2012; 33(5): 1594-1604.
  9. *Koman LA, Smith BP, Shilt JS*. Cerebral palsy. *Lancet*. 2004; 363(9421): 1619-1631.
  10. *Lang TC, Fuentes-Afflick E, Gilbert WM, Newman TB, Xing G, Wu YW*. Cerebral palsy among asian ethnic subgroups. *Pediatrics*. 2012; 129(4): 992-998.
  11. *Lee RW, Poretti A, Cohen JS, Levey E, Gwynn H, Johnston MV, Hoon AH, Fatemi A*. A diagnostic approach for cerebral palsy in the genomic era. *Neuromolecular Medicine*. 2014; 16(4): 821-844.
  12. *Majnemer A, Shevell M, Law M, Poulin C, Rosenbaum P*. Indicators of distress in families of children with cerebral palsy. *Disabil Rehabil*. 2012; 34(14): 1202-1207.
  13. *McDowell I, Newell C*. The Beck depression inventory (Aaron T. Beck, 1961, Revised 1978) measuring health: A guide to rating scales and questionnaires. (2nd ed.). New York: Oxford University Press. 1996. pp. 355-344.
  14. *Morris C, Bartlett D*. Gross motor function classification system: impact and utility. *Dev Med Child Neurol*. 2004; 46(1): 60-65.
  15. *Mugno D, Ruta L, D'Arrigo VG, Mazzone L*. Impairment of quality of life in parents of children and adolescents with pervasive developmental disorder. *Health Qual Life Outcomes*. 2007; 5: 22.
  16. *O'Shea TM*. Diagnosis, treatment, and prevention of cerebral palsy in near-term/term infants. *Clinical obstetrics and gynecology*. 2008; 51(4): 816-828.
  17. *Parminder R, O'Donnell M, Rosenbaum P, Brehaut J, Walter S, Russell D, Swinton M, Zhu B, Wood E*. The health and well-being of caregivers of children with cerebral palsy. *Pediatrics*. 2005; 115(6): 626-636.
  18. *Prudente CO, Barbosa MA, Porto CC*. Relation between quality of life of mothers of children with cerebral palsy and the children's motor functioning, after ten months of rehabilitation. *Rev Lat-Am Enfermagem*. 2010; 18(2): 149-155.
  19. *Richards CL, Malouin F*. Cerebral palsy: definition, assessment and rehabilitation. *Handb Clin Neurol*. 2013; 111: 183-195.
  20. *Rosenbaum P, Paneth N, Leviton A, Goldstein M, Bax M, Damiano D, Dan B, Jacobsson B*. A report: the definition and classification of cerebral palsy April 2006. *Dev Med Child Neurol Suppl*. 2007; 109: 8-14.
  21. *Sawyer MG, Bittman M, La Greca AM, Crettenden AD, Borojevic N, Raghavendra P, Russo R*. Time demands of caring for children with cerebral palsy: what are the implications for maternal mental health? *Dev Med Child Neurol*. 2011; 53(4): 338-343.
  22. *Van Naarden Braun K, Doernberg N, Schieve L, Christensen D, Goodman A, Yeargin-Allsopp M*. Birth prevalence of cerebral palsy: A population-based study. *Pediatrics*. 2016; 137(1): 1-9.
  23. *Wu YW, Xing G, Fuentes-Afflick E, Danielson B, Smith LH, Gilbert WM*. Racial, Ethnic, and Socioeconomic Disparities in the Prevalence of Cerebral Palsy. *Pediatrics*. 2011; 127(3): 674-681.