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ANXIETY AND CHRONIC PAIN IN CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY IN ARMENIA: DESCRIPTIVE STUDY

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Abstract

Caregiving a child with special needs requires additional physical, psychological and financial resources. Current knowledge confirms that caregivers of children with functional limitations (i.e., cerebral palsy) are under greater risk of developing physical and psychological health problems. However, health characteristics of caregivers are not well investigated in low- and middle-income countries. Current observational study aimed to discover the anxiety and pain syndromes among caregivers of children with cerebral palsy residing in Armenia.

Cross-sectional study was conducted in tertiary care center in 2015-2016. Demographic and health information was collected from eligible participants. Anxiety was measured by Norakidze's modification of Taylor Manifest Anxiety Scale 60-items scale. Descriptive statistics was utilized for demographic data, chi square and regression analysis for exploratory analysis of anxiety and pain among caregivers.

From 193 caregivers 188 (97.4%) were mothers with mean age of 37 (SD=10.6). Over two third of participants reported to have chronic pain syndromes. Moreover, 14% participants precepted pain every day. Pain syndromes mainly were associated with caregiving time. High anxiety levels according to Taylor Manifest Anxiety Scale 60-items scale were presented in 135 (69.9%) of caregivers. Correlations between anxiety and caregivers/children characteristics were investigated.

This is the first publication about health characteristics of caregivers of children with cerebral palsy in Armenia. Current study design lacks to find causations, and has not control for confounders. However, study findings emphasize the necessity for further research of health problems of caregivers of children with cerebral palsy.

Keywords: *caregivers, anxiety, pain, cerebral palsy.*

Introduction

Family members of children with chronic disabilities need to be considered as integral part of any effective intervention program. Current knowledge provides enough evidence to claim, that parenting a child with limitations has significant association with different physical and psychological health problems. [*Brehaut J et al., 2009; 2011*]. Different external factors, such as socio-cultural and overall political and environmental settings may differ by countries. [*Di Giulio P et al., 2014; Yamaoka Y et al., 2016*] Thus, the data about the burden of disability as well as caregivers' health risks cannot be merely generalized between countries. Moreover, distribution of functional limitations, as well as the health aspects of caregivers (CGs) are not well investigated in Armenia. Prevalence of disabilities among children and youth is mainly constant in Armenia. For example, the prevalence of cerebral palsy (CP) fluctuates around 1700 last 4 years [*HHC-2015; Khachatryan S et al., 2016; Andreasyan D et al., 2017*].

Cerebral palsy is a collective name of syn-

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dromes with different etiology and pathogenesis [*Bax M et al., 2005; Sankar C, Mundkur N, 2005; Morris C, 2007*]. The common sign of these syndromes is the chronic movement disorder due to non-progressive nor hereditary injury of "developing brain" [*Shevell M, 2004; Baxter P et al., 2007; Armour B et al., 2016*]. The severity of CP may vary according to the levels of movement limitations. Moreover, cases can be accompanied with deficiencies of several functions (i.e., other motor, communicational, mental and sensory functions), as well as with seizure syndromes. [*Bax M, 2008; Sellier E et al., 2012*]. Thus, overall caregiving demands of children may differ, depending on type and severity of functional limitations.

Therefore, this descriptive study was aimed to discover the anxiety and chronic pain of CGs of CP children residing in Armenia.

MATERIAL AND METHODS

Cross-sectional study was conducted among CP children and their CGs in "Ararat" Mother and Child's Health Center, Jermuk, Armenia (Center). This was Center-based census study for years 2015-2016: all eligible children (3-18 years old, verified CP diagnosis) and CGs (under 75 years old, able to understand, speak and read Armenian) were approached and provided consent to participate.

Face to face interviews were conducted with CGs to collect health and demographic information. Primary headache, back pain and other pain syndromes were confirmed by neurological exam. Norakidze's modification of Taylor Manifest Anxiety Scale (TMAS) 60-items scale was utilized to assess the anxiety (50 items for anxiety and 10-items as lie index) [*Hoyt D et al., 1954; Glotova G, 2001; Malkina-Pikh I, 2005*]. TMAS has 4 ordinal levels: highest level of anxiety (40-50), high anxiety level (25-40), moderate anxiety with the tendency to high level (15-25), moderate, with tendency to low level (5-15) and low anxiety level (0-5) [*Malkina-Pikh I, 2005*]. Demographic information was collected. Questions to identify and categorize the different types of pain and Visual Analogue Scale for pain to assess the pain intensity were utilized [*Jensen M et al., 2003; Shmueli A, 2005*]. Gross Motor Function Classification System, Manual Ability Classification System, and Communication Function Classification System were utilized to assess the functional levels of children [*Eliasson A et al., 2006; Palisano R et al., 2008; Hidecker M et al., 2011; Murphy N et al., 2011; Rosenbaum P et al., 2014; Eun-Young P, Won-Ho K, 2015; Eliasson A et al., 2017*]. All three systems have 5 ordinal levels, from Level I (minimal limitations) to Level 5 (maximal limitations). Additional health information from children (CP type, seizure syndromes) was collected from medical documents at Center and additional neurological exam.

To overcome it is possible, due to the uniting the knowledge and will of all doctors in the world

Double data entry was conducted in SPSS 21.0. Descriptive statistics was conducted to analyze demographic and health characteristics of participants. Chi square test was conducted to check the association between anxiety and chronic pain amongst CGs and the limitation levels of children. Binary regression analysis was further conducted to highlight determinants associated with CGs anxiety. Current study is a part of PhD project, accepted by ethical committee of Yerevan State Medical University (IRB equivalent).

RESULTS

From 248 eligible CGs with CP children, 205 accepted to participate. Recruitment resulted with 201 successfully completed interviews and screenings (18.9% refusal rate) of CGs and their CP children from all regions of Armenia. To control the social desirability bias, data of participants reported higher than 5 score by "The lie scale of Norakidze", TMAS (n=8), have been excluded from further analysis. Thus, data analysis ended up with 193 CGs and their CP children from Armenia and Artsakh (Figure). Demographic and health characteristics of CGs are represented in table 1. One hundred eighty-eight (97.4%) CGs were mothers. Mean age of CGs was 37 (SD=10.6)

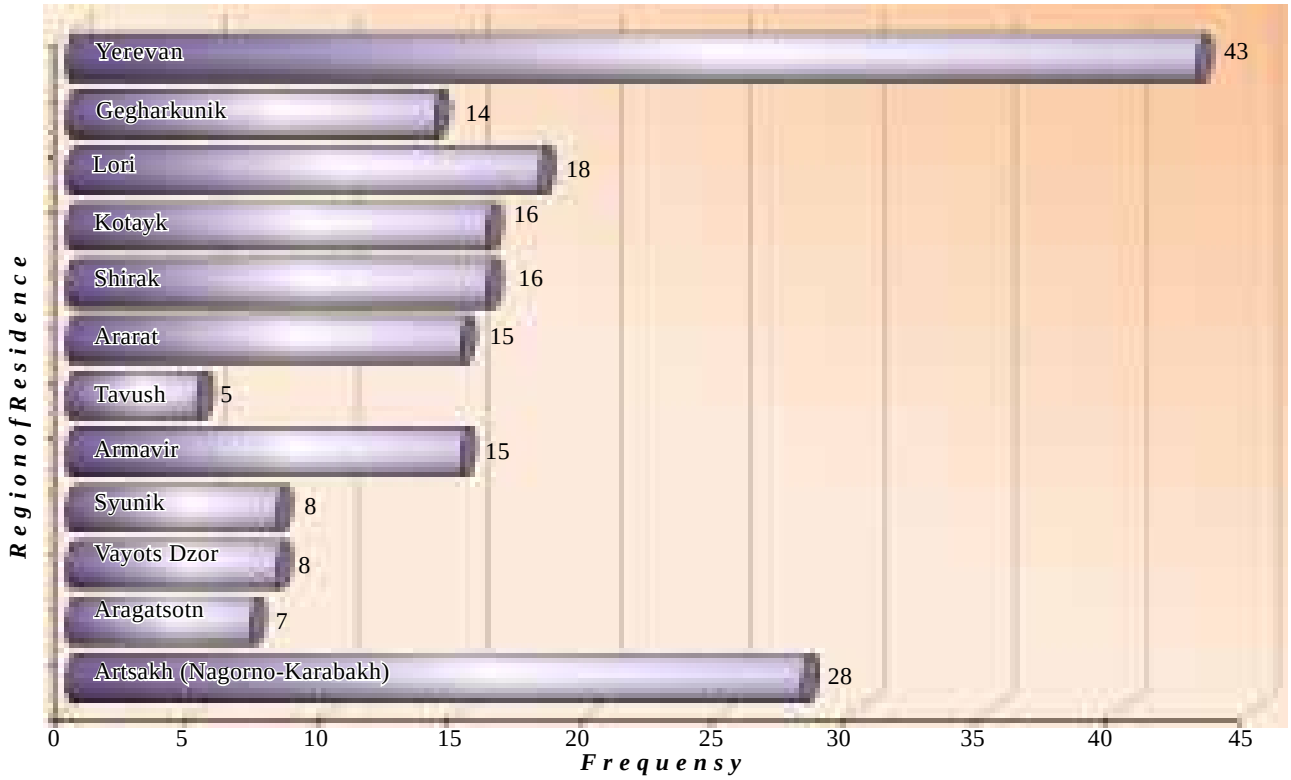

Figure. *Distribution of participants by regions*

Table 1

Descriptive statistics of caregivers of children with cerebral palsy

Caregivers age, Mean (SD, Range)	39.5 (10.6, 21-71)
Married, n (%)	159 (82.4)
Caregivers Education level,	n (%)
School level or less (≤10 years)	105 (54.4)
Professional technical or higher (>10 years)	87 (45.1)
Unemployed, n (%) (192)	150 (77.7)
Residing in rural, n (%)	114 (59.1)
Caregiving time, Mean (Median, SD)	4.7 (3.0, 4.8)
Caregiving time ≤ 3 hours	105 (55.6)
Caregiving time > 3 hours	84 (44.4)
Reported to be healthy, n (%) (191)	114 (59.1)
Chronic pain syndrome/s, n (%) (191)	136 (70.5)
Primary headache, n (%) (189)	141 (73.1)
Low back pain, n (%)	127 (65.8)
TMAS*, Mean (SD, Range) (n=192)	27.5 (5.6, 11-39)
Moderate anxiety with the tendency to low level, (%)	5 (2.6)
Moderate anxiety with the tendency to high level, n (%)	52 (26.9)
High anxiety level, n (%)	135 (69.9)

Note: **- TMAS - Taylor Manifest Anxiety Scale*

years. Majority of participants were married (82.4%), and had school or lower-level education (54.4%). Among all participants, 150 (77.7%) were unemployed and 77 (39.9%) reported to not being healthy. One hundred thirty-five (69.9%) CGs had high anxiety level by TMAS. One hundred forty-one (70%) of CGs had chronic pain syndromes. Moreover, 141 (73.1%) had primary headaches, and 127 (65.8%) reported about having a back pain. Ninety-six of those with chronic pain syndromes (64.0%) accepted to provide further information about the pain characteristics: pain intensity measured via visual analogue scale was above 50 *mm* in 40 (41.7%) of CGs. Fifty-nine (61.5%) CGs complained from pain over 5 days per month, whereas 27 (14.0%) reported to have pain almost every day. Furthermore, in 50 (52.1%) CGs pain duration was over 6 hours per day. Chronic pain syndromes of CGs were significantly associated with caregiving time (p=0.002). Demographic and health characteristics of children is illustrated in table 2. Although there was no significant association between the pain intensity and the CP subtype, but the pain intensity was significantly

TABLE 2.

Descriptive statistics of children with cerebral palsy

Characteristics	Measures
Child age, Mean (SD, Range)	9.7 (4.0, 3-17)
Child sex, n (%)	
Male	122 (63.2)
Female	71 (36.8)
Type of the CP (by ICD-10)	
G80.0 (Spastic quadriplegic)	56 (29.0)
G80.1 (Spastic diplegic)	66 (34.2)
G80.2 (Spastic hemiplegic)	29 (15.0)
G80.3 (Athetoid)	12 (6.2)
G80.4 (Ataxic)	9 (4.7)
G80.9 (Unspecified)	21 (10.9)
Seizure syndromes, n (%) (191)	31 (16.2)

TABLE 3

Functional classification by gross motor function classification system (GMFCS), manual ability classification system (MACS), communication function classification system (CFCS), n (%)

Levels	GMFCS	MACS	CFCS
I	40 (20.7)	59 (30.6)	69 (35.8)
II	74 (38.3)	86 (44.6)	62 (32.1)
III	31 (16.1)	17 (8.8)	16 (8.3)
IV	13 (6.7)	15 (7.8)	15 (7.8)
V	35 (18.1)	16 (8.3)	31 (16.1)

associated with child's gross motor function level (r_s=0.249, p=0.014) (Table 3). Study did not find significant association between pain intensity of CGs and the Manual Ability Classification System (r_s=0.083, p=0.421) or communication function classification system (r_s=0.062, p=0.551) levels of children. Binary analysis resulted with evidences of significant association between CG anxiety and child's age (p=0.003), CGs self-health perception (p=0.001), chronic pain syndromes (p=0.005) and back pain (p=0.002) (Table 4).

TABLE 4

Factors associated with anxiety of caregivers of children with cerebral palsy: Bivariate analysis

Independent variable	Beta coefficient	p value	95% C.I. Lower	95% C.I. Upper
Age	0.025	0.517	-0.050	0.100
Marital status	-1.080	0.314	-3.189	1.029
Job status	-0.770	0.426	-2.677	1.136
Education level	-1.261	0.121	-2.857	0.336
Health status	2.759	0.001	1.173	4.344
Chronic pain syndromes	2.512	0.005	0.779	4.246
Primary headache	1.528	0.096	-0.276	3.332
Back pain	2.671	0.002	1.020	4.322
Caregiving >3hours	-1.051	0.197	-2.652	0.549
Child age	0.293	0.003	0.103	0.484
Child sex	1.353	0.105	-2.991	0.285
Seizure syndromes	-1.027	0.342	-3.155	1.101
GMFCS	-0.280	0.346	-0.865	0.305
MACS	-0.104	0.761	-0.776	0.569
CFCS	-0.541	0.057	-1.097	0.015

DISCUSSION

We recognize, that given observational study design has all predicted weaknesses. However, this is the first report highlighting potential physical and psychological health problems in CGs of CP children residing in Armenia. Anxiety of CGs was not associated with the level of limitations of movement and communication functions of their children. The absence of association between parental anxiety and CP severity was also described in previous study of Basaran and peers [*Basaran A et al., 2013*]. One child's characteristic significantly associated with CG's anxiety was child's age.

Study indicates the need of attention of health care specialists on prevention and treatment of pain syndromes among CGs. Those, caregiving a child with more motor limitations have to be under higher attention. Anxiety and pain intensity of CGs were not associated with communication and hand functions levels of CP children. However, further controlled studies are needed for comparative analysis of pain and anxiety among CGs of CP children. Health risks of family members of children with special needs (i.e., CP) have to be acknowledged by physicians and policy makers in development of comprehensive management strategies of CP as well as in development of target intervention programs.

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