

## BURDEN AND QUALITY OF LIFE MEASURING THE RELATION TO ANXIETY AND DEPRESSION SYMPTOMS IN PRIMARY CAREGIVERS OF CHILDREN AND ADOLESCENTS WITH MENINGOMYELOCELE

### Hypothesis / aims of study

The aim of this study was to assess the burden and quality of life of primary caregivers of children with meningomyelocele by measuring the relation to anxiety and depression symptoms.

### Study design, materials and methods

A descriptive study performed with structured and valid questionnaires, and interviews was conducted to 43 primary caregivers of children and adolescents with meningomyelocele. The health-related quality of life was assessed by the Medical Outcomes Study Short Form-36 Survey (SF-36). Burden was assessed by a specific instrument, the Caregiver Burden Scale (CBS), which evaluates general aspects of daily life. Depressive and anxiety symptoms were investigated by the Beck Depression Inventory (BDI) and the Beck Anxiety Inventory (BAI). Correlations among numeric valuables were assessed using Pearson's *r* and Spearman's *r* coefficients. The Heckman two-step method was used to deal with the selection bias problem <sup>(1)</sup>.

### Results

Most caregivers were mothers with a mean age of about 35 years. They were non-white, and were living in consensual union with preliminary education. They reportedly had lower scores on the SF-36 on general health ( $53.2 \pm 17.4$ ) and vitality ( $55.9 \pm 25.4$ ). The CBS global score was 2.2. According to the BDI, 55.8% were considered non-depressive. The BAI inventory scores were between 0 and 9 in 30 subjects. There were positive and negative correlations, respectively, between scores of both Beck inventories and most dimensions of CBS and SF-36 (table 1).

Table 1: Correlation coefficient between SF-36 and CBS dimensions with anxiety (BAI) and depression (BDI) for caregivers of children and adolescents with meningomyelocele.

Dimensions	Correlation		Correlation	
	Anxiety (BAI) Coefficient( <i>r</i> )	<i>p</i>	Depression (BDI) Coefficient ( <i>r</i> )	<i>p</i>
<b>SF-36 (n=43)</b>				
Physical function	<b>-0.334 *</b>	<b>0.03</b>	-0.103 **	0.51
Role physical	-0.163 *	0.30	-0.104 *	0.50
Bodily pain	<b>-0.365 *</b>	<b>0.02</b>	<b>-0.383 **</b>	<b>0.01</b>
General health	-0.269 *	0.08	<b>-0.308 **</b>	<b>0.04</b>
Vitality	-0.175 *	0.26	<b>-0.356 **</b>	<b>0.02</b>
Social function	<b>-0.359 *</b>	<b>0.02</b>	<b>-0.429 **</b>	<b>0.004</b>
Role emotional	-0.278 *	0.07	-0.186 *	0.23
Mental health	<b>-0.373 *</b>	<b>0.01</b>	<b>-0.550 **</b>	<b>&lt;0.001</b>
<b>CBS (n=43)</b>				
General strain	<b>0.570 *</b>	<b>&lt;0.001</b>	<b>0.627 **</b>	<b>&lt;0.001</b>
Isolation	<b>0.385 *</b>	<b>0.01</b>	<b>0.416 **</b>	<b>0.006</b>
Disappointment	<b>0.355 *</b>	<b>0.02</b>	<b>0.522 **</b>	<b>&lt;0.001</b>
Emotional involvement	-0.065 *	0.68	0.052 *	0.74
Environment	<b>0.411 *</b>	<b>0.006</b>	<b>0.243 *</b>	<b>0.04</b>
Global score	<b>0.557 *</b>	<b>&lt;0.001</b>	<b>0.615 **</b>	<b>&lt;0.001</b>
General sum	<b>0.525 *</b>	<b>&lt;0.001</b>	<b>0.574 **</b>	<b>&lt;0.001</b>
<b>Beck Inventories</b>				
Anxiety (BAI)	-	-	<b>0.527 *</b>	<b>&lt;0.001</b>
Depression (BDI)	<b>0.527 *</b>	<b>&lt;0.001</b>	-	-

(\*) Spearman's correlation (\*\*) Pearson's correlation

The Heckman model (Table 2) was used to identify the impact of children malformations on caregivers' burden, controlling for selection bias problems. There was a positive correlation of burden in children with anorectal dysfunction and caregivers who live together with partners, and a negative correlation with worked hours per day and monthly income.

Table 2: Impact of clinical children characteristics on Burden (CBS) of non-depressives caregivers of children and adolescents with meningomyelocele.

Variables	OLS		Heckman Two Step	
	Coef.	p Value	Coef.	p Value
Motor Impairment Child	0.086	0.921	1.302	0.288
Sensitivity Impairment Child	-0.418	0.487	-1.166	0.171
Anorectal Function Child	0.775	0.387	2.071	<b>0.041</b>
Malformation Child	1.021	0.256	0.113	0.916

Bladder Function	-0.311	0.800	-0.517	0.735
Household Head	1.851	0.113	2.025	0.231
Children Age	0.213	<b>0.032</b>	0.+104	0.410
Daily Work Hours	-1.780	0.063	-2.693	<b>0.028</b>
Monthly Income	-0.855	<b>0.022</b>	-1.385	<b>0.027</b>
Marital Status	2.341	<b>0.003</b>	2.546	<b>0.011</b>
Constant	11.763	<b>0.000</b>	15.179	<b>0.000</b>
R2	0.4081			
LR				
			<b>lambda</b>	<b>confidence interval</b>
Inverse Mills Ratio*			<b>-2.436</b>	-5.186 .3132
Obs	43		43	

\*Variable derived from the Heckman Selection Equation

### Interpretation of results

Our findings with SF-36 and CBS further demonstrate that caregiver depression is a complex interplay of emotional and social factors, including subjective burden and quality of life. The subjective impact of burden on caregivers' life is an extremely complex issue where several factors are interrelated, including depression for other causes or anxiety. The statistical method could isolate variables that influenced the burden of the studied population, controlling the possibility of the caregiver to be depressive.

Burden had a higher impact on those caregivers who had children with anorectal incontinence, which may be explained by daily dependence on diapers and the smell of feces. Authors described less than 25% of children and young adults with MMC with completely independent bowel control <sup>(2)</sup>. The psychosocial stress may be a result of the disease parameters, such as illness severity and functional limitations of the child, and about the continuous dependence of a caregiver to do daily activities.

### Concluding message

The primary caregivers of children and adolescents with MMC reported lower quality of life and higher burden. There are more anxiety and depression symptoms in subjects with burden and impaired quality of life. Children with fecal incontinence and caregivers who live together with a partner or are unemployed or have low income were determinants to evoke burden in caregivers.

### References

1. Sales AE, Plomondon ME, Magrid DJ, Spertus JA, Rumsfeld JS. Assessing response bias from missing quality of life data: The Heckman method. *Health and Quality of Life Outcomes*. 2004; 2:49.
2. Verhoef M, Barf HA, Post MWM, Asbeck FWA, Gooskens RHJM, Prevo AJH. Functional independence among young adults with spina bifida, in relation to hydrocephalus and level of lesion. *Developmental Medicine & Child Neurology*. 2006; 48: 114: 119.

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<b>What were the subjects in the study?</b>	<b>HUMAN</b>
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<b>Specify Name of Ethics Committee</b>	<b>Institutional Ethics Committee (Hospital Universitário Oswaldo Cruz) - Recife - Pernambuco - Brazil Protocol number: 52/2008</b>
<b>Was the Declaration of Helsinki followed?</b>	<b>Yes</b>
<b>Was informed consent obtained from the patients?</b>	<b>Yes</b>