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Stress, Anxiety and Depression among Parents of Children with Chronic Health Conditions

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Abstract: ***Background: Parents coping with child's chronic health conditions react differently to symptoms of anxiety, stress and depression compared to parents with children without chronic health conditions1. Understanding their reaction to these symptoms may be useful for understanding and creating an insight of the needs and approaches of mothers and fathers of children with a pediatric chronic health condition. Objectives: The primary aim of this study was to examine symptoms of stress, anxiety and depression in a sample of mothers and fathers of children with pediatric chronic conditions. Methods: We assessed these symptoms via a validated Albanian version of DASS-42 questionnaire and explored the relationship between demographic variables and symptoms of SAD among parents. Results: A total of 405 parents participated in this study, of which 252 (62.2%) Females and 153 (37.8%) Males. Most emotional reactions are seen among mothers reporting significantly higher levels of anxiety (P =0,048) and stress (P = 0,026) fathers. Although there was a difference between anxiety and stress symptoms among father and mothers, no significant difference was noticed for depression (P = 0,861). Among parents agegroups there wasn't any significant link with SAD symptoms. We noticed a significant link between duration of coping and stress (P = 0,004), but no link with anxiety and depression. Conclusions: Social and health policies in Albania must be informed about the psychological alternations of parents with children having a chronic health condition. This can contribute to tailoring psychological care to those parents most in need. We found more parental stress, anxiety and emotional strain among mothers and those parents that had a longer time dealing.***

Keywords: Depression, Anxiety, Stress, Pediatrics, Parents

1. Introduction

Ten to twenty percent of children have a chronic illness2. As much as all other children they need to be part of family life, social life and relationships with family members, peers and others, educational activities and leisure activities. In families where a child is affected by chronic illness, there can be additional challenges for the child, the siblings and the parents. Definitions of pediatric chronic health conditions vary from a simple listing of specific conditions to consideration of impairments, functional limitations and service utilization3. For the framework of this study, chronic health conditions are defined similar to Stein and colleagues4, as any health condition that lasts or is expected to last more than 12 months (dating from the time of diagnosis) AND that causes at least one of the following: impairments, functional limitations, and/or the need for medical care or care services. Common childhood chronic conditions include but are not limited to: asthma, allergies, diabetes, autism spectrum disorders, epilepsy, heart conditions, etc. It is natural for parents to experience despair and distress on hearing that their child has been diagnosed with a chronic illness especially when it is likely to continue for a lifetime. Families show a wide range of reactions and ways of confronting it but as a general rule they are able to cope better where supportive services are provided for them and their child. Parental psychology can be threatened if they feel that they are responsible for giving birth to an unhealthy child or were unable to prevent chronic disease affecting their child. In some special cases the family's philosophy on life, values, dreams, expectations and other hopes can be shattered6. Under these circumstances, they are confronted with important decisions they must make and radical changes that can further influence even the structure of the family. Some parents, in a exhausting effort to manage the situation, focus only on a day to day coping with no long-term objectives. Struggling to survive in the face of seemingly unconquerable difficulties5 ^6.

A common characteristic of these families is parental despair, although the parents do not usually show overt stress, anxiety and depression and their mood tends to lift with time and at some point resolve. However, bad psychology hits back occasionally. It tends to be in acute phases, notably when the parents are conscious of the fact that their child is not reaching important developmental levels or when they see independence in other children of the same age. Because families experience different degrees of anxiety, stress and depression, their need for support also varies7.

Health care professionals can help directly parents in order to help alleviate despair and to mobilize outside help from medic, allied health professionals, and social or other support services, where available. The extended family in Albania and close relations between family members often provides a vital source of practical support for the Albanian family. In some situations the burden of care can be shared maybe with a grandparent who may well be in not a good health condition thus placing both the child and the carer at extra risk of further hospitalization. Open and continuous communication is important in the adaptation to chronic illnesses. This does not mean only tips about the health condition and its treatment, but also the expression and acceptance of new perceptions and sentiments that each member of the family experiences with the changing circumstances during a crisis6. When support systems function constructively they guarantee family cohesio n and the sharing of tasks in a constructive way so that demands are met realistically without overtaxing one particular individual8. Some parents may consciously adopt secretive attitudes and deliberately avoid informing their child about his illness, treatment or prognosis. On the other hand, there

are those who spontaneously encourage an open dialogue discussing all the difficulties as they arise and their possible coping strategies. In political strategies there must be the objective of establishing support groups and its infrastructure, as there is a lack of these gatherings and type of problem management. To complicate the issue, if the child is misinformed or 'left in the dark' he may well be ashamed and decide to keep the existence of his chronic illness to himself, refusing to talk about it.

When he is embarrassed over his condition, his shame will high or lower depending on the perceptions and attitudes of the family, medical and nursing personnel and the reaction of teachers, friends and schoolmates9. All these events sum up and burden parents' psychology by adding stress, depression and anxiety symptoms into his/her daily routine. The primary purpose of this study was to examine symptoms of **S**tress, **A**nxiety and **D**epression [**SAD**] in a sample of mothers and fathers of children with pediatric chronic conditions. We assessed these symptoms via a validated Albanian version of DASS-42 questionnaire and explored the relationship between demographic variables and symptoms of SAD among parents.

2. Materials and methods

Participants

Approval for the study was given by the bio-ethical and forensic medicine committee. All participants were invited and recruited voluntarily. Pediatricians' working in the Department of Pediatrics, at University Hospital Center of Tirana 'Mother Theresa' [UHCT] referred parents of a child with chronic conditions, to our study coordinator and a verbal informed consent was obtained to participate in order to fill out the questionnaire. Parents replied anonymously and all data was confidential and used for study purposes only. Due to this recruitment methodology the response rate was not determined. A total of 405 parents filled out the DASS 42 questionnaire.

The DASS 42 is a self-administered instrument with well-established psychometric properties in clinical and community samples, and has been shown to differentiate between the three states of depression, anxiety and stress10 ^ 11 ^ 12 ^ 13 ^ 14 ^15. The depression scale assesses dysphoria, hopelessness, devaluation of life, self-deprecation, lack of interest or involvement, anhedonia and inertia.

The anxiety scale assesses autonomic arousal, skeletal muscle effects, situational anxiety and subjective experience on anxious effects. The stress scale was sensitive to levels of chronic non-specific arousal. The scale assesses difficulty relaxing, nervous arousal and impatience 12 ^ 14. The reliability coefficients (Cronbach's Alpha) of Albanian version of DASS-42 in our study were found for depression, stress and anxiety to be 88.1%, 83,5% and 86.7%, respectively. Scores of Depression, Anxiety and Stress are calculated by summing the scores for the relevant items14. The depression scale items are 3, 5, 10, 13, 16, 17, 21, 24, 26, 31, 34, 37, 38 and 42. The anxiety scale items are 2, 4, 7, 9, 15, 19, 20, 23, 25, 28, 30, 36, 40 and 41. The stress scale items are 1, 6, 8, 11, 12, 14, 18, 22, 27, 29, 32, 33, 35 and 39. The score for each of the respondents over each of the sub-scales are then evaluated as per the severity-rating index below:

Stress Anxiety Depression
Normal 0-14 0-7 0-9
Mild 15-18 8-9 10-13
Moderate 19-25 10-14 14-20
Severe 26-33 15-19 21-27
Extremely severe 34+ 20+ 28+
Source: www.psy.unsw.edu.au/groups

Norms: *Normative data are available on a number of Australian samples. From a sample of 2914 adults the means (and standard deviations) were 6.34 (6.97), 4.7 (4.91), and 10.11 (7.91) for the depression, anxiety, and stress scales, respectively. A clinical sample reported means (and standard deviations) of 10.65 (9.3), 10.90 (8.12), and 21.1 (11.15) for the three measures.*

3. Results

A total of 405 individuals participated in this study. From 405 subjects 252 (62.2%) were females and 153 (37.8%) males. Most emotional reactions were seen among mothers reporting significantly higher levels of anxiety (P = 0,048) and stress (P = 0,026) fathers. Although there was a difference between anxiety and stress symptoms among father and mothers, no significant difference was noticed for depression (P = 0,861). Among parents age-groups there wasn't any significant link with SAD symptoms. We noticed a significant link between duration of coping and stress (P = 0,004), but no link with anxiety and depression. You can read these results in the ***Table 1*** which describes the distribution of SAD symptoms among different age-groups, durations and sex.

Table 1: Cross-Tabulation Of Stress, Anxiety And Depression With Sex, Age-Group And Duration Of Coping

		SEX					AGE-GROUP									DURATION OF COPING						
		MALE		FEMALE			< 25 YRS.		26 - 35 YRS.		36 - 45 YRS.		> 45 YRS.			6 muaj deri 2 vite.		2 vite - 5 vite.		Mbi 5 vite		
		N	%	*N*	%	P	*N*	%	*N*	%	*N*	%	*N*	%	P	*N*	%	*N*	%	*N*	%	P
STRESS	NORMAL	64	15.8%	88	21.7%		22	5.4%	66	16.3%	48	11.9%	16	4.0%		55	13.6%	82	20.2%	15	3.7%	
	MILD	37	9.1%	80	19.8%		7	1.7%	59	14.6%	35	8.6%	16	4.0%		50	12.3%	42	10.4%	25	6.2%	
	MODERATE	29	7.2%	55	13.6%	0.048*	3	0.7%	30	7.4%	34	8.4%	17	4.2%	0.166	31	7.7%	32	7.9%	21	5.2%	0.04*
	SEVERE	22	5.4%	28	6.9%		8	2.0%	14	3.5%	20	4.9%	8	2.0%		13	3.2%	27	6.7%	10	2.5%	
	EXTREMELY SEVERE	1	0.2%	1	0.2%		0	0.0%	0	0.0%	1	0.2%	1	0.2%		2	0.5%	0	0.0%	0	0.0%	
ANXIETY	NORMAL	58	14.3%	107	26.4%		15	3.7%	78	19.3%	47	11.6%	25	6.2%		64	15.8%	79	19.5%	22	5.4%	
	MILD	33	8.1%	55	13.6%		11	2.7%	30	7.4%	35	8.6%	12	3.0%		36	8.9%	35	8.6%	17	4.2%	
	MODERATE	35	8.6%	59	14.6%	0.026*	8	2.0%	40	9.9%	35	8.6%	11	2.7%	0.318	38	9.4%	43	10.6%	13	3.2%	0.541
	SEVERE	26	6.4%	30	7.4%		6	1.5%	20	4.9%	20	4.9%	10	2.5%		13	3.2%	25	6.2%	18	4.4%	
	EXTREMELY SEVERE	1	0.2%	1	0.2%		0	0.0%	1	0.2%	1	0.2%	0	0.0%		0	0.0%	1	0.2%	1	0.2%	
DEPRESSION	NORMAL	111	27.4%	180	44.4%		35	8.6%	119	29.4%	90	22.2%	47	11.6%		108	26.7%	128	31.6%	55	13.6%	
	MILD	17	4.2%	30	7.4%		4	1.0%	26	6.4%	16	4.0%	1	0.2%		24	5.9%	21	5.2%	2	0.5%	
	MODERATE	13	3.2%	25	6.2%	0.861	0	0.0%	14	3.5%	19	4.7%	5	1.2%	0.115	14	3.5%	16	4.0%	8	2.0%	0.157
	SEVERE	12	3.0%	17	4.2%		1	0.2%	10	2.5%	13	3.2%	5	1.2%		5	1.2%	18	4.4%	6	1.5%	
	EXTREMELY SEVERE	0	0.0%	0	0.0%		0	0.0%	0	0.0%	0	0.0%	0	0.0%		0	0.0%	0	0.0%	0	0.0%	

4. Discussion

Samples in hospitals can be considered representative for mothers and fathers in the general population that have a child with a chronic condition and gives an insight which can be drawn by DASS-42 questionnaire. Consequently, any research on the stress, anxiety and depression of parents who have children with a chronic health condition (CHC) in Albania could be informed by comparing their results with the results of stress in this study, as there is a lack of studies of this topic in Albania. Parents characteristics included in the analysis, covered some of the areas identified by Klassen et al.16 to be important in the studying of psychological alternations of parents of children with CHC. Mothers reported higher levels of stress and anxiety than fathers, but with no significant difference for depression.

This is consistent with previous findings that populations of women report higher levels of stress than men17. Statistical analysis showed that mothers and fathers in families with a loger duration of coping with theirs child chronic condition had significantly higher stress levels than those with a shorter duration. A study of recent American parents caring for a child with cancer has also identified that self – reports of mothers and fathers are positively correlated, but mothers reported higher levels of stress compared to fathers. Points of stress, anxiety and depression to parents of children with a CHC suggest that health care providers should consider the level of stress to both parents when planning interventions and supportive approach.

Results showed that parents of children with cancer require a support strategy based not only on individual requirements and parental options, but that health care providers should assess the family context of these parents about the requirements and opportunities.

5. Conclusions

In this study it was observed that the mothers who had a chronically ill children reported higher levels of stress and anxiety compared to fathers, a fact which is consistent with the literature17. Mothers and fathers of children with chronic illness reported different levels of stress for each other, but analysis showed that there were statistically

significant differences between the reporting of stress and anxiety for mothers and fathers. The findings provide us the evidence for the need for psycho-social support for families who have children with care and chronic disease in Albania. Social and health policies in Albania must be informed about the psychological alternations of parents with children having a chronic health condition. This can contribute to tailoring psychological care to those parents most in need.

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