Original Research Article

Anxiety and depression in parents caring for a child with chronic disease: A cross sectional comparative study

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Abstract

Background: Caring for a child with a chronic illness can be stressful for the parent which can in turn affect the parent child interaction and treatment adherence. We aimed to screen parents who are caregivers of children with a chronic illness for symptoms of anxiety and depression and also to compare the symptoms between the care giving mothers and the fathers. We also aimed to study the factors associated with anxiety and depression. **Materials and Methods:** In this case control study, care giving parents of children with a chronic illness were administered the Patient Health Questionnaire-9 and the Generalised Anxiety Disorder-7 and the scores were compared with a control group of parents of children without a chronic illness. **Results:** Of the 158 parents screened, 92 parents had a child with a chronic illness. Thirty percent (n=28), 32.6% (n=30), 37%(n=34) of parents of children with a chronic illness were found to have moderate to severe, mild and no depressive symptoms and 39 % (n= 36), 33.7% (n=31), 27.2% (n=25) of parents had moderate to severe, mild and no anxiety respectively. This was significantly more than the control group (p value<0.05). No statistically significant difference was observed between the mothers and the fathers. The presence of a chronic neurological hematological, cardiovascular and respiratory illness along with low educational status of the parents were independent factors associated with parental depression. Whereas the presence of chronic renal, neurological, respiratory illness along with low educational status of the parents were independent factors associated with anxiety.
Key Words: Anxiety, Caregivers, Chronic Illness, Depression, Generalized Anxiety Disorder-7, Patient Health Questionnaire-9.

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Received Date: 12/10/2017 Revised Date: 19/11/2017 Accepted Date: 24/12/2017
DOI: https://doi.org/10.26611/1012437

Access this article online

Quick Response Code:

Website: www.medpulse.in

Accessed Date: 30 December 2017

INTRODUCTION

A chronic illness is defined as an illness that lasts for 3 months or more, affects a child's normal activities and requires frequent hospitalizations, home health care and /or extensive medical care[1]. The 3 main features of a chronic illness are that they are prolonged in duration, do not get cured completely and rarely have a spontaneous resolution.[2] A family which cares for a child with a chronic illness, can experience disappointment at not having a normal child, in addition to the expenses and time commitment. They can also have social isolation in addition to opportunities lost at work. Once they come to know the diagnosis of the child, they may experience shock, denial, depression, guilt and anxiety. They may be at different stages of acceptance of their child's condition. With improvements in the diagnosis and treatment of diseases, the number of children with a chronic illness is steadily increasing. Hence, the number of parents caring for a child with chronic illness in also on the rise. Parenting a child with a chronic illness can be stressful to

How to cite this article: Shenoy S, V M Mridhula, Kalaiah K M. Anxiety and depression in parents caring for a child with chronic disease: A cross sectional comparative study. *MedPulse International Journal of Pediatrics.* December 2017; 4(3): 82-86.
http://medpulse.in/Pediatrics/index.php

the caregiver[3,4]. These parents are exposed to a lot of psychosocial stress when the diagnosis is made and during the multiple admissions and outpatient visits occurring during the course of the illness. This parental stress also reflects on the mother-child interaction[5] and can also affect treatment adherence. There are very few studies from the Indian subcontinent comparing the symptoms of depression and anxiety among the male and female caregivers of the child. The aim of this study was to study anxiety and depression in parents caring for a chronically ill child. We also compared the anxiety and depression between care giving fathers and mothers and studied various factors associated with anxiety and depression.

MATERIALS AND METHODS

This cross sectional comparative study was conducted in a tertiary referral hospital of a developing country over a period of 2 months. The study was approved by the institutional ethics committee. Data was collected from the parents of children with a chronic illness during the outpatient visits and inpatient ward admissions after a written informed consent. Parents of children without a chronic illness attending the out patients department for vaccination and minor illness were taken as controls. The control group was age and gender matched with the cases. The parents with history of psychiatric illness or chronic disease and those on antiepileptics or psychosomatic drugs were excluded from the study. Details regarding the child's age, gender, the parental age, gender, educational status, occupation, income, marital status, type of family, number of children, presence of an affected sibling, disease characteristics like diagnosis, age at onset of disease, frequency of hospital outpatient visits and hospitalization, need for daily medication were noted in a predesigned proforma. The educational status was divided into low (middle school certificate and less), intermediate (high school and higher secondary certificate) and high (graduate and postgraduate degree). The parents were given self administered questionnaires, Patient Health Questionnaire (PHQ-9) and Generalised Anxiety Disorder (GAD-7) to assess the level of anxiety and depression. The PHQ-9 is a 9 item depression module whose score can range from 0 to 27 as each of the 9 items can be scored from 0(not at all) to 3 (nearly every day). A score of 5, 10, 15 and 20 are thresholds for mild, moderate, moderately severe and severe depression. A score of >10 has a sensitivity and specificity of 88% for major depression.[6] The Generalised Anxiety Disorder (GAD-7) is a 7 item questionnaire whose score ranges from 0 to 21 with 5,10 and 15 being cut off scores for mild, moderate and severe anxiety respectively[7].

Sample size with proper justification: 112 (56 in each group). In a study done by Oers *et al*[8] the mean anxiety score among mothers caring for a chronically ill child was 5.9 points whereas among reference group, it was 4.9 points. In the present study, expecting similar mean scores with 20% average variation considering the precision with 80% power, 95% confidence level and effect size of 0.47 (one tail), the study required 56 subjects in each group.

Statistical Methods: Data analysis was done using SPSS Inc Released 2009. PASW Statistics for Windows, Version 18.0. Chicago. SPSS Inc. After categorizing the data into none, mild and moderate to severe, chi- square test was used to analyse the associated factors for depression and anxiety. Multiple linear regression was done taking the raw scores to analyse the independent factors for depression and anxiety.

OBSERVATIONS AND RESULTS

Table 1: Parental and child characteristics

	Cases (n=92) n (%)	Control (n=66)
Age parent (mean)	33y	33.6y
Gender parent (female)	47 (51)	41(62)
Educational status		
Low	18 (19.6)	4(6)
Intermediate	48(52.2)	44(66.7)
High	26(28.3)	18 (27.3)
Number of children living at home		
1	51(55)	29(44)
2-3	39 (43)	33 (50)
>3	2 (2)	4 (6)
Age child		
<1y	6(5.4)	1(1.5)
1-5y	46(50)	35(52.5)
6-10y	30(33.6)	21(32.8)
11-15y	10(11)	9(13.1)
Gender child (female)	37(40.2)	37(56.1)

Table 2: Univariate and multivariate analysis of variables on parental depression

Variable		No depression n (%)	Mild depression n (%)	Moderate to severe depression n (%)	Univariate analysis p value	Multiple regression p value
Hematological illness	Yes	4 (22.2)	7 (38.9)	7 (38.9)	0.064	0.00
	no	66(47.1)	48(34.3)	26(18.6)		
Cardiovascular illness	yes	0 (0)	3 (60)	2 (40)	0.127	0.015
	No	70(45.8)	52(34)	31(20.3)		
Chronic respiratory illness	yes	1 (12.5)	3 (37.5)	9 (50)	0.069	0.007
	no	69(46)	52(34.7)	29(19.3)		
Neurological illness	Yes	5(33.3)	3(20)	7 (46.7)	0.034	0.18
	No	65(45.5)	52(36.4)	26(18.2)		
Educational status	Low	8 (33.3)	8 (33.3)	8 (33.3)	0.056	0.02
	Intermediate	28 (36.8)	31 (40.8)	17 (22.4)		
	High	34 (58.6)	16 (27.6)	8 (13.8)		
Duration of illness	No illness	36(52.2)	27(39.1)	6(8.7)	0.019	
	<3y	28 (40)	22 (31.4)	20(28.6)		
	>3y	6(31.6)	6 (31.6)	7 (36.8)		

Table 3: Univariate and multivariate analysis of variables on parental anxiety

Variable		No anxiety n (%)	Mild anxiety n (%)	Moderate to severe anxiety n (%)	Univariate analysis p value	Multivariate analysis p value
Chronic renal illness	Yes	18 (39.1)	14 (30.4)	14 (30.4)	0.561	.001
	No	49(43.8)	38(33.9)	25(22.3)		
Neurological illness	Yes	1 (6.7)	6(40)	8 (53.3)	0.005	0.00
	No	66(46.2)	46(32.2)	31(21.7)		
Hematological	Yes	4(22.2)6	6(33.3)	8(44.4)	0.076	0.00
	No	63(45)	46(32.9)	31(22.1)		
Chronic respiratory illness	Yes	2 (25)	0(0)	6 (75)	0.002	0.00
	No	65(43.3)	52(34.7)	33(22)		
Duration of illness	No illness	43(62.3)	22(31.9)	4(5.8)	0.00	
	<3y	19 (27.1)	26(37.1)	25 (35.7)		
	>3y	5 (26.3)	4 (21.1)	10 (52.6)		
Educational status	Low	7 (29.2)	7(29.2)	10(41.7)	0.016	0.001
	intermediate	27(35.5)	27(35.5)	22(28.9)		
	High	33 (56.9)	18(31)	7 (12.1)		

We screened a total of 158 parents of which 92 were parents of children with a chronic illness and 66 were control subjects. There were 47 mothers and 45 fathers among the cases and 41 mothers and 25 fathers among the controls. The mean (SD) age of the parents among the cases and controls was 33y (6) y and 33.6 (5) y. (Table 1) The mean (SD) age of the affected children was 5.7 (3.8) y and that of the control was 6(3.6) y. The M: F ratio was 1.4:1 among the chronically ill children as compared to 1.3:1 among the control group. Majority of the children were in the 1-5y and 6-10y age group forming 50 % and 33% respectively in the cases and 52.5% and 32.8% in the control group. There were 11% and 13.1% in the 11-15 y age group among the cases and controls respectively. Of the affected children, there were 17 hematological cases including thalassemia, chronic ITP, 46 renal cases, 15 neurological cases including cerebral palsy and seizure disorders, 8 cases of chronic respiratory illness and 5 cases of cardiovascular illness. Thirty percent (n=28), 32.6% (n=30), 37%(n=34) of parents of children with a chronic illness were found to have moderate to severe, mild and no depressive symptoms as compared to

7.6%(n=5), 37.9%(n=25) and 54.4% (n=36) in the control group. (p value 0.02). With respect to anxiety, 39 % (n= 36), 33.7% (n=31), 27.2% (n=25) of parents had moderate to severe, mild and no anxiety as compared to 4.5% (n=3), 31.8% (n=21) and 63.6% (n=42) in the control group. (p value 0.00) On comparing the caregiving mothers and fathers of chronically ill children, 31.9 %(n=15) of mothers had moderate to severe depression as compared to 28.8% (n=13) of fathers but this was not found to be statistically significant (p value- 0.3). Moderate to severe anxiety was seen in 40.4% (n=19) of mothers as compared to 37.7 %(n=17) of fathers which was also not statistically significant (p value- 0.164) On analyzing the effect of disease and patient variables on the parental anxiety and depression, duration of illness and presence of a neurological disorder were found to have significant correlation with parental anxiety as well as depression.(p value <0.05) For multiple regression analysis, where the anxiety and depression scores were taken as continuous variables, the presence of hematological, cardiovascular, chronic respiratory illness and neurological disorders were found to correlate with parental depression and the presence of hematological, renal, chronic respiratory illness and neurological disorders were found to correlate with parental anxiety (Table 2 and 3). The educational status was also found to have a significant effect on both depression and anxiety among the caregiving parents with low educational status being associated with more symptoms. The parent and child variables like child's age, gender, parental age, gender, marital status, type of family, number of children living in the house, presence of another affected sibling and disease variables like requirement of frequent hospitalization, daily medications were not found to have any effect on the parental anxiety as well as depression.

DISCUSSION

We found that parents of children with a chronic illness had significant depression and anxiety than parents in the control group. One third of the parents had moderate to severe depression and another one third had mild symptoms. This was similar to another study where 38% had moderate to severe depression.[9] Our study had more parents reporting moderate to severe anxiety compared to the previous study. Amongst the care giving mothers and fathers, mothers were found to have more depression and anxiety compared to fathers but that was not statistically significant. In a study done[9], no sex predilection was noticed for anxiety and depressive symptoms. Whereas a study done by Azeem *et al*,[10] found mothers to have more depression and anxiety compared to fathers. Amongst the chronic illnesses, presence of a neurological disease was found to be significantly associated with parental depression and anxiety compared to other illnesses. A study done by Pruthi *et al*[11] showed higher psychosocial burden in parents caring for children with thalassemia and cerebral palsy compared to control group. A meta-analysis also revealed that the presence of cerebral palsy was amongst the diseases associated with high levels of parental stress and the parental strain was higher among children with limited mobility[12, 13]. This could be because of higher levels of functional limitation and dependence on the caregivers. Studies have shown higher stress[14] and lower quality of life, higher levels of depression and anxiety among parents of epileptic children[15]. A possible explanation could be the need for frequent admissions, the unpredictability of the seizures and the fear of recurrence of the episodes. A study on caregivers of asthmatic children also showed more depression and higher anxiety symptoms than the general population[16]. The presence of night symptoms, chronic medication use, recurrent exacerbation, limitation of activities could possibly contribute to the depression. Another factor found to correlate with the parental symptoms was the duration of illness with longer the duration of illness more the severity of depression and anxiety. Studies have shown longer duration of illness to be correlated with more caregiver anxiety, depression and burden.[17,18] Possible explanation could be the chronicity of the illness, increasing frustration, progression of the disease course which could contribute to the parental symptoms. The educational status was also found to have a significant association with depression as well as anxiety with the severity being more in those who were less educated. A lower educational status of the caregiver has been found to correlate with higher caregiver burden in another study.[19] Although the study by van Oers *et al* found younger parents to have higher levels of anxiety, our study did not find any influence of the parental age on the symptoms.[8] Our study demonstrates the presence of high levels of anxiety and depression among the care giving parents. The emotional wellbeing of the caregivers should also be looked into while managing a child with a chronic illness. This highlights the need for a psychological consultation for the caregivers in addition to the routine care in order to provide holistic care to the entire family. A major limitation of our study was the small sample size due to which the diseases were also grouped into major systems. A study taking a larger sample size along with further classification of the diseases along with its severity would probably help evaluate the factors affecting the parental depression and anxiety.

CONCLUSION

Caregivers of children with a chronic illness are at risk for depression and anxiety symptoms. The low

educational level and the presence of chronic neurological, respiratory, cardiovascular and hematological were independent predictors for depression whereas the presence of chronic renal, neurological, respiratory and hematological illness was independent factors for anxiety.

REFERENCES

1. Mokkink LB, Van Der Lee JH, Grootenhuis MA, Offringa M, Heymans HS. Defining chronic diseases and health conditions in childhood (0–18 years of age): national consensus in the Netherlands. Eur J Pediatr 2008; 167(12):1441-7.
2. Stanton AL, Revenson TA, Tennen H. Health psychology: psychological adjustment to chronic disease. Annu. Rev Psychol 2007 10; 58:565-92.
3. Cousino MK, Hazen RA. Parenting stress among caregivers of children with chronic illness: a systematic review. J Pediatric Psychol 2013 Sep; 38(8):809-28.
4. Wallander JL, Varni JW. Effects of pediatric chronic physical disorders on child and family adjustment. J Child Psychol Psychiatry. 1998 Jan; 39(1):29-46.
5. Lovejoy MC, Graczyk PA, O'Hare E, Neuman G. Maternal depression and parenting behavior: A meta-analytic review. Clin Psychol Rev 2000 Aug 31; 20(5):561-92.
6. Kroenke K, Spitzer RL, Williams JB. The PHQ-9: validity of a brief depressive symptoms severity measure. J Gen Intern Med. 2001 Sep; 16(9):606-13.
7. Spitzer RL, Kroenke K, Williams JB, Löwe B. A brief measure for assessing generalized anxiety disorder: the GAD-7. Arch Intern Med. 2006 May 22; 166(10):1092-7.
8. Van Oers HA, Haverman L, Limperg PF, van Dijk-Lokkart EM, Maurice-Stam H, Grootenhuis MA. Anxiety and depression in mothers and fathers of a chronically ill child. Matern Child Health J. 2014 Oct 1; 18(8):1993-2002.
9. Khanna AK, Prabhakaran A, Patel P, Ganjiwale JD, Nimbalkar SM. Social, psychological and financial burden on caregivers of children with chronic illness: A cross-sectional study. Indian J Pediatr. 2015 Nov; 82(11):1006-11.
10. Azeem MW, Dogar IA, Shah S, Cheema MA, Asmat A, Akbar M, Kousar S, Haider II. Anxiety and depression among parents of children with intellectual disability in Pakistan. J Can Acad Child Adolesc Psychiatry. 2013 Nov; 22(4):290.
11. Pruthi GK, Singh TB. Psychosocial Burden and Quatlity of life in parents of Children with Thalassemia and CP. Delhi Psychol. 2010;2:46-57
12. Pinquart M. Parenting stress in caregivers of children with chronic physical condition—A meta-analysis. Stress and Health. 2017; 1–11. https://doi.org/10.1002/smi.2780
13. Prakash V, Patel AM, Hariohm K, Palisano RJ. Higher Levels of Caregiver Strain Perceived by Indian Mothers of Children and Young Adults with Cerebral Palsy Who have Limited Self-Mobility. Phys Occup Ther Pediatr. 2017 Jan 1; 37(1):64-73.
14. Chiou HH, Hsieh LP. Parenting stress in parents of children with epilepsy and asthma. J Child Neurol. 2008 Mar; 23(3):301-6.
15. Lv R, Wu L, Jin L, Lu Q, Wang M, Qu Y, Liu H. Depression, anxiety and quality of life in parents of children with epilepsy. Acta Neurol Scand 2009 Nov 1; 120(5):335-41.
16. Szabo A, Mezei G, Kõvári É, Cserháti E. Depressive symptoms amongst asthmatic children's caregivers. Pediatr Allergy Immunol 2010 Jun;21(4 Pt 2):e667-73.
17. Ampalam P, Gunturu S, Padma V. A comparative study of caregiver burden in psychiatric illness and chronic medical illness. Indian J Psychiatry. 2012 Jul;54(3):239.
18. García-Alberca JM, Lara JP, Berthier ML. Anxiety and depression in caregivers are associated with patient and caregiver characteristics in Alzheimer's disease. Int J Psychiatry Med. 2011 Jan; 41(1):57-69.
19. Bozkurt Zincir S, Sunbul M, Zincir S, Aydin Sunbul E, Oguz M, Feriha Cengiz F, Durmus E, Kivrak T, Sari I. Burden and depressive symptoms associated with adult-child caregiving for individuals with heart failure. Scientific World Journal. 2014 Nov 5; 2014.

Source of Support: None Declared
Conflict of Interest: None Declared