

To study the prevalence of sleep disorders in parents of children undergoing cancer treatment

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INTRODUCTION

Cancer is a disease which takes its toll on the entire family; a view which the parents of children being treated for cancer reinforce. The effect of the cancer is felt by the child suffering from the cancer leading to major emotional disturbances due to repeated admissions in the hospital. The parents also undergo a major emotional upheaval which leads to further problems. The siblings of the child suffering from cancer also undergo emotional trauma as well as a feeling of neglect due to the fact that the parents are more focused on the needs of the child who is suffering from cancer. However, the trauma suffered by parents of child afflicted with cancer is not the same either for both parents or at different stages of treatment. The literature present on the subject also indicates that the experience of the parents of children with cancer vary in different cases.

The very nature of the cancer treatment is traumatic considering the invasive and painful procedures involved in the diagnosis and treatment of this disease accompanied by prolonged periods of hospitalization to be endured by the cancer patients and their families.

According to National Foundation for Cancer Research, at any given time in India there are 2.5 million cases of cancer. In the year 2007, in India alone 1.5 million cases were diagnosed and the same number died because of the disease. Even more alarming is the fact that 50,000 cases of the estimated cancer patients in India are children. Approximately 25% of these children will die from brain

cancer. In our country the out of pocket expenses are very high so these children and their parents struggle under a double burden of the disease and poverty. Care and treatment of such children requires the joint efforts of a team working together to provide on one hand medical treatment (chemotherapy, radiation and surgery) as required and psychological support for the child as well as the family.

Consequently, not just the childhood cancer patients but their parents also suffer from fatigue and sleep disorders. It is well known that sleep disturbances are significant stressors and lead to the deterioration of the quality of life of both the patient and their parents. Lot of research goes into the actual medical treatment of the child but in the process we somehow neglect the care of the caregivers and fail to see the stress which they undergo.

The increasing rate of childhood cancer will shortly lead to a global health problem and thus it is necessary to see the effects of cancer not only in the children affected but also in the parents and caregivers of these children. This research is, therefore, concerned with studying the incidence of sleep disorders among the parents of the childhood cancer patients.

AIMS AND OBJECTIVES

To study the prevalence of sleep disturbances in parents whose children are suffering with cancer

To sensitize health care providers about the need for psychological support to the parents

To analyze the factors affecting the parental stress whose children are suffering with cancer

METHODOLOGY

Parents of children diagnosed to have malignancy and on treatment for at least 6 months were enrolled in the survey. This survey was conducted at Sir Ganga Ram Hospital, Delhi. This survey was conducted from 1st November, 2008 to 30th April, 2009. In all I contacted 128 parents whose children were undergoing cancer treatment and explained survey objectives and asked their consent to participate in the survey. Only 52 parents (whose children were detected with cancer) could participate in the research

EXCLUSION CRITERIA

*All those parents who had any pre existing sleep disorders

*All parents who were on any antidepressants or anti anxiety medications

Before their child was diagnosed with cancer

52 parents who were matched demographically and whose children were healthy were taken as control for the study. A self-administered questionnaire was given to them after explanation of sleep disturbances. Epworth sleepiness scale was used to assess the patients. The Epworth scale was developed by Dr. Murray Johns at Epworth hospital in Melbourne Australia in 1991 and used widely by sleep professionals all over the world to measure sleep deprivation. This is a validated tool to help us identify level of daytime sleepiness which can be a symptom of sleep disorder and it tells us how likely are we to doze off or fall asleep in the given conditions

in contrast to feeling just tired. [Johns MW, 1991] The whole study was done under the able supervision of my research guide Dr. Anupam Sachdeva. The questionnaire used is given in the Annexure 1.

To check the statistical significance I applied chi-square test. The degree of freedom was 51 and the significance level was 5%. The values obtained from the parents whose children were healthy were considered as the expected values and the values from the parents whose children were detected with cancer and undergoing treatment were considered as observed value. The sample was divided into two groups i.e. people with normal sleep and people with daytime sleepiness. The parents with Epworth score between 0-9 are considered as having normal sleep and the parents with Epworth scores between 10-23 were considered as having daytime sleepiness.

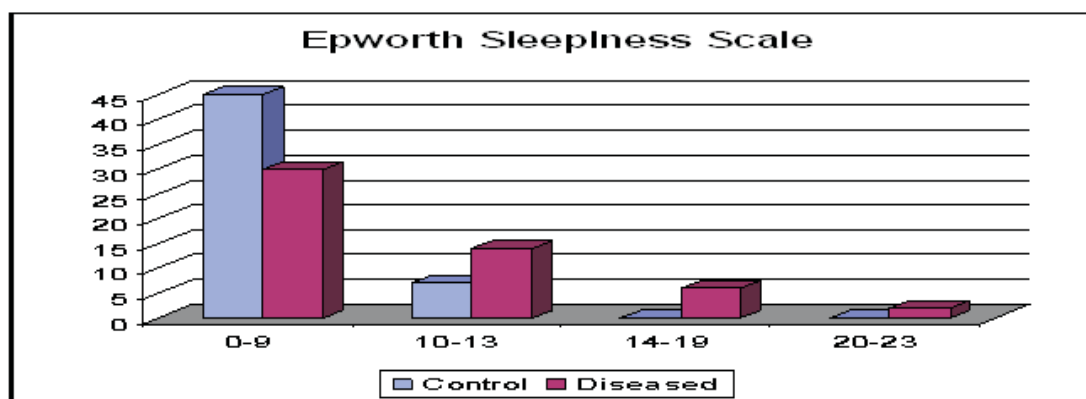
RESULTS

104 parents were enrolled for the study out of which 52 parents were those whose children were undergoing cancer treatment and 52 those whose children were healthy. Mean age was 37.3 years.

As per the Epworth sleepiness score, the incidence of daytime sleepiness in those parents whose children were undergoing cancer treatment was 42.29% ranging from mild daytime sleepiness seen in 26.92% to severe daytime sleepiness seen in 3.84%. And 57.69% ranged in the normal category according to Epworth's scale.

As compared to this, in the set of the parents who served as control 86.54% parents were normal and only 13.46% showed mild symptoms of daytime sleepiness.

Score	Control	Diseased
0-9(normal)	45	30
10-13(mild)	7	14
14-19(moderate)	0	6
20-23(severe)	0	2



For calculation of chi-square test the above is categorized into two categories

Score	Control	Diseased
0-9	45	30
10-23	7	22

Observed	Expected	O-E	Square (O-E)	Sqr (O-E)/E
30	45	-15	225	5.00
22	7	15	225	32.14
			Value of chi-square	37.14

The table value of chi-square at 5% significance level and at 51 degree of freedom is 35.6. The calculated value is 37.14 that is more than the critical value which shows there is a significant difference in the observed value and expected values.

CONCLUSION

This study shows the high prevalence of daytime sleepiness in parents whose children are suffering with cancer and undergoing treatment. Also it should be mentioned that the control group is significantly different than the diseased group. This shows how much psychological support is required not only by the child but also by the family. It was found that the long-term parental adjustment depends on number of factors. For instance, some of the parents who are likely to show greater short term and long-term adjustment are those who:

- *Are involved with their jobs.
- *Enjoy support from members of family, friends, and other social support systems.

*Undergo relatively lower levels of stress during routine parenting.

*Consider their children likely to enjoy improved quality of life.

*Are optimistic about the results of the treatment. [Rourke *et al.*, 1999; Kazak *et al.*, 1997; Grootenhuis *et al.*, 1997]

In contrast, parental adjustment may suffer on account of the following factors: Parents have no positive expectations about the results of the treatment.

*Parents with a sense of helplessness, uncertainty, and anxiety.

*Do not enjoy any kind of social support structure.

*Their interactions with Healthcare team members have been negative.

*They do not consider the child's quality of life to improve in any significant manner. [Dockerty *et al.*, 2000; Santacroce, 2002]

Nevertheless, various studies indicate that emotional trauma and the apparent levels of stress of the parents decrease with time. This

is despite the perception that burden of caring for a cancer afflicted child would remain the same as would be the aspects like parental control, caring and sensitivity. [Steele *et al.*, 2003] High level of social support extended at the time of diagnosis would account for such perceptions. Even though the quantity of support may decline gradually, but steady support during all phases of the cancer treatment is enough to bolster the positive perceptions.[Hoekstra-Weebers *et al.*, 2001] Parents are generally known to be strong yet flexible, with immense ability to withstand shock and trauma,[Dockerty *et al.*, 2000] but if a child suffers the side effects of the treatment over a prolonged period, parents are likely to suffer increased feelings of uncertainty and isolation long after the active phase of treatment has been over.[Van Dongen-Melman *et al.*,1995] It has been found in various studies that nearly 30%-36% parents of cancer survivors have experienced severe, prolonged symptoms of stress far beyond the level diagnosed for post-traumatic stress disorder (PTSD), which, by all standards, is a major problem for these parents.[Brown *et al.*,2003;Kazak *et al.*,2004]

Greater impact of the disease would be felt by the families where

*The patient falls in younger age group.[Sargent *et al.*, 1995]

*Cancer treatments has become prolonged and painful.[Hamama *et al.*, 2000]

*The childhood cancer patient dies despite the treatment.[MacLeod *et al.*, 2003]

The stress which the family undergoes should be kept in mind whilst formulating any childhood cancer treatment protocols and healthcare providers should always plan things to reduce the stress. Proper psychosocial support teams need to be formed to make any such care program successful. By sensitizing the parents to their potential medical problems we can make them seek early medical help and also make them adapt to this situation in a better way. Propagation of awareness of snoring as a major risk factor for sleep apnea will help these people to take early medical help. We can also educate them about safe

driving habits to avoid motor vehicle accidents. Studies done previously have also reported frequent health and behavior related problems in family members of cancer patients. This study also reports high prevalence of subjective disorders of sleep in parents of children diagnosed and treated for cancer. Better study designs like large sample size, and more sophisticated tools like polysomnography which add to the strength of the study and make it more scientific and will help in drawing conclusions more objectively.

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SLEEP DISORDER QUESTIONNAIRE

DATE:

NAME:

DATE OF BIRTH:

EPWORTH SLEEPINESS SCALE

Please use this scale to evaluate the following questions:

0 = would never doze

2 = moderate chance of dozing

1 = slight chance of dozing

3 = high chance of dozing

1. Watching T.V.
2. Sitting inactive in a public gathering
3. As a passenger in a car for an hour without break
4. Lying down in the afternoon circumstances permitting
5. Sitting and talking to someone
6. Sitting quietly after lunch not having consumed alcohol
7. Driving a car that has stopped briefly at a red light
8. Sitting and reading

Total Epworth Sleepiness Score

Epworth Sleepiness Score (ESS)

0-9 = Normal

10-13 = Mild

14-19 = Moderate

20-23 = Severe

If your results are greater than 9 and/or you feel you may have sleep apnea, this means significant sleep disorder.