Original Article

Parent Stress in Childhood Cancer MAK Basher¹, MR Karim², N Sultana³, KJ Hossain⁴, MM Kamal⁵

Abstract:

The objective of the study was to assess level of stress of the parents with a child suffering from cancer. A total of 396 parents of which 146 fathers and 250 mothers were recruited from the National Institute of Cancer Research & Hospital, Bangabandhu Sheik Mujib Medical University, Dhaka Medical College Hospital and Dhaka Shishu Hospital (DSH), Dhaka from January 2011 to November 2011. They were selected consecutively on the basis of the defined criteria. The research instruments were interviewer questionnaire and stress measuring standard scales. Results showed that all of the parents were found educated. In graduate and above, fathers were comparatively higher educated than that of mothers. In profession, 48.7%(n=193)were household workers, 33.7%(n=133) service holders and 17.6%(n=70) were businessmen. The monthly family income of the respondent were Tk. 10,000 to 20,000 in 77.0%(n=305). Results also showed that 86.8%(n=344) of them in both sexes had age in between 18 to 40 years of which 44.9%(n=178) had age 31-40 years and 41.9%(n=166) were 18-30 years respectively. Only 13.2%(n=52) of both sexes had age above 40 years. The mean age of them were 33 ± 8 years. The type of cancers among the children of the respondents was described in the Table 2. The results showed that 61.4%(n=243) of the children had been suffering form leukemia, 17.4%(n=69)lymphoma, 8.3%(n=33) reticuloblastoma, 2.5%(n=10)neuroblastoma, 1.1%(n=4) solid tumors and 9.3%(n=48)were from other cancers such as embryoma, rhabdomyosarcoma, testicular tumors etc. The age of the children who had been suffering from different type of cancers was summarized in the Table-3. About 44.4%(n=176) of the children had age 1-5 years, 35.6%(n=141) age 6-10 years and 20.0%(n=79) were of age 11-15 years respectively.

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Leukemia was found the highest incidence among all age groups of the boys and girls. Results also showed that 63.8%(n=253) of the parents had certainly affected due to the stress. About 6.7% (n=26) of the parents had severely affected and 28.7%(n=114) may be affected induced by the cancers of their children. The poorly educated, up to class-X, fathers and mothers constituted 49.8%(n=197) were found certainly affected with the stress. Middle age group (31-40 years) having middle class socioeconomic status had also similar characteristics of the stress among the respondents. In duration of the disease at the time of assessment, results showed that 21.8%(n=86) of the parents with one child suffering from cancer in between 7-12 months were found certainly and severely affected with the stress. Careful designed investigations of the long-term psychological and behavioral consequences of the parents are vital important for early interventions to assess and treat psychological distress of them.

Introduction:

Cancers are common, developing at some time in the life of more than one-third of the global population. It is the second most leading cause of death in the world, after myocardial infarction.¹ Bangladesh is with 150 million populations of which 37 percent are children under the age of 15 years. Childhood cancers are gradually becoming a matter of increasing concern to general populations. Annually 5000-6000 children have been developing different type of cancers in Bangladesh, which is much higher than that of other non-communicable diseases.² Diagnosis of childhood cancer has an enormous impact on the child and his/her family. They are confronted with a life-threatening disease mostly implying extensive treatment with negative side-effects and the risk of long-term consequences.³ Parents are recognized as one of the main sources of emotional support for children with cancer. However, parent's ability to provide care during their child's illness and treatment is known to be dependent on how they manage to cope with the diagnosis and its consequences. Disclosure of the cancer diagnosis together with the knowledge of the fatality of the disease constitutes a potentially traumatic stress or the diagnosis of post traumatic stress syndrome (PTSS).⁴ Medical traumatic stress is a set of psychological and physiological responses of the children and their parents to pain, injury, serious illness, medical procedures, and invasive or frightening treatment experiences. Patterns of stress among the parents in a family of children treated for cancer differ from those in families of the children treated for other diseases. The reaction of parents of children with cancer diagnosis is a life-threatening illness often consistent with traumatic stress responses.⁵ Persistent high stress among the parent has been found in many studies both at the time of diagnosis and early stage of treatment and also persists over many years.⁶ The level of stress among the parents is varied of cancers and course of treatment such as length of treatment, frequency of treatment, period of hospitalization and relapse.⁷ Symptoms of acute stress and PTSS may evolve in parents at any phase in the course of their child's disease and its treatment, and interfere with their ability to provide healthcare for themselves and their children. Child cancer survivors are at risk to develop PTSS. Approximately 5-21% of childhood cancer survivors have been found to have a diagnosis of PTSS as a result of their cancer. The childhood cancer may be traumatic for the child's parents. It is not surprising then that high rates of PTSS have been found among the parents of childhood cancer survivors. Specifically, approximately 6-25% of parents of childhood cancer survivors have been found to have PTSS.⁸

In Bangladesh, mental healthcare services are yet not developed among the general populations. As due to strong religious impact and backward social tradition, cancer related matters are not discussing freely in the community. There is a social stigmatism; cancer is a curse of God. Psycho-education and psychotherapy, in addition to pharmacotherapy, seems to be key intervention in the enhancement of treatment and improvement of long term outcome in several medical conditions such as cancers, diabetes, and cardiac illness etc.⁹ In addition, behavioral therapies, psycho-education, family and social participation jointly can overcome social stigmatism, can learn to control the parents crisis and be trained to maintain their normal and productive life in family or in work place or in community.

Update treatment facilities of cancers is very inadequate in Bangladesh. A little information about childhood cancer treatment may be obtained from government or nongovernmental hospitals. Even there is not, so far known, a single scientific study on mental health of the parents living with childhood cancers in Bangladesh. However, it is necessary to initiate scientific study on mental health particularly stress of the parents in childhood cancers, because once their mental state assessment data have been collected, a plan for effective management modality against stress can be established. International studies showed that the beliefs and practices engendered by the intense stigma associated with cancers in traditional-bound country like India, Bangladesh are likely to affect the mental health of the parents living with childhood cancers.¹⁰ Therefore, the aim of this work and in continuation of research in this field was to assess the level of stress among the parents with childhood cancers. The outcome will, significantly, be supportive and enhance the national preventive activities against cancers.

Materials and Methods: Study population:

The studied population was parents with childhood cancers. The respondents were mothers or fathers, any one of them having a child suffering from cancer. They were recruited from the National Institute of Cancer Research & Hospital (NICRH), Dhaka; Bangabandhu Sheik Mujib Medical University (BSMMU), Dhaka; Dhaka Medical College Hospital (DMCH), Dhaka; and Dhaka Shishu Hospital (DSH), Dhaka respectively from January 2011 to November 2011. They were selected on the basis of the defined criteria that included each respondent must had one child living with cancer of age 1 to 15 years irrespective of religion. Physical and mental disabled parents were not included. A total of 396 parents were recruited of which 146 fathers and 250 mothers.¹¹⁻¹² The research instruments were interviewer questionnaire and stress measuring standard scales. Prior to data collection, institutional permission was taken from the head of the selected institutions. Written informed consent was also taken from each of respondents. A questionnaire was developed and pre-tested among the parents, who were excluded from the study population. The questionnaire was designed to include general information, socioeconomic and family profile of the respondents. The socioeconomic profile included education, occupation and monthly income. Initially, appointed research assistants briefed objectives, benefits, risks and burdens of this study to the parents. Only positive respondents were selected as research participant consistent with the selection criteria. A written informed consent was taken from each of the selected parents maintaining full autonomy. The research assistant also recorded socioeconomic-family profile of them following the questionnaire. The level of stress of the respondents was assessed by the Resident Psychiatrist (RP) using standard scale.¹³ The stress assessment scale prepared by the Reed BS in 2007 known as Impact of Event Scale (IES) was used to assess stress of the respondents. In the scale, 15 self answered items were used. Four answers were in the scale for each item such as not at all or rarely or sometimes or often which scored 0, 1, 3 and 5 respectively. The scores categorized as 0-8, 9-25, 26-43 and 44-75 were- no meaningful impact, may be affected, certainly affected and severely affected respectively. The respondents were interviewed face-to-face in a separate room maintaining their privacy strictly.

Statistical analysis:

A software package of SPSS (version 12.0: SPSS Inc., Chicago, IL, USA) was used to analyze the data. Descriptive statistics was used for all variables. Values were expressed as percentage

Results:

Socioeconomic profile of the studied parents having one child suffering from cancer was summarized in the Table-1. All of the parents were found educated, among them, 33.6%(n=133), 46.0%(n=182), 13.4%(53) and 7.0%(n=28) were primary (1-5 class), secondary (6-10 class), higher secondary (11-12 class) and graduate and above (13-17 class) respectively. In graduate and above, fathers were comparatively higher educated than that of mothers. In profession, 48.7%(n=193) mothers were household workers, 10.1(n=40) service holders and 4.2%(n=17) were businessmen. Among fathers, 23.6%(n=93) were service holders and 13.4%(n=53) were businessmen. The monthly income of the respondent's family were up to Tk. 10,000 in 15.9%(n=63), Tk. 10,000 to 20,000 in 77.0%(n=305) and were above Tk. 20,000 in 7.1%(n=28) families respectively. Results also showed that 86.8%(n=344) of them in both sexes had age in between 18 to 40 years of which

44.9%(n=178) had age 31-40 years and 41.9%(n=166) were 18-30 years respectively. Only 13.2%(n=52) of both sexes had age above 40 years. The mean age of them were 33 8 years. The type of cancers among the children of the respondents was described in the Table 2. The results showed that 61.4%(n=243) of the children had been suffering form leukemia, 17.4%(n=69) lymphoma, 8.3%(n=33) reticuloblastoma, 2.5%(n=10) neuroblastoma, 1.1%(n=4) solid tumors and 9.3%(n=48) were from other cancers such as embryoma, rhabdomyosarcoma, testicular tumors etc. The age of the children who had been suffering from different type of cancers was summarized in the Table-3. About 44.4%(n=176) of the children had age 1-5 years, 35.6%(n=141) age 6-10 years and 20.0%(n=79) were of age 11-15 years respectively. Leukemia was found the highest incidence among all age groups of the boys and girls (Table-2 & 3).

Table 1: Socioeconomic status of the Parents	(n=396)
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Parameters	Mothers (250)		Fathers (146)		Total (n=396)	
	Number	%	Number	%	Number	%
Education						
1 – 5 Class	83	20.9	50	12.7	133	33.6
6 - 10 Class	126	31.8	56	14.2	182	46.0
11 – 12 Class	30	7.6	23	5.8	53	13.4
13 – 17 Class	11	2.8	17	4.2	28	7.0
Occupation						
Household works	193	48.7	Nil	Nil	193	48.7
Services	40	10.1	93	23.6	133	33.7
Business	17	4.2	53	13.4	70	17.6
Family income ¹ (Tk)						
Up to 10,000	37	9.3	26	6.6	63	15.9
10,000 - 20,000	203	51.3	102	25.7	305	77.0
20,000 - 30,000	10	2.5	18	4.6	28	7.1
Age in year						
18 - 30	104	26.3	62	15.6	166	41.9
31 - 40	112	28.3	66	16.6	178	44.9
41 - 50	22	5.6	13	3.2	35	8.8
51 - 59	12	3.1	5	1.3	17	4.4

1. **Family income:** It includes self income + Spouse income + Income of other members + Income from other sources such as House rent, Bank interest, Share business + Cultivation etc

Categorized into following socioeconomic class Lower class: Monthly income up to Tk. 10,000 Middle class: Monthly income Tk. 10,000 - 20,000 Upper class: Monthly income above Tk. 20,000

 Table 2: Type of cancers among the children of the respondents (n=396)

Type of Cancers	Mothers (n=250)		Fathers (n=146)		Total %(n)
	Boys	Girls	Boys	Girls	
Leukemia	101	50	62	30	61.4(243)
Lymphoma	29	14	17	9	17.4(69)
Reticuloblastoma	13	7	9	4	8.3(33)
Neuroblastoma	4	2	2	2	2.5(10)
Solid tumor	2	Nil	1	1	1.1(4)
Others	18	9	8		9.3(37)
Total	167	82	99	48	

Others: Embryoma, rhabdomyosarcoma, testicular tumor etc **Table 3:** Distribution of cancers by age of the children (n=396)

Name of the cancers	Age of the children in years					
	1 – 5y	6 – 10y	11 – 15y			
Leukemia	123	123 76				
Lymphoma	10	39	20			
Reticuloblastoma	26	7	0			
Nuroblastoma	0	7	3			
Solid tumor	0	4	0			
Others	17	8	12			
Total: % (n)	44.4(176) 35.6(141) 20		20.0(79)			

Table 4:	Stress	assessment	of the	parents	in	childhood
cancers (n	=396)					

Parameters	Mothers (250)		Fathers (146)		Total (n=396)	
	Number	%	Number	%	Number	%
No meaningful stress	0	0.0	3	0.8	3	0.8
May be affected	70	17.6	44	11.1	114	28.7
Certainly affected	160	40.4	93	23.5	253	63.8
Severely affected	20	5.1	6	1.5	26	6.7
Total:	250	63.1	146	36.9	396	100.0

Table 5: Distribution of stress of the parents by education, socioeconomic classes, age and duration of disease at the time of data collection (n=396)

Items	No meaningful stress %(n)	May be affected %(n)	Certainly affected %(n)	Severely affected %(n)
Education				
1 - 5 Class	0.8(3)	8.3(33)	21.2(84)	3.3(13)
6 - 10 Class	0	14.9(59)	28.6(113)	2.5(10)
11 - 12 Class	0	4.0(16)	8.3(33)	1.0(4)
13 – 17 Class	0	1.0(4)	6.1(24)	0
Socioeconomic class				
Lower class	0.8(3)	6.6(26)	7.6(30)	1.0(4)
Middle class	0	20.7(82)	50.4 (200)	5.8(23)
Upper class	0	0	7.1(28)	0
Age in year				
18 - 30	0	13.1(52)	24.2(96)	4.5(18)
31 -40	0.8(3)	11.6(46)	30.5 (121)	2.1(8)
41 - 50	0	1.8(7)	7.1(28)	0
51 - 59	0	1.8(7)	2.5(10)	0
Duration of disease				
Less than month	0	0.8(3)	0	0
1-6 months	9.1(36)	12.6(50)	4.0(16)	2.3(9)
7-12 months	19.2(76)	22.4 (89)	15.2 (60)	6.6(26)
Above 12 months	2.5(10)	3.5(14)	1.0(4)	0.8(3)

The assessment of stress among the parents in childhood cancers was summarized in the Table 4. Results showed that 63.8%(n=253) of the parents had certainly affected due to the stress, of which 40.4%(n=160) were mothers and the rest (23.5%, n=93) were fathers respectively. About 6.7%(n=26) of the parents had severely affected and 28.7%(n=114) may be affected induced by the cancers of their children. Of them, mothers were found higher than that of fathers. A few of the parents (0.8%, n=3) had not found any meaningful stress. Distribution of stress in relation to the education, socioeconomic status, age of the respondents and duration of cancer at the time of stress assessment were also analyzed and summarized in the Table 5. The poorly educated, up to class-X, fathers and mothers constituted 49.8%(n=197) were found certainly affected with the stress. Middle age group (31-40 years) having middle class socioeconomic status had also similar characteristics of the stress among the respondents (Table-5). In duration of the disease at the time of assessment, results showed that 21.8%(n=86) of the parents with one child suffering from cancer in between 7-12 months were found certainly and severely affected with the stress. The stress assessment and its relation to the socioeconomic factors were described in detail in the Table-4 and Table-5.

Discussion:

The diagnosis of childhood cancer is one of the most intense, disruptive, and enduring experiences that parents can have. The often unexpected and life-threatening diagnosis and the initiation of invasive medical treatment and its sequalae interfere with the entire family's normal activities for a long period and impose stresses of varying duration, predictability, and impact.¹⁴⁻¹⁸ Nowadays, three out of four children diagnosed as cancer survives along with the disease and treatment.¹⁹ The diagnosis and treatment of cancer in one's child can cause long-lasting psychological effects in a parent. Feeling of uncertainty, anxiety, depressive symptom, and post traumatic stress syndrome (PTSS) are most prevalent shortly after the parents are confronted with the of childhood cancer. These emotional diagnosis manifestations of strain decrease to near normal levels over time in the majority of the parents, but have been found to persist in a substantial proportion of the parents, even many years of post-treatment. Moreover, as is often found in the general population, mothers tend to report more and higher levels of symptoms than fathers with respect to anxiety, depression, and PTSS. These differences may well be related to the traditional distribution of care-giving tasks and responsibilities. Since parents of children with cancer are at risk for the development of disruptive emotional manifestations of strain, which persist over time among a subset of parents, it seems important to obviate risk factors early in order to detect and support parents most at risk for later maladjustment.

Cancer is the uncontrolled and abnormal growth of cells in the body. There are many causes of it, including benzene and other chemicals, certain poisonous mushrooms and a type of poison that can grow on peanut plants (aflatoxins), certain viruses, radiation, sunlight and tobacco use. However, the viruses, radiation, sunlight and tobacco use. However, the cause of many cancers remains unknown. In addition, social stigmatism, warm and humid climates, poor sanitation, malnutrition, unhygienic environment and overcrowding are the major influencing factors for cancers, which are highly prevalent in Bangladesh. People living with cancer or any other chronic diseases are the victim of social infernos of stigmatism that results suffering of mental disturbances. The childhood cancers as well as social stigmatism in Bangladesh critically affect physical, mental and social health of the parents. Government of Bangladesh in joint collaboration with World Health Organization (WHO) has undertaken multiple preventive measures against this human catastrophe.²⁰ It is one of the major causes of human disability in Bangladesh. In light of the incidence of the childhood cancers and its disability and fatality, the present study was undertaken to assess mental disturbances particularly stress of the parents having a child suffering from cancer.

NICRH, the only specialized public hospital for cancers, BSMMU, DMCH, and Dhaka Shishu Hospital presents a special opportunity to study the mental stress of the parents in a semi-controlled environment. There is a shortcoming; compliance with mental treatment regimens very much limited in these hospitals. It is well established that scientific evaluation and enlightened motivated attitudes towards chronic diseases including cancers might abolish the forcible incarceration of the parents from pejorative languages and social stigmatism. It may need to aware of the parents to the concomitant loss of many of their civil rights.²¹. In addition, it helps in the development of faithful adherence of the parents to the treatment schedules for their children.

In this study, it had been found that majority of the parents were poorly educated (1-10 class), only 20% were above 10 class educated. Among them, fathers were found higher status in degree and above than that of mothers. In profession, most of the mother's occupation was household works, and fathers had specific jobs such as business or service and had monthly income of the family were Tk. 10 thousands to 30 thousands. As a whole, Bangladesh is a densely populated country. About 150 million people live in this country. The trend in population growth, fertility, morbidity, mortality and migration from rural to urban areas are persistently creating hurdles in socioeconomic development. At present, nearly 48.0% people live below the poverty line. The socioeconomic characteristics of the studied parents are consistent with the reported national statistical data16. The possible explanation is that the patriarchal society, religious stigmatism or fundamentalism as well as conventional socio-cultural impact may be the important contributing factor for such type of socioeconomic characteristics of the mothers in Bangladesh. Socio-culture and religious backward tradition may be the unavoidable factors against women empowerment in the community. This trend of socioeconomic status is gradually changing in Bangladesh. However, the socioeconomic status of the studied parents was found comparatively better than that of others. Education, family income and relatively better

occupation are the leading factors for better socioeconomic status of them.

Majority of the children had been suffering from blood cancers (leukemia) and lymphoma which was found the highest prevalent in preschool age group (1-5 years) followed by primary school group (6-10 years) and high school group (11-15 years) of children respectively. Similar findings were also found in other studies1-3. In the results of the stress assessment, it had been found that majority of parents (63.8%) were certainly and 6.7% severely suffering from post traumatic stress syndrome (PTSS) (Table-4). The PTSS were found significantly affected in the middle class parents of 6-10 class educated and 31-40 years of age. In addition, after 7-12 months period of diagnosis of childhood cancers parents were found to have high PTSS (Table-5). Their levels of stress and relation to education, socioeconomic class, age of the parents and duration of childhood cancers are consistent with some other studies. 3-6-22-24 The clinical significance of the findings refers to their signaling the call for continuous attention to the psychological needs of parents following a child's cancer diagnosis, and not only immediately at the first referral hospital. Healthcare professionals meeting the families should bear in mind that parent may be particularly vulnerable to situational crisis during the period when the medical care system demands most of their collaboration. Moreover, many parents may struggle with the consequences of severe stress, even though the child was diagnosed few years ago. Indeed, a few parents may be more or less permanently affected by the stress reactions related to the child's cancer.

In conclusion, this study may be the first attempt to assess psychological distress and post traumatic stress reactions among the parents with a child suffering from cancer. The finding results showed that majority of the parents had been suffering from certainly or severely stress reactions. It may persist years after completing cancer treatment of the child. Therefore, both prospective and retrospective studies are needed to quantify the incidence and prevalence of adverse consequences in representative cohorts of survivors. As evidence continues to emerge regarding late-effects, treatment care providers will have systems in place to disseminate information to the parents and survivors about possible late-effects and psychological supports.²⁵ This is especially important given the significant gaps that the parents or survivors have demonstrated regarding knowledge of their medical history and vulnerability.⁶ The present study suggests that careful designed investigations of the long-term psychological and behavioral consequences of the parents having one child suffering from cancer are vital important for early interventions to assess and treat psychological distress of them no doubt.²⁶

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