

## Original Article



# Assessment of Parental Hopelessness For A Child With Cancer

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### Abstract

**Background:** The feeling of hopelessness begins immediately after the diagnosis & continues through the treatment. Caring and treatment of a child with cancer brings an enormous physical, psychological, social & economical burden upon the family. **Objective:** The objective of the study was to assess the level of hopelessness of the parents with a child suffering from cancer. **Materials and Methods:** The study was conducted among 217 parents with childhood cancer among which 129 were mothers and 88 were fathers, recruited from the Bangabandhu Sheikh Mujib Medical University and Dhaka Medical College Hospital, Dhaka from January 2018 to November 2018. The research participants were selected following the convenient method of sampling on the basis of defined selection criteria. The data were collected by face to face interview of the respondents respectively maintaining privacy and confidentiality using a questionnaire called Beck Hopelessness Scale. The research instruments were interviewer's questionnaire and hopeless measuring standard scales. **Results:** A total 19.4% (n=42) had severe hopelessness and 4.6%(n=10) had minimal hopelessness status. That, mothers were more severely affected by hopelessness than fathers. Among the 19.4% of the parents with severe hopelessness 28.7%,(n =37) were mothers and only 5.7%,(n=5) were fathers. That parents who were less educated were more severely affected by hopelessness than higher educated parents. **Conclusion:** Efficiently designed investigations are important to assess and treat psychological distress of the parents with childhood cancer patient.

**Key words:** Hopelessness of the Parents, Childhood ,Cancer.

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### Introduction

Cancer is a long-term chronic illness that affects both parents and child as well. Thus, childhood cancer can be considered as a family disease. According to the parents' statement diagnosis and treatment of childhood cancer is one of the stressful times in their life. The stress and depression starts with the feeling of hopelessness.<sup>1</sup> The feeling of hopelessness begins immediately after the diagnosis and continues through the treatment. Caring and treatment of a child with cancer brings an enormous physical psychological, social and economical burden upon the family.<sup>2</sup>

The feeling of hopelessness is the reflection of unwanted events and difficulties which is caused by the disease upon the

members of the family. The difficulties for the families are consisting of burden of care, financial need, housekeeping and work activities and subjective burden such as psychological reaction that family member experience such as communicating the siblings of an ill child, dealing with the reaction of others and concern about the child future and depression.<sup>3</sup>

Frequent and long term treatment and hospitalization, medical problem of the children and even present risk of relapse are also the reason of hopelessness of the parents with sick child. Having a child with cancer the parents a social isolation because cancer diagnosis needs long and expensive treatment and care plan. Sometimes either father or mother has to quite

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job, cannot participate in social activities or having time for themselves resulting high level of hopelessness and depression.<sup>4</sup>

As Bangladesh is a middle income country and data was collected from government hospital where most of the respondents are middle class or lower middle class so the economical burden were very painful for them. The parents were psychologically so disturbed that they assume it was their fault of their previous mistake that their child has to suffer such a dangerous disease.<sup>3-5</sup>

In our country parents don't get any kind of psychological support or consultancy in spite of huge psychological depression, hopelessness and anxiety. But parents should also be psychologically strong and they need to learn some coping strategy to fight against hopelessness and depression as they are the only emotional, physical and psychological supporter and care giver of their child. This study contributed to understand the effect of hopelessness of the parents with childhood cancer. The study is crucial for the professional in order to develop culturally sensitive intervention.

## Materials and Methods

A cross sectional study was conducted to find out the proportion of hopelessness among parents of childhood cancer patients. Respondents were selected from indoor and outdoor patient attended in pediatric hematology department of Dhaka Medical College and oncology department of BSMMU. The total period of study was from January 2018 to November 2018. The protocol was approved in 1st week of February and then review of literature and development of research instruments were performed. Data were collected from 1st week of September to last week of August. Study population was either father or mother of 217 cancer children who was less than 18 years of age, who will voluntarily participate in the study. Study places were selected purposively for the convenience of the study. Purposive sampling technique was adopted. All the available parents during data collection period who fulfilled the study selection criteria were included in the study. The research instruments were interviewer's questionnaire and Beck hopelessness scale. Prior to data collection instrument permission was taken from the head of selected institutions. Written informed consent was also taken from each respondent. A questionnaire was developed and pre-tested among the parents, who were excluded from 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. Only positive respondents were selected as research participants consistent with the selected criteria. The research assistant recorded socioeconomic profile of them following questionnaire. The levels of hopelessness of the respondent were assessed by resident psychiatrist using standard scale. Beck hopelessness scale was used to assess hopelessness level of the respondents. In the scale 20 self answered questions were used. Two answers were in the scale for each item. The score categorized as 0-3, 4-8, 9-14 & 15-20 were minimum, mild, moderate, and severe. The respondents were interviewed face to face maintaining their privacy. The interview was conducted anonymously as far

possible. Before preceding the data collection, the detail of the study was explicitly explained to each eligible respondent and verbal consents from the respondents were obtained.

After collection all the data were checked and edited. Hopelessness score was constructed by summation of all 20 items of hopelessness scale. The data were entered into the computer with the help of software SPSS for windows programmed version 21. After frequency run, data were cleaned and frequencies were checked. An analysis plan was developed keeping in view with the objectives of the study. Cross tabulation was prepared and chi-square test was done to find out when and whenever required.

## Results

Socioeconomic profile of the studied parents having one child suffering from cancer was summarized in Table-I. Among the respondents 43.8% (n=95) were educated up to primary level, 22.1% (n=48) were educated up to SSC level, 17.5% (n=38) were up to HSC level and 16.65 (n=36) were illiterate. Fathers were comparatively higher educated than that of mothers. 38.7% (n=84) of respondents were house-wife, 24.9% (n=54) service holder 12% (n=26) were belonged to business, 16.6% (n= 36) were belonged to household workers, 5% (n=11) were belonged to rickshaw-puller and few percentage 2.8% (n=6) were belonged to farmer. majority 61.3% (n=133) of the parents had monthly family income up to 10000 taka, 17.1 (n=37) had monthly family income in between 10001 to 15000 taka and rest 21.7% (n=47) of them had monthly family income more than 15000 taka. The average monthly income of the family was 11903 with the SD  $\pm$  5313.7. Among the respondents 41.9% (n=91) were between 26 to 30 years, 27.6% (n=60) were between 20 to 25 years, 15.7% (n=34) were between 31 to 35 years and rest of them were 36 to 40 years. Mean age of the respondent was 28.7 $\pm$ 4.6 years. Maximum age of the respondent was 40 years and minimum age was 20 years.

**Table I:** Demographic status of the Parents (n=217)

Characteristics	Frequency	Percent (%)
<b>Educational status</b>		
Primary	95	43.8
SSC	48	22.1
HSC	38	17.5
Illiterate	36	16.6
<b>Occupation</b>		
household workers	36	16.6
service holder	54	24.9
Business	26	12
Farmer	6	2.8
House wife	84	38.7
Rickshaw-puller	11	5
<b>Family income</b>		
<10000	133	61.3
10000-15000	37	17.1
>15000	47	21.7
<b>Age (in years)</b>		
20-25 years	60	27.6
26-30 years	91	41.9
31-35 years	34	15.7
36-40 years	32	14.7

**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.

Among the children more 37.3% (n=81) had leukemia, more than one-fourth 20.7% (n= 45) had neuroblastoma, 19.8% (n=43) had lymphoma, 16.6% (n=36) had rhabdomyosarcoma and few percentage 5.5% (n=12) had reticuloblastoma. The type of cancer among the children of the respondents was described in table-II. Among the children 52.1% (n=113) were between 6 to 10 years, 30.4% (n=66) were between 3 to 5 years and rest of them were less than 10 years. Mean age of the children was 7.5± 2.9 years. Maximum age of the children was 15years and minimum age was 3 years.

**Table II:** Type of cancer among the children of the respondents

Cancer type	Frequency	Percent (%)
Leukaemia	81	37.3
Lymphoma	43	19.8
Neuroblastoma	45	20.7
Reticuloblastoma	12	5.5
Rhabdomyosarcom:	36	16.6

The assessment of the hopelessness among the parents with childhood cancer was summarized in table III. Results showed that 54.8% (n=119) of the parents had moderate hopelessness, of which 55.8%, (n=72) were mothers and the rest 53.4%, (n=47) were fathers respectively. About (19.4%, n=42) of the parents had severe hopelessness, of which 28.7%,(n =37) were mother and only 5.7%, (n=5) were fathers respectively. Mothers were found higher hopeless than that of fathers.

**Table III:** Hopelessness assessment of the parents with childhood cancer (n=217)

Parameters	Mothers(129) n (%)		Fathers (88) n (%)		Total= 217 n (%)	
Minimal	5	3.9	5	5.7	10	4.6
Mild	15	11.6	31	35.2	46	21.2
Moderate	72	55.8	47	53.4	119	54.8
Severe	37	28.7	5	5.7	42	19.4
Total	129	100.0	88	100.0	217	100.0

Among the respondents of up to primary level 51.3% (n=58) had moderate hopelessness and (26.4% (n=32) of them had severe hopelessness whereas respondents of more than primary level 20.7% (n=14) had moderate hopelessness and only (10.6%) had severe hopelessness status.

Educational status of parents was significantly associated with hopelessness status. (p=0.000). Among the lowest income group of less than 10000 taka more than half 52.5% (n=58) had moderate hopelessness and one-third 27%(n=33) of them had severe hopelessness whereas in the highest income group more than 15000 taka only 10% (n=5) had moderate 5.2% (n=3)had severe hopelessness status. Monthly family income was significantly associated with hopelessness status. Parents who had no financial support 22.1% (n=25) of them had severe hopelessness whereas respondents those who were had

financial support only 6.8% (n=5) had severe hopelessness status. Financial support of parents was significantly associated with hopelessness status (p=0.002). The hopelessness assessment & its relation to socioeconomic factors was described in detail in table- IV.

**Table IV:** Distribution of hopelessness of the parents by education, income level, and financial support from family. (n=217)

Education level	Minimal (0-3) n (%)	Mild(4-8) n (%)	Moderat (9-14) n (%)	Severe (15- 20) n (%)
Up to primary level	3.6(0.0)	2(10.7)	58(51.3)	32(26.4)
More than primary level	5(1.4)	13(4.3)	14(20.7)	5(10.6)

### Discussion

A parents providing care and support to their child with cancer in this study reported, many factors that accounted for their feeling of hopelessness and burden, with which their child had to cope, worries about their child's recovery, feeling of inadequacy the care process, staying in the hospital for long time and being unable to make time for the other member of the family.<sup>2</sup> The contributing factor for stressors are similar to those reported to previous studies, such as the illness and treatment process, frequent long treatment and hospitalization, medical problem of the children and ever present risk of relapse. A mother's interviewed described psychological problem also. They said that they were easily agitated, felt anger at the slightest impetus and felt more sensitive and fragile.<sup>6,7</sup> Other studies have also shown that during the course of disease the mother have anxiety and stresses Mother tend to report more higher level of symptoms than father of child. Though this emotional manifestation decreases to near normal level over time in the majority of the parents but have been found to persist in a strong population of the parents, even many years of the post treatment. Moreover, mother tend to report more higher level of symptoms than father. This difference may be traditional distribution of care giving, task and responsibilities, parents with children with cancer are at risk of developing emotional manifestation of strains, which persist over time among a subset of parents. This is important to eliminate risk factors for the early detection and give support to the parents.<sup>7-9</sup>

Cancer is the uncontrolled and abnormal growth of cells in the body. There are many causes of it including benzene and others chemicals, certain poisonous mushrooms and a type of poison that can grow on peanut plant (aflatoxins), certain viruses, radiation, sunlight and tobacco use. However, the causes of many cancer are still unknown. There are some influential factors for cancer also such as social stigma, malnutrition, unhygienic environment and overcrowding. All these influencing factors are highly prevalent in Bangladesh.<sup>8-12</sup> People living with cancer and any other chronic diseases the victim of social stigma that cause mental disturbance and depression. Government of Bangladesh with joint collaboration with World Health Organization has undertaken multiple prevalent measures against this human catastrophe. It is one of the major causes of human disability.

In Bangladesh this present study was undertaken to assess depression particularly hopelessness of the parents having a child suffering from cancer.<sup>13</sup>

BSMMU a specialized public hospital for cancer and DMCH present a special opportunity to study the hopelessness of the parents in a semi-controlled environment. Mental treatment regiments are very much limited in hospital. Scientific evaluation and enlightened motivated attitude toward chronic disease including cancer might reduce the oppressive warding of the parents from social stigma. It may need to aware of the parents to the concomitant loss of many of their civil rights. It will help to develop a confidence of the parents to the treatment of the child.

In this study we have found that majority of the parents were poorly educated that is 43.8% was in primary level and 16.6% were illiterate. Father was found higher educated than that of mother. Most of the respondents were house wife. 24.9% were service holder and 16.6% were house hold workers. Most of the mothers were house wives. 61.3% family income level were less than 10000 taka. Only 21.7% parent's in income level were more than 15000 taka. Most of the parents had two children 22.6% had 1 child and 185 had 3 or more than 3 children. Most of the children were suffering from leukemia which is 37.3%. 19.8% children had lymphoma, 20.7% children had neuroblastoma. Retinoblastoma and rhabdomyosarcoma affected children were respectively 5.5% & 16.6%. 19.4% parents had severe hopelessness and very few that is 4.6% had minimal hopelessness. This study showed that mothers were more affected than fathers. This study also showed that 54.8% of the parents had moderate hopelessness of which 55.8% were mother and 53.4% were father about 19.4% of the parents had severe hopelessness of which 28.7% were mother and 5.7% were father.

Most of the study have showed that mothers are more severely affected by hopelessness and depression than fathers. A diagnosis of cancer in a child and the sequela of this disease cause to view the life in negative terms. Father and mother should be provided with social support to cope with the disease. Positive support can act as a buffer against hopelessness.<sup>14</sup> In this study the level of hopelessness of parents were lower who received support from their family. Other studies have found a positive correlation between hope and social support and negative correlation between social support and depression. In one study parents with cancer reported that they received support from their family and health care staff but the greatest support was provided by their spouses. Authors found that mothers tend to receive support from their families and friends and fathers tend to receive support from their male friends and work colleagues.<sup>15-17</sup> Researchers found that social support has a positive impact on coping with cancer experience. An author reported that fathers of a chronically ill child are deprived of support from their spouses during the period.cancer treatment can reduce the arduous and exhausting burden placed on parents for this reason the physician should ensure that parents have social support and they can get access to psychological care well.<sup>11</sup>

A study from Iraq showed that 54.1% of parents with childhood cancer had severe depression. The depression level is severe there because according to the author, mother spend more time with children than father and also majority of the parents have four children which is another cause of depression among the parents. Another study from Pakistan showed that 79% of mothers were found to be depressed, among them 5% were severely depressed. The cause of depression on that study was political instability.<sup>11</sup>

Hope is very important to cope with stress and achieve positive health outcome physical well-being and lower level of depression and anxiety are among the characteristics of helpful/ optimistic individual. One study reported that optimistic mother of hospitalized children experiences less stress and that they are more active and use effective coping strategy. Physician should be aware of the sorrow experience of the family and they should also provide supportive initiative to maintain their hope, beliefs and to cope with their depression.

Melalhal et al reported that the level of depression of the mother increased as their hopelessness and depression of the father. ( $r=0.598$ ,  $p<0.011$ ) & the level of depression of the father increase as the hopelessness level increase. He also found statistically significant difference between the mother who stated that they were supported by their families and the mother who stated either. Basher et al stated in a study that held in 2011 in Dhaka. In that study all parents were found educated in graduate and above.<sup>3</sup> 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 was  $33 \pm 8$  years. The type of cancers among the children of the respondents were 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. 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. 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.

According to the author, 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.

## Conclusion

In this study mothers were found highly hopeless than that of fathers. The patriarchal society, religious stigmatism as well as socio-cultural impact may be the important contributing factor for increased level of hopelessness of mother. Most of the parents were poorly educated. Moreover Cancer treatment is very much costly and it is also a long term treatment procedure. Hence financial burden is one of the major causes of hopelessness among the parents.

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