

A descriptive study to assess the psychosocial distress among caregivers of prospective bone marrow transplant patients in a selected tertiary hospital of Delhi

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Abstract

Cancer is a condition where the body's cells begin to grow and reproduce in an uncontrollable way. The three main causes of death due to cancer are cancer of Lung, Stomach and Liver. The distress of caregiver is a major phenomenon faced by prospective care givers of young bone marrow transplant recipients. The care giver experiences an unpleasant emotional experience of psychological, social or physiological nature which affects the ability of care giver towards its treatments. **Objective** To assess the level of psychosocial distress among various demographic variables. To evaluate the relationship between psychosocial distress with demographic variables in the care giver of the prospective BMT patients. **Material and Method** an evaluator approach was used to assess the level of stress among the caregivers of children undergoing BMT in a selected tertiary hospital of Delhi. Demographic data was collected through a semi –structured tool. The level of stress was assessed using Distress Thermometer. Analysis was done using descriptive and inferential statistics **Results and Discussions** In the present study out of 30 samples 80% had moderate stress and 20% had severe stress. Mean distress score of the sample was that there exist statistically significant association between psychosocial distress and selected demographic variables. The distress level of Males was higher as compared to Females .The personality characteristics of the caregiver are related to social support. The present study corresponds with the study conducted by PC Trask et al that Psychosocial distress is associated with a numbers of negative outcomes during BMT and half patient at the time of initial consultation for BMT already experience significant levels of psychological distress.

Keywords: Distress, anxiety, bone marrow transplant, caregiver, psychosocial distress

Introduction

Cancer is a general term used to refer to a condition where the body's cells begin to grow and reproduce in an uncontrollable way. Bone marrow transplantation has been used with increasing frequency to treat numerous malignant and non - malignant diseases. With the advance techniques, indications and therapy over the years, the transplant of hematopoietic stem cells has evolved as an advancing field in the treatment of human diseases.

The diagnosis of childhood cancer is one of the most intense, troublesome and enduring experiences that parents can have. The often unexpected and life-threatening diagnosis and the initiation of invasive medical treatment and its sequel interfere with the entire family's normal activities and routines for a long period of time and improve stressors of varying duration predictability and impact. When parents are confronted with a diagnosis of cancer in their child a process starts, referred to as psychosocial diseases.

In addition, Distress is defined as a multi factorial unpleasant emotional experience of a psychological, social or physiological nature which affects the ability of care giver towards its treatments. Now a days, family member are gradually taking on the role of full time care giver for patients suffering from cancer. The increasing burden and task of care taking can cause psychological distress to the care givers thus leading to depression/anxiety. The symptom of distress can range from person showing dis-interest, sadness, anxiety, nervousness followed by somatic symptoms such as headache, fatigue and insomnia. Psychological distress is not merely associated with the inability to conduct daily course but it is a major cause for other psychiatric disorder symptom such as *major depression* and *generalized anxiety disorder*.

Need for the Study

Incidence of childhood cancer in India is 38-124 per 10 lakh children per year and 40,000 new cancer cases seen in India each year. Nearly 30% of children with blood cancers require BMT. The cure rate of cancer with BMT is 50%. In September 2005, data were collected from six transplant centers in India and a total 1540 transplants have been performed in India these centers .In AIIMS-210, CMC Vellore-639, TMH, Mumbai-268. Indications for autologous transplant were multiple myeloma, NHL, HL and acute myeloid leukemia and indications for allogenic transplants were thalassemia major, aplastic anemia, chronic myeloid leukemia and acute lymphoblastic and myeloid leukemia.

India's first successful allogenic BMT was done on 20th March 1983 at Tata Memorial hospital was then just a nine year old girl. Her disease (acute myeloid leukemia) disappeared; she went on to complete her studies and currently enjoying happy married life. BMT is an effective but high-risk and demanding procedure used increasingly in the treatment of childhood leukemia, as well as other malignancies and serious childhood illnesses. Although it remains a risky procedure with a range of possible physical complications, medical advances have decreased mortality rates for children who undergo the treatment. BMT survivors continuing to increase, research has therefore focused on the psychosocial difficulties for their families who are undergoing this stressful procedure.

The illness involves a series of distinct stressors (e.g., diagnosis, invasive procedures, hospitalizations) for the child and parent that last for many years. The available research suggests that the majority of children surviving cancer transition out of treatment with relative ease and few symptoms of behavioral or emotional distress, but a small subset may experience higher distress which can compromise both psychosocial and medical outcomes.

Typically, one parent stays with the child throughout the procedure and experience lot of psychosocial distress.

Aim Of the Study

To assess the stress level of caregivers a study was conducted at Army Hospital R&R using descriptive design on a sample of 30 candidates. The caregivers stress level was assessed with the help of distress thermometer standardized tool.

Methodology

To assess the level of psychosocial distress among various demographic variables. To conduct this study Caregivers coming to the hematology OPD in a tertiary care hospital were identified as the target population using non probability purposive sampling. The data collection was done using a structured questionnaire .Data was collected for April –July 2018.Purposive sampling technique was used to select the sample .In Hematology OPD every Thursday during TLB meeting for pre BMT children during 1100 hrs to 1300 hrs. The investigator had interviewed a maximum of 3-4 samples per schedule day. A verbal informed consent was obtained from each sample after giving a detailed description of the study to alleviate the anxiety of the sample, and the tool was administered in the language they understand.

NCCN Distress Thermometer was used as tool. Tool consisted of two parts mainly sociodemographic characteristics and distress level. Questionnaire consisted of 4 heading namely practical problems, family problems, emotional problems, spiritual and religious concerns and physical problems. Tool: NCCN Distress Thermometer: - The DT has been developed by the National cancer center network for identifying distress in cancer. It has been described as a non threatening way to indicate distress that they may otherwise not report. The scale is modified visual analog scale that look like a thermometer and ranges from ‘0’ (no distress) to ‘10 ‘ (extreme distress). Caregiver instructed to give / tick Yes or No in the scale for accessing the stress level of the caregiver of prospective BMT children The collected data was coded, tabulated and analyzed using descriptive and inferential statistics, The collected data was coded, tabulated and analyzed using descriptive and inferential statistics, Analysis of the results was done and summary was drawn on the distress of caregivers.

NCCN National Comprehensive Cancer Network*
NCCN Distress Thermometer and Problem List

NCCN DISTRESS THERMOMETER
 Instructions: Please circle the number (0–10) that best describes how much distress you have been experiencing in the past week including today.

Extreme distress 10
 9
 8
 7
 6
 5
 4
 3
 2
 1
 No distress 0

PROBLEM LIST
 Please indicate if any of the following has been a problem for you in the past week including today.
 Be sure to check YES or NO for each.

YES	NO	Practical Problems	YES	NO	Physical Problems
<input type="checkbox"/>	<input type="checkbox"/>	Child care	<input type="checkbox"/>	<input type="checkbox"/>	Appearance
<input type="checkbox"/>	<input type="checkbox"/>	Housing	<input type="checkbox"/>	<input type="checkbox"/>	Bathing/dressing
<input type="checkbox"/>	<input type="checkbox"/>	Insurance/financial	<input type="checkbox"/>	<input type="checkbox"/>	Breathing
<input type="checkbox"/>	<input type="checkbox"/>	Transportation	<input type="checkbox"/>	<input type="checkbox"/>	Changes in urination
<input type="checkbox"/>	<input type="checkbox"/>	Work/school	<input type="checkbox"/>	<input type="checkbox"/>	Constipation
<input type="checkbox"/>	<input type="checkbox"/>	Treatment decisions	<input type="checkbox"/>	<input type="checkbox"/>	Diarrhea
			<input type="checkbox"/>	<input type="checkbox"/>	Eating
			<input type="checkbox"/>	<input type="checkbox"/>	Fatigue
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with children	<input type="checkbox"/>	<input type="checkbox"/>	Feeling swollen
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with partner	<input type="checkbox"/>	<input type="checkbox"/>	Fevers
<input type="checkbox"/>	<input type="checkbox"/>	Ability to have children	<input type="checkbox"/>	<input type="checkbox"/>	Getting around
<input type="checkbox"/>	<input type="checkbox"/>	Family health issues	<input type="checkbox"/>	<input type="checkbox"/>	Indigestion
			<input type="checkbox"/>	<input type="checkbox"/>	Memory/concentration
			<input type="checkbox"/>	<input type="checkbox"/>	Mouth sores
<input type="checkbox"/>	<input type="checkbox"/>	Depression	<input type="checkbox"/>	<input type="checkbox"/>	Nausea
<input type="checkbox"/>	<input type="checkbox"/>	Fears	<input type="checkbox"/>	<input type="checkbox"/>	Nose dry/congested
<input type="checkbox"/>	<input type="checkbox"/>	Nervousness	<input type="checkbox"/>	<input type="checkbox"/>	Pain
<input type="checkbox"/>	<input type="checkbox"/>	Sadness	<input type="checkbox"/>	<input type="checkbox"/>	Sexual
<input type="checkbox"/>	<input type="checkbox"/>	Worry	<input type="checkbox"/>	<input type="checkbox"/>	Skin dry/itchy
<input type="checkbox"/>	<input type="checkbox"/>	Loss of interest in usual activities	<input type="checkbox"/>	<input type="checkbox"/>	Sleep
			<input type="checkbox"/>	<input type="checkbox"/>	Substance abuse
			<input type="checkbox"/>	<input type="checkbox"/>	Tingling in hands/feet
<input type="checkbox"/>	<input type="checkbox"/>	Spiritual/religious concerns			

Other Problems: _____

Description of the Tool: Tool consisted of two parts *Part 1 Socio demographic characteristics and Part 2 Distress thermometer (Coping with stress)*. Part 1 Socio demographic characteristics: This section gave overall information regarding socio demographic characteristic of caregiver that is age, gender, occupation, marital status. Part 2 Distress thermometer (Coping with stress): The DT has been developed by the National cancer center network for identifying distress in cancer. Questionnaire was to assess the stress level of prospective BMT patient. Pilot study was conducted on the basis of this distress thermometer.

Questionnaire was consisted of 4 heading namely practical problems, family problems, emotional problems, spiritual and religious concerns and physical problems such as Practical problems consisted of 5 questions, Family problems consisted of 4 questions, Emotional problems, spiritual/religious concerns consisted of 7 questions and Physical problem consisted of 21 questions with 2 options yes and no for each. For each yes 2 marks were allotted and total of 74 score. The % range of less than 30% were mild stress 31-51% were moderate stress and more than 52% were sever distress.

A pilot study was conducted in March 2018, to check the feasibility of the study and validity and reliability of tool and to foresee problems which might arise. Study was conducted on 5 samples as per the inclusion criteria and who were willing to participate. Reports 80% of caregivers had moderate distress and 20% had severe distress.

Results

Analysis is the process which enters into research in one form or another from the very beginning. It may be fair to say that research consist in general of larger steps the gathering data, and analysis of this data. The process of analysis, relationships or differences, supporting or conflicting with original or new hypothesis should be subjected to statistical tests of significance to determine with what validity data can be said to indicate any conclusions.

Data was collected from 30 caregivers. Whose children were prospective BMT patients? The samples were taken from Haematology OPD of a tertiary care hospital. The purpose of analysis was to reduce the data to an intelligible and interpretable form so that the relation of research problem could be studied and hypotheses could be tested.

Mean score was calculated as Practical problems 10 (2×5), Family problems 8 (2×4) and Emotional problems, spiritual/religious concerns 14 (2×7). Physical problem 42 (2×21) For each yes 2 marks were allotted and total of 74 score. Total 30 samples of caregivers and mean score was range between ≤ 30 were mild stress, 31-51 were moderate stress and ≥ 52 was severe distress.

Table1: Description of samples according to distress level in the selected samples.

<u>SNO</u>	<u>ITEM</u>	<u>FREQUENCY</u>	<u>PERCENTAGE</u>

(a)	Mild	0	0
(b)	Moderate	24	80
(c)	Severe	6	20

Table 1 and Fig 1 depicts that out of 30 selected samples, majority of them 80% were having moderate level of stress and 20 % were in severe stress.

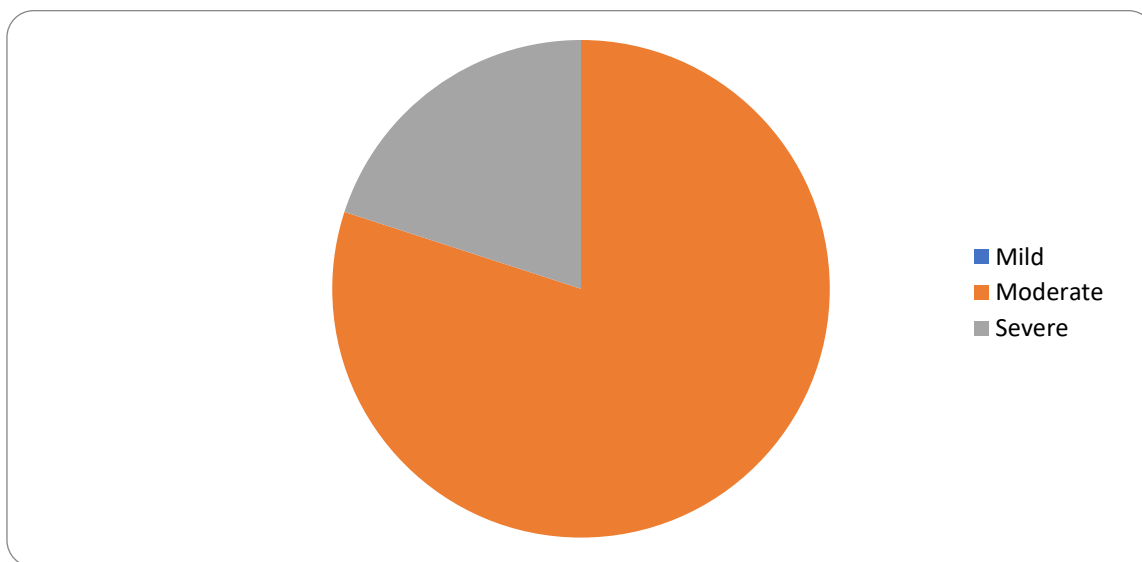


Figure 1 : Distribution of caregiver as per Stress Level

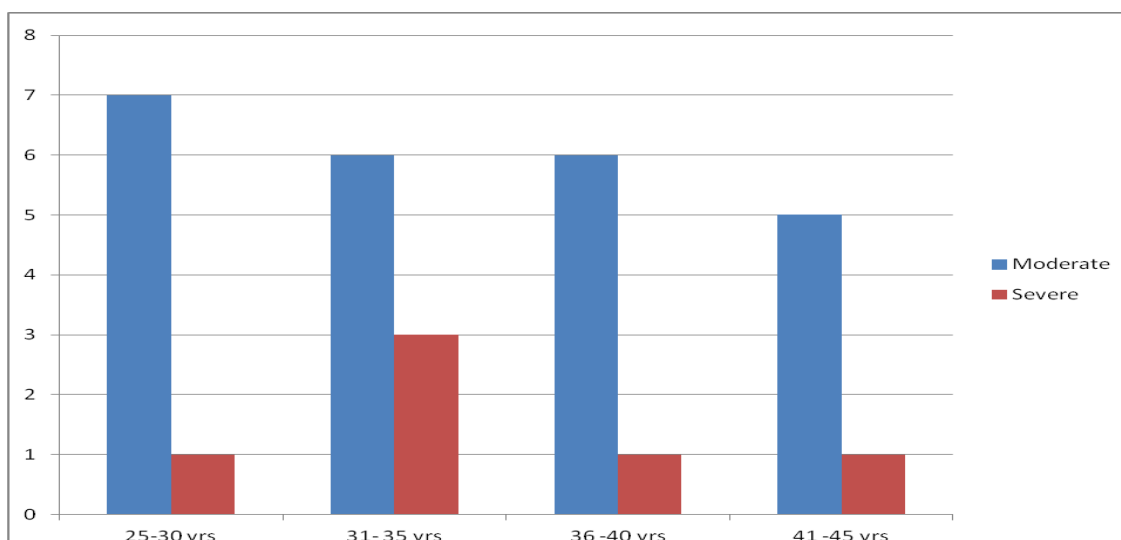


Figure 2 : Distribution of sample as per Stress Level of Age

Table 2 : Association between Age of caregiver and level of stress

S No	Level of stress Age of	Moderate	Severe	Total	Chi-square	P-value
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	<u>caregiver</u>					
(a)	25-30 yrs	7	1	8	1.4658	0.69019
(b)	31-35 yrs	6	3	9		
(c)	36-40 yrs	6	1	7		
(d)	41-45 yrs	5	1	6		
Total	30	24	6	30		

Table 2 Fig 2 depicts that out of the selected sample stress level of age group 31-35 yrs were higher as compare to 25-30 yrs, 36-40 yrs and 41-45 yrs. The chi-square statistic is 1.4658 and The p value is 0.69019. The result is not significant at $p < 0.05$.

Discussion

In this study, we compared the caregiver's psychosocial distress and analyzed the relative contribution of variety of socio demographic factors regarding the stress level of caregivers. The study was conducted in Haematology OPD of a tertiary hospital (N=30) on the caregiver of the prospective BMT Children. A descriptive design was adopted for the population consisted of caregivers whose children were prospective BMT patients.

To assess the level of psychosocial distress among caregiver of prospective BMT patients. In the present study among 30 selected samples, majority of them were having moderate level of stress i.e. 80% and 20% were in severe stress. Questionnaire was consisted of 4 heading namely practical problems, family problems, emotional problems, spiritual and religious concerns and physical problems. The % range of less than 30% were mild stress 31-51 were moderate stress and more than 52% were severe distress. majority of them were having moderate level of stress i.e., 80% and 20% were in severe stress.

To evaluate the relationship between psychosocial distress with demographic variables in caregiver of prospective BMT patients. In the present study out of the selected sample stress level of age group 31-35 yrs were higher as compare to 25-30 yrs, 36-40 yrs and 41-45 yrs. The chi-square statistic is 1.4658 and The p value is 0.69019. The result is not significant at $p < 0.05$.

The present study correspond with the study conducted by PC Trask et al that Psychosocial distress is associated with a numbers of negative outcomes during BMT and half patient at the time of initial consultation for BMT already experience significant levels of psychological distress. In the present study 80% of caregivers had experience moderate distress and 20% caregivers had experience severe distress in their initial consultation.

In the both study tool Distress thermometer is useful screening device.

Conclusion

It is important to note that the personality characteristics of the caregiver are related to social support. Intervention programs could be targeted more easily to obtaining and maintaining supportive interactions than to changing the caregiver's personality characteristics. However, the results of the current study suggest that both social support and caregiver personality characteristics are amenable to change, and therefore both are worthwhile targets for intervention.

Health care practitioners dealing with informal caregivers at home should provide skills to obtain and maintain feelings of mastery and positive interactions, without neglecting attention to negative interactions. We also Advise researchers who are studying the cancer care giving process to include various aspects of social and psychological resources in their models.

More research can be conducted to investigate the role of resources in care giving in general, and with respect to different types of caregivers and different diseases over a longer period of time to identify ways to maintain and maximize the health of informal caregivers. Clearly, more research is needed regarding the role that these factors play in influencing how caregivers maximize their own health as well as the health of their partners.

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