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Care Giving a Child with Cancer: A Psycho –Social Perspective Study

Dr. K.Sathyamurthi,

Associate Professor, Dept. of Social Work, Madras School of Social Work, Chennai -8 Email : ksm@mssw.in.Mob: 9940406590.

ABSTRACT

Cancer is a scary disease that can often have very scary consequences, and when it afflicts a young child, the prospect of a worst-case scenario can often push a parent or caregiver's emotions to the limit. Each year, an estimated 215 000 cancers are diagnosed in children younger than 15 years, and about 85 000 cancers in those aged 15–19 years. Childhood cancer contributes to less than 5% of the total cancer burden in India, with approximately 45,000 children diagnosed with cancer every year. The parental care giving a child with cancer with psycho social care and support paper was studied in the hospitals in Chennai by selecting samples conveniently with consent from the care givers. Majority of the care givers were found stress from the Care Givers Strain Index (CGSI) and the psycho social care and support was less to the care givers. Research findings indicate that caregiver stress can lead to psychological and sleep disturbances and changes in caregivers' physical health, immune function, and financial well-being. Based on the research findings of the study among the caregivers of children with cancer, by using the social work methods the stress can reduce many of these negative effects and improve caregivers' coping skills, knowledge, and quality of life. Although these social work interventions also improve care givers physical and mental health, they are seldom implemented in practice.

Keywords *: Care Giver, Psycho-Social care and support, Cancer and Children*

I. Introduction

Cancer is a scary disease that can often have very scary consequences, and when it afflicts a young child, the prospect of a worst-case scenario can often push a parent or caregiver's emotions to the limit. Cancer is defined as a group of diseases that is due to uncontrolled division of abnormal cells in any part of the body. Childhood cancer is a life threatening, non-communicable condition that has been on the rise globally. Sometimes, a child or parent will feel at fault, and while this is also normal, it must be understood that most types of childhood cancer could not have been prevented. Cancer is the leading cause of death from disease among children and adolescents in the United States. Although substantial progress has been made in the treatment of several types of childhood cancer over the past five decades, progress against other types has been limited. Even when long-term survival is achieved, many survivors of childhood cancer may experience long-term adverse effects from the disease or its treatment.

Each year, an estimated 215 000 cancers are diagnosed in children younger than 15 years, and about 85 000 cancers in those aged 15–19 years. These estimates are based on data collected by the International Agency for Research on Cancer (IARC) from population-based cancer registries around the world. In 2018, WHO launched the Global Initiative for Childhood Cancer with partners to provide leadership and technical assistance to support governments in building and sustaining high-quality childhood cancer programmes. The goal is to achieve at least 60% survival for all children with cancer globally by 2030.

II. Background of the Study

Childhood cancers (age at diagnosis: 0-14 years) comprise a variety of malignancies, with incidence varying worldwide by age, sex, ethnicity and geography, that provide insights into cancer etiology. A total of 1,334 childhood cancers registered in population-based cancer registry, Chennai, India, during 1990-2001 and categorized by International Classification of Childhood Cancer norms formed the study material. The age-standardized rates for all childhood cancers together were 127 per million boys and 88 per million girls. A decreasing trend in incidence rates with increasing 5-year age groups was observed in both sexes. The top five childhood cancers were the same among boys and girls: leukaemias, lymphomas, central nervous system neoplasms, retinoblastomas and renal tumors. The highest 5-year absolute survival was observed in Hodgkin's disease (65%) followed by Wilm's tumor (64%), retinoblastomas (48%), non-Hodgkin's lymphomas (47%), osteosarcomas (44%), acute lymphoid leukemia and astrocytoma (39%). Multifactorial analysis of age at diagnosis and sex showed no differences in the risk of dying for all childhood cancers. Childhood cancer contributes to less than 5% of the total cancer burden in India, with approximately 45,000 children diagnosed with cancer every year. In the developed countries 80% of the children with cancer are cured. Therefore, in India, the cure for children with cancer should be a priority. To achieve such rates of cure, we need to define the burden with accurate data, determine where the barriers exist and intervention may be beneficial, and measure the impact of any intervention made. To this end, Arora and his colleagues have taken the admirable first step of providing a comprehensive picture of the epidemiology of childhood cancer in India, and have done a commendable job of reviewing the available literature and including data from 13 population-based cancer registries (PBCR) across India.

Lund L Ross (2014) study highlights that most caregivers experienced psychosocial burden with 75% reporting being overwhelmed by the role. Symptoms of burnout such as headaches, insomnia and fatigue have been reported to be prevalent amongst caregivers. Anna Boynton (2018) study highlight that Childhood cancer does not just affect the child, but it affect the broader family. There are impacts for the social, emotional and financial well-being of the family. There are support agencies available to assist families during and after their cancer journey. More research is needed to investigate the psychosocial supports required by the entire family.

In India, it is estimated that nearly 40-50,000 new childhood cancer cases occur each year. It is a Cankids estimate that not more than 20000 cases are being diagnosed. Of those that are diagnosed a large percentage come in fairly advanced stages of cancer. Despite the high cure rates in developed countries, it is estimated that in India 70% children die of cancer due largely to lack of awareness, late detection and late diagnosis, inadequate facilities, the high cost of treatment and the absence of supportive care. (CANKIDS, 2019).

Advances in medicine and technology have drastically reduced the mortality due to cancer. To this end, the World Health Organization (WHO) attests that the survival rates of paediatric cancers have risen up to about 75 per cent. Consequently, improvements in treatment have brought about transition of cancer from being a fatal to a chronic condition. Cancer is associated with multiple impairments, which calls for a multi-disciplinary approach to care.

Treatment invariantly includes regular visits to specialised healthcare institutions for chemotherapy, radiotherapy, surgery, rehabilitation amongst other specialist medical services. Additionally, due to the complexity of the condition, family members assume an essential role in the management of children with cancer. With the increase in costs of medical services, there is now emphasis on early discharge and self-management, strong shift of care from health-care settings to community care. This consequently increases the burden of caregiving to informal caregivers. An informal caregiver is defined as an individual who provide ongoing care and assistance, without pay, for a child in need of support due to physical, cognitive, or mental health conditions. The caregiver is involved in numerous caregiving roles throughout the illness trajectory, but often do not have training for the presumed role. The roles of the caregiver include being a legal assistant, managing medical emergencies, planning transition from home to hospital and offering psychological and social support. The caregiving roles can be fulfilling in that they bring about personal satisfaction and bonding with child. For mothers in the African culture, caregiving is a cultural obligation and an expected role for women.

III. Methods

a. Study Setting

The study of care giving a child with cancer was conducted in Chennai City of Tamil Nadu, the study participants were identified through the hospitals and nongovernmental organisations working with the children affected by cancer and their care givers.

b. Study Participants

The study participants were the care givers of children affected with cancer were identified as the respondents those who are receiving the treatment in various private, Government and Non-Governmental organisations and willing participate by giving consent for the study. The caregivers were supposed to have provided care for at least a month prior to the study, were caregiving a child of less than 18 years of age and were not themselves suffering from a psychiatric morbidity or a chronic health care condition.

c. Sampling

In the year 2018-19, children receiving treatment in the paediatric wards/oncology ward in Hospitals or beneficiaries for the above said period. Thus assuming universe of the study and that the participants would report of caregiver burden. The minimal sample size was 67 at 0.05 alpha, design effect of one and one cluster. The sample size was calculated using StalCal function of Epi-info version 7. Caregivers were conveniently/purposively selected.

d. Tools of Data Collection

Interview Schedule was used as the tool for Data Collection as the researcher cannot expect that all the respondents would be literates. The content of the tool would include Demographic Profile, Awareness regarding the Disease, Psychological Aspects, Social Aspects, Economical Aspects and the Treatment for the illness. The tool also had the questions related to Caregiver Strain Index (CSI) which had contributed in measuring the level of stress among the respondents.

Ethical considerations:

Written consent was sought from caregivers who were assured that decline to participate would not prejudice their access to medical care and that participation was entirely on voluntary basis.

Data analysis:

Raw data were entered on Excel and we used SPSS 22 for data analysis. Descriptive statistics were used to present participants socio-demographics, frequencies of reported problems.

IV. Results

The Primary data collected was analyzed as univariat, bivariat analysis, diagrams and correlation was done with the independent and dependent variable.

a. Demographic profile

The demographic profile of the respondent's age of the child, age of the care taker, religion, place of residence, marital status, family income and family type and number of siblings. Nearly half (47.8%) of the children is between 4 to 7 years age, more than one third (35.8%) of children is between 8 to 11 years age. Fifty (50.7%) per cent of the care givers were between 26 to 35 years, more than half (58.3%) of the care givers were hindu, sixty four percent of caregivers from rural areas, vast majority (95.5%) were married and 4.5 per cent were divorced care givers. Fifty two percent of the care givers live in Nuclear family and monthly income of the care givers were between Rs.1000 to 10000 only and sixty two percent of the children affected with cancer has maximum of three siblings out of which sixty three percent of them have two siblings.

Table No. 1 Demographic Profile of the respondents

Variable		Frequency	Per cent	Total
Age of the Child	0 to 3 years	11	16.4	67 (100)
	4 to 7 years	32	47.8	
	8 to 11 years	24	35.8	
Age of the Care taker	Below 25 years	6	9.0	
	26 to 35 years	34	50.7	
	36 to 45 years	18	26.9	
	46 to 55 years	9	13.4	
Religion	Hindu	39	58.3	
	Muslim	17	25.3	
	Christian	11	16.4	

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Place of Residence	Rural	43	64.2	
	Urban	24	35.8	
Marital Status of Care taker	Married	64	95.5	
	Divorced	3	4.5	
Family Type	Nuclear	35	52.2	
	Joint	32	47.8	
Family Income	Less than Rs.1000	4	6.0	
	Rs.1000 to 3000	10	14.9	
	Rs 3001 to 5000	27	40.3	
	Rs. 5001 to 10000	14	20.9	
	Above Rs.10000	12	17.9	
Number of Siblings	One	12	17.9	
	Two	42	62.7	
	Three	13	19.4	

The below figure shows, that the age when the child was diagnosed with cancer and reasons for cancer and their belief about the cancer affected the child. It is found that, the age is distributed among the various ages from below 2 years to 6 years and above, thirty four percent of them believe that the cause of cancer is curse or fate and one fifth (20.9%) of them opinioned that tumor or malign.

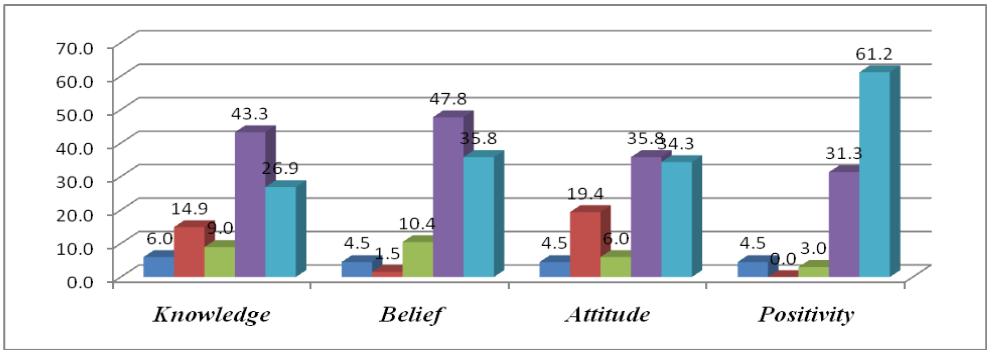
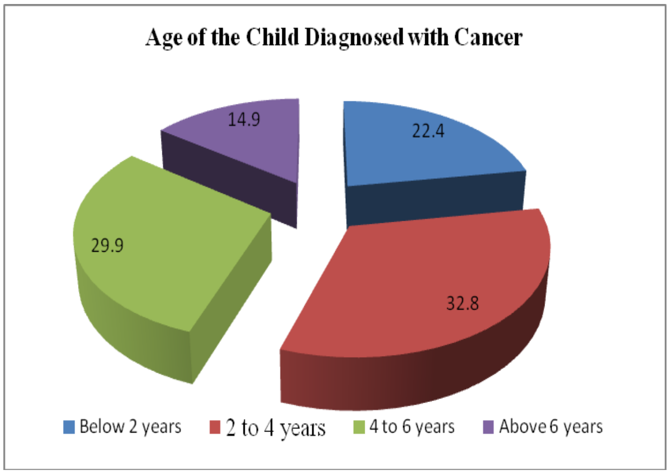


Figure No. 1. Respondents Psychological belief and attitude about their Chid with Cancer

Figure No. 2. Age of the Child diagnosed with Cancer and Reason for illness



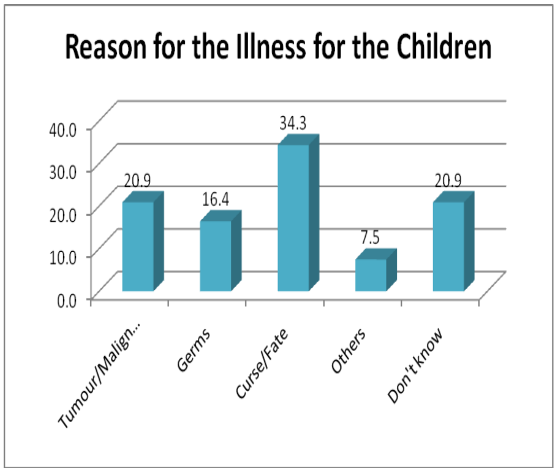


Table No. 2 Initial Psychological Reaction of Care Taker

S.No	Initial reaction	Frequency	Percent
1	Denial	1	1.5
2	Shocked	19	28.4
3	Depressed	25	37.3
4	Lost hope	14	20.9
5	Felt overburdened	8	11.9
Total		**67**	**100.0**

The above table shows that the initial psychological reaction of care taker after the child was diagnosed with cancer, thirty seven per cent were depressed, twenty eight per cent were shocked, one fifth of them were lost hope after their child was diagnosed with cancer.

Table No. 3 Type of Child Cancer

S.No	Type of Cancer	Frequency	Percent
1	Leukemia	40	59.7
2	Lymphoma	2	3.0
3	Brain Cancer	15	22.4
4	Bone Cancer	10	14.9
Total		**67**	**100.0**

Almost more than half (59.7%) of the child was diagnosed with leukemia, twenty two per cent were brain cancer fifteen per cent were with bone cancer and negligible per cent of them with lymphoma.

Table No. 4 Care Giver Strain Index

S.No	Care Giver Strain Index	Frequency	Percent
1	No Stress	4	6.0
2	Moderate level of Stress	58	86.6
3	High level of Stress	5	7.5
Total		**67**	**100.0**

The Care Giver Strain Index (CGSI) was adopted and classified as no stress (6%), Moderate level (86.6%) and high level (7.5%) for the care givers. Based on the study findings, the caregivers need to be supported by the psychologist, social workers and other mental health professionals to help them to cope up with the stress. It is also found that almost ninety four per cent of the care givers had stress.

Table No. 5 Level of Psycho Social Care and Support

S.No	Level	Frequency	Percent
1	Low	36	53.7
2	Moderate	21	31.3
3	High	10	14.9
Total		**67**	**100.0**

Psychosocial support can be both preventive and curative. It is preventive when it decreases the risk of developing mental health problems. It is curative when it helps individuals and communities to overcome and deal with psychosocial problems that may have arisen from the shock and effects of crises. These two aspects of psychosocial support contribute to the building of resilience in the face of new crises or other challenging life circumstances. It is found that, among the care givers fifty four per cent of them felt the support is very low, thirty one per cent has moderate and fifteen per cent of them has high level of psycho social care and support.

Correlation between Care Giver Age, Child Age, Religion, Education, Place of Residence, Marital Status, occupation, family type, income and Level of Care Giver Strain Index.

Correlations

		Care Giver Age	Child Age	Religion	Education	Place of Residence	Marital Status	Occupation	Family Type	Income	Level of Care Giver Strain
Care Giver Age	Pearson Correlation	1	.467**	-.221	.071	.346**	-.116	.179	-.083	-.161	-.022
	Sig. (2-tailed)		.000	.072	.569	.004	.349	.146	.502	.193	.860
	N		67	67	67	67	67	67	67	67	67
Child Age	Pearson Correlation		1	.133	.266*	.328**	-.268*	-.132	-.009	.080	.164
	Sig. (2-tailed)			.284	.030	.007	.029	.286	.943	.521	.184
	N			67	67	67	67	67	67	67	67
Religion t	Pearson Correlation			1	-.098	-.024	-.119	-.109	.190	.249*	-.097
	Sig. (2-tailed)				.429	.849	.338	.382	.124	.042	.433
	N				67	67	67	67	67	67	67
Education	Pearson Correlation				1	.465**	-.131	.056	-.495**	.694**	.238
	Sig. (2-tailed)					.000	.291	.654	.000	.000	.053
	N					67	67	67	67	67	67
Place of Residence	Pearson Correlation					1	-.162	-.051	-.029	.220	.225
	Sig. (2-tailed)						.191	.684	.817	.073	.068
	N						67	67	67	67	67
Marital Status	Pearson Correlation						1	.581**	-.063	-.124	-.206
	Sig. (2-tailed)							.000	.615	.319	.095
	N							67	67	67	67
Occupation	Pearson Correlation							1	-.198	-.033	-.143
	Sig. (2-tailed)								.108	.789	.249
	N								67	67	67
Family type	Pearson Correlation								1	-.393**	-.039
	Sig. (2-tailed)									.001	.754
	N									67	67
Income	Pearson Correlation									1	.284*
	Sig. (2-tailed)										.020
	N										67
Level of Care Giver Strain	Pearson Correlation										1
	Sig. (2-tailed)										
	N										

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

Care Giver Age, Child Age, Religion, Education, Place of Residence, Marital Status, occupation, family type, income and Level of Care Giver Strain Index were correlated to understand the relationship. Care Giver age is positively related with child age, education, place of residence and Occupation and other variables having the negative relationship.

Correlation between Care Giver Age, Child Age, Religion, Education, Place of Residence, Marital Status, occupation, family type, income and Level of Care Giver Strain Index

Correlations

		Care Giver Age	Child Age	Religion	Education	Place of Residence	Marital Status	Occupation	Family Type	Income	Level of Psycho-social care and support
Care Giver Age	Pearson Correlation	1	.467**	-.221	.071	.346**	-.116	.179	-.083	-.161	-.327**
	Sig. (2-tailed)		.000	.072	.569	.004	.349	.146	.502	.193	.007
	N		67	67	67	67	67	67	67	67	67
Child Age	Pearson Correlation		1	.133	.266*	.328**	-.268*	-.132	-.009	.080	-.262*
	Sig. (2-tailed)			.284	.030	.007	.029	.286	.943	.521	.032
	N			67	67	67	67	67	67	67	67
Religion t	Pearson Correlation			1	-.098	-.024	-.119	-.109	.190	.249*	.057
	Sig. (2-tailed)				.429	.849	.338	.382	.124	.042	.649
	N				67	67	67	67	67	67	67
Education	Pearson Correlation				1	.465**	-.131	.056	-.495**	.694**	-.111
	Sig. (2-tailed)					.000	.291	.654	.000	.000	.370
	N					67	67	67	67	67	67
Place of Residence	Pearson Correlation					1	-.162	-.051	-.029	.220	-.114
	Sig. (2-tailed)						.191	.684	.817	.073	.357
	N						67	67	67	67	67
Marital Status	Pearson Correlation						1	.581**	-.063	-.124	.115
	Sig. (2-tailed)							.000	.615	.319	.355
	N							67	67	67	67
Occupation	Pearson Correlation							1	-.198	-.033	-.081
	Sig. (2-tailed)								.108	.789	.513
	N								67	67	67
Family type	Pearson Correlation								1	-.393**	.099
	Sig. (2-tailed)									.001	.427
	N									67	67
Income	Pearson Correlation									1	-.189
	Sig. (2-tailed)										.126
	N										67
Level of Psycho-social care and support	Pearson Correlation										1
	Sig. (2-tailed)										
	N										

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

Care Giver Age, Child Age, Religion, Education, Place of Residence, Marital Status, occupation, family type, income and Level of Psycho-social care and support were correlated to understand the relationship. Care Giver age is positively related with child age, education, place of residence and Occupation and other variables having the negative relationship.

V. Conclusion, Implications and Recommendations

The weaknesses of the study were a small sample size, use of generic outcome measurements and as the study was descriptive in nature, causality could not be established. Further, participants were drawn conveniently. In light of these limitations, there seems to be empirical evidence that caregiving a child with cancer may be associated with high caregiver burden and poorer Psycho Social Care and support. Therefore, it thus becomes important to develop interventions for buffering the impact of caregiving, as the efficacy of treatment regimens may be heavily dependent on the psycho social care and support of informal caregivers. This is especially important in low resource settings where there is scarcity of respite care services. As this was a descriptive study, there is need of future studies that employ large sample sizes, longitudinal designs to determine the changes in burden of care along the trajectory of the disease process. Further, there is also need to develop context-specific and culturally appropriate tools for routine screening of caregivers' perceived burden of care. It is also important to early identify caregivers who may exhibit signs of clinical distress so that they may be refereed for support at an early stage. There is also an urgent call for rehabilitation professionals to be actively involved in the cancer treatment with qualified social workers and psychologists.

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References :

(1) Swaminathan R, Rama R, Shanta V. Childhood cancers in Chennai, India, 1990-2001: Incidence and survival. Int J Cancer 2008;122:2607-11

(2) Arora RS, Eden T, Pizer B. The problem of treatment abandonment in children from developing countries with cancer. Pediatr Blood Cancer 2007;49:941-6.

(3) Ayoub L, Fú L, Peña A, Sierra JM, Dominguez PC, Pui CH, *et al* . Implementation of a data management program in a pediatric cancer unit in a low income country. Pediatr Blood Cancer 2007;49:23-7

(4) McMillan SC, Small BJ, Weitzner M, et al.: Impact of coping skills intervention with family caregivers of hospice patients with cancer: a randomized clinical trial. Cancer 106 (1): 214-22, 2006.

(5) Hazelwood DM, Wallner M, Anderson KH, Mayer H (2012) Patients with Cancer and Family Caregivers: Management of symptoms caused by Cancer or Cancer Therapy at Home symptoms caused by cancer or cancer therapy at home. HeilberufeScience 3: 149-158.

(6) Cancer Control: Knowledge into Action: WHO Guide for Effective Programmes (2020) World Health Organization.

(7) Kudubes AA, Bektas M, Ugur O (2020) Symptom Frequency of Children with Cancer and Parent Quality of Life in Turkey. Asian Pacific J Cancer Prev 1: 3487-3493.

(8) Lund L, Ross L, Petersen MA, Groenvold M (2014) Cancer caregiving tasks and consequences and their associations with caregiver status and the caregiver's relationship to the patient:: a survey. BMC Cancer 14: 1-13.

(9) Sullivan R, Kowalczyk JR, Agarwal B, Ladenstein R, Fitzgerald E, et al. (2013) New policies to address the global burden of childhood cancers. Lancet Oncol 14: e125-e135. 6. Care M of H and C (2014) National Cancer Prevention and Control Strategy for Zimbabwe.

(10) WHO International Agency for Cancer Research (2014) International Childhood Cancer Day 2015. World Cancer Rep 2014.

(11) Vrettos I, Kamposioras K, Kontodimopoulos N, Pappa E, Georgiadou E, et al. (2012) Comparing health-related quality of life of cancer patients under chemotherapy and of their caregivers. Sci WorldJournal

(12) Fluchel MN, Kirchhoff AC, Bodson J, Sweeney C, Edwards SL, et al. (2014) Geography and the Burden of Care in Pediatric Cancers. Paediatr Blood Cancer. 61: 1918-1924. 10. Sajjadi H, Vameghi M, Ghazinour M, Khodaeiardakani M (2013) Caregivers ' Quality of Life and Quality of Services for Children with Cancer: A Review from Iran. Glob J Health Sci 5: 173-182. 11. Davis, ES, Waters, Boyd R, Cook K, Davern M (2009) The impact of caring for a child with cerebral palsy: quality of life for mothers and fathers. Childcare, Heal Dev 36: 63-73.

(13) Narekuli A, Raja K, Kumaran S (2011) Impact of physical therapy on burden of caregivers of individuals with functional disability. Disabilty, CBR Incl Dev 22: 108-119.