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A Study on the Economical and Social Confrontations of Childhood Cancer Care in Chennai District – A Policy Paralysisor a Work in Progress

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ABSTRACT

In India according to a report by FICCI and EY cancer occurrence in year 2022 is likely to be 19 to 20 lakhs whilst real numbers are likely to be triple times higher than the reported cases. On the incidence of Cancer worldwide the WHO in its report states, following China and US, India is ranked third in the World. The burden of cancer itself is shocking but it is even more shocking if Women and Children are ensnared by any form of cancer. The website of the nearly 72 year organization the Indian Cancer Society says that yearly nearly 17 percent of the worldwide childhood cancer cases are from India. It goes on to say that it's rare and curable if detected early and treated effectively. In Tamil Nadu alone yearly 1236 cases of childhood cancer are reported as per the ICMR report 2021. Chennai leads with the largest number of Child Cancer cases in India with 159 new cases per ten lakh population reported annually says a 2014 Times of India news article. In today's India the detection and treatment of Cancer require substantial resources both monetary and logistics, substantial duration(time) of minimum 6 to 12 months depending on the form of cancer and the nature of treatment and recovery (Chemotherapy, Surgery, Radiation). If it is Childhood cancer, we require a specialized paediatric cancer treatment hospital and in childhood cancer the total dynamics of cancer treatment is different. The childhood cancer detection, treatment and follow-up require not only the full commitment of the patient but also the patient's parent's and family. The costs and logistics are challenging for all sections of people from different economic brackets. This paper's purpose is to study the economics aspects of childhood cancer in Chennai city and the Government of India's policies towards childhood cancer with regard to implementing WHO's Global Initiative for Childhood Cancer.

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1.0 INTRODUCTION

The Constitution of India in Article 21 has been described by the Honorable Supreme Court of India as the heart of the Indian Constitution. The Article states about the protection of life and personal liberty. Interpreting this Article, the Court intervened and has said in a Catena of Landmark Judgments that it is not to be narrowed and restricted but has wider ramifications. The Hon'ble Supreme Court in its judicious wisdom has included "Right to health and medical aid" as a Fundamental right included within the wider meaning of Right to life. The Duties of the State enshrined in Part IV of the Indian Constitutions cast the Indian State with the duties to ensure to its Citizens the following:

- 1) To promote the welfare of its people Article 38:
- 2) Protect their health and strength from abuse Article 39(e),
- 3) Provide public assistance in case of sickness, disability or "undeserved want" Article 41; and
- 4) Ensure just and humane conditions of work; and raise nutrition levels, improve the standard of living and consider improvement of public health as its primary duty Article 47.

The popular American essayist, poet, and philosopher, Ralph Waldo Emerson said in all his good judgment that "The first wealth is health".

1.1 Cancer - The Disease

Cancer is a disease that occurs when some cells in the human body begin to divide without control and spread to other areas of the body. Because the human body is composed of billions of cells, cancer may start in almost any region of the human body. In general, human cells can expand and multiply (via a process that is termed cell division) to generate new cells whenever the body needs them. Old or damaged cells eventually die and are replaced by fresh new ones. This systematic process sometimes fails, and abnormal or damaged cells proliferate when they shouldn't. Tumours, which are lumps of tissue, may arise from these kinds of damaged cells. Tumours may either be cancerous or non-cancerous (also known as benign). Cancer of the human body if left undetected or diagnosed at an early stage is very like to endanger life of the affected person.

The stakeholders in cancer treatment world over are the patient, the patient's family, the healthcare providers, the government, the society/community and the nation. In order to combat the different types of cancer that threaten people today, a multifaceted strategy is required. Each kind of cancer has unique measures and strategies for detection, diagnosis, and therapy. However, certain fundamental stages can be assessed on a global scale. Prevention and deterrent efforts must include education campaigns that emphasise the need for a healthy lifestyle, including proper nutrition and regular exercise. The second step is to launch massive cancer screening campaigns targeting people in high-risk age ranges or demographics. The use of technology in this respect may be quite helpful. Advanced wireless, cloud-AI-based, and portable Point of Care (POC) devices may help provide a fast diagnosis to even the most distant areas of India. After this point, at the tertiary level, the patient requires access to the most advanced care possible. Additionally, each stakeholder-the patient, the patient's family, the healthcare providers, the government and the society/community/nation need to collectively create an environment towards enhancing cancer treatment accessibility, inexpensiveness and reassurance of survivability.

In today's India the detection and treatment of Cancer require substantial resources both monetary and logistics, substantial duration(time) of minimum 6 to 12 months depending on the type of cancer and the nature of treatment(Chemotherapy, Surgery, Radiation). If it is Childhood cancer we require a specialized paediatric cancer treatment hospital and in childhood cancer the total dynamics of cancer treatment is different. The childhood cancer detection, treatment and follow-up require not only the full commitment of the patient but also the patient's parent's and extended family. The costs and logistics are challenging for all classes of people from almost all sections of the economic bracket.

1.2 Review of Literature

John (2014) "Doctors discounting environmental reasons opined that efficient healthcare system and appropriate reporting of cases are responsible for Chennai topping the list. Doctors also opined cases are likely to increase in the following years. Chennai has one of the best cancer care medical facilities in India. Patient coming for treatment to city for treatment is increasing year by year. Efficient reporting is also a reason for detecting many cases. Further Dr R Swaminathan, head of Madras Metropolitan Tumor Registry stated modernization and improvements in medical technology and diagnostics the medical fraternity especially pediatricians are detecting cancers at an early stage. It is reported that he risk of childhood cancers is more among boys than girls. While the incidence of cancer for boys are 159 new cases and for girls it is 112 new cases per 10 lakh population. Baffled Doctors say this disparity could be because of social reasons. Dr Anita Ramesh, head of the department of oncology at Sri Ramachandra medical college stated that she sees 100-150 new Childhood Cancer cases every year and noted that one of the reasons for this could be because Chennai is an important referral centre. She further added that most of the cases are from children outside the city."

According to research conducted by Faruqui *et al.*, (2020), there are several challenges in the way of Indian children receiving treatment for cancer. Finding solutions for improved access to care is crucial for achieving Universal Health Coverage (UHC). Thus, it's important to understand those challenges and how different stakeholders perceive them. The research set out to hear from Indian healthcare providers about their experiences helping children with cancer get the needed treatment. Seven tertiary cancer hospitals in Delhi and Hyderabad participated in the research (3 public, 3 private, and 1 charity trust hospital). Twenty-seven Paediatric Oncology specialists were recruited. After obtaining permission, interviews were taped. NVivo 11 was used for the thematic and inductive analysis of the information. Participants identified a wide range of interrelated obstacles to receiving treatment, including a lack of resources and support services, a lack of patient education and understanding, a lack of understanding of the importance of referrals, and a lack of respect for cultural differences.

Sajna *et al*, (2021) stated that compared to developed countries, in India the Study related to Childhood cancer and its burden and implication on the public healthcare was in adequate. The research found that Chennai city has a high prevalence of childhood cancer, with rates ranging from 38 to 124 per million children per year in India. This research aimed to examine the demographic determinants, burden of illness, and long-term trends in childhood cancer. Children aged 0-14 diagnosed with cancer in Chennai during a 34-year period (1982-2016) were included in the research, which used data from the Madras Metropolitan Tumour Registry (MMTR). The research

compared the incidence of paediatric tumours across age ranges, sexes, and cancer types and looked at the long-term trend. The research had discovered that between 2007 and 2011, the trend indicated that most instances were recorded, whereas, between 2012 and 2016, the number of reported cases decreased.

1.3 Research Gap

There is dearth of research with regard to the economic and social issues faced during and after childhood cancer care. The first paediatric cancer centre evolved in India only in 1970 at the Cancer Institute, Chennai by the very foresighted Dr. V. Shantha. After a gap of one decade and five years after the first Paediatric cancer centre, the first dedicated Paediatric Oncology Unit was established in Mumbai at the Tata Memorial Hospital in 1985. There is no specific data on childhood cancer patients in the Tamil Nadu Cancer Registry Project Report 2021 (conducted in collaboration with Department of Health and Family Welfare of the State Government covering 73 million populations, the largest by any registry in the world). This makes authentic data unavailable. The research gap can be more precisely understood by the WHO's pictorial representation of the Sustainable Development Goals and Childhood Cancer.

Figure 1
Sustainable Development Goals (SDGs)



Source: https://sdgs.un.org/goals

Figure 1 depicts the Sustainable Development Goals established by the United Nations Organization. Out of these 17 SDGs, Government of India needs to frame ten specific SDGs policies, to achieve a level of confidence for all the stakeholders in the treatment of childhood cancer. They are:

- 1) Financial Protection,
- 2) Reduce hunger and malnutrition,
- 3) Attainment of multiple health targets through focused investment,
- 4) Quality and focused education for children undergoing prolonged cancer treatment,
- 5) Achieve gender equality and parity in quality health care,
- 6) Access to quality water and sanitation,
- 7) Investment in diverse occupations essential for care kindles monetary growth and employment,
- 8) Prop up entree to care for all communities to reduce ruinous health costs and inequalities,

- 9) Investing in child health promotes social stability and reduces exploitation and discrimination, and
- 10) Multi- sectoral collaboration and international cooperation improve childhood cancer outcomes.

1.4 Objectives of the Study

- To find out whether childhood cancer is having a socio-economic impact on the childhood cancer patient and the parents of the childhood cancer patient in Chennai.
- To understand whether the Indian Government, Tamil Nadu State Government, Healthcare providers and the important stakeholders are acting on implementing the WHO's Global Initiative for Childhood Cancer.

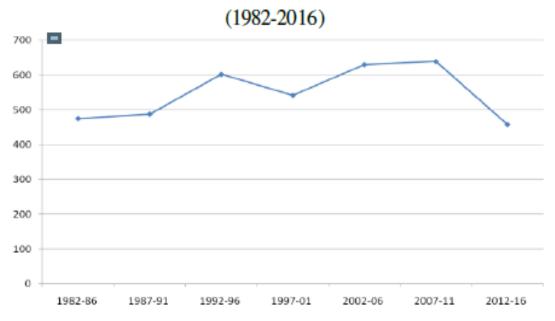
2.0 RESEARCH METHODOLOGY

The study is based on secondary sources. The study is descriptive in nature. Data and content for the study was collected from books, journals, articles, newspaper reports and social media reports.

3.0 ANALYSIS AND DISCUSSION

The source for the Secondary statistical data is mostly from the Madras Metropolitan Tumor Registry, Tamil Nadu Cancer Registry Project and the National Cancer Registry Programme. The official data for period after 2016 is unavailable. Other reports and studies indicate that there is a steady increase in childhood case throughout India.

Figure 2
Number of Cancer Cases Reported Among the Children in Chennai



Source: MMTR

Figure 2 shows there is alarming increase from the base year 1982 onwards though there is a decline in childhood cancer cases towards 2016.

Table 1
Sex-wise Distribution of Cancer Cases Reported

Sex	Frequency	Percentage
Male	2313	60.3
Female	1521	39.7
Total	3834	100.0

Sex-wise distribution of paediatric cancer during this study period shows that more cases are reported among male children (2313 cases) constituting 60.3% of total cases reported (3834). Compared to this, only 1521 cases (39.7%) are reported among female children (refer Table 1)

Table 2
Distribution of Reported Cases across the Age Groups

Age Group	Frequency	Percentage
0-4 years	1417	37.0
5-9 years	1242	32.4
10-14 years	1175	30.6
Total	3834	100.0

Table 2 describes the age group distribution of paediatric cancer for 1982-2016. When the children are classified into three age-groups, the data shows that more paediatric cancer is reported in 0-4 years of age (1417 cases) accounting for 37.0% of the total cases reported (3834 cases).

Figure 3
Sex-wise distributions of reported cases and types of cancer (Share in %)

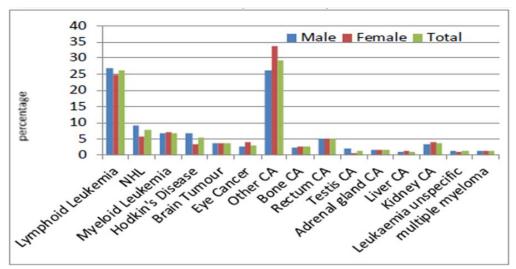


Figure 3 shows the distribution of reported cases with their types and gender 1982-2016. The trend indicates that most of the types of cancer reported remain high among the male children, except myeloid leukaemia (7.1%), eye cancer (4%), bone cancer (2.7%), liver cancer (1.2%), kidney cancer (4.1%) and other types of cancers (33.9%).

Table 3

Number and Relative Proportion in % of Childhood Cancers Relative to all Cancers in 28 Populations Centers in India

Sl.	■ 870400 • 104240000000]	Boys		G	irls		Bot	h Sexes	3
No.	Registry	N	n	%	N	n	%	N	n	%
			NO	RTH						28
1	Delhi	31032	1445	4.7	29065	766	2.6	60097	2211	3.7
2	Patiala district	5394	158	2.9	6077	78	1.3	11471	236	2.1
			so	UTH	*					
3	Hyderabad district	5143	166	3.2	6453	117	1.8	11596	283	2.4
4	Kollam district	9930	159	1.6	9780	129	1.3	19710	288	1.5
5	Thi'puram district	13506	206	1.5	14327	177	1.2	27833	383	1.4
6	Bangalore	13221	343	2.6	15828	234	1.5	29049	577	2.0
7	Chennai	14468	365	2.5	16803	234	1.4	31271	599	1.9
	EAST									
8	Kolkata	10186	105	1.0	9151	80	0.9	19337	185	1.0
	WEST									
9	Ahmedabad urban	14579	303	2.1	11025	165	1.5	25604	468	1.8
10	Aurangabad	1923	80	4.2	2001	43	2.1	3924	123	3.1
11	Osmanabad & Beed	3635	78	2.1	4467	64	1.4	8102	142	1.8
12	Barshi rural	726	18	2.5	813	19	2.3	1539	37	2.4
13	Mumbai	26256	592	2.3	27458	371	1.4	53714	963	1.8
14	Pune	9687	204	2.1	10818	128	1.2	20505	332	1.6
			CEN	TRAI	-					
15	Wardha district	2389	71	3.0	2537	40	1.6	4926	111	2.3
16	Bhopal	3567	96	2.7	3589	59	1.6	7156	155	2.2
17	Nagpur	5952	155	2.6	6047	99	1.6	11999	254	2.1
	NORTH EAST									
18	Manipur state	3702	103	2.8	4500	90	2.0	8202	193	2.4
	Imphal West district	1137	25	2.2	1500	30	2.0	2637	55	2.1
19	Mizoram state	4323	72	1.7	3736	58	1.6	8059	130	1.6
	Aizawl district	2180	39	1.8	1900	27	1.4	4080	66	1.6
20	Sikkim state	1172	15	1.3	1131	21	1.9	2303	36	1.6
21	Tripura state	6559	113	1.7	4914	77	1.6	11473	190	1.7

Source: NCPR

Table 3 presents concerning statistics indicating the elevated and escalating incidence of childhood cancer in major Indian cities such as Delhi, Mumbai, Chennai, and other significant population centers.

Table 4
Cost of Cancer Treatment

Cancer type (1 USD = INR 64.505)*	Cancer Surgery Costs	Min., cost of Chemotherapy / radiotherapy (per Cycle)
Head and Neck	₹2.5L - ₹4.1L	₹25,801
Breast	₹2.9L - ₹3.5L	₹32,252
Cervical	₹1.9L - ₹3.2L	₹12.900
Oesophagus	₹3.8L - ₹5.1L	₹51,603
Stomach	₹3.2L - ₹4.5L	₹51,603
Colon	₹3.5L - ₹4.8L	₹64,504
Ovarian	₹2.3L - ₹3.6L	₹25,801
Lung	₹2.9L – 3.5L	₹25,802
Prostrate	₹2.3L*	Cost of radical prostatectomy surgery - ₹5.2L

^{*} As per rates on 19th December 2017. Please note – The cost mentioned above are estimates of treatment in India from healthcare advisory companies, it could vary from case to case.

Source: Future General Website

Table 4 shows the exorbitant and unaffordable cost for treatment of cancer in India. The above data from the Population Based Cancer Registries (PBCRs) maintained in India shows a very worrisome trend not only throughout India but also in the Metropolitan cities such as Chennai and Delhi. Delhi presently has the highest incidence of childhood cancer cases; Chennai too shows an equally concerning trend.

4.0 CONCLUSION

In a recent interview reported in the New Indian Express a doctor had related an incident about a mother of a childhood cancer patient abandoning the treatment midway and on resuming treatment had discovered that the cancer had advanced. The reason given by the mother should shake our collective conscious. The mother had stated that she had to sell of her possessions for her child's treatment and she did not have anything more to pawn off to continue the treatment.

Disease and death are normally linked to old age that is the unwritten normal. Cancer the disease too followed this rule and normally affected the Human Body at old age. Now, Cancer the disease sets to disrupt this normal by affecting even children from ages 0 to 14 (International comparison is done for ages 0 to 19 by the National Cancer Registry Programme in India). The onset of Cancer throws the whole normal way of life into disarray, the thought of the Child facing death in the family is the greatest sorrow that can befell a family, a society or a nation for that matter. Cancer now is treatable, and science has made great progress in the treatment of cancer, yet the access to treatment, the cost of treatment, the logistics involved with treatment is a very big confrontation and challenge not only to the patient, but also to his support system in recovery such as his family,

healthcare workers, society and the nations as a whole. Recognizing these challenges, the Tamil Nadu state health authorities are contemplating to declare cancer as a notifiable disease, it is a welcome move. It is also time that a wholesome childhood cancer care policy is put in place by the all powerful Government to mitigate the woes of the Child cancer patient, his family, society and the nation.

4.1 Limitations of the Study

The study is based squarely on secondary data and sources. This is an area where there is more articles and interviews given by experts in the medical field when compared to policy makers. There is totally dearth of knowledge related to childhood cancer patients or survivors as not much has been stated by persons in governance or Policy Making.

4.2 Scope for Further Research

The alarming rise in childhood cancer cases in Chennai is a subject of utmost concern. There should be continuous study on the subject of Childhood Cancer not only by persons from the Medical Fraternity but also from economist and social scientists. In a Lancet Oncology Committee report it is estimated that in the next 30 years more than 11 million children will needlessly die from cancer with the majority of deaths occurring in developing (low income and lower middle income) countries. Most of these deaths can be prevented with modest funds aimed at intensifying access to diagnostics, treatment, and supportive care. The area of prevention is where policy makers, academicians and persons in governance need to step in with vigorous measures and investments in terms of state-of-the-art medical infrastructural facilities and subsidies for prevention/treatment/after care of childhood cancer.

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