**Scope of Work**

Mentor Mentee Program

**Topic:** Determining the economic burden of diagnostic delay for pediatric cancer in India

**Title:** The brunt of late diagnosis of pediatric cancers in India: how much the country has to pay?

**Background:**

Childhood cancers constitute 0.7-4.4% of total cancers diagnosed in India as per population-based cancer registries report (2012-2014).1It is lower than that observed in HICs, reflecting the missed diagnosis in our country. However, approximately 70% of cancer deaths occur in low-and middle-income countries (LMICs).2In India, services in pediatric oncology are still mostly confined to the urban areas and a male predilection is reflected in the health seeking behavior. The age adjusted incidence rate of pediatric cancers per million (AARpm) population of India shows a wide geographic variation, with urban areas reporting highest rates (Delhi- 235.4 and 152.3 for boys and girls) while other areas have lower rates.1The average male to female ratio in India is 1.56 while it is 1.12-1.15 in High income countries (HICs).3 It is also well noted that survival of children with cancer in India lags behind the developed countries. One of the main deterrents is the lack of timely diagnosis and treatment. The healthcare system in India is a labyrinth, which many a caregiver finds extremely difficult to navigate.Multiple determinants influence the journey to appropriate care via the supply-side of health service provision, organisation and cost of services, and the demand-side of disease burden, patient/caregiver knowledge and attitude.4 Studies from India have reported time intervals to diagnosis ranging from 0.3- 52 weeks in various childhood cancers.5,6,7A study from India has observed a median time interval of 58 days from onset to diagnosis.8There is paucity of data on the full economic costs and cost-effectiveness of childhood cancer treatment in LMICs. Pediatric cancers do not come in the frame of major health policies due to supposed belief of low cost-effectiveness of treating these disorders. A systematic review on 2802 studies concluded that costs/ disability-adjusted life year (DALY) averted were substantially lower than per capita GDP, suggesting LMIC childhood cancer treatment is consistently very cost-effective.9 However, this study also remarked that many of the included studies did not account for key cost inputs, thus underestimating true treatment costs. Hence, there is a true need to evaluate the economic burden of delaying the diagnosis in childhood cancers and cost-effectiveness of their treatment

**Aim:** to determine the economic burden of delay in the diagnosis of childhood cancers in India

**Objectives:**

1. To estimate the average yearly expenditure of treatment of childhood cancer in a paediatric oncology unit
2. To estimate the loss of money for a family by the diagnosis and treatment of childhood cancer
3. To estimate the costs/DALY averted by timely diagnosis of childhood cancer
4. To estimate the hospital costs of a paediatric cancer unit in diagnosing and treating childhood cancer
5. To estimate the cost effectiveness of treating childhood cancer: location specific and whole

**Outcomes**

1. Identification of specific areas pertaining to each area where financial support required for families of childhood cancer patients
2. Creation of a national health policy to support early diagnosis and treatment of childhood cancer

**Study methodology**

1. **Step 1:** collection of costing data for the year 2020. A detailed abstraction tool will be developed after compartmentalizing costs into the following categories: personnel (both medical and support), other services (IT, training), room and board for patients and for their families (“hotelling”), outpatient clinic, shared services (pharmacy, pathology, surgery, radiation, imaging, and blood bank), and other central hospital services (utilities, human resources, etc.). The personnel cost of running cancer registry and outcome-tracking tool will be included if available in the participating centres. Overhead costs will be obtained from the budget of the hospital overall and will be attributed according to the paediatric oncology unit share of total inpatient admission. WHO-CHOICE value for India will be used for calculating in-patient hotelling costs.10The cost of intensive care unit bed will be multiplied by the ratio of the cost per day for ICU compared to that of a regular hospital bed in each centre. The structure is given in Appendix 1.11
2. **Step 2:** collection of data on inpatients, outpatients per year, number of new childhood cancer cases per year, and estimated survival rates per year from each centre. It will be assumed that all children with cancer will die if left untreated. Five-year survival rate will be obtained from each centre using data from new cases of 2014-2018.
3. **Step 3:** calculation of cost-effectiveness. This will be done using the DALYs approach used by the Global Burden of Disease Study.12 Average length of therapy will be taken as 2 years.

**Study setting**

Data from pediatric oncology units 1 each representative of North, South, West, and Eastern part of India

North –Rajiv Gandhi Cancer Institute and Resarch Centre, Delhi

North west – Post Graduate Institute of Medical Education and Research, Chandigarh

West – Tata Memorial Hospital, Mumbai

East – Tata Memorial Centre, Kolkata

South –Kidwai memorial institute of Oncology

Hospital records will be retrieved to collect all data.

**Participants**

Inclusion criteria

Centres treating children diagnosed with cancer before the age of 18 years

Exclusion criteria

Centres not willing to share the data

**Timelines**

2 weeks (10 Sep-24 Sep): recruitment and establishment of data collection system in the participating centers

1 month (25 Sep- 24 Oct): data collection

2 weeks (25 Oct- 7 Nov): statistical analysis

2 weeks (8 Nov – 26 Nov): first draft of research paper

**Statistical analysis**

The following variables will be included in the Cost-Effectiveness model13:

Discount rate

Life expectancy

Mean age at diagnosis

Duration of disability (length of therapy)

Disability weight during therapy

Utility score at age 24 using Medical Expenditures Panel Survey14

Utility score at age 35 using Medical Expenditures Panel Survey

Utility Score at age 24 using Childhood Cancer Survivorship Study CCSS Survivors

Utility Score at age 35 using Childhood Cancer Survivorship Study CCSS Survivors

Number of new incident cases

Proportion of patients with 5-year overall survival

India GDP per capita 2018 in USD

Scenarios will be created for 10%, 20% and 30% reduction in life expectancy to account for early mortality due to late effects associated with cancer.

Discount rate will be base case of 3% with 0 and 6% as additional estimates.

WHO thresholds for cost-effectiveness will be used for comparison: interventions costing less than per capita income per DALY averted are considered very cost effective and those costing less than three times per capita income per DALY averted are cost effective.

References

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3. R. Khera, S. Jain, R. Lodha, S. Ramakrishnan. Gender bias in child care and child health: global patterns. Arch. Dis. Child. 2014;99: 369-374
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5. Chawla B, Hasan F, Azad R, Seth R, Upadhyay AD, Pathy S, et al. Clinical presentation and survival of retinoblastoma in Indian children. Br J Ophthalmol. 2016;100:172-8.
6. Kulkarni KP, Marwaha RK, Trehan A, Bansal D. Survival outcome in childhood ALL: experience from a tertiary care Centre in North India. Pediatr Blood Cancer. 2009;53:168–73.
7. Arivazhagan A, Devi BI, Kolluri SV, Abraham RG, Sampath S, Chandramouli BA. Pediatric intracranial meningiomas--do they differ from their counterparts in adults? PediatrNeurosurg. 2008;44:43–8.
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9. Fung A, Horton S, Zabih V, Denburg A, Gupta S. Cost and cost-effectiveness of childhood cancer treatment in low-income and middle-income countries: a systematic review. BMJ Glob Health. 2019;4:e001825.
10. Stenberg, K., Lauer, J.A., Gkountouras, G. *et al.* Econometric estimation of WHO-CHOICE country-specific costs for inpatient and outpatient health service delivery. *Cost Eff ResourAlloc. 2018;* **16,**11.
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12. Murray, Christopher J. L, Lopez, Alan D, World Health Organization, World Bank & Harvard School of Public Health. (‎1996)‎. The Global burden of disease: a comprehensive assessment of mortality and disability from diseases, injuries, and risk factors in 1990 and projected to 2020 : summary / edited by Christopher J. L. Murray, Alan D. Lopez. World Health Organization. <https://apps.who.int/iris/handle/10665/41864>
13. Bhakta N, Martiniuk AL, Gupta S, Howard SC. The cost effectiveness of treating paediatric cancer in low-income and middle-income countries: a case-study approach using acute lymphocytic leukaemia in Brazil and Burkitt lymphoma in Malawi. Arch Dis Child. 2013; 98:155-60.
14. Quality USDoHaHS-AAfhRa. [Accessed 27 Aug, 2021];*Medical Expenditure Panel Survey.*2017 <https://meps.ahrq.gov/mepsweb/>

**Compensation**

The Consultancy fee for this engagement is USD 5,000(Inclusive of all indirect taxes). The payment will be disbursed in three instalments, in the proportions given below and the consultant should provide the invoice against each deliverable.

|  |  |  |  |
| --- | --- | --- | --- |
| **Instalment** | **Percentage** | **Amount (USD)** | **Deliverable/ Milestone** |
| 1 | 25 | 1250 | On Signing Contract |
| 2 | 25 | 1250 | On submission of literature review and methodology (including stakeholders for a qualitative interview and analysis plan) approved by the Mentor, and |
| 3 | 50 | 2500 | On submission of the final deliverable approved and accepted by the Mentor & AHI Team. |

**Term**

This engagement shall commence upon execution of this Agreement. The Agreement shall continue in full force and is effect from **September 15, 2021** to **December 15, 2021** and is extendable based on the review of Consultant’s performance by the Foundation and mutual concurrence on revised terms of engagement.

Appendix 1

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| Personnel | Number of personnel working full-time in pediatric oncology | Average yearly full-time salary | Number of personnel working part-time in pediatric oncology | Average part time (full time equivalent) FTE | | Salary cost in pediatric oncology (full time salary x proportion of time in pediatric oncology) | |
| Pediatric oncologist |  |  |  |  | |  | |
| General pediatricians |  |  |  |  | |  | |
| Nursing |  |  |  |  | |  | |
| Type/level of resident | No working on average in pediatric oncology at any given time | % of time/ responsibility dedicated to pediatric oncology | Average yearly salary | | Salary cost in pediatric oncology (full time salary x proportion of time in pediatric oncology) | |
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Pharmacy

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Personnel | Number of personnel working full-time in pediatric oncology | Average yearly full time salary | Number of personnel working part-time in pediatric oncology | Average part time (full time equivalent) FTE | Salary cost in pediatric oncology (full time salary x proportion of time in pediatric oncology) |
|  |  |  |  |  |  |
|  |  |  |  |  |  |

Surgeons

|  |  |  |  |
| --- | --- | --- | --- |
| Type | Number of personnel | Average yearly full time salary | % of time/ responsibility dedicated to pediatric oncology |
| Orthopedic surgeon |  |  |  |
| Neurosurgeon |  |  |  |
| General surgeon |  |  |  |

Ancillary services

1. Diagnostic imaging

Four randomly chosen weeks in last calendar year

|  |  |  |
| --- | --- | --- |
| Diagnostic imaging | Quantity | Charge per unit |
| Xray |  |  |
| Ultrasound |  |  |
| CT |  |  |
| MRI |  |  |

1. Radiation

|  |  |  |
| --- | --- | --- |
| Radiation service | Quantity | Charge per unit |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |

1. Pathology

|  |  |  |
| --- | --- | --- |
| Pathology service | Quantity | Charge per unit |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |

1. Laboratory

|  |  |  |
| --- | --- | --- |
| Blood laboratory tests | Quantity | Charge per unit |
|  |  |  |
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|  |  |  |
|  |  |  |

1. Blood bank

|  |  |  |
| --- | --- | --- |
| Blood product | Quantity | Charge per unit |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |

BEDS and ROOM and BOARD

1. Inpatient unit

|  |  |
| --- | --- |
| Question | Response |
| Average daily occupancy of non -ICU beds by pediatric oncology patients |  |
| Daily bed space charge for non-ICU beds |  |

1. ICU

|  |  |
| --- | --- |
| Question | Response |
| Average daily occupancy of ICU beds by pediatric oncology patients |  |
| Daily bed space charge for ICU beds |  |

1. Operating room

|  |  |
| --- | --- |
| Total hours | |
| Major surgeries | Minor surgeries |
|  |  |

1. Accommodation

|  |  |
| --- | --- |
| Question | Response |
| Is accommodation close to hospital provided for families of pediatric oncology patients |  |
| If yes, is it free or at cost? |  |
| If free, who is the funder? |  |
| What is the annual budget for this service? |  |
| If annual budget not available, daily average number of accommodation beds taken up by family members of pediatric oncology patients and charge for one day | Number of beds |
| Charge for 1 day |

1. Food

|  |  |
| --- | --- |
| Question | Response |
| Is food provided for families of pediatric oncology patients |  |
| If yes, is it free or at cost? |  |
| If free, who is the funder? |  |
| What is the annual budget for this service? |  |
| If annual budget not available, daily average number of meals taken up by family members of pediatric oncology patients and charge for one day | Number of meals |
| Charge for 1 day |

MEDICATIONS : look prospectively for 2 weeks provided to inpatient or outpatient patients

1. Chemotherapy

|  |  |  |
| --- | --- | --- |
| Type | Dose | Charge per unit |
|  |  |  |
|  |  |  |
|  |  |  |
|  |  |  |

1. Supportive care medications

|  |  |
| --- | --- |
| Non chemotherapy medications | Charge per unit |
|  |  |
|  |  |
|  |  |

OUTPATIENT CLINIC

|  |  |
| --- | --- |
| Question | Response |
| Number of pediatric oncology patients seen in an average month in OPD |  |
| Number of overall patients seen in an average month in OPD |  |
| Outpatient clinic annual budget (excluding salary of nurses and doctors) |  |

SURVIVAL STATISTICS

|  |  |
| --- | --- |
| Question | Response |
| Number of new pediatric oncology diagnosis made annually |  |
| Percentage of pediatric oncology patients seen at hospital who survived their diagnosis >/= 5 years |  |