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abstract

The Indian Childhood Cancer Survivorship (C2S) Study: Making Of The Indian Childhood Cancer Survivorship Registry & Cohort; An INPHOG Study

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Introduction: A priority area for the pediatric oncology community is care of childhood cancer survivors (CCS), monitoring of late effects and optimizing quality of life. This has been a neglected area and no registry for CCS existed in India in the past. The C2S study established the first Indian registry of CCS and formed the multicentre Indian childhood cancer survivorship cohort. Methodology: Centres across India were invited to participate in the Childhood Cancer Survivorship (C2S) study. Clinical, demographic, treatment exposure including cumulative dose details of children completing cancer treatment were recorded on an online database. Follow up was done by teleconsultation/physical visit to hospital. Outcomes of follow up were recorded.

Results: The study was initiated in 2016 and has completed eight years. Twenty-four centres across India are participating and data of 4101 survivors (16 centres) available till December 2023 was analysed. A majority were males (68. %) and in the age group of 2-14 (62%) years.

The commonest malignancy was acute leukemia/lymphoma (64%). Regional variations within India observed. Chemotherapy (cyclophosphamide, anthracyclines, etoposide) was the commonest treatment exposure (96%) followed by radiation (71%) and surgery (67%).

The period of follow up from treatment completion of more than 5 years was seen in 20.1%, 2-5 years in 35.5% and less than 2 years in 44.4% patients. Median duration of follow up from treatment completion was 2.44 years and from diagnosis was 3.53 years. Majority (91%) are alive and in remission. Relapse was seen in 5% (4% on palliative care, 1% in remission after retreatment) 4% patients have expired.

Conclusion: The C2S Study is the first multicentric childhood cancer survivor study/registry from India. The study cohort has captured data on treatment exposures and is a platform for further studies on late effect in long term survivors.