



Building a Foundation for the Care of Children with Cancer in Rural North India

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Ind J Med Paediatr Oncol 2022;43:120–123.

Abstract

Keywords

- India
- pediatric oncology
- charitable foundation
- childhood cancer

One of India's biggest challenges is to improve its global standing by increasing healthcare access and outcomes for children with cancer, with inferior overall survivorship compared with its Western counterparts. In conjunction with the government's efforts, private enterprise is crucial in delivering optimal cancer care consistently to its vast and diverse pediatric population, despite existing limitations. This article describes the successful implementation of a value-based, collaborative clinical and research framework by a philanthropic foundation in a rural Northern Indian city to establish and run a local childhood cancer service. It is proof of concept that substantial change could be brought about at grass roots level through resourceful partnerships and reduce prevailing imbalance in pediatric oncology service provision.

Introduction

India has an increasingly prominent presence on the global front in many aspects. However, modest childhood cancer outcomes indicate a significant gap in healthcare achievements, despite substantial improvement in service provision. According to the Indian National Census 2011, ~1.3 million Indians are diagnosed with cancer annually, of whom ~52,000 are aged between 0 and 14 years and ~77,000 are aged between 0 and 19 years, accounting for 10 to 15% of the world's childhood cancer burden.^{1,2}

Leukemia (~33%) predominates the landscape of childhood cancer followed by brain tumors (~20%) and lymphomas (~11%).² Current Indian pediatric cancer mortality is

estimated to be ~37%,³ while that in the United States of America it is ~20%.⁴ This significant survival differential is driven by many factors unique to low-and-middle-income countries (LMIC) such as diagnostic delay, poor supportive care during intensive therapy, treatment refusal, abandonment, and the disparity between pediatric cancer burden and resources, inevitably resulting in maximum Disability Associated Life Years⁵ and turning cancer into one of the leading causes of nonaccidental deaths.^{5,6}

However, true Indian incidence and mortality data are skewed by under ascertainment of population coverage and hospital-based cancer registries and female gender bias in seeking timely healthcare.⁶

DOI <https://doi.org/10.1055/s-0042-1742444>.
ISSN 0971-5851.

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Thieme Medical and Scientific Publishers Pvt. Ltd., A-12, 2nd Floor, Sector 2, Noida-201301 UP, India

Regional childhood cancer patterns are similar to international incidence trends. In the state of Uttar Pradesh (UP), ~3,300 leukemia, ~2,000 central nervous system tumors, and ~1,000 lymphomas are seen annually between 0 and 14 years.² However, the burden of specialized pediatric oncology care has to be borne by a single public tertiary hospital, while private healthcare would be unaffordable for the predominantly rural population, contributing to under presentation, therapy abandonment, and poorer outcomes.

Work of the Charitable Foundation

This situation was precisely the case in the under-served region of Poorvanchal, Eastern UP, with the nearest pediatric oncology expertise 270 km away in Lucknow. The dire necessity for a rural specialty pediatric oncology service was recognized and the ChildCan Cancer Foundation was registered in early 2021 (No: U85300UP2021NLP143579) as a not-for-profit organization amidst the coronavirus disease 2019 (COVID-19) pandemic, with the primary aim of bridging the chasm in equitable care at a micro-level, by creating cancer awareness for early detection and facilitating access to the underprivileged, resulting in affordable optimal cancer treatment.

Our biggest advantage was our established affiliation with the philanthropic Hanuman Prasad Poddar Cancer Hospital (HPPCH) in the city of Gorakhpur, a 100-bedded multimodality cancer care center, catering to ~4000 new adult cancer diagnoses annually. HPPCH has been providing free-of-cost cancer care to 13 districts of eastern UP and adjacent parts of Bihar and Nepal, for the past 30 years.

We have been fortunate and grateful to utilize HPPCH's inbuilt infrastructure and skilled workforce for junior medical, nursing, diagnostic and technological services. We have linked into their multimodality anticancer therapy teams, including surgery, chemotherapy, intensity-modulated-radiation-therapy, pharmacy, hematology, and supportive paraclinical care.

Daily clinical care coordination is led by a pediatric oncology-trained local pediatrician and assisted by HPPCH-sourced ancillary staffing as detailed above. The Gorakhpur team liaises with two pediatric oncologists from Apollo Hospital, Delhi and King George Medical University (KGMU Lucknow) twice-a-week through dedicated case conferences. Formal affiliative links have now been established with these premier institutions for ongoing academic and training support. A childhood cancer nurse with experience in palliative care coordinates care with families and is a priceless link with the community. HPPCH dormitories also offer a free home-away-from-home facility for families, a valuable factor in ensuring adherence to treatment. We have also commenced collaborating with the All India Institute of Medical Sciences (AIIMS, Delhi) for expert clinical and palliative care guidance through telemedicine.

We are deeply appreciative of fruitful partnerships with national nongovernmental organizations like Leukaemia Crusaders and CanKids, who have provided continued sup-

port in establishment of the pediatric inpatient, outpatient, and outreach framework.

In a year since inception, our pediatric oncology unit has had 39 presentations of which 31 had cancer diagnoses, with 13 leukemia, 10 lymphoma, 6 soft tissue tumors, and 2 brain tumors. Six patients requiring surgery were referred to higher centers. However, three patients elected to discontinue treatment due to personal reasons. Although premature to assess survival outcomes at this early stage, we believe this provides proof of concept that a charity-founded initiative can bring about clear subjective difference to the local community, providing them with vital access to care that was not as immediately available beforehand. Progression-free and overall survival, along with other indicators, will be serially evaluated at appropriate time points to inform future practice. Despite the COVID-19 pandemic being a major barrier to timely achievement of the foundation's objectives, this is a preliminary win against many odds but a massive inspiration to soldier on. Work is nearing completion and an exclusive 6-bed pediatric oncology unit is expected to open soon within the HPPCH premises.

Patient-centered collaborative leadership formed the nucleus of our Charitable Foundation's organizational culture, moving beyond hierarchical positional authority, and fostering genuine commitment rather than compliance from associated partners.^{7,8}

Even though time-consuming, building the right workforce is pivotal to their long-term retention and sustainable progress. We were fortunate that most of our team members have graciously volunteered their services, inspired by local philanthropist and scholar, late Mr. Hanuman Prasad Poddar, founder of HPPCH.

Creating a cohesive work environment where each member feels valued and connected to interactive decision-making has been the key to our success to date. We found that active listening and intrateam social connectivity help empower the team's collective efficiency; uplift their self-esteem, prosocial behavior, societal engagement; and help maintain the drive to uphold the foundation's goals. We aim to harness their motivation for success, fueled by trust, autonomy, and freedom of speech, leading to rational self-determined actions that in turn generated a positive reinforcement loop.⁹ We promote constructive criticism and feedback and continuous professional development to enhance competency and autonomy. Our aim is that our team members thrive while achieving organizational goals and discover their intrinsic potential.¹⁰

Current Perspectives

Growth, success, and sustainability of such an enterprise are crucially predicated on establishing local, national, and global partnerships, fostering research excellence and enabling clinical translation. To this end, the World Health Organization (WHO) launched the Global Initiative on Childhood Cancer in 2018, (<https://www.who.int/docs/default-source/documents/health-topics/cancer/who-childhood-cancer-overview-booklet.pdf>), aiming for a 60% survival rate

by 2030, by prioritizing childhood cancer at national and global levels and expanding access to quality cancer care, with strategic support from partners such as International Society of Pediatric Oncology (SIOP) and St Jude Children's hospital (United States of America). The national and state governments, the Indian Pediatric Oncology Group, private healthcare sector, and WHO are organizations collaborating to achieve universal health coverage in India. Although these steps have been implemented and largely benefitted metropolitan tertiary and private health cancer care⁶ due to better infrastructure and socioeconomic patient status, it remains geographically and financially inaccessible to a majority of India's rural population residing in smaller towns, despite the Government of India's Ayushman Bharat program, which offers some childhood cancer financial health protection. These in turn contribute to late diagnoses, treatment non-compliance, and poor outcomes.^{11,12}

Roadmap for the Foundation's Future

Our ambition is to expand into more comprehensive children's cancer care, including play, occupational, speech and physiotherapy, dietetics and social care, and hospital school facilities. We plan a survivorship and adolescents and young adults program, with attached fertility preservation and psycho-oncology teams.

We foresee local capacity building by establishing student mentorships, trainee fellowships, and training local pediatricians, till full-fledged resident pediatric oncologists are appointed. This will not only help us attain educational self-sufficiency but will nurture the next generation of professionals, working with our academic partners, KGMC and AIIMS.

We are preparing to amalgamate digital health systems and telemedicine into routine care, which has been shown to be valuable in resource-poor settings, bringing in expert help through virtual tumor boards and delivering outreach services without physical presence.^{13,14} The National Cancer Grid tumor board run out of Tata Memorial and Max Hospitals, Mumbai, India, illustrates such an initiative (<https://tmc.gov.in/ngc/index.php/activities-ngc/virtual-tumor-board>). Tapping into a larger Global Cancer Alliance² would be of major strategic and logistic advantage, particularly in pandemic and post-pandemic eras and help in complex clinical decision-making. There is also the invaluable benefit of learning from the collective wisdom of pioneering specialists.

We plan continuing health education programs that raise community awareness of childhood cancer, suppress gender bias, dispel myths, promote early diagnosis and referral, and reduce abandonment. Children, unlike adults, do not suffer the minefield of mutagenic environmental risk factors that may lead to cancer development.¹⁵ Hence, early diagnosis, rather than prevention, is the best road to recovery.

We acknowledge that patient and parent support group networks would help identify unmet needs, smoothen patient journeys, and significantly inform future cancer care policies.¹⁶ We understand that positive consumer perception

is critical to a health system's performance and have advocated involving families in formulating policy right from the beginning. While community engagement is fundamental to healthcare success, earning their trust and loyalty is the collective responsibility of both public and private healthcare stakeholders.

We aim to contribute to the Indian National Cancer Registry Program since systematic collection of patient data informs more accurate ascertainment of cancer occurrence, trends, and projection and is paramount in formulating health policy.¹⁷ We advocate for tissue biobanking that may fuel advancements in cancer genetics and drug discovery.¹⁸

A robust and sustainable research strategy is central to the success of national policy implementation. We subscribe to aligning our practice broadly with the framework proposed by the WHO Target for Childhood Cancer in India, focusing on standardized data collection and reporting; uniform referral and care pathways, local workforce training, accreditation, and cancer therapy; drug safety and diagnostics; boost governmental and independent funding opportunities and sharing scientific information through peer-reviewed publications.

We support in principle a much-needed move to a multi-center collaborative clinical trial model to refine cancer treatments. Even though LMICs account for more than 90% of the global childhood cancer burden, they access less than 0.1% of the global childhood cancer research funding.¹⁹ It is surprising that there is only one published prospective multicentric pediatric cancer trial from India,²⁰ with ongoing efforts to push this concept forward in India.²¹ We will actively encourage our pediatric patients to participate in appropriate clinical trials when available.

We have seen an exponential increase in understanding of the biological underpinnings of childhood cancer in the last decade and a half, leading to increasing personalization of therapy based on the cancer's genetic or epigenetic makeup and immune microenvironment. Comprehensive genomic testing, this may carry the additional familial impact if patients harbor germline predisposition. Hence, novel "precision oncology" approaches should also be embraced into future healthcare policies.²²

Summary

India has no dearth of a homegrown and enthusiastic pediatric oncology and technology workforce, whose expertise, regional and national partnerships, global engagement, and WHO assistance are sufficient to make a further dent into our national mortality statistics. The national government will play a key role in prioritizing childhood cancer services in the national cancer control response, encompassing diagnostic, therapeutic, supportive, palliative, psychological, survivorship, and digital aspects of healthcare. Pursuing this nationally coordinated holistic approach will not only make cancer care more equitable but contribute to enhancing India's progressive outlook on the international stage. Our ongoing work, even on a comparatively miniscule scale, indicates the

prospect of achieving this positive impact through a concerted team approach.

Conclusions

A childhood cancer diagnosis indicates the beginning of a traumatic journey, fraught with debilitating clinical, physical, emotional, and financial impact, on the child and family, in the short and long term. While being mindful of our health system's assets and limitations, we remain impassioned and optimistic in our journey toward a world without childhood cancer and in reducing the burden of multidimensional treatment toxicity. Children are our ambassadors for tomorrow and life affords no greater responsibility, privilege, or challenge and yet no greater joy than raising a healthier next generation.

Authors' Contributions

SN was involved in conceptualization, designing, definition of content, literature review, manuscript preparation, editing and review. PJR edited and reviewed the manuscript. RG acquired data and edited and reviewed the manuscript. SC was involved in conceptualization, designing, definition of content, manuscript preparation, editing and review.

Funding

None required.

Conflict of Interest

None declared.

Acknowledgments

We would like to thank Dr. Ulhas Vasave for providing contribution in setting up the ChildCan Cancer Foundation; Dr. Amita Bajaj and Hareesh Gupta, CanKid Foundation, for continued support in developing ChildCan Foundation services; and Mr. Rasendu Fogla, Joint Secretary of the Hanuman Prasad Poddar Cancer Hospital, for the provision of unrestricted access to hospital resources and patronage for our pediatric oncology unit.

References

- Sung H, Ferlay J, Siegel RL, et al. Global Cancer Statistics 2020: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA Cancer J Clin* 2021;71(03): 209–249
- Arora RS, Bagai P, Bhakta N. Estimated national and state level incidence of childhood and adolescent cancer in India. *Indian Pediatr* 2021;58(05):417–423
- Gupta S, Morris SK, Suraweera W, Aleksandrowicz L, Dikshit R, Jha P. Childhood cancer mortality in India: direct estimates from a nationally representative survey of childhood deaths. *J Glob Oncol* 2016;2(06):403–411
- Siegel DA, Richardson LC, Henley SJ, et al. Pediatric cancer mortality and survival in the United States, 2001–2016. *Cancer* 2020;126(19):4379–4389
- Force LMAI, Advani SM, et al; GBD 2017 Childhood Cancer Collaborators. The global burden of childhood and adolescent cancer in 2017: an analysis of the Global Burden of Disease Study 2017. *Lancet Oncol* 2019;20(09):1211–1225
- Ganguly S, Kinsey S, Bakhshi S. Childhood cancer in India. *Cancer Epidemiol. Apr* 2021;71(Pt B):101679. Doi: 10.1016/j.canep.2020.101679
- Vaughn VM, Saint S, Krein SL, et al. Characteristics of healthcare organisations struggling to improve quality: results from a systematic review of qualitative studies. *BMJ Qual Saf* 2019;28(01): 74–84
- Fowler S. Toward a new curriculum of leadership competencies: advances in motivation science call for rethinking leadership development. *Adv Dev Hum Resour* 2018;20(02):. Doi: 10.1177/1523422318756644
- Gagne M, Deci EL. Self-determination theory and work motivation. *J Organ Behav* 2005;26:331–362
- Tamir DI, Hughes BL. Social rewards: from basic social building blocks to complex social behavior. *Perspect Psychol Sci* 2018;13 (06):700–717
- WHO Global Initiative for childhood cancer – India responds. *Pediatric Hematology Oncology Journal* 2020;5(04):145–150
- Faruqi N, Bernays S, Martiniuk A, et al. Access to care for childhood cancers in India: perspectives of health care providers and the implications for universal health coverage. *BMC Public Health* 2020;20(01):1641. Doi: 10.1186/s12889-020-09758-3
- Ganguly S, Bakhshi S. Teleconsultations and shared care in pediatric oncology during COVID-19. *Indian J Pediatr* 2021;88 (01):1–2
- Othman MY, Blair S, Nah SA, et al. Pediatric solid tumor care and multidisciplinary tumor boards in low- and middle-income countries in Southeast Asia. *JCO Glob Oncol* 2020;6:1328–1345
- Maris JM. Defining why cancer develops in children. *N Engl J Med* 2015;373(24):2373–2375
- Rao VN, Anantharaman Rajeshwari R, Rajagopal R, Normen M. Inception of a pediatric cancer caregiver support group guided by parental needs. *Cancer Rep (Hoboken)* Jun 6 2021:e1469. Doi: 10.1002/cnr2.1469
- Mathur P, Sathishkumar K, Chaturvedi M, et al; ICMR-NCDIR-NCRP Investigator Group. Cancer Statistics, 2020: report from National Cancer Registry Programme, India. *JCO Glob Oncol* 2020; 6:1063–1075
- Patil S, Majumdar B, Awan KH, et al. Cancer oriented biobanks: a comprehensive review. *Oncol Rev* 2018;12(01):357. Doi: 10.4081/oncol.2018.357
- Loucaides EM, Fitchett EJA, Sullivan R, Atun R. Global public and philanthropic investment in childhood cancer research: systematic analysis of research funding, 2008–16. *Lancet Oncol* 2019;20 (12):e672–e684. Doi: 10.1016/s1470-2045(19)30662-x
- Magrath I, Shanta V, Advani S, et al. Treatment of acute lymphoblastic leukaemia in countries with limited resources; lessons from use of a single protocol in India over a twenty year period [corrected]. *European journal of cancer (Oxford, England: 1990)* Jul 2005;41(11):1570–83. Doi: 10.1016/j.ejca.2004.11.004
- Arora RS, Raj R, Mahajan A, Radhakrishnan N, Chinnaswamy G, Banavali S. Collaborative cancer research: progress report from the Indian Pediatric Oncology Group. *Lancet Child Adolesc Health* 2021;5(04):239–240
- Wong M, Mayoh C, Lau LMS, et al. Whole genome, transcriptome and methylome profiling enhances actionable target discovery in high-risk pediatric cancer. *Nature medicine* 2020/10/05 2020. Doi: 10.1038/s41591-020-1072-4