

Pediatric Oncology in Pakistan

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Summary: Pediatric oncology in Pakistan has developed over last decade with substantial increase in the facility for treatment and number of expertise. Though large numbers of children still do not reach treatment center more children have now access to quality cancer treatment. There has been gradual improvement in Pediatric oncology nursing and allied services. Pediatric Palliative care in Pakistan is in initial phase of development. Pediatric Oncology services are largely supported by philanthropists. Children Cancer Hospital a project of Children Cancer Foundation Pakistan Trust is not only providing quality treatment to every child regardless of paying ability but also playing a pivotal role in capacity building and creating awareness about childhood cancer in Pakistan.

Key Words: pediatric oncology, Pakistan, palliative care, children cancer hospital

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Pakistan is a low-to-middle income developing country with an annual per capita income of US \$1085.¹ It is the sixth most populous country with a total population of approximately 180 million people, of whom 35.4% are 0 to 14 years, 60.4% are 15 to 64 years, and 4.2% are over 65 years of age.² The average number of people per family is 6.8, and almost 17.2% people live below the poverty line.³ The average life expectancy for men is about 63 and that for women is 67 years.⁴ The infant mortality rate is 71%, one of the highest in the region.⁵

Cancer is becoming a major health care problem in Pakistan. There is no national population-based cancer registry; the precise incidence, mortality rates, number of new cancer cases, and number of deaths annually for Pakistan are not known. However, according to the World Health Organization estimates, as many as 61,624 incident cases and 42,624 cancer deaths in the male population and 75,095 incident cases and 43,188 deaths in the female population are reported annually.⁶ The 5 most common types of cancer in male patients are cancers of the lung (20.3%), oral cavity (13.8%), larynx (8.6%), bladder (8.9%), and esophagus (6.4%). In female patients, the 5 most common types of cancer are those of the breast (51.7%), oral cavity (14.1%), ovaries (10.2%), cervix (6.5%), and esophagus (6.5%).⁷

Most of the available information on pediatric cancer comes from hospital-based data or data from the International Agency for Research on Cancer registry in Karachi.⁷ On the basis of these data and the current population it is estimated that about 8000 children (younger than 18 y) get cancer every year in Pakistan. With the limited number of pediatric oncology centers it is estimated that not more

than 50% children are properly diagnosed and treated. The median age at presentation is 6 years for female patients and 7 years for male patients. Most cancers present in the advanced stage. There are hardly any stage I lymphomas in our registry. About 30% present with stage II disease, whereas 70% are in the advanced stage of disease (50% stage III and 20% stage IV).

The relative frequency of various pediatric cancers seen at Children Cancer Hospital (CCH), Karachi, and from the International Agency for Research on Cancer registry is shown in Table 1.

Less than 2% of the gross national product is allocated to health in Pakistan. Primary, secondary, and tertiary governmental health care facilities do exist; however, the infrastructure, access, and funding are far from satisfactory, particularly for cancer treatment. Private sector hospitals are too expensive and the health insurance system is very limited. Treatment of cancer is therefore beyond the reach of the majority of the population. Fortunately, there is tremendous philanthropic support in health care. Most of the pediatric oncology units are run on community support.

Until recently, only foreign-qualified pediatric oncologists headed pediatric oncology units and at any time there were not more than 6 in the entire country. The specialty was not recognized by the College of Physicians and Surgeons of Pakistan. To meet the demands for pediatric oncologists, 3 institutions, Aga Khan and Children Hospital in Karachi and Shaukat Khanum Cancer Hospital in Lahore, initiated a 3-year fellowship in pediatric oncology with institutional certification. A large number of pediatricians with a fellowship in pediatrics are being trained, but because of brain drain at any given time there are only about 10 to 12 such practitioners in the entire country. There is also a third category of caregivers: pediatricians and medical officers working in pediatric oncology with extensive experience in this field. Pediatric oncology and hematology as a subspecialty is now recognized by the College of Physicians and Surgeons of Pakistan. It is expected that the number of trained pediatric oncologists will now improve significantly.

There are 3 levels of nursing force in pediatric oncology: registered nurses, nurse technicians, and nurse aids. There are very few fully trained pediatric oncology nurses because of lack of Pediatric Oncology Nursing Education departments. The Shaukat Khanum Cancer Hospital in Lahore and The CCH in Karachi have taken the initiative in training of pediatric oncology nurses. The concept of an advanced practice nurse is evolving and we are in the process of developing courses and certification for nurse practitioners. As far as palliative care nurses are concerned, there are only 2 institutions with some training programs in palliative care.

The recently registered Pakistan Society of Pediatric Oncology is the national society for pediatric oncology in Pakistan. Pediatric oncologists practicing in Pakistan and abroad are eligible for membership. The society is planning

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TABLE 1. Common Pediatric Cancers

Type of Cancer	Children Cancer Hospital Karachi, 1997–2011 (%)	IARC Data of Karachi Region, 1995–1999 (%)
Leukemia	38	26
Lymphoma	18	22
Sarcoma	7	5
Bone tumor	7	10
Brain tumor	7	13
Retinoblastoma	6	4
Wilms tumor	4	4
Germ cell tumor	4	2
Neuroblastoma	4	2
Others	5	11

IARC indicates International Agency for Research on Cancer.

to initiate a pediatric cancer registry in Karachi and organize an International Pediatric Oncology Conference next year.

Although Pakistan has a National Cancer Control Plan in place, it is poorly implemented, especially with regard to the development of palliative care services and morphine availability. In fact, palliative care was only included in the second phase of implementation of the plan.⁸ Obtaining morphine is a real challenge. Even at the major cancer centers, supply is sporadic and there is little support from the government to improve its availability. One has to go through 3 ministries: health, excise, and narcotics.

Pediatric palliative care continues to remain in the early stages of development. Although awareness has increased significantly, the services have not grown. The palliative care unit at Children's Hospital Lahore was established by a grant awarded by 'My Child Matters' in 2008 with mentorship provided by Dr Aziza Shad. Although the psychosocial aspect of the program has developed significantly, lack of trained personnel, insufficient supply of morphine, and absence of outreach continue to remain major problems.⁹

The Palliative Care Program at the CCH was initiated immediately after the First Palliative Care Workshop held in Karachi in February 2007 with the support of International Network for Cancer Treatment and Research (INCTR). Since then, it has developed into a small but viable program, run by a physician and social worker, with a 2-bed inpatient unit, availability of parenteral and oral morphine, tramadol, and other analgesics, outpatient care for all children with relapsed or advanced disease, and psychosocial services for families. Future plans include the addition of a trained nurse and psychologist.

The First International Pediatric Oncology Conference was held in 2005 with the support of INCTR. In July 2007, a 2-day workshop was held on leukemia and febrile neutropenia. Pediatric oncology workshops and sessions are regular features of Shaukat Khanum Cancer Hospital symposium and Pakistan Pediatric Association conferences.

There have been several workshops on palliative care in Pakistan with the support of INCTR. The first was in Karachi in February 2007, then at the Annual Symposia of Shaukat Khanum Cancer Hospital, Lahore, and recently in 2011 in Karachi at the Pakistan Society of Clinical Oncology annual conference.

Almost all children are treated with a common protocol mostly from Children Oncology Group and International Society of Pediatric Oncology after establishing accurate histopathologic diagnosis. Some of the protocols

are modified according to local needs. The Pakistan Society of Pediatric Oncology is trying to develop national protocols for common cancers such as leukemia and lymphoma.

The CCH, a project of Children Cancer Foundation Pakistan Trust, is the only hospital exclusively dedicated to the care of children suffering from cancer in Pakistan. We receive referrals from all over Pakistan and also from Afghanistan and overseas Pakistanis in the Middle East.

Our vision is to provide diagnosis and treatment to every child suffering with cancer regardless of paying ability. Our core values are (i) to seek the pleasure of Allah; (ii) to provide quality services; (iii) patient welfare; (iv) capacity building; and (v) research.

CCH started in a single room in 2000 with an annual budget of only US \$1000 and now it has 3 outpatient clinics, 10 daycare beds, a 28-bed ward including 4 high dependency and 2 intensive care units, and 2 palliative care beds along with all the support services such as pharmacy, laboratory, food services, social services department, medical records (evolving into electronic medical record), seminar room, and library. Last year our budget was US \$1 million; 85% of this came from philanthropic support.

We have a social worker with a Master's degree in social sciences who received on the job training. We also have a spiritual counselor who comes daily and teaches the children. We do not have art therapists, but every Saturday volunteers who are mainly high school and college students spend time with children by painting and coloring with them.

Capacity building is one of the major objectives of the Children Cancer Foundation. The hospital is making all efforts to establish a proper medical education department for training doctors and nurses in pediatric oncology. Application for recognition of the CCH for fellowship in pediatric oncology and hematology is in process.

INSTITUTIONAL FELLOWSHIP IN PEDIATRIC ONCOLOGY

A 3-year structured pediatric oncology fellowship training program with rotation in major oncology centers was started in 2007. Three candidates with a fellowship in pediatrics have successfully completed the fellowship and are working as pediatric oncologists.

ONE-WEEK CASE-BASED LEARNING COURSE IN PEDIATRIC ONCOLOGY

The Children Cancer Foundation Pakistan Trust with the help of a grant from International Union Against Cancer, My Child Matters Program has started a training program for doctors. The objective of this project is to make doctors more proficient in early detection, diagnosis, and treatment of pediatric cancer and develop shared care with the CCH. We have successfully run 3 courses so far.

HALF-DAY WORKSHOP FOR GENERAL PRACTITIONERS AND PEDIATRICIANS

To make doctors more proficient in early detection, a half-day continuous medical education is carried out every 3 months for general practitioners and pediatricians.

REGULAR MONTHLY EDUCATIONAL ACTIVITIES FOR DOCTORS

In collaboration with other institutions we have 5 regular activities every month, including 2 Solid Tumor Boards,

Leukemia/Lymphoma Tumor Board, Journal Club, and a Fellow Talk.

At CCH, we strongly believe that medicine cannot progress without research. Unfortunately, in the past, because of lack of funding and space, we could not establish a good research department. However, at our center we have been treating children with a common uniform and standard chemotherapy protocol since the outset. We have reasonable medical record keeping and a cancer registry with documentation of patient demographics and clinical, diagnostics, and outcome data. We have started developing electronic medical records and archiving previous records. A clinical research officer has been hired to collect and publish our data. We have been presenting our data at both national and international meetings. In the near future we will be conducting prospective studies and participating in international trials.

Cancer still means death to many people, and a large segment of society continues to have a very nihilistic approach to cancer. Advocacy of pediatric cancer is one of the priorities of the Children Cancer Foundation. It has been creating awareness about pediatric cancer and its excellent outcome both in print and electronic media through interviews, articles, leaflets, and booklets. The Children Cancer Foundation is a member of the International Union Against Cancer and actively participates in World Cancer Day activities. We also regularly organize awareness seminars on pediatric cancer, particularly on International Childhood Cancer Day. Our marketing and communications department help us not only in fund raising but also in advocacy of pediatric cancer.

Within the limited resources we try to maintain quality, whether it is the standard of medical and psychosocial care for children, documentation of data, or standard

operating procedures in various clinical and administrative departments.

The dream that began from a single room taking the shape of a 28-bed hospital on rented premises now stands poised to transform into a regional center for pediatric hematology and oncology. The new purpose-built hospital will not only provide treatment but also serve as a center for capacity building, clinical trials, research, and advocacy to bring about a real change in pediatric cancer and blood diseases.

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