Guidelines for Pediatric Cancer Centers

ABSTRACT. Since the American Academy of Pediatrics published guidelines for pediatric cancer centers in 1986 and 1997, significant changes in the delivery of health care have prompted a review of the role of tertiary medical centers in the care of pediatric patients. The potential effect of these changes on the treatment and survival rates of children with cancer led to this revision. The intent of this statement is to delineate personnel and facilities that are essential to provide state-of-the-art care for children and adolescents with cancer. This statement emphasizes the importance of board-certified pediatric hematologists/oncologists, pediatric subspecialty consultants, and appropriately qualified pediatric medical subspecialists and pediatric surgical specialists overseeing the care of all pediatric and adolescent cancer patients and the need for facilities available only at a tertiary center as essential for the initial management and much of the follow-up for pediatric and adolescent cancer patients. Pediatrics 2004;113:1833–1835; cancer, pediatrics, hematology, oncology, cancer center.

INTRODUCTION

A pediatric cancer center must have the staff and facilities to ensure that the pediatric patient with cancer will receive the best care that is available for his or her diagnosis. The medical staff at such a center is composed of the primary care pediatrician, pediatric medical subspecialists, and pediatric surgical specialists—hematologists/oncologists, surgeons, urologists, neurologists, neurosurgeons, orthopedic surgeons, radiation oncologists, pathologists, child life specialists, and diagnostic radiologists. These physicians and nurse practitioners, pediatric nurses, social workers, pharmacists, nutritionists, and other allied health professionals serve as a multidisciplinary team committed to the care of the child or adolescent with cancer.

In the United States, the oncologic care of the child or adolescent with cancer should be coordinated by a pediatric hematologist/oncologist who is board certified in the subspecialty of pediatric hematology and oncology by the American Board of Pediatrics. Other subspecialists should be similarly board certified when applicable.

Oncologic care should be provided in a pediatric center that has the following personnel, facilities, and capabilities.

Personnel

- Communication with the primary pediatrician, which is essential in the provision of family-centered supportive care
- Board-certified pediatric hematologists/oncologists
- Pediatric oncology nurses who are certified in chemotherapy, knowledgeable about pediatric protocols, and experienced in the management of complications of therapy
- Board-certified radiologists with specific expertise in the diagnostic imaging of infants, children, and adolescents
- Board-certified surgeons with expertise in pediatric general surgery
- Surgical specialists with pediatric expertise (ie, training and certification, if available) in neurosurgery, urology, orthopedics, ophthalmology, otolaryngology, dentistry, and gynecology
- A board-certified radiation oncologist trained and experienced in the treatment of infants, children, and adolescents
- A board-certified pathologist with special training in the pathology of hematologic malignancies and solid tumors of children and adolescents
- Board-certified pediatric subspecialists available to participate actively in all areas of the care of the child with cancer, including anesthesiology, intensive care, infectious diseases, cardiology, neurology, endocrinology and metabolism, genetics, gastroenterology, child and adolescent psychiatry, nephrology, and pulmonology
- Pediatric physical and mental rehabilitation services including pediatric physiatry
- Pediatric (oncology) social worker(s), pediatric psychologists, child life specialists, and access to family support group services
- Pediatric nutrition experts with the capability of preparing, administering, and monitoring total parenteral nutrition

Facilities

- An immediately accessible and fully staffed, on-site pediatric intensive care unit
- Up-to-date diagnostic imaging facilities to perform radiography, computed tomography, magnetic resonance imaging, ultrasonography, radionuclide imaging, and angiography; positron-emission tomography scanning and other emerging technologies are desirable
• Up-to-date radiation-therapy equipment with facilities for treating pediatric patients
• A hemopathology laboratory capable of performing cell-phenotype analysis using flow cytometry, immunohistochemistry, molecular diagnosis, and cytogenetics and access to blast colony assays and polymerase chain reaction-based methodology
• Access to hemodialysis and/or hemofiltration and apheresis for collection and storage of hematopoietic progenitor cells

Capabilities

• A clinical chemistry laboratory with the capability to monitor antibiotic and antineoplastic drug levels
• A blood bank capable of providing a full range of products including irradiated, cytomegalovirus-negative, and leucodepleted blood components
• A pharmacy capable of accurate, well-monitored preparation and dispensing of antineoplastic agents and investigational agents
• Capability of providing sufficient isolation of patients from airborne pathogens, which could include high-efficiency particulate air (HEPA) filtration or laminar flow and positive/negative pressure rooms
• Access to stem cell transplant services
• Educational and training programs for health care professionals including the primary care physician
• Coordination of services including home health, pain management, palliative, and end-of-life care
• A regularly scheduled multidisciplinary pediatric tumor board
• An established program designed to provide long-term, multidisciplinary follow-up of successfully treated patients at the original treatment center or by a team of health care professionals who are familiar with the potential adverse effects of treatment for childhood cancer
• Membership or affiliation with the Children’s Oncology Group to provide access to state-of-the-art clinical trials; availability of support for coordination to track patients’ progress and maintain clinical trials data
• Capability of providing parent, caregiver, and patient education
• Full-time access to translation services to ensure accurate translation and effective communication among all health care professionals and the patient and family
• An ongoing program of assessment of care for continuing quality improvement and safety
• A formal program for cancer education for the family and instruction on self-management

ROLE OF CENTERS IN DIAGNOSIS AND TREATMENT

Approximately 12,000 new cases of cancer are diagnosed in children younger than 20 years annually in the United States.1,2 Cancer remains the second most frequent cause of death, after injury, in children older than 3 months.3 Great progress has been made in the development of successful treatment programs for children and adolescents with cancer. These improvements have been possible because of the availability of pediatric cancer treatment centers with collective expertise in the clinical management of children with cancer and the existence of a network of experienced investigators and allied health professionals who recognize the central importance of randomized clinical trials as the best available method for identifying more successful treatment strategies and who have the resources to evaluate new treatment modalities as they become available.

The importance of comprehensive, multidisciplinary treatment in improving patient outcome in a cost-effective manner has been well documented for children with acute lymphoblastic leukemia,3 non-Hodgkin lymphoma,5,6 brain tumors,7,8 rhabdomyosarcoma,5,8 Wilms’ tumor,9,10 and Ewing sarcoma.5 Almost 80% of these children can be treated successfully if modern diagnostic and therapeutic approaches are initiated expeditiously.2 Early detection, accurate diagnosis, and appropriate treatment depend on a multidisciplinary treatment approach to children and adolescents with cancer, an approach that is uniquely available at a pediatric cancer center. The roles of specialized nursing, pharmacy, rehabilitation, and paramedical personnel and access to increasingly complex equipment and facilities are critical to improving long-term survival and quality of life.

The center-based pediatric hematologist/oncologist is the coordinator for the diagnosis and treatment of most children and adolescents with cancer. Pediatric hematology/oncology is an established specialty with specific training requirements that lead to subspecialty board eligibility. Because most pediatric tumors show a striking response to specific regimens of intensive chemotherapy, pediatric hematologists/oncologists are necessarily resolute in carrying out therapies that can have devastating morbidity and appreciable mortality. For these therapies to be administered safely, a pediatric hematologist/oncologist who is trained and experienced in the management of children and adolescents with cancer and who has extensive knowledge of the relevant drug indications and toxicities must coordinate this care.

The pediatric hematologist/oncologist must be assisted by skilled nurses, social workers, pharmacists, nutritionists, and psychologists who specialize in pediatric oncology. Professional organizations such as the Association of Pediatric Oncology Nurses and Association of Pediatric Oncology Social Workers facilitate the professional growth and education of these individuals. Diagnostic radiologists and radiation oncologists with specific training and interest in pediatric oncology should be available at the pediatric cancer center. Principles of surgery that are unique to childhood tumors have evolved, and in fields such as general (pediatric) surgery, urology, neurology, and orthopedics, the presence of surgeons whose sole (or major) effort is directed toward pediatric oncology has become indispensable in achieving maximum survival.
A pathologist experienced in pediatric oncology is an essential member of the multidisciplinary team at the pediatric cancer center. State-of-the-art diagnosis of many pediatric hematologic malignancies and tumors requires immunochemistry and/or molecular techniques. Because solid tumors in children and adolescents are rare in the experience of most pathologists, an incorrect histologic diagnosis may be given when initial surgical management occurs at a non-specialized hospital. Ideally, the diagnostic biopsy should be performed at the cancer center, at which the facilities are available to order and obtain all the special studies that would be appropriate and would obviate the need for subjecting the patient to repeat procedures.

**PRACTICE OF PEDIATRIC ONCOLOGY OUTSIDE RECOGNIZED CENTERS**

The clinical results in children with cancer have been shown to be superior when specialized diagnostic, supportive, and specific care is given at a pediatric cancer center. After diagnosis has been established and the treatment plan has been determined by the pediatric cancer center, certain aspects of care may be continued in the office of a primary care pediatrician for selected children. When such a plan for shared treatment is undertaken, it must be with the understanding that the child will be referred back to the pediatric cancer center if complications develop or there is recurrence of the tumor. For many children, the facilities and expertise available at the pediatric cancer center are required for all aspects of therapy. However, it must be emphasized that the primary care pediatrician should retain an important supportive role for the patient with cancer and his or her family, which requires excellent regular communication between the oncologist and the pediatrician.

**SUMMARY**

On the basis of the effectiveness of pediatric cancer centers in treating children and adolescents with cancer, the American Academy of Pediatrics recommends the following:

- Children and adolescents with newly suspected and/or recurrent malignancy should be referred to a pediatric cancer center for prompt and accurate diagnosis and management.
- Children and adolescents with newly diagnosed and/or recurrent malignancies should have their treatment coordinated by a board-certified pediatric hematologist/oncologist; treatment should be prescribed and initiated at a pediatric cancer center but may be continued at a center not specialized in the care of the pediatric oncology patient under the continuing oversight of the center’s multidisciplinary team.
- Multidisciplinary team members should have pediatric expertise within their specialty area.

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