



POLICY STATEMENT

Standards for Pediatric Cancer Centers

abstract

FREE

Since the American Academy of Pediatrics—published guidelines for pediatric cancer centers in 1986, 1997, and 2004, significant changes in the delivery of health care have prompted a review of the role of 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, capabilities, and facilities that are essential to provide state-of-the-art care for children, adolescents, and young adults with cancer. This statement emphasizes the importance of board-certified pediatric hematologists/oncologists and appropriately qualified pediatric medical subspecialists and pediatric surgical specialists overseeing patient care and the need for specialized facilities as essential for the initial management and much of the follow-up for pediatric, adolescent, and young adult patients with cancer. For patients without practical access to a pediatric cancer center, care may be provided locally by a primary care physician or adult oncologist but at the direction of a pediatric oncologist. *Pediatrics* 2014;134:410–414

INTRODUCTION

A pediatric cancer center must have the staff and facilities to offer the pediatric patient with cancer treatment that are consistent with the current standard of care for his or her diagnosis. The medical staff at such a center is often composed of the primary care pediatrician, pediatric medical subspecialists, and pediatric surgical specialists such as hematologists/oncologists, surgeons, urologists, neurologists, neurosurgeons, orthopedic surgeons, radiation oncologists, pathologists, palliative care specialists, critical care physicians, emergency medicine specialists, and diagnostic radiologists. At certain institutions, hospitalists, advance practice nurses, and physician assistants may be used to provide continuous around-the-clock care. Physicians, advanced practice nurses, physician assistants, pediatric nurses, social workers, pharmacists, dietitians, child life specialists, mental health/behavioral health specialists, and other allied health professionals are among the multidisciplinary team members committed to the care of the child, adolescent, or young adult with cancer.

In the United States, the oncologic care of the child or adolescent with cancer should be directed by a pediatric hematologist/oncologist who is board certified in the subspecialty of pediatric hematology and oncology by the American Board of Pediatrics. Initial diagnostic assessment, induction therapy, and management of complications or

SECTION ON HEMATOLOGY/ONCOLOGY

KEY WORDS

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The recommendations in this statement do not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

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

PERSONNEL

- 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; Association of Pediatric Hematology/Oncology Nurses certification is preferable
- Board-certified radiologists with specific expertise as evidenced by certification and training in the diagnostic imaging and radiologic intervention of infants, children, adolescents, and young adults
- Board-certified surgeons with expertise in pediatric general surgery
- Surgical specialists with pediatric expertise, as evidenced by certification and training in neurosurgery, urology, orthopedics, ophthalmology, otolaryngology, and gynecology
- Dentists who have completed additional training in pediatric dentistry
- A board-certified radiation oncologist trained and experienced in the treatment of infants, children, and adolescents
- Pathologists with special expertise as evidenced by certification and training in the pathology of hematologic malignancies, tumors of the central nervous system, and solid tumors in children, adolescents, and young adults
- Board-certified pediatric medical subspecialists available to participate actively in all areas of the care of the child with cancer, including anesthesiology, critical care, infectious diseases, cardiology, neurology, endocrinology and metabolism, genetics, gastroenterology, child and adolescent psychiatry, nephrology, palliative medicine, pulmonology, adolescent medicine, and behavioral and developmental specialists
- Pediatric physical and mental rehabilitation services, including pediatric physiatry and pediatric psychiatry
- Social worker(s) with experience in pediatric oncology, pediatric psychologists, child life specialists, and school reintegration specialists, and access to personnel skilled in providing family support and group services and chaplaincy personnel who provide spiritual support
- Experts with knowledge in complementary and alternative therapies
- Nutrition experts with experience in pediatrics and the capability of preparing, administering, and monitoring total parenteral nutrition
- Pharmacist(s) with experience and training in providing chemotherapy and supportive care medicines for pediatric patients with cancer; a board-certified clinical pharmacologist, where available, may be helpful in patient management
- Continued active involvement by the primary care pediatrician is important for the provision of patient- and family-centered supportive care

FACILITIES

- An immediately accessible and fully staffed, on-site PICU
- Up-to-date diagnostic imaging facilities to perform radiography, computed tomography, MRI, ultrasonography, radionuclide imaging, and angiography; positron-emission tomography scanning and other

emerging technologies are desirable

- Access to up-to-date radiation-therapy equipment with facilities for treating pediatric patients
- An established relationship with a hematopathology laboratory capable of performing cell-phenotype analysis using flow cytometry, immunohistochemistry, molecular diagnosis, cytogenetics, and polymerase chain reaction–based methodology and fluorescence in situ hybridization
- Access within the community to pediatric hemodialysis and/or hemofiltration and apheresis
- Appropriate isolation facilities for patients with severe immunosuppression, including high-efficiency particulate air (HEPA) filtration, or laminar flow rooms and positive/negative pressure rooms

CAPABILITIES

- A clinical chemistry laboratory with the capability to monitor antibiotic and antineoplastic drug concentrations
- A blood bank capable of providing a full range of products, including irradiated and leuko-depleted blood components
- A pharmacy capable of accurate, well-monitored preparation and dispensing of antineoplastic agents and investigational agents
- Access to stem cell transplant services with the capability or availability of HLA antigen typing
- Educational and training programs for health care professionals, including the primary care physician
- A regularly scheduled multidisciplinary care conference
- Care coordination of family-centered services including home health, pain management, palliative, and end-of-

life care and treatment plan compliance

- A regularly scheduled multidisciplinary pediatric tumor board
- Ability to function as the medical home incorporating anticipatory guidance as defined in Bright Futures for the child with cancer during active treatment; on completion of therapy, care may transition back to the primary care medical home with oversight by the cancer center's multidisciplinary team
- An established program designed to provide long-term, multidisciplinary follow-up of successfully treated patients at the original treatment center or by a physician-led team of health care professionals who are familiar with the potential adverse effects of treatment of childhood cancer; as survivors of childhood cancer move into adulthood, transition to an adult provider may be appropriate¹
- Membership or affiliation with a cooperative clinical trials group, such as 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
- Full-time access to professional medical interpreters to ensure accurate translation and effective communication among all health care professionals and the patient and family; written materials should be available in the native language of the patient/family, and an ongoing program to deliver culturally effective care should be available
- A formal, ongoing program to continually assess and improve quality and safety including feedback from patients and families
- A formal program for cancer education for the patient, family, and/

or caregiver and instruction on self-management

- Access to instruction and learning activities for hospitalized children and adolescents

ROLE OF CENTERS IN DIAGNOSIS AND TREATMENT

More than 15 000 new cases of cancer are diagnosed in children younger than 20 years annually in the United States.^{2,3} Cancer is the second leading cause of death after accidents in children ages 5 to 14 years.

Great progress has been made in the development of successful treatment programs for children, adolescents, and young adults with cancer. These improvements have been possible because of the availability and collaboration of pediatric cancer treatment centers with collective expertise in the clinical management of children with cancer. Experienced investigators and allied health professionals recognize the importance of a national clinical trials network in developing more successful treatment strategies.⁴

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,⁵ non-Hodgkin's lymphoma,^{6,7} brain tumors,⁸ rhabdomyosarcoma,^{6,8} Wilms tumor,⁹ and Ewing sarcoma.⁶ Almost 80% of these children can be treated successfully if modern diagnostic and therapeutic approaches are initiated expeditiously.⁵ Accurate diagnosis, appropriate treatment, and supportive care depend on a multidisciplinary treatment approach to children, adolescents, and young adults 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 further improving long-term survival and quality of life.

The center-based pediatric hematologist/oncologist directs the diagnostic evaluation and treatment of most children, adolescents, and young adults 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 use therapies that can have substantial morbidity and potential mortality. For these therapies to be administered safely, a pediatric hematologist/oncologist who is trained and experienced in the management of children, adolescents, and young adults with cancer and who has extensive knowledge of the relevant drug indications and toxicities must oversee the care of these patients.

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 Hematology/Oncology Nurses and the Association of Pediatric Oncology Social Workers facilitate the professional growth and education of nurses and social workers. 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 in fields such as general (pediatric) surgery, urology, neurosurgery, and orthopedics. The presence of surgeons with demonstrated expertise in the surgical aspects of 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, adolescents, and young adults 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 pediatric cancer center, at which the facilities are available to order and obtain all the special studies that would be appropriate, reducing the need for repeat procedures.

PRACTICE OF PEDIATRIC ONCOLOGY OUTSIDE RECOGNIZED CENTERS

Clinical results in children with cancer have been shown to be superior when specialized diagnostic testing, supportive care, and initial cancer treatment are carried out at a pediatric cancer center.⁵⁻⁹ After diagnosis has been established and the treatment plan has been determined by the pediatric cancer center, certain aspects of care that are not investigational may be continued in the office of a primary care pediatrician for selected children when mandated by distance from the cancer center or other individual specific circumstances. In some circumstances, communication via telemedicine may be beneficial. When such a plan for shared treatment is

undertaken, it must be a collaborative effort between the pediatric cancer center and the primary pediatrician, with ongoing communication between the local and distant site. 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. Most of a patient with cancer's course is spent at home under the care of family members and the primary care physician. The role of families in the decision-making, care, and advocacy for the child is critical. Hematology/oncology team members must be available, responsive, and versed in discussing supportive care provided away from the tertiary center.

SUMMARY

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

- Children, adolescents, and young adults with newly suspected and/or recurrent malignancies should be referred to a pediatric cancer center for prompt and accurate diagnosis and management. Centers that are unable to accept the referral should arrange for the child

to be seen promptly at another appropriate facility.

- 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 therapy that is not investigational may be continued at a center not specialized in the care of the pediatric oncology patient. Care should be delivered with the oversight of the pediatric cancer center's multidisciplinary team.
- Multidisciplinary team members should be physician led and have pediatric expertise within their specialty area.

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