

FACTS

Knowing No Bounds:

Stroke in Infants, Children, and Youth

OVERVIEW

Although stroke is often viewed as occurring primarily in the elderly, it also strikes infants, children, young adults and can even occur before birth – and with equally devastating results. The risk of stroke in children is greatest in the first year of life, and peaks during the perinatal period (roughly the weeks before and immediately after birth).¹ Stroke also occurs in about one of every 3,500 live births. The risk of stroke from birth through age 19 is nearly 5 per 100,000 children per year.² In fact, stroke is one of the top 10 causes of death for children between the ages of one and 19.³

Of children surviving stroke, about 60% will have permanent neurological deficits, most commonly hemiparesis or hemiplegia.² Hemiplegia/hemiparesis (total or partial paralysis on one side of the body) is the most common form of cerebral palsy in children born at term, and stroke is its leading cause.⁴ Other long-term disabilities caused by a stroke occurring around the time of birth include cognitive and sensory impairments, epilepsy², speech or communication disorders, visual disturbances⁵, poor attention, behavioral problems, and poor quality of life.²

When it comes to stroke, children are not just little adults. Stroke risk factors, symptoms, prevention efforts, and treatment are often different in children than in adults. However, they do share one thing in common: speedy diagnosis, treatment, and age-appropriate rehabilitation and therapy can minimize death and disability in children just as they can in adults. In addition, more research is needed to better understand the unique aspects of diagnosing and treating stroke in children.²

CAUSES OF CHILDHOOD STROKE

Stroke risk factors for children are much different than those for adults. About half of the children presenting with a stroke had a previously-identified risk factor. For example, sickle cell

disease and congenital or acquired heart disease are the most common underlying risk factors.² Other risk factors for stroke in children include²:

- Head and neck infections;
- Systemic conditions, such as inflammatory bowel disease and autoimmune disorders;
- Head trauma;
- Dehydration;
- Maternal history of infertility;
- Maternal infection in the fluid surrounding an unborn baby (chorioamnionitis);
- Premature rupture of membranes during pregnancy; and
- Maternal preeclampsia (pregnancy-related high blood pressure).

PREVALENCE AND MORTALITY

Delayed or misdiagnosis of stroke in children is still common.⁶ The incidence of stroke in US children ages 0-15 is estimated at 6.4 out of 100,000.¹ Nevertheless, the incidence of stroke in children has been stable over the last 10 years, although at least one recent study found that the incident rate in U.S. children may be two to four times higher than previously published estimates.⁷ Childhood mortality from stroke fell by 58% between 1979 and 1998 in the U.S.¹ However, the decline appears to be the result of decreasing fatalities after stroke, not a decrease in stroke incidence.⁸

- Between 20% and 40% of children die after a stroke.²
- About 3,000 children and young adults had a stroke in the United States in 2004.⁸
- Boys have a nearly 1.3-fold higher risk for stroke than girls.¹
- African American children are at higher risk for stroke, and death from stroke, compared to Caucasian and Asian children.¹

PREVENTION AND TREATMENT

Prevention, presentation and treatment of stroke also differ between children and adults. The major treatment difference is the use of the clot-busting drug tPA for ischemic stroke. TPA is the cornerstone for treating adult ischemic stroke, but

its use is generally not recommended for treating young children, especially infants, because it has not been tested for safety and efficacy in children.

Young children with stroke often have remarkably different symptoms compared with adults. In newborns, the first symptom of stroke is often seizures involving only one arm or leg. Seizures are a much less common stroke symptom in adults. Some children with perinatal stroke may appear quite normal and later present with early hand dominance or developmental delay.²

Because an initial stroke is often the first sign of a problem in a child, preventing a first childhood stroke can be difficult. The American Heart Association/ American Stroke Association guidelines for managing stroke in children consequently focus on promptly recognizing and diagnosing the stroke and then taking steps to reduce the likelihood of another stroke.² Since 10% of children who have a stroke will have a recurring stroke, assessing, and if possible, addressing underlying risk factors is particularly important to survival and quality of life.⁵

COST FOR FAMILIES AND SOCIETY

The exact costs of childhood stroke to families and society are unknown at this time. However, one study found that the average cost of medical care in the first year after childhood stroke is nearly \$43,000,⁹ and the subsequent health care needs of these children can last decades, even far into adulthood.⁴ Another study found that the financial burden of strokes in infants and children is both substantial and long-term, with children with stroke experiencing five-year health care costs 15 times higher than children of the same age without stroke.¹⁰

The costs to families and society extend beyond the direct medical costs. Familial and societal impacts include: altered family relationships and home life, lost income and productivity, and educational costs, such as the need for special services and placement.¹¹

ACCESS TO HEALTH CARE

The health care reform law, the Affordable Care Act, includes a range of provisions to address insurance barriers faced by children with stroke, such as banning health insurers from denying coverage to children based on a pre-existing condition and prohibiting lifetime limits. When the reform law is fully implemented in 2014, it will go a long way towards addressing many of the problems accessing care that children with stroke currently face. For example, underinsurance, resulting in high out-of-pocket medical bills, is a

significant concern for families with children who have had a stroke. Other common barriers include:

- Managed insurance plans with “gatekeepers” may make it more difficult for patients to gain access to needed specialty and rehabilitation care, resulting in possibly suboptimal care; and
- Insurance plans imposing annual therapy or procedure limits on needed medical care, such as rehabilitation services.

THE ASSOCIATION ADVOCATES

The American Stroke Association, a division of the American Heart Association, is committed to advancing public policies that will allow children and adults with stroke to live longer and fuller lives. These policies include:

- More public resources devoted to researching the causes and treatment of pediatric stroke;
- Support for the Centers for Disease Control’s Birth Defects Centers to advance our knowledge of the risk factors of pediatric stroke;
- Support for activities to increase awareness among parents, families, caregivers, and health care providers about pediatric stroke; and
- Monitoring the implementation of health care reform to ensure access to adequate, affordable insurance coverage, including coverage for age-appropriate rehabilitative and habilitative services.

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