



News Release

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Hidden population: Thousands of youths take on caregiver role at home

SAN DIEGO – While the typical preteen or adolescent can be found playing sports or video games after school, more than 1.3 million spend their free time caring for a family member who suffers from a physical or mental illness, or substance misuse.

These “caregiving youth” are a hidden population who are at risk of school failure and poor health due to the chronic physical and emotional stress of their responsibilities at home, said Julia Belkowitz, MD, FAAP, author of an abstract titled “Caregiving Youth Project: A School-Based Intervention to Support a Hidden Population in Need.” The study will be presented Saturday, Oct. 11 at the American Academy of Pediatrics (AAP) National Conference & Exhibition in San Diego.

Dr. Belkowitz, assistant professor of pediatrics at the University of Miami Miller School of Medicine, and her colleagues worked with the American Association of Caregiving Youth (AACY) to better understand the experiences of caregiving youth in Palm Beach County, Fla. They also studied the impact of services provided by AACY to caregiving youth, including a support system, skills-building classes, home health and community resources, tutoring and respite services along with sponsored fun activities.

“AACY services in Palm Beach County reach only the tip of the iceberg,” said Connie Siskowski, RN, PhD, founder and president of AACY. “Today in the U.S., there are many more than the 1.3 million children identified in 2005 who face the challenges of juggling adult-sized responsibilities of caring for ill, injured, aging or disabled family members while trying to keep up at school.”

Researchers analyzed approximately 500 intake forms completed by the AACY with youth caregivers. The forms included information on demographics, caregiving activities and health status collected at eight middle schools in Palm Beach County, Fla. They also reviewed approximately 200 family intake forms completed when a social worker conducted a home visit with the families, as well as feedback forms completed annually by youth participating in AACY activities.

Sixty-two percent of the youth caregivers were girls; 38% were boys. The median age of caregivers was 12 years.

Youth caregivers reported spending a median of 2.5 hours each school day and four hours each weekend day performing caregiving tasks at home. Estimates of median caregiving task time reported by family members were slightly lower at 1.5 hours on weekdays and 2.25 hours on weekend days.

These tasks include assisting family members with getting around, eating, dressing, toileting, bathing and continence care. Youth caregivers also kept the family member company, provided emotional support, cleaned the house, shopped for groceries, administered medications, translated in clinical settings and handled medical equipment at home.

“This study is an important step toward raising awareness about the issue of caregiving youth,” said Dr. Belkowitz, who also is assistant regional dean for student affairs at the regional campus of the Miller School. “The AACY is developing partnerships throughout the nation to further understand this special population and expand programming to provide the resources and support these young people need and deserve.”

The study will be presented at 1:33 p.m. PDT Saturday, Oct. 11 in Marina Ballroom Salon E at the San Diego Marriott Marquis. To view the abstract, visit

<https://aap.confex.com/aap/2014/webprogrampreliminary/Paper23915.html>.

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The American Academy of Pediatrics is an organization of 62,000 primary care pediatricians, pediatric medical subspecialists and pediatric surgical specialists dedicated to the health, safety and well-being of infants, children, adolescents and young adults. For more information, visit www.aap.org.