



## Many Go Undiagnosed: Youth May Have Chronic Fatigue Syndrome

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DePaul University researchers wanted to understand how common myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), was in a diverse group of children. ME/CFS is a severe chronic illness affecting health including sleep, pain, fatigue, and cognition.

Previous studies examined children who were already being treated by a doctor, leaving out those who may not have had access to health care.

Additionally, reduced-cost clinics often do not refer patients to specialists or have resources needed to properly diagnose youth with ME/CFS. Random community-based samples are important because they include people of various backgrounds.



Figure 1 Photograph by College Degrees 360. CC BY-SA 2.0

“The prevalence of pediatric ME/CFS was 0.75%, with a higher percentage being African American and LatinX than Caucasian. Of the youth diagnosed with ME/CFS, less than 5% had been previously diagnosed with the illness.”

This study has shown ME/CFS is common among children and often goes undiagnosed. This is especially true for females, older youth, and some racial minorities. Future research and programs must look at how ME/CFS can be better diagnosed and treated in youth. To do this, there needs to be more funding and attention from the government.

### Highlights

**There are children living with ME/CFS who do not know it.**

**When children have this illness, it impairs their school and home life.**

**The highest rates of those with ME/CFS were African American and LatinX.**

**Girls and older youth are also more likely to have ME/CFS.**

## **Methods**

This seven-year study randomly surveyed about 10,000 households with children ages 5-17 from the Chicago area. Of these youth, we brought 165 children who had fatigue and 42 children who did not have fatigue into a hospital for a medical exam, to complete surveys about their symptoms, and to answer questions about their mental health. A team of doctors then reviewed their cases and made diagnoses of ME/CFS.

## **Results**

- About 1 child out of every 134 children has ME/CFS; this is a rate higher than previously found.
- Of those who received an ME/CFS diagnosis, only 5% were previously diagnosed.
- The highest number of those with ME/CFS were African American and LatinX.
- Higher incidence of ME/CFS were also found for girls and older youth.

### **What Does This Mean For?**

**Practice:** Of the 42 children who were identified as having ME/CFS, only two had been previously diagnosed with the illness. These findings show most children with this illness do not receive a proper diagnosis of ME/CFS. Additionally, these results point to the need to develop better ways to find youth with this illness and to develop appropriate treatment plans.

**Research and Evaluation:** Future research should look at why girls, minorities, and older children experience higher rates of ME/CFS. Differences in how parents and children experience and report symptoms should be examined. More effort should be put into designing a universal method for diagnosing children.

**Social Action:** The higher prevalence rate for African American and LatinX youth might be due to a lack of healthcare or to any number of environmental challenges. These differences mean researchers need to pay attention to risk factors for ME/CFS across groups. Government officials and patient groups from around the world have contacted the authors for more details, indicating the far reach of the study.

**Similar Settings:** Community-based sampling is a helpful method for reaching populations not typically represented in research studies. Additionally, having both patient and doctor reports gives more information about ME/CFS.

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