

Lack of sleep, stress describe a mother's experience after child's ALL treatment

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Study shows mothers' sleep and stress difficulties after child's ALL treatment.
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Many months after their child's diagnosis and treatment, 46 percent of mothers exhibited symptoms of clinical anxiety and 26 percent of mothers showed depressive symptoms.

"It's a whole new cancer world" and "I don't remember what it's like to

have sleep" were the most common themes of [mothers](#) interviewed by University of Colorado Cancer Center researchers during the maintenance period after a child's treatment for [acute lymphoblastic leukemia](#) (ALL). Results of this qualitative study are published in a recent issue of the *Journal of Pediatric Nursing*. A second study, published today in the *Journal of Pediatric Oncology Nursing*, shows the quantitative differences between stress, [anxiety and depression](#) in these [parents](#) of chronically ill children and parents of healthy children. Many months after their child's diagnosis and treatment, 46 percent of mothers exhibited symptoms of clinical anxiety and 26 percent of mothers showed [depressive symptoms](#).

"Even though these mothers were in the maintenance phase of their child's illness and the prognosis was good, we heard them say over and over that things could never go back to what they were before," says Madalynn Neu, PhD, RN, assistant professor at the CU College of Nursing, an education partner of the CU Cancer Center.

"Many had lost their normal lives – lost jobs, houses, friends. Some were juggling their time around their child's needs and they had fears about many things – fear of recurrence, fear of making a mistake with medication, fear their kids might get sick with an infection," says Ellen Matthews, PhD, RN, CU Cancer Center investigator and associate professor at the CU College of Nursing.

The researchers explain that they chose to work with mothers in this maintenance period of relative stability following treatment so as to avoid making further demands on mothers during the acute period of their child's illness. This allowed Neu, Matthews and colleagues to look at the mid- and longer-term effects of a child's diagnosis on a mother's wellbeing. For example, the researchers found that once sleep arrangements changed during a child's treatment, they frequently stayed changed rather than going back to what parents had seen as "normal"

before treatment.

"Mothers talked about the difficulty of sleep while giving steroid medication. And if the ill child got to stay up late watching movies, the siblings wanted to stay up too. The same was true of sleeping in a parent's room: if an ill child wanted to sleep close to a parent (or if a parent wanted to sleep close to an ill child!), siblings tended to move in as well. Sleep can be challenging for parents of well children and our studies show it's even more so for parents of children who have experience ALL," Neu says.

Interestingly, the researchers point out that while depression and stress was higher in mothers of children treated for ALL, anxiety levels as measured by salivary cortisol levels were similar to mothers of well children.

"This may have been affected by the fact that even the control group wasn't without anxiety. Financial, marital, social and career concerns mean that parents of young children experience anxiety even without ALL," Matthews says.

The group hopes that awareness of maternal concerns after a child's treatment for ALL will help design interventions that will help mothers manage these lifestyle issues affected by their [child](#)'s illness.

More information: www.ncbi.nlm.nih.gov/pubmed/24486174

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