

SLEEP, FATIGUE, AND CAREGIVER BURDEN IN PARENTS OF  
CHILDREN WITH ACUTE LYMPHOBLASTIC LEUKEMIA (ALL)

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Sleep, Fatigue, Parents

**Purpose:** The purpose of this study is to evaluate whether dexamethasone may be responsible for altered sleep efficiency and sleep duration in children with ALL and if the children's altered sleep quality may in turn contribute to reduced sleep efficiency and sleep duration in their primary caregiver (most commonly the mother).

**Design:** This descriptive comparative study is a companion study to the Sleep, Fatigue, and Dexamethasone in Childhood ALL protocol (SLEEP) and the St Jude Children's Research Hospital Total XV protocol for children with ALL. Research participants will consist of parent(s) or guardian(s) of children enrolled on Total XV (in the treatment phase of continuation) and enrolled on SLEEP. Both mothers and fathers will be eligible to participate.

**Methods:** Research participants will be asked to complete a demographic sheet, a fatigue measure and caregiver burden instruments. Research participants will also be asked to keep a sleep diary and to wear a wrist actigraph to measure sleep efficiency. Parent sleep efficiency, sleep duration, level of fatigue, and caregiver burden will be measured during the two consecutive 5-day periods, (the first when their child is off dexamethasone and the second 5-day period when the child is on dexamethasone). Fatigue and caregiver burden of the participants will be compared between the two time periods. Sleep efficiency of the parents will be compared between the two time periods and compared with the sleep efficiency of their ill child during the same consecutive 5-day periods.

**Discussion:** Parents often report that their child diagnosed with ALL and receiving steroid therapy experience altered sleep patterns, fatigue, irritability and other behavioral changes. As a consequence, parents sleep is disrupted and fatigue along with increased caregiver burden can also result. A relationship between the parent and child sleep patterns will provide more credence to the hypothesis that the differences seen in sleep efficiency and sleep duration in the caregiver may be attributed to the child having altered sleep due to dexamethasone.