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Exploring Sleep-Wake Experiences of Mothers During Maintenance Therapy for Their Child's Acute Lymphoblastic Leukemia[1]

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Abstract A qualitative study was designed to explore sleep-wake experience of mothers of children in maintenance treatment for Acute Lymphoblastic Leukemia. Interviews were conducted with 20 participants using open-ended, semi-structured questions and were transcribed verbatim. Two main themes emerged: "It's a whole new cancer world" and "I don't remember what it's like to have sleep." Mothers experience difficulty sleeping during their children's treatment, and expressed several serious issues. Although the mothers were able to employ various mechanisms to address sleep deprivation and disruption, interventions such as social support, journaling, spiritual guidance, and/or self-talk may be most beneficial.

Background

Cancer is the second most common cause of death among children between the ages of one and fourteen in the United States. Leukemia accounts for approximately 25% of childhood cancer and acute lymphoblastic leukemia (ALL) comprises approximately 75 % of childhood leukemia cases. Current five-year survival rate for children with ALL is approximately 87 % (Bertolone & Landier, 2011; Siegel, Naishadham, & Jemal, 2013). Relapse-free survival is highest in children between ages one and ten years at diagnosis who have a total white blood cell count of less than 50,000 (Bertolone & Landier, 2011; Pieters & Carroll, 2008). If relapse occurs, it is most common in the first year off therapy but may occur as late as three years after therapy completion (Furlong et al., 2012).

Treatment for ALL ranges from two and a half years for girls to three years for boys. The first six to eight months of treatment are intensive. As shown in Table 1, after the initial hospitalization for diagnosis and stabilization, the child must be brought to the clinic weekly for a multi-phased plan of oral, intravenous (IV), and intrathecal chemotherapy (Zupanec & Tomlinson, 2010). Parents face their children's loss of body hair, potential infection resulting from bone marrow suppression, weight gain from increased appetite and fluid retention, insomnia, and adjustment to new routines and limitations in daily activities imposed by treatment. Parents must also prepare for possible late effects of therapy, such as cardiac toxicity, osteopenia/osteonecrosis, and neurocognitive/psychosocial sequelae (Furlong et al., 2012; Hobbie, Carlson, Harvey, Ruccione, & Moore, 2011; Hooke, Garwick, & Gross, 2011; Whitsett, Gudmundsdottir, Davies, McCarthy, & Friedman, 2008).

[1] Presentation of preliminary analysis: Matthews, E.E., Neu, M., Laudenslager, M., Garrington, T., King, N. (June, 2011). Mother-Child Sleep Patterns During Maintenance Therapy for Acute Lymphoblastic Leukemia (ALL). Poster presentation for the American Academy of Sleep Medicine and Sleep Research: Sleep. Minneapolis, MN.

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Table 1 Phases of Treatment for Standard Risk ALL.

Phase	Duration of Treatment and Goal of Therapy	Examples of commonly used chemotherapy agents (may vary by protocol and institution)
Induction	1 month Induce remission	IV vincristine, oral prednisone or dexamethasone, IV or IM pegaspargase, Intrathecal (IT) cytarabine initially, then IT methotrexate
Consolidation	4 - 8 weeks Intensive CNS prophylaxis	IV vincristine, oral mercaptopurine, weekly IT methotrexate
Interim Maintenance	8 weeks Solidify remission and eradicate any remaining leukemia cells in the CSF and marrow	IV vincristine, IV methotrexate, monthly IT methotrexate, oral mercaptopurine, IM or IV pegaspargase
Delayed Intensification	8 weeks Intensify treatment to capture any resistant cells	Oral dexamethasone or prednisone pulse, IV vincristine, IV doxorubicin, IM or IV pegaspargase, IV cyclophosphamide, oral thioguanine, IV or SC cytarabine
Maintenance	24 - 36 months Low intensity prolonged treatment to maintain remission	IV vincristine monthly, oral dexamethasone or prednisone pulses monthly, oral mercaptopurine daily, oral methotrexate weekly, IT methotrexate once per cycle

The initial, intensive months of treatment are followed by up to three years of maintenance therapy. "Maintenance" entails monthly clinic/hospital visits and less intensive chemotherapy, and bursts or "pulses" of steroid therapy (Pieters & Carroll, 2008). Most children resume normal activities during maintenance because they experience fewer serious side effects and lower risk of infection.

Sleep disturbance is a common and distressing problem for parents of children with leukemia and other cancers. Sufficient sleep is necessary for health and well-being of these parents (Mindell & Owens, 2010). Dealing with routine responsibilities, work, and school with treatment-related duties such as hospital visits and medication schedules tax logistical and emotional capacities of most parents of chronically ill children (Norberg & Green, 2007). This strain tremendously disturbs parents' sleep. For instance, tiredness and exhaustion also were reported by parents of children with mild to severe atopic dermatitis (Al Robaee & Shahzad, 2010). Maternal-child sleep onset ($r = .70$), and number of night awakenings ($r = .62$) are strongly related so mothers' sleep is even influenced when children have undefined sleep problems (Kalak et al., 2012). Compared to mothers of children with typical sleep patterns, mothers of children with sleep disturbance reported significantly poorer sleep quality, and more negative mood, parenting stress, fatique, and daytime sleepiness (Meltzer & Mindell, 2007). Other consequences of sleep deprivation in adults are poorer performance in cognitive functioning (e.g., alertness, memory, attention, and learning ability), reduced dietary restraint, weight gain, and decreased driving ability leading to motor vehicle accidents (Kahol et al., 2008; Markwald et al., 2013; Pizza, Contardi, Mondini, & Cirignotta, 2012).

Chronic stress and depression are associated with sleep quality and sleep deprivation is a contributor to poor adaptation to stressful situations and depression (Boelen & Lancee, 2013; Germain, 2013). Mcgrath and Phillips (2008) reported parental stress due to their child's invasive treatment (e.g., toxicity of the chemotherapeutic drugs, injections, intravenous access, and spinal taps). Other factors associated with stress in mothers of children with cancer include appraisal of the child's distress, ability to cope with the illness, decreased family cohesion, uncertainly about the future, and change in daily role functioning (Rodriquez et al., 2012; Sloper, 2000). Fear of relapse or possible sequelae of cancer, and symptoms of depression (sadness, hopelessness, guilt or helplessness also have been reported (Norberg & Boman, 2008; Vrijmoet-Wiersma et al., 2008). In one study, 38% of mothers of children with cancer reported high to moderate stress and negative mood (Steele, Dreyer, & Phipps, 2004), while chronic stress as evidenced by intrusive thoughts, physiologic arousal, and avoidance was found in 68% of mothers during their child's cancer treatment (Kazak, Boeving, Alderfer, Hwang, & Reilly, 2005). Stress and depression in mothers of children with varied cancer diagnoses in the aforementioned studies were present months to several years after diagnosis.

Three qualitative studies addressed emotional states, striving for normality, and adaptation of parents of children with cancer. McGrath (2002) examined perspectives of 12 mothers and 4 fathers during initial stages of diagnosis and treatment for their child's ALL. Parent's insights suggest this period as highly stressful and overwhelming. Emotional states were expressed as: stress of uncertainty, shock of diagnosis, and feelings of being trapped in a difficult emotional roller-coaster ride (McGrath, 2002). In a study of 32 mothers of children recently diagnosed with ALL, Earle, Clarke, Eiser, and Sheppard (2006) interviewed mothers during the initial-treatment, maintenance, and near-conclusion phases of treatment. Mothers described struggling to maintain a normal life (as it was before the cancer diagnosis) for their family throughout the treatment period (Earle et al., 2006). Fletcher (2011) described the experience of nine mothers of