Beginning Treatment for Childhood Acute Lymphoblastic Leukemia: Insights From the Parents’ Perspective

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Purpose/Objectives: To report the perspective of parents during the initial stages of diagnosis and treatment for their children’s acute lymphoblastic leukemia (ALL).

Design: Descriptive and phenomenologic.

Setting: Royal Children’s Hospital, Brisbane, Australia.

Sample: Parents (mothers, n = 12; fathers, n = 4) of 12 children (ages 0–10) undergoing treatment for ALL.

Methods: Open-ended, audiotaped interviews were transcribed verbatim and analyzed.

Main Research Variables: Parents’ experiences of their children’s diagnosis and treatment of ALL.

Findings: The parents’ insights provided a clear indication that the initial stage of treatment is highly stressful and parents may be overwhelmed by the experience. The situational stress translated into three potentially overwhelming emotional states: the stress of uncertainty, the shock of diagnosis, and a feeling of being trapped in an unpleasant emotional roller-coaster ride. Honesty from healthcare professionals, the opportunity to share feelings, and an affirmation of the harshness of the situation were reported as helpful in dealing with the sense of being overwhelmed.

Conclusion: Parents need honest information and sensitive emotional support to come to terms with the stresses associated with their children’s diagnosis and initial treatment of ALL. Parents must have access to a safe environment where they can express their feelings and have the harsh reality of the initial stage of treatment affirmed.

Implications for Nursing: Parents need considerable emotional support to negotiate the initial stage of treatment for ALL. Parents of children diagnosed with ALL must have honest information about diagnosis and treatment, as much information as possible for planning their daily lives, an opportunity to express real feelings, access to moments of personal space where feelings can be processed, and compassionate understanding of the emotional difficulties associated with this difficult life journey.

Key Points . . .

➤ The initial stage of treatment for childhood acute lymphoblastic leukemia is highly stressful, and parents may be overwhelmed by the experience.

➤ The treatment brings situational stresses, including the stress of uncertainty, the shock of diagnosis, and a feeling of being trapped in an unpleasant emotional roller-coaster ride, which are exacerbated by difficult inner feelings associated with the ability to cope with the situation.

➤ Honesty from healthcare professionals, the opportunity to share feelings, including having the space to cry, and an affirmation of the harshness of the situation are helpful to parents in dealing with the sense of being overwhelmed.

In the 1950s, children diagnosed with acute lymphoblastic leukemia (ALL) were expected to die in just over a year. Today, 60%–80% of all newly diagnosed children are cured (Pui, 2000; Rubnitz & Pui, 1997). In fact, ALL has provided a landmark in cancer therapy as the first disseminated and otherwise lethal malignancy to be curable in the majority of patients (Greaves, 1993; Keene, 1999; Nygaard & Moe, 1989). Because of the advances in treatment, the psychosocial focus of healthcare has changed from exclusive concern about the dying process to the examination of issues associated with diagnosis, treatment, and survival (Keene; Macner-Licht, Rajalingam, & Bernard-Opitz, 1998; McGrath, 2000).

Although pediatric ALL treatments achieve great success, this benefit is gained at the cost of a long, invasive, and very arduous treatment protocol that parents perceive as being as problematic as the actual disease (Adams, 1992). A standard protocol for ALL extends over a 2–3 year period and involves intensive chemotherapy treatments of remission induction, consolidation, and maintenance (Keene, 1999; Souhami & Tobias, 1995). Children with ALL must spend lengthy periods of time in the hospital (Henderson, Goldacre, Fairweather, & Marcovitch, 1992; Keene), and many families have to cope with relocation to a metropolitan area for specialist treatment (McGrath, 1998, 1999a, 1999b). The experience of undergoing such intensive treatments affects not only children with ALL but their entire families (McGrath, 1999b, 2000).

Research on parental adaptation to children’s chronic illnesses is scant, particularly on the experience of treatment for pediatric ALL (Cayse, 1994; McGrath, 2000). Healthcare providers have come to understand that the stress and distress