

# I skuggan av cancer

## – benmärgstransplantation hos barn ur ett föräldraperspektiv

*In the Shadow of Cancer – Bonemarrow Transplantation of Children in a Parent Perspective*

av

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### **Abstract**

Twenty-five years ago only five percent of children with leukaemia survived. Today more than 85 % survive. Bone marrow transplantation is responsible for a part of this positive development. The treatment is far from being the conventional method, however, as the operation entails certain risks. Furthermore, patients risk serious side effects such as extremely stunted growth, cataract and cognitive impairments. Contracting cancer later in life is another risk. Although the risks of the treatment were hardly unknown in Sweden when bone marrow transplant were first used on a large scale at the beginning of the 1980s, the full extent of the effects on children was largely unknown. The present study focuses on the parents of the first group of children in Sweden to receive a bone marrow transplant and survive.

The dissertation consists of two separate studies; their common aim is to develop in-depth knowledge of the psychosocial situation, in a long-term perspective, of parents of children who had been diagnosed as terminally ill but who survived thanks to a risk-filled and arduous course of treatment. I conducted two series of qualitative interviews with the parents of 20 children who had undergone bone marrow transplants. The first interview study took place four to eight years after the operation. The focus was on the parents' life situation and how they dealt with the crisis. A finding of the study was that the parents of seven of the 20 children, four to eight years after treatment, had not coped with the crisis brought on by the diagnosis and subsequent treatment. For all the parents, the child's illness and treatment still gave rise to considerable anxiety. I conducted a second study of a more explorative nature eight years later in which I interviewed the same parents again. Twelve to sixteen years had passed since the initial bone marrow transplantation. Using a qualitative analysis of both sets of parent interviews, I constructed a series of adaptation tasks with which the parents had to deal as a consequence of the diagnosis and subsequent treatment. I analysed the parents' adaptation strategies using the interview responses and a self-report questionnaire (Jalowic 1991).

The result shows that survival and cure are complex concepts. A second result shows that it is important to adopt an eclectic theoretical approach if we are to understand the parents' experiences. Trauma-coping theory and system theory proved to be fruitful approaches. However, these theories have to be combined with an understanding of the existential meaning of the crisis experience. Concepts like "relearning the world" (Attig 1994) and psychosocial transition (Parkes 1971) capture well the parents' situation. The dissertation also shows the importance of sharing the experience with a close family relative.