



Chapter 6

MANAGING A DUAL ROLE – EXPERIENCES AND
COPING STRATEGIES OF PARENTS DONATING
HAPLOIDENTICAL G-CSF MOBILIZED PERIPHERAL
BLOOD STEM CELLS TO THEIR CHILDREN

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Abstract

Hematopoietic stem cell transplantation is an effective therapy for life-threatening hematological diseases. Parents may be asked to donate hematopoietic stem cells for their child when no compatible related or unrelated donor is available.

Objective: Parents donating G-CSF mobilized peripheral blood stem cells simultaneously and uniquely fulfill the dual role of donor and caregiver for their ill child. The experiences of both sibling and unrelated stem cell donors have been extensively reported but not those of parental donors.

Methods: We therefore undertook a study specifically to investigate the experiences and coping strategies of parental stem cell donors. In-depth qualitative interviews were conducted with 13 parental donors, which were subsequently transcribed and subjected to thematic analysis. In addition, parental coping was assessed utilizing the Utrecht Coping List.

Results: Qualitative analyses revealed four main thematic categories describing the way parental stem cell donation was experienced, namely 'Hope and Fear', 'Need for Information', 'Do Anything for your Child' and 'Transplant Outcome'. In addition, parents noted similar difficulties which were unrelated to their specific role as a donor, for example they felt socially isolated.

Conclusions: Individual information for the parents needs to address not only the transplantation procedure but particularly those aspects related to the donation process. We feel there is a need for a protocol specifically designed to support and coach parental donors.

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