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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.
Introduction

Allogeneic hematopoietic stem cell transplantation (HSCT) is a proven treatment for selected children suffering from malignant and non-malignant life-threatening diseases. Since the first bone marrow transplantations were performed, several methods of HSCT have evolved. At present, hematopoietic stem cells are obtained from bone marrow, peripheral blood or umbilical cord blood of a healthy donor. Donors are matched for human leukocyte antigen (HLA) type, and may be family members or unrelated volunteers. The source of hematopoietic stem cells depends on the patient’s disease and the availability of a donor.

The most important factor affecting the outcome of HSCT is the degree of the HLA match between donor and recipient. A sibling with the same inherited HLA is considered the best donor, but is found in only 30% of all patients requiring HSCT. For patients without a family donor, an unrelated donor might be optional. Currently, the HLA characteristics of 14.6 million donors are registered in Bone Marrow Donors Worldwide (www.bmdw.org). Despite this, a significant number of children requiring urgent HSCT will be left without an HLA matched donor. For these children, haploidentical HSCT is a feasible alternative. Haploidentical HSCT is a procedure utilizing stem cells from a donor who is one full HLA haplotype mismatched with the patient. In a pediatric setting, stem cells are commonly obtained from a parent, undergoing G-CSF administration to mobilize peripheral blood stem cells, which are then collected by a leukapheresis procedure. Although technical advances have improved outcome, haploidentical transplantation has a higher risk for transplant-related complications and mortality. A delay in immune recovery leads to vulnerability to viral reactivations post transplant. Despite these potential disadvantages, haploidentical transplantation is, in specific cases, the only chance for cure for patients without an acceptable fully matched donor.

Parents requested to donate stem cells for their own child may feel that they have no alternative but to agree. This perception of limited options raises questions about the degree to which parents may feel pressured or even compelled to donate. Taylor concluded that a parent has to fulfill dual roles, the role of parent and caregiver of a seriously ill child and that of stem cell donor. Conflict of interest in the decision-making process seems to be implied, but parents’ perception of donating stem cells can be equally considered as an extension of parental care.

Although an individual child’s chance of a cure with HSCT may be considered poor, parents tend to believe that their child will survive. Despite this optimism, Oppenheim et al. found that the main source of parents’ distress was the fear of the child’s death, whether imminent or at a later stage. Experiences of stem cell donors, both related and unrelated, have been extensively investigated. Although levels of parental distress prior to HSCT have been shown to be temporary and unrelated
to the type of transplant\textsuperscript{17-19}, the distress in haploidentical parent donors has not been specifically studied. This seems an area of particular concern as these donors are likely to be more vulnerable, given the fact that their child is seriously ill and they have a vested interest in protecting and caring for their child.

Table 1: Demographic characteristics of parents (donors) and children (recipients)

<table>
<thead>
<tr>
<th>Study participant</th>
<th>Study non-participant</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Parent characteristics</strong></td>
<td></td>
</tr>
<tr>
<td>Age at donation in years</td>
<td>(median; range)</td>
</tr>
<tr>
<td>Mothers</td>
<td>38.4 (33.6–47.7)</td>
</tr>
<tr>
<td>Fathers</td>
<td>38.2 (28.9–44.5)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>6</td>
</tr>
<tr>
<td>Male</td>
<td>7</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
</tr>
<tr>
<td>At donation</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>13</td>
</tr>
<tr>
<td>Separated</td>
<td>0</td>
</tr>
<tr>
<td>At follow-up</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>12</td>
</tr>
<tr>
<td>Separated</td>
<td>1</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
</tr>
<tr>
<td>Dutch</td>
<td>10</td>
</tr>
<tr>
<td>Non-Dutch</td>
<td>3</td>
</tr>
<tr>
<td>Time from donation to study in yrs (median; range)</td>
<td>2.7 (0.4–5.0)</td>
</tr>
<tr>
<td><strong>Child characteristics</strong></td>
<td></td>
</tr>
<tr>
<td>Age at transplant in years (median; range)</td>
<td>8.7 (1.1–13.8)</td>
</tr>
<tr>
<td>Girls</td>
<td>7.1</td>
</tr>
<tr>
<td>Boys</td>
<td>8.8</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>3</td>
</tr>
<tr>
<td>Male</td>
<td>8</td>
</tr>
</tbody>
</table>
Parents are in the position of fulfilling both caregiver and donor roles. As parental perceptions have not been investigated in this context, the central goal of this investigation was to investigate experiences of parents who had donated G-CSF mobilized peripheral blood stem cells to their child.

**Participants and methods**

Twenty-three haploidentical transplantations were performed in 18 children between 1997 and 2002 in the pediatric transplant unit of the Leiden University Medical Centre. The majority of children were referred for HSCT from other academic pediatric units, located throughout the Netherlands. Three children received transplants from both their father and mother, and one father donated twice. A total of 21 parents donated stem cells to their child. Of these, five parents were excluded for various reasons, i.e. living abroad (n=2), not able to understand and communicate in Dutch (n=1) or suffering known severe psychiatric disease (n=2). Sixteen parents were invited to participate, of whom 13 (82%) consented. At the time of the interview, six children had died either from infection (n = 1), graft failure (n=2) or relapse (n=3). Bereavement was not an exclusion criterion. Characteristics of donors and children are summarized in Table 1. The protocol was approved by the institutional Medical Ethics Committee.

For the purpose of this study, a phenomenological approach is appropriate. In-depth qualitative interviews were conducted with study participants with the goal of examining their ‘lived experiences’ in the context of the donation process\(^\text{20}\). All interviews were conducted by the lead research investigator (SMvW), the majority in participants’ homes, and audio-recorded, using a minidisk recorder. Participants were able to stop the recording at any time. Three parents paused the recording due to emotional reactions to the topics being discussed. All interviews opened with an invitation for parents to describe their donation-related experiences.

“Mr, Mrs, you have donated stem cells to your child .......... which placed you in a special position, you had a dual role: the role of a parent and the role of a donor. Could you please tell me what it was like for you to
be a parent of a child with a life threatening disease and the donor for that child at the same time? From the moment you were confronted with being a donor, would you describe your experience, and share as many of your thoughts, perceptions and feelings as you can recall.”

The parents were allowed to freely describe their experiences in their own words. Probes were used to elicit additional information and examples when necessary. The interviewer focused particularly on instances of how the experience of donating stem cells to their child had influenced parents’ physical, emotional, cognitive and social functioning before, during and after the donation process. The length of the interviews varied per participant, but was never longer than 120 min (mean interview duration 45:28 min, range 28:20–115:54 min). Appointments for follow-up by telephone approximately 2 weeks later were made immediately after the interview. Field notes were made during the research process to obtain information on appointments, cancellations. Immediately after each interview, the researcher wrote a short impression with observational details concerning environment, weather, reception, interview setting and participant during the interview. These specific details are relevant and serve as a record of the researcher’s own construction of meaning21. Each session ended with debriefing and parents were asked how they felt about the interview in order to minimize the risk of related emotional stress. In the follow-up call this was repeated. Without exception, all parents were positive about their participation in the study.

Interviews were transcribed and analyzed using standard qualitative analytic techniques21, the central goal of which was to discover thematic elements that emerged as part of the parent interviews. Although we had some ideas about themes that might emerge, a grounded approach to the data analysis was used – i.e. themes were allowed to emerge as part of the analysis rather than being predetermined. The process of qualitative coding focused on identifying statements or phrases that seemed particularly essential or revealing about the phenomenon or experience being described. In this way, how parents expressed their feelings and the use of language were taken into consideration and subsequently utilized in the interpretation of the findings20,21. From the initial raw data we documented tentative themes, which were later refined and categorized by re-analysis of the data. Finally, four main categories were determined. To improve the validity of this analysis, themes identified during the qualitative analysis were discussed and confirmed, clarified, or revised with parents by telephone. Six interviews were categorized by senior transplant nurses, instructed in the method, and given the opportunity to listen to (parts) of the interviews. Results were compared and any intra observer differences were discussed and resolved by consensus, i.e. investigator triangulation22. In an attempt to quantify the qualitative findings gathered via the in-depth interviews, participating parents were asked to complete the UCL23, which identifies the primary coping strategy of
individuals confronting a problem. This self-report questionnaire consists of 47 items on a 4 point Likert-scale. The items comprise seven subscales assessing different types of coping strategies: (1) Active problem focusing: view the situation from different angles and approach problems in a purposeful and confident manner. (2) Palliative reaction pattern: look for diversion and occupy oneself with other things (like smoking or drinking) so as not to have to think about the problem. (3) Avoidance behavior: let the case run its course. (4) Social support seeking: share feelings and seek comfort from others. (5) Passive reaction pattern: show hopelessness by immersing in the problem or the situation (6) Expression of emotions: show annoyance or anger or work off the tension. (7) Reassuring thoughts: console oneself with the thought that things will get better. To allow for a structured analysis, the UCL strategies were traced back to the reduced classification of Lazarus and Folkman as described by Heck et al. (Table 2). The specific categories developed from the interviews were analyzed and logically assigned to the UCL coping strategies. To assess the internal consistency of the UCL the Cronbach’s coefficient alpha was calculated for all seven subscales. Descriptive analysis was used to compare the results of fathers and mothers, as well as parents of surviving and deceased children.

Table 2: Comparison between the theory of Lazarus and Folkman and the scales of the UCL (Heck et al., 1989) in correlation to the categories found in the study

<table>
<thead>
<tr>
<th>Lazarus and Folkman</th>
<th>Utrecht coping list</th>
<th>Categories in this study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotionally directed coping</td>
<td>Expression of emotions</td>
<td>Hope and Fear; Need for Information</td>
</tr>
<tr>
<td></td>
<td>Passive reaction pattern</td>
<td>Transplant Outcome</td>
</tr>
<tr>
<td></td>
<td>Rejection</td>
<td></td>
</tr>
<tr>
<td>Problem directed coping</td>
<td>Active approach</td>
<td>Needs for Information</td>
</tr>
<tr>
<td></td>
<td>Seeking social support</td>
<td>Do Anything for Your Child</td>
</tr>
<tr>
<td></td>
<td>Palliative reaction pattern</td>
<td>Need for Information</td>
</tr>
<tr>
<td>Evaluation</td>
<td>Reassuring thoughts</td>
<td>Transplant Outcome</td>
</tr>
</tbody>
</table>

Results

Analysis of the interviews revealed four main categories (investigator triangulation less than 2% adjustment):

- Hope and Fear
- Need for Information
- Do Anything for Your Child
- Transplant Outcome
Each category contained themes that were related to a specific time period in the total process of HSCT. These periods were (1) Facing haploidentical transplantation: parents are informed that no HLA compatible donor was available and confronted with the donation of haploidentical stem cells; (2) Decision making: parents have to decide to continue with HSCT and become their child’s donor; (3) Donation process: parents are assessed as donor and given medication for the procedure; (4) Reflection: parents reflect on the transplantation period and outcome. The attempt to relate these categories to coping strategies as determined by Lazarus and Folkman and the UCL are summarized in Table 2.

Feelings of Hope and Fear were found throughout the transplantation process. The feelings hope for cure, and fear of losing one’s child was often experienced simultaneously, leading to turmoil and confusion. Parents reported that on hearing that no HLA compatible donor was available, they experienced feelings of despair, frustration, powerlessness and sorrow:

“When we first heard that we could not find a compatible donor this was a very disappointing situation. We did not know how to go on”

However, the use of reassuring thoughts as a way of coping with the extreme stressful situation was also evident. Parents expressed hope gained from the new developments in transplantation techniques and the offered opportunity:

“This was a surprise for us... We were told that only a donor with compatible bone marrow was acceptable. When we were told about this opportunity, we were very happy, and faced it very positively”

This was despite the emotional stress of their role as a donor:

“... at that moment, you are so emotional, yes, so overwhelmed that you can do something for our child... everything else they tell you goes in one ear and out the other”

The ‘Need for Information’ in relation to all aspects and periods of transplant procedure and donation varied, but was reported by all parents. This concerned not only the treatment for their child, but also about the donor procedure:

“The information session is more about the patient. They talk to the parents about their child. There should also be a specific session for the donor”

Parents were uniformly dissatisfied with the donor information, e.g. they were unprepared for the bone marrow puncture undertaken during the physical examination:
“I had this talk with the physician and some blood samples were drawn. ‘You will also have a bone marrow puncture’. What? ‘Didn’t you know?’ No, I was really upset and frightened. Nobody told me about it before; the nurses didn’t tell me anything’. ‘It would have been better if they had put the side effects and long term effects in a folder. What can you expect, what is going to happen, how often you get the injections etcetera? (...) I still do not know what the long term effects of the growth factors are, what it can cause to my bones for instance”

The lack of familiarity with the hospital environment, staff and the isolation procedures compounded the difficulties. Parents used the Internet to supplement the information, which is a way of problem directed coping. Parents spoke of the uncertainty and lack of information about the future. The experimental character of the treatment meant the medical staff were not always able to resolve these issues for the parents.

“What I can remember, every time, we talked about that period and they said: it could have been different. If you hadn’t done it, he might have also died. And then what? So..., yes such things, they told us such things, mostly. Yes, what I said before, when we left after such a meeting, we felt: why did we go there,”......

Parents would ‘Do anything for their child’ but often had feelings of powerlessness or having no choice. The decision-making process was mentioned by all participants. All parents were unanimous about their decision to donate although they all felt that they simply had no choice.

“...... In fact, we had no choice, it was made very clear. Without transplantation he would certainly die”

Two parents mentioned the importance of taking the opinion of their child (7 and 8 years old) into consideration during the decision-making process.

“I think that it is very important, that we, as parents, despite how naive our children seem to be, do not underestimate them. Children who have suffered so much, have heard so much, have seen and felt and experienced so much, they are able to make that decision for themselves”

“It was clear for him. He wanted to go there, he wanted to be cured. We talked it over with him, I was afraid he was not able to comprehend everything, but it was clear for him. And I think he made the right choice”

One parent felt guilty for making the decision on behalf of his child who was
not capable of doing so. The last category, ‘Transplant Outcome’ is more or less a reflection by the parents concerning the whole process.

“I realize now that the whole period in Leiden, was complicated, but also gave us a lot of hope”

Some parents expressed feelings of helplessness, but equally did not blame any individual for the outcome.

“I cannot blame anyone. This is what Life has caused me”

All parents mentioned that maintaining contact with other people was important to overcome these feelings. Most of them were able to receive practical support from family members, although some found it difficult to discuss their situation with close family. Almost half of the parents reported it was important to have contact with a ‘partner in misfortune’, i.e. someone with a similar experience. Many emphasized the necessity to send newsletters to keep family, friends, school and colleagues updated about the progress of their child, in order to minimize their social isolation. This approach is also an example of seeking social support.

If children had died due to non-engraftment, rejection or post transplant infection some parents felt that they had fallen short of being a good donor. They felt the transplant outcome reflected on them personally and diminished their self esteem.

“I had these periods in the hospital, if only I could reverse, turn back the time. In particular the first time, when my cells were rejected”

Fathers were less likely to place importance on their career and job prospects whereas mothers became more critical of other parents concerns such as minor illnesses and school achievements. They considered such things to be of less importance having confronted a life-threatening illness or even death of their child.

“You have learned to put things into perspective, you are aware the relativity of things. In early times I would get really wound up about things (...) The death of my son was my greatest lesson for life. How it went and also the way I face religion and after life, it has really changed me”

Mothers were more likely than fathers to actively try to reduce stress by seeking social support and contact.

Parents whose child had died had, as might be expected, a more negative reaction to life events. They were more likely to seek reassuring thoughts to maintain the balance in their lives.
“You can’t do anything about it. That’s the way it goes. Parents didn’t choose for it, neither has the child, to become ill’. ‘I kept a diary, this period, and I can advice it to every parent. It really helped me to assimilate this period. There are also pictures in it, it brings back the memories”

Parents universally reported that participating in the interviews was a positive experience. Several expressed relief and gratitude for the opportunity to tell their story. None of the parents expressed the need of additional psychosocial care as a result of the in-depth interview.

Discussion

Haploidentical G-CSF mobilized peripheral blood stem cell transplantation from a parent offers a new option and the hope for cure. The experiences of these parents have not been previously investigated. The use of an interviewer independent of the transplantation unit may have allowed parents more opportunity to discuss their feelings. Although this retrospective information may not be a genuine reflection of past experiences, is does however reflect the current view of parents regarding their dual role.

We were able to establish four distinct categories that encompassed the experiences of parental donors. The first of these, ‘Hope and Fear’, have been reported in previous publications in relation to being a stem cell donor or being the parent of a stem cell recipient. It is therefore not surprising that this category is of similar importance to parental donors, representing both roles. From a linguistic point of view, hope and fear are opposites; in practice they seem more often to coexist in these parents. The impact of being told that there was no suitable bone marrow donor made them confront the possibility of their child’s death. It subsequently seemed incomprehensible to many that they would be considered an alternative donor. In our experience, parents oscillate between these contrary feelings attempting to find an emotional balance. Emotionally directed coping as described by Lazarus and Folkman, comparable to the expression of emotions (UCL), is reflected in this category. Parents acting as donors become in their own eyes the hope for cure. Vossen pointed out the fear, uncertainty and mental suffering of parents and patients. He stated that taking care for these patients is not in the least routine, and demands an integrated approach to the delivery of good quality care.

Consenting to HSCT as a life-saving treatment for one’s child places an overwhelming burden of responsibility on parents. Aversa stated that virtually every patient has a donor, but parental donation is not usually discussed during the initial information session. A parent as donor is not the first choice. The reported lacks of sufficient information often lead to uncertainty and sometimes feelings of guilt.
The perception of the information provided may have been distorted because of emotional difficulties. Breaking bad news (i.e. no donor was identifiable) seemed to make parents numb and less receptive. We were not able to determine to what extent these recollections were altered by time, nor were we able to document what information had been given to the parents. However as this was uniformly reported it would seem likely that the extent of information given was either inadequate and/or poorly communicated. Parents’ ‘Need for Information’ under comparable circumstances has been reported\textsuperscript{16,30}. Fisher\textsuperscript{30} reviewed eight studies on the needs of parents of chronically ill children. She found that the majority of parents were dissatisfied with the information they received. Similarly, this has been reported in parents of children diagnosed with acute leukemia\textsuperscript{31}. Dermatis and Lesko\textsuperscript{27} found that the strongest predictor of parental level of distress was the quality of the physician/parent communication. This category highlights both passive and active reaction patterns of emotional and problem directed coping strategies. In light of our findings we feel that this issue is of paramount importance which needs to be addressed by all centers undertaking haploidentical transplantation. As a result of this study we have optimized the information, using a standardized checklist and introducing the option of haploidentical transplant in an early stage of the consultation.

The third identified category, ‘Do Anything for your Child’, is a proactive approach and can be considered as a way of problem-oriented coping. Although the chances for a successful outcome were not always hopeful, all parents took the offered opportunity, hoping they could thus save their child’s life. This decision was not always easily made. Due to circumstances, some parents hardly had time to consider the procedure. Decision making as part of the consenting process for both the experimental treatment of their child and being a donor themselves suggests a possible conflict of interest. High levels of distress may limit the ability of decision making. Caregivers need to realize that parents are the ones who must live with their decision for the rest of their lives\textsuperscript{32}. The urgency of transplant often reduced the opportunities for parents to balance the risks versus benefits. Although no parent was reluctant to donate, some admitted being fearful of the procedure. Knibbe\textsuperscript{33} found in parents, who were asked to act as a living liver donor for their child, that donation was ‘not a matter of choice’, due to the intimate relation with their child. This has also been reported by sibling donors\textsuperscript{34}. Having a choice implies more than one option and for parents facing donation, not-donating means the certainty of losing their child, which is not an acceptable choice. In this respect, Atkins and Patenaude\textsuperscript{26} and Christopher\textsuperscript{16} both highlight donor’s fears, emphasizing the importance of discussing the impact of a potential negative outcome on the donor’s life. The perceived extension of parental duty must be considered. The willingness of parents to Do anything for their child should not be equated as a license to do anything with the parents. Counseling parents who are prospective donors may require specific
advocacy, as is the norm for unrelated HSCT donors\textsuperscript{35,36}.

The sense of isolation common to many parents whose child is undergoing HSCT was a major theme for all participants. The geographical dislocation from their home, away from family, resulted in isolation. Their unique situation as donor may have contributed to their loneliness. Many parents found it difficult to relate to others who had not donated stem cells. This study was not able to distinguish the extent to which this problem was related to the experience of parents acting as donors. Writing newsletters may have helped them to work through their emotions and in some way shielded them from direct confrontation with well-meaning enquiries. As a result family, friends, school and colleagues remain updated about the situation. This approach is both exemplar for palliative reactive pattern (emotion directed coping) and seeking social support (problem oriented coping). Again, like hope and fear, this illustrates the dichotomy of feelings.

Eight parents (including the two couples) were bereaved. Coping with this loss was seen as an inhuman burden and some parents had continued feelings of guilt and/or anger. Irrespective of Transplant outcome the parents’ lives were altered. Severe depression as experienced by a survivor’s father has been described by van Dongen-Melman\textsuperscript{25}, as maintaining the problem and feelings of loss. Losing a child can be experienced as a loss of oneself. This has been succinctly described in Louise Kaplan’s book ‘No Voice Is Ever Wholly Lost’\textsuperscript{37}, by a father:

"..., if losing a child is losing a piece of your own self, you can still get yourself back, maybe not all of yourself, but just enough to bring back the spirit of your child. Your child cannot live again. Some part of you will never live again. But you can still speak with the spirit of your child that was the spirit of you"

Coping strategies can be problem directed (active approach, seeking social support or a palliative reaction), emotion directed (express emotions, palliative reaction pattern, rejection) or reappraisal (reassuring thoughts)\textsuperscript{38,39}. Each of these ways of coping is meant to finally reduce the experienced stress. The transplant requires various coping abilities. Wochna\textsuperscript{10} has found that helping family donors to cope during the search is an appropriate method to reduce stress. Rodrigue et al.\textsuperscript{28} advises counseling and appropriate education to minimize parental stress. Frequently, the initial information session is the first time parents and transplant center staff meet and makes difficult the initiation of strategies aimed at assisting parents develop ways to cope with the dual role.

**Conclusions and recommendations**

The phenomenon of the dual role of parent and stem cell donor was not strongly
evident in the qualitative interviews, but parents’ experiences were similar to both roles as described in the current literature. As the transplantation was the only chance for cure, parents considered the role of being a donor one of relatively minor importance. Their decision to consent to the procedure concurred with their feelings of having no other choice. Parents regularly experience simultaneously feelings of hope and fear which, although linguistically opposites, may be experienced simultaneously. Parents’ efforts to balance these feelings is often the cause of confusion and additional stress. All coping mechanisms were evident in the conducted interviews. Parents were found to adhere to different coping strategies in different circumstances. These results show that parents’ coping strategies need to be continually evaluated. Staff members of the transplant unit need to be aware of and respond to these changes accordingly, in order to be able to give appropriate support. Individual information for the parents needs to address not only the transplantation procedure but particularly those aspects related to the donation process. Based upon the findings of this study, we now routinely inform parents on a more frequent basis, with both spoken and written information, regarding not only the transplant but also their role in the donation procedure. We recommended that all units undertaking parental haploidentical stem cell transplantation should aim to develop specific guidelines and follow-up program for future parental stem cell donors. To this extent the World Marrow Donor Association is active in developing recommendations which may assist in the development of such guidelines. Future studies should be conducted ideally in a multi-center setting to accrue sufficient numbers of parents and be designed to prospectively follow-up parents’ experiences before, during and following donation. A donor subcommittee of the Late Effects Working Party of the European group for Blood and Marrow Transplantation is preparing such a study that will focus on both long-term follow-up of physical and psychosocial consequences of haploidentical G-CSF mobilized peripheral stem cell donation.

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