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## Having a sibling as donor: Patients' experiences immediately before allogeneic hematopoietic stem cell transplantation

Annika Kisch<sup>a,b,\*</sup>, Ingrid Bolmsjö<sup>b</sup>, Stig Lenhoff<sup>a</sup>, Mariette Bengtsson<sup>b</sup>

<sup>a</sup> Department of Haematology, Skåne University Hospital, S-221 85 Lund, Sweden

<sup>b</sup> Faculty of Health and Society, Malmö University, S-205 06 Malmö, Sweden

### A B S T R A C T

#### Keywords:

Allogeneic stem cell transplantation  
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**Background:** Allogeneic hematopoietic stem cell transplantation (HSCT) offers a potential cure for a variety of diseases but is also associated with significant risks. With HSCT the donor is either a relative, most often a sibling, or an unrelated registry donor.

**Purpose:** The aim was to explore patients' experiences, immediately before transplantation, regarding having a sibling as donor.

**Method:** Ten adult patients with sibling donors were interviewed before admission for HSCT. The interviews were digitally recorded, transcribed verbatim and subjected to qualitative content analysis.

**Results:** The main theme *Being in no man's land* is a metaphor for the patients' complex situation with its mixture of emotions and thoughts prior to transplantation. The three subthemes *Trust in the sibling donor*, *Concern about others* and *Loss of control* cover the various experiences. The patient's experiences are influenced by their personal situation and the quality of the relationship with the sibling donor. While patients feel secure in having a sibling donor, they are dependent for their survival on the cell donation and feel responsible for the donor's safety during donation. These emotions intensify the patients' sense of dependency and loss of control.

**Conclusions:** In caring for HSCT patients the nurses should be aware of the complexity of the patients' situation and keep in mind that having a sibling donor might imply extra pressure, including a sense of responsibility. Caring for both patients and sibling donors optimally is a challenge, which needs further improvement and exploration.

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### Introduction

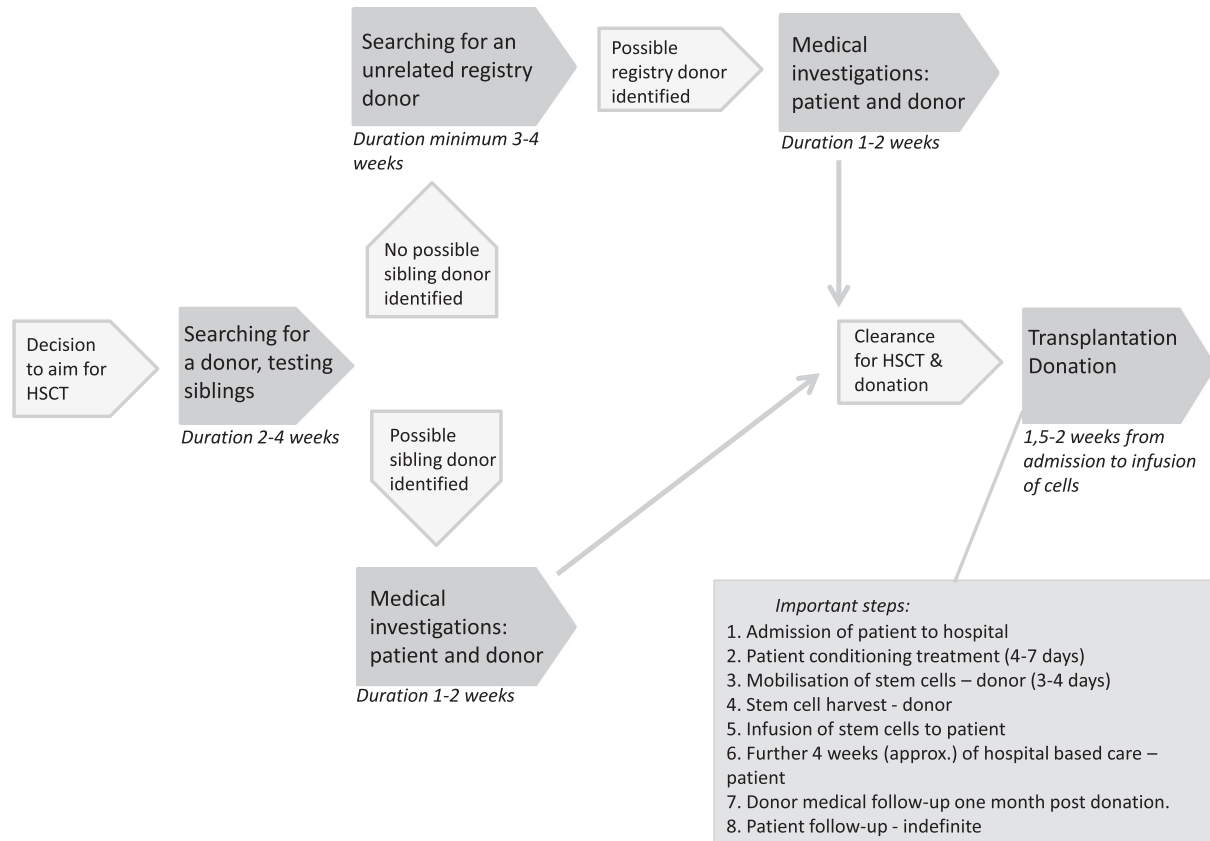
Allogeneic hematopoietic stem cell transplantation (HSCT) offers a potential cure for a variety of diseases, mainly hematological malignancies. However there is a significant risk of complications and side effects, including the risk of mortality (Copelan, 2006; Ljungman et al., 2010; Pidala et al., 2009). There are several eligibility criteria which have to be met before an HSCT can be performed, i.e. a diagnosis which indicates HSCT, reasonable control over the disease, approved medical examination showing no or low levels of risk factors and comorbidities and being young enough (Sorrör et al., 2005). One essential prerequisite for an HSCT is a

suitable donor, i.e. finding a donor who is reasonably HLA-matched. Thus, the patient is in need of a donor to increase their chances of survival (Coolbrandt and Grypdonck, 2010). Usually the search for a donor starts among the patient's siblings, where there is a 25 percent chance that each sibling will be HLA-matched. Around a third of all HSCTs are performed with stem cells from sibling donors, two thirds with cells from unrelated registry donors and, to a small extent, from relatives other than siblings.

In HSCT the donor usually donates the stem cells on the same day or one to two days prior to the patient receiving them. The method of donation is either harvesting of bone marrow, where the donor is sedated, or peripheral stem cell apheresis, which lasts for many hours with the donor awake. Thus, when the stem cells are being harvested from the donor the patient has already undergone the conditioning treatment with chemotherapy, sometimes combined with irradiation. This treatment is strenuous and severely impairs the hematological system meaning that the patient is dependent on receiving new stem cells from the donor. Fig. 1 shows a schematic flowchart of the transplantation – donation procedure.

\* Corresponding author. Department of Haematology Skåne, University Hospital, S-221 85 Lund, Sweden. Tel.: +46 46 176133, +46 46 172318, +46 708 211373; fax: +46 46 176021.

E-mail addresses: [annika.kisch@mah.se](mailto:annika.kisch@mah.se), [annika.kisch@telia.com](mailto:annika.kisch@telia.com) (A. Kisch), [ingrid.bolmsjo@mah.se](mailto:ingrid.bolmsjo@mah.se) (I. Bolmsjö), [stig.lenhoff@skane.se](mailto:stig.lenhoff@skane.se) (S. Lenhoff), [mariette.bengtsson@mah.se](mailto:mariette.bengtsson@mah.se) (M. Bengtsson).



**Fig. 1.** Flowchart illustrating the transplantation – donation procedure. The time schedule is approximate and the flowchart is schematic, showing the timeframe when a peripheral blood stem cell harvest is performed.

The eligibility criteria for related and unrelated donors usually differ. Donors who would not be eligible as volunteer, unrelated donors, can be accepted as related donors, for instance donors who are elderly or who have various comorbidities. Since relatives with comorbidities are sometimes accepted as donors, it is a challenge to take optimal care of both them and the patients. When a patient receives a stem cells transplant from a sibling donor who, for instance, may be mentally weak or elderly, there is little knowledge about the psychological impact, if any, on the patient or the donor, or on their relationship. Work is ongoing trying to define criteria intended to help to define the eligibility of related donors in general (Halter et al., 2013).

Searching for a stem cell donor might be a time-consuming issue, which might prove fatal for the patient. Testing siblings for stem cell donation usually takes less time than searching for an unrelated donor. Most studies show that HSCT has a better outcome when the donor is a sibling than when the donor is unrelated (Ringdén et al., 2009; Weisdorf et al., 2009). However, in recent years studies have shown that results of HSCT using young, well-matched unrelated donors are comparable with HSCT using sibling donors (Ho et al., 2011; Mielcarek et al., 2007; Schetelig et al., 2008).

Our own experiences (Kisch et al., 2008, 2013) and other studies (Christopher, 2000; van Walraven et al., 2010; Wiener et al., 2008) show that donating stem cells to a sibling or another relative and receiving stem cells from a sibling or another relative might be a complex issue. To our knowledge, the patients' experiences immediately before a transplantation with stem cells from a sibling donor have not been explored. It is far from clear what thoughts and emotions patients have regarding having a sibling as donor. Thus, the aim of this study was to explore patients' experiences, immediately before the transplantation, regarding having a sibling as donor.

## Method

### Design

A qualitative inductive approach with interviews was chosen for this study. A semi-structured interview guide was developed based on clinical experiences, relevant research and principles on developing an interview guide (Kvale and Brinkman, 2009).

### Participants

Patients for whom HSCT was planned with a sibling donor, at a University Hospital in Sweden between March 2011 and December 2012 were asked to participate in the study. The inclusion criteria were: age at least 18 years with a sibling donor also aged at least 18 years and good competence in the Swedish language. Ten consecutive patients who met the inclusion criteria were asked to participate in the study and all ten agreed to do so. All donors of the patients participated in a corresponding interview study, the results of which will be presented in a separate report.

### Data collection

Data were collected using face-to-face interviews before admission to hospital for the transplantation. For eight participants the interviews took place on the day of admission, for one participant one day prior to admission and for one participant eleven days prior to admission. The interviews were conducted at places chosen by the participants. All the interviews were conducted in a secluded room in the hospital by the first author (AK) who has significant professional experience with this patient group, but was

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