



## Being a haematopoietic stem cell donor for a sick sibling: Adult donors' experiences prior to donation



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### A B S T R A C T

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**Background:** There is a lack of knowledge about sibling stem cell donors' experiences pre-donation and the waiting period before the donation might have been long. The donors and their corresponding sibling recipients were simultaneously included in two different interview studies. The results from the recipient study have been presented in a separate paper.

**Purpose:** The aim was to explore the experiences of being a stem cell donor for a sibling, prior to donation.

**Method:** Ten adult sibling donors were interviewed prior to stem cell donation. The interviews were digitally recorded, transcribed verbatim and subjected to qualitative content analysis.

**Results:** The main theme *Being a cog in a big wheel* describes the complex process of being a sibling donor prior to donation, covering a mixture of emotions and thoughts. The four subthemes *Being available*, *Being anxious*, *Being concerned* and *Being obliged* cover the various experiences. The sibling donors' experiences are influenced by the quality of the relationship with the sick sibling.

**Conclusions:** Sibling stem cell donors go through a complex process once they have accidentally got involved in. They have been asked to become a donor; it was not a voluntary choice. In caring for sibling stem cell donors the nurses should be aware of the complexity of the process they experience and take into consideration their personal situation and needs. Providing optimal care for both sibling donors and their corresponding recipients is a challenge, and further improvement and exploration are needed.

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### Introduction

Allogeneic haematopoietic stem cell transplantation (HSCT) is used as a treatment for patients with a variety of diseases, mainly haematological malignancies. It offers a potential cure; however, there is a significant risk of complications and side effects, including mortality (Copelan, 2006; Ljungman et al., 2010; Pidal et al., 2009). Approximately one third of all HSCTs are performed with stem cells from HLA-matched sibling donors, two thirds with cells from unrelated registry donors or, to a small extent, from relatives other than HLA-matched siblings. Usually the search for a donor begins among the patient's siblings, where there is a 25 percent chance that each sibling will be HLA-matched. Stem cell

collection is performed either by means of bone marrow harvest or, more commonly, by peripheral blood stem cell collection. The most frequent symptoms experienced by haematopoietic stem cell donors post donation are transient muscle pain, fatigue and bone pain (Fortanier et al., 2002; Kennedy et al., 2003; Switzer et al., 2001). Major side effects are rare but there is a small risk of fatalities and serious adverse events, e.g. deep vein thrombosis, splenic rupture and cardiac arrest (Halter et al., 2009).

During recent years attention has been given to the situation of the sibling stem cell donors. Recommendations for information and care for sibling stem cell donors have been published since 2010 (Clare et al., 2010; O'Donnell et al., 2010; van Walraven et al., 2010), pointing out the importance of separating all aspects of the care for donors and their recipients, but there is an absence of standardized guidelines (Billen et al., 2014). An information and care model (the IC model) for potential adult sibling donors was developed and introduced in a Swedish university hospital in 2005 (Kisch et al., 2008), which corresponds well with the recommendations referred to above. Evaluation suggested that the IC model

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works well but needs improving to further prevent complicating influence on the donors' decision (Kisch et al., 2013). The adequacy of the preparation for donation has been shown to influence the experience of distress, and anxiety that has been reported in relation to not receiving sufficient information (Munzenberger et al., 1999; Pillay et al., 2012; Wiener et al., 2008; Williams et al., 2003).

For sibling donors there may be a considerable time lapse between being asked to become a donor and making the donation. Fig. 1 shows a schematic flowchart of the donation process for sibling donors. During this waiting thoughts and emotions, including uncertainty about whether the donation will actually be performed and its consequences, may arise. Studies on the psychosocial consequences and experiences of adult sibling donors are limited, however, those that have been performed show that these donors are in a vulnerable situation. Negative experiences, such as anxiety, pain and guilt as well as positive experiences, such as happiness about being a match, an increased sense of self-worth and of pride and a closer relationship with the sick sibling have been described. Siblings are often concerned about the outcome of the transplantation for the sick sibling with the responsibility for doing what is needed to be done to help a family member (Christopher, 2000; de Oliveira-Cardoso et al., 2010; Munzenberger et al., 1999; Pillay et al., 2012; Wiener et al., 2008; Williams et al., 2003). However, there is a lack of knowledge about sibling stem cell donors' experiences of being asked to become a donor and other experiences before donation. To our knowledge only one qualitative study exploring adult sibling stem cell donors' experiences pre-donation has been carried out (de Oliveira-Cardoso et al., 2010), but this was performed in bone marrow donors only. The majority of qualitative studies about sibling donors' experiences pre-donation have been performed after the donation process, entailing uncertainty about what the donors remember about their pre-donation experiences (Wiener et al., 2008). Considering the lack of knowledge about sibling stem cell donors' experiences pre-donation and the fact that they might have had a long waiting period, it is of value to gain knowledge about their experiences while they are close to the donation to facilitate the provision of adequate information and care. Therefore, the aim of this study was to explore the experiences of being a stem cell donor for a sibling, prior to donation.

## Method

### Design

A qualitative approach with interviews was chosen for this study, since qualitative research on sibling donors is valuable and

can provide rich narrative data and insight into donor experiences and perspectives (Garcia et al., 2013).

### Participants

Sibling donors and their corresponding sibling recipients were simultaneously included in two different interview studies. The results from the recipient study have been presented in a separate paper (Kisch et al., 2014). The inclusion criteria for the donor study were: age for both donor and recipient at least 18 years and ability to speak and understand Swedish. From March 2011 to December 2012 ten consecutive intended sibling donors at a university hospital in Sweden who met the inclusion criteria were asked to participate in the study and all ten agreed to do so.

### Data collection

Data were collected using face-to-face interviews prior to the stem cell donation. The interviews took place between 1 and 18 days prior to donation (median 4.5 days prior to donation). The interviews were conducted at places chosen by the participants; seven in a secluded room in the hospital, one in the home of the donor, one in the home of the sick sibling and one at the donor's working place. All the interviews were conducted by the first author (AK) who has significant professional experience with this donor group, but was not involved in the care of the participants in this study. The interviews were digitally recorded and lasted between 33 and 131 min (median 57.5 min).

A semi-structured interview guide was developed based on clinical experiences, relevant research and principles for developing an interview guide (Patton, 2002). Open-ended questions were used and all interviews started with an open question: Can you tell me about your feelings and thoughts when you got to know that your sibling needed a stem cell donor for transplantation and you were asked if you were willing to be tested to become *that donor*? The interviews continued with further questions in order to lead the informants to expand their answers and to clarify their thoughts and experiences about being a stem cell donor for a sibling.

### Data analysis

The interviews were transcribed verbatim. The transcribed text was subjected to content analysis, inspired by the description of Graneheim and Lundman (2004). Content analysis was used not only to understand the manifest data but also to interpret the latent

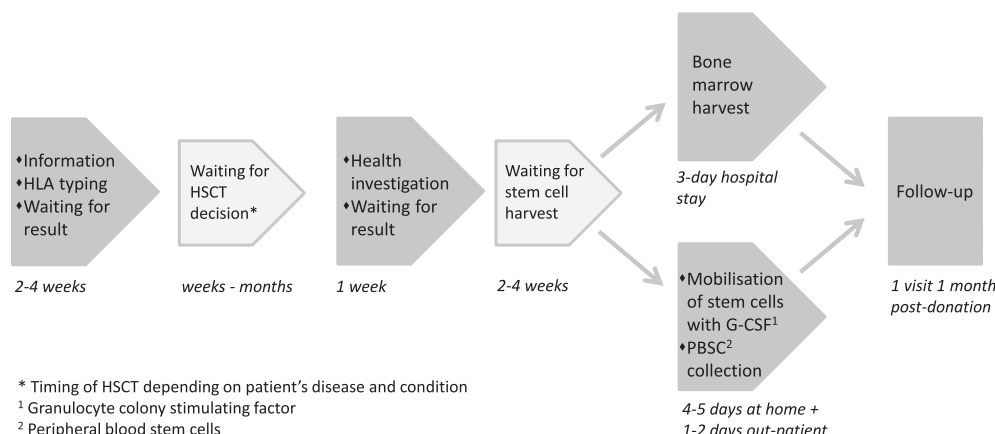


Fig. 1. Flowchart illustrating the donation process for sibling donors. The time schedule is approximate and the flowchart is schematic.

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