

# Immigrant parents\* perception about the stem cell transplantation of their child and the provided care in the Netherlands.

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The purpose of the present study is to examine the perception of immigrant parents of their child\*s beta thalassemia and the provided care during treatment with stem cell transplantation in the Netherlands. It is important to study and learn about...

<b>Ethical review</b>	Approved WMO
<b>Status</b>	Pending
<b>Health condition type</b>	Anaemias nonhaemolytic and marrow depression
<b>Study type</b>	Observational non invasive

## Summary

### ID

NL-OMON33333

### Source

ToetsingOnline

### Brief title

Immigrant parents and SCT

### Condition

- Anaemias nonhaemolytic and marrow depression

### Synonym

beta thalassemia

### Research involving

Human

### Sponsors and support

**Primary sponsor:** Academisch Medisch Centrum

**Source(s) of monetary or material Support:** Ministerie van OC&W

## Intervention

**Keyword:** care, experiences, parents, stem cell transplantation

## Outcome measures

### Primary outcome

Standardized interview

### Secondary outcome

not applicable

## Study description

### Background summary

See the protocol

### Study objective

The purpose of the present study is to examine the perception of immigrant parents of their child's beta thalassemia and the provided care during treatment with stem cell transplantation in the Netherlands. It is important to study and learn about the experiences of immigrant parents, because they make up for a growing percentage of patients in the Dutch health care system. In most quantitative, self-report studies immigrant parents are excluded because of language barriers or dropping out early. Learning from their experiences will enhance knowledge and will improve care.

### Study design

Parents receive written information about the study (Appendix 1 and 5) and an informed consent form (Appendix 2 and 6) to fill in and return. When they agree to participate, an appointment will be made to conduct the interview (Appendix 3 and 4) at the parents' home. Efforts will be made to schedule appointments with both parents present, but the mother will be the main interviewee. If present, the father will be asked to participate in the interview after completion of the interview with the mother.

The interview will be translated in the native language by use of an interpreter. The interview guide is based on the interview guide developed by

Anna Klassen, a psychologist-researcher who used it in a study on immigrant parents of children with leukemia in Canada. It has been adapted for use in this patient group, in cooperation with the treating physician of thalassemia patients. Results of the study undertaken by Klassen et al. have been submitted.

Each interview will be recorded and listened to again before transcription. Interpretation of the data will exist of uncovering recurrent thematic statements.

### **Study burden and risks**

not applicable

## **Contacts**

### **Public**

Academisch Medisch Centrum

Albinusdreef 2  
2300 RC Leiden  
Nederland

### **Scientific**

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## **Trial sites**

### **Listed location countries**

Netherlands

## **Eligibility criteria**

### **Age**

Adults (18-64 years)

Elderly (65 years and older)

## Inclusion criteria

All parents whose child underwent SCT in the past years due to beta thalassemia

## Exclusion criteria

Parents living abroad, serious illness of the child at present, death of the child, lost to follow up and no current address available.

## Study design

### Design

**Study type:** Observational non invasive

Masking: Open (masking not used)

Control: Uncontrolled

Primary purpose: Other

### Recruitment

NL

Recruitment status: Pending

Start date (anticipated): 01-06-2009

Enrollment: 20

Type: Anticipated

## Ethics review

Approved WMO

Date: 07-09-2009

Application type: First submission

Review commission: METC Leids Universitair Medisch Centrum (Leiden)

## Study registrations

## **Followed up by the following (possibly more current) registration**

No registrations found.

## **Other (possibly less up-to-date) registrations in this register**

No registrations found.

## **In other registers**

<b>Register</b>	<b>ID</b>
CCMO	NL28395.058.09