

Parental experiences and perspectives of end-of-life decision-making in allogeneic paediatric stem cell transplant

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Primary Objective: *How do parents experience and perceive EOL decision-making after allogeneic paediatric SCT?* Secondary Objectives: - How do parents gain insight in their child*s condition and treatment options during EOL process?- With which EOL...

Ethical review	Approved WMO
Status	Recruitment stopped
Health condition type	Other condition
Study type	Observational non invasive

Summary

ID

NL-OMON40690

Source

ToetsingOnline

Brief title

PERSPECTIVES

Condition

- Other condition
- Leukaemias
- Family issues

Synonym

parental decision-making

Health condition

ouderlijke besluitvorming rondom het levenseinde post stamceltransplantatie bij kinderen.

Research involving

Human

Sponsors and support

Primary sponsor: Universitair Medisch Centrum Utrecht

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

Intervention

Keyword: Decision-making, End-of-life, Paediatric, Stemceltransplant

Outcome measures

Primary outcome

Description of parents* experiences and about EOL decision-making after allogeneic paediatric SCT.

Secondary outcome

- Identification of the way parents get insight in their child*s condition and treatment options during the EOL process;
- Identification of EOL decisions from the parents* perspectives;
- A description of parents* considerations concerning the EOL decisions they felt confronted with;
- Identification of the factors which influence the parents* decision-making in the EOL process;
- Identification of supportive strategies in EOL decision-making from the parents* perspectives.

Study description

Background summary

Stem cell transplantation (SCT) is a potentially curative therapy for a group

of children, but still a number of them die. A better understanding of the parents* perspective about end-of-life (EOL) decision-making after paediatric SCT can help healthcare professionals to support parents in the decision-making and can help to improve (after) care.

Study objective

Primary Objective: *How do parents experience and perceive EOL decision-making after allogeneic paediatric SCT?*

Secondary Objectives:

- How do parents gain insight in their child*s condition and treatment options during EOL process?
- With which EOL decisions are parents confronted?
- What are the parents* considerations concerning the EOL decisions with which they are confronted?
- Which factors influence parental decision-making in the EOL process?
- What kind of support helped parents in EOL decision-making?

Study design

A retrospective, qualitative study using a Grounded Theory. Face to face, in-depth open interviews with individual parents will be conducted and analysed qualitative. Interviews will be coded, categorized and themes will be described.

Study burden and risks

Participation does not offer direct benefits for the parents; study participation can help to improve support for parents in the same situation in the future. Participation requires effort from the parents and could possibly be burdensome. Experiences from comparable studies demonstrate that parents mostly are willing to talk about their experiences and this can also be experienced as helpful.

Contacts

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Trial sites

Listed location countries

Netherlands

Eligibility criteria

Age

Adults (18-64 years)

Elderly (65 years and older)

Inclusion criteria

Parents with experience in End-Of-Life decision-making.

Parents of deceased children after paediatric allogeneic Stemceltransplant.

Parents of children who died within a year after a Stemceltransplant.

Parent whose child passed away between two years and six weeks ago.

Exclusion criteria

The parent is unable to speak and read Dutch

The parent lives abroad.

Study design

Design

Study type: Observational non invasive

Masking: Open (masking not used)

Control: Uncontrolled

Primary purpose: Health services research

Recruitment

NL
Recruitment status: Recruitment stopped
Start date (anticipated): 14-05-2014
Enrollment: 20
Type: Actual

Ethics review

Approved WMO
Date: 24-03-2014
Application type: First submission
Review commission: METC Leids Universitair Medisch Centrum (Leiden)
Approved WMO
Date: 19-08-2014
Application type: Amendment
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

Register	ID
CCMO	NL48113.058.14

Study results

Results posted: 11-03-2020

First publication

05-02-2020