Experiences of parents of palliative care for their child with cancer.

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

Summary

ID

NL-OMON32118

Source
ToetsingOnline

Brief title
Experiences of parents of palliative care for their child with cancer.

Condition

- Other condition

Synonym
cancer, life threatening illness

Health condition

alle kinderoncologische aandoeningen

Research involving
Human

Sponsors and support

Primary sponsor: Erasmus MC, Universitair Medisch Centrum Rotterdam
Source(s) of monetary or material Support: Ministerie van OC&W

Intervention

Keyword: childhood cancer, palliative care, parental depression, parental grief

Outcome measures

Primary outcome

The primary parameters of the study are:

- depression of parents

- level of grief of parents

Secondary outcome

The experiences of care.

Study description

Background summary

The researchfield of pediatric palliative care is in its infancy. The - mostly qualitative - studies that have been done show that there are certain aspects of care that are of great importance to bereaved parents in the palliative phase. Providing good care is of great influence for parents who lose there child to cancer. Good communication, involvement in the care by the health care professionals and continuity of care are all important. Besides good care bereaved parents often mention spirituality as an important aspect in the last phase of their child's life. In this study, spirituality is subdivided into 'religion', 'giving meaning to life and the death of the child' and 'hope'.

The aim of this study is to get more insight into the problems that can arise in the palliative care for children with cancer, who are treated at Erasmus MC-Sophia. A second aim is to get more insight into the level of spirituality of bereaved parents at the end of their childs life and the role that health care provides can potentially play in this. These factors will be adressed by asking 100 bereaved parents to complete a questionnaire on this topic.

Study objective

The aim of this study is to get more insight into the problems that can arise in the palliative care for children with cancer, who are treated at Erasmus MC-Sophia. A second aim is to get more insight into the level of spirituality of bereaved parents at the end of their childs life. The effect of these aspects on grief and depressive symptoms 3 to 9 years after the loss of a child is our primary interest. Our secundair objective ist he investigation of experiences (both positive and negative) of parents and there effect on their psychological functioning at the moment.

Study design

The study design is observational. Parents will complete 3 questionnaires (experiences, grief, depression) who will be sent to them. Parents complete the questionairre separately from each other.

Study burden and risks

The study population, bereaved parents, may find some of the questions upsetting. This group consists of potentially vulnerable people, who are in a emotional situation.

Despite the possible emotional burden of this study it is of great importance to get more insight in the quality of care from the Erasmus MC-Sophia. This study has the potential of helping other parents who in the future will be in the same situation. Earlier studies show that bereaved parents perceive the participation in this kind of research to be valuable. (Dyregrov, K. (2004). Bereaved parents' experience of research participation. Social science & medicine 58, 391-400; Kreicbergs, U., Valdimarsdottir, U., Steineck, G., & Henter, J.I. (2004). A population-based nationwide study of parents' perceptions of a questionaire on their child's death due to cancer. The Lancet 364, 787-789.)

Contacts

Public
Erasmus MC, Universitair Medisch Centrum Rotterdam

Dr. Molewaterplein 50
3015 GE Rotterdam
Nederland
Scientific
Erasmus MC, Universitair Medisch Centrum Rotterdam

Dr. Molewaterplein 50
3015 GE Rotterdam
Nederland

Trial sites

Listed location countries

Netherlands

Eligibility criteria

Age
Adults (18-64 years)
Elderly (65 years and older)

Inclusion criteria

Having experienced the loss of a child to cancer.

Exclusion criteria

Dutch language skills not sufficient to complete a questionairre.

Study design

Design

Study type: Observational non invasive

Masking:	Open (masking not used)
Control:	Uncontrolled
Primary purpose:	Other

Recruitment

NL

Recruitment status:	Recruiting
Start date (anticipated):	21-01-2008
Enrollment:	100
Type:	Actual

Ethics review

Approved WMO

Date:	14-01-2008
Application type:	First submission
Review commission:	METC Erasmus MC, Universitair Medisch Centrum Rotterdam (Rotterdam)

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	NL20407.078.07