Experienced Quality of Care and Life in advanced oncological patients and their relatives: a prospective observational cohort study

Gepubliceerd: 30-06-2017 Laatst bijgewerkt: 18-08-2022

Ethische beoordeling	Niet van toepassing
Status	Werving nog niet gestart
Type aandoening	-
Onderzoekstype	Observationeel onderzoek, zonder invasieve metingen

Samenvatting

ID

NL-OMON23456

Bron
NTR

Verkorte titel
eQuiPe

Aandoening

Advanced cancer (gevorderde kanker)

Ondersteuning

Primaire sponsor: Integraal Kankercentrum Nederland (IKNL)
Overige ondersteuning: ROPARUN FOUNDATION

Onderzoeksproduct en/of interventie

Uitkomstmaten

Primaire uitkomstmaten

Experienced quality of care and quality of life in patients with advanced cancer and relatives.

Toelichting onderzoek

Achtergrond van het onderzoek

Rationale: By investigating quality of life and quality of care as experienced by advanced cancer patients in the palliative trajectory, more insight into the needs of these patients and their relatives will occur and will inform us how to further improve early palliative care for patients with advanced cancer and their relatives.

Objective: The primary objective of this study is to gain insight in the experienced quality of care and quality of life of patients with advanced cancer and their relatives in the Netherlands over time. Furthermore, factors that are associated with experienced quality of care and quality of life of patients with advanced cancer and their partners will be explored.

Study design: This study is a prospective observational cohort study. Patients and relatives are invited to complete questionnaires on quality of care and quality of life every three months until death and a final questionnaire for the bereaved relative after death. The survey data will be directly linked to the routinely collected detailed data on patient characteristics, cancer, treatment and co-morbidity from the Netherlands Cancer Registry (NCR).

Study population:

All patients with metastatic cancer are eligible for inclusion with two additional criteria:

- patients with breast cancer are eligible when metastasis are located in multiple organ systems.

- patients with prostate cancer are eligible for inclusion when their cancer is castration resistant.

• they are older than 18 years

• they are able to complete a Dutch self-report questionnaire

• they understand the objective of the study and they have signed the informed consent

Relatives of included patients are eligible for inclusion if;

• they are chosen by the patient as relative

• they are older than 18 years

• they are able to complete a Dutch self-report questionnaire

• they understand the objective of the study and they have signed the informed consent

Main study parameters/endpoints: The main outcome of this study is the experienced quality of care and quality of life in patients and relatives. Secondary outcomes are health care needs and consumption, shared decision making, social support, illness perception, (dyadic) coping, resilience, and body image. Perceived burden, personal self-care, pre-death grief, impact of death, openness of communication about illness and death, and evaluation of services is also measured in relatives.

Onderzoeksopzet

Every three months.

Onderzoeksproduct en/of interventie

n.a.

Contactpersonen

Publiek

Janneke van Roij
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The Netherlands
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Wetenschappelijk

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Deelname eisen

Belangrijkste voorwaarden om deel te mogen nemen (Inclusiecriteria)

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Belangrijkste redenen om niet deel te kunnen nemen (Exclusiecriteria)

Patients and their relatives are excluded for participation in the study if;

• the treating physician believes the patient is not able to participate in this study

• they have a poor expression of the Dutch language

• they suffer from dementia

• they have a history of severe psychiatric illness

Onderzoeksopzet

Opzet

Type:	Observationeel onderzoek, zonder invasieve metingen
Onderzoeksmodel:	Anders
Toewijzing:	N.v.t. / één studie arm
Blindering:	Open / niet geblindeerd
Controle:	N.v.t. / onbekend

Deelname

Nederland

Status:	Werving nog niet gestart
(Verwachte) startdatum:	01-09-2017
Aantal proefpersonen:	0
Type:	Verwachte startdatum

Ethische beoordeling

Niet van toepassing

Soort:	Niet van toepassing

Registraties

Opgevolgd door onderstaande (mogelijk meer actuele) registratie

Geen registraties gevonden.

Andere (mogelijk minder actuele) registraties in dit register

Geen registraties gevonden.

In overige registers

Register	ID
NTR-new	NL6408
NTR-old	NTR6584
Ander register	: METC17.1491

Resultaten

Samenvatting resultaten
none