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

No registrations found.

Ethical review	Not applicable
Status	Pending
Health condition type	-
Study type	Observational non invasive

Summary

ID

NL-OMON23456

Source
NTR

Brief title
eQuiPe

Health condition

Advanced cancer (gevorderde kanker)

Sponsors and support

Primary sponsor: Integraal Kankercentrum Nederland (IKNL)
Source(s) of monetary or material Support: ROPARUN FOUNDATION

Intervention

Outcome measures

Primary outcome

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

Secondary outcome

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.

Study description

Background summary

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.

Study design

Every three months.

Intervention

n.a.

Contacts

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Eligibility criteria

Inclusion criteria

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Exclusion criteria

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

Study design

Design

Study type:	Observational non invasive
Intervention model:	Other
Allocation:	Non controlled trial
Masking:	Open (masking not used)
Control:	N/A , unknown

Recruitment

NL

Recruitment status:	Pending
Start date (anticipated):	01-09-2017
Enrollment:	0
Type:	Anticipated

Ethics review

Not applicable

Application type:	Not applicable

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
NTR-new	NL6408
NTR-old	NTR6584
Other	: METC17.1491

Study results

Summary results
none