


The effects of ACP in cancer patients

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ACTION: Advanced Care Planning; an Innovative Palliative Care Intervention to Improve Quality of Life in Cancer Patients - A Multi-Centre Cluster Randomized Clinical Trial (FP7)



Advanced cancer

- A diagnosis of advanced cancer often has a tremendous impact on patients' emotional wellbeing
- Patients' preferences regarding care should be central
- Currently, treatment aimed at prolonging life has been found to often prevail over care aimed at relieving patients' suffering and enhancing their quality of life, which may not always be in accordance with patients' needs

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Communication

- Timely and efficient communication is an important prerequisite for appropriate care that adequately addresses patients' needs and preferences
- However, research findings consistently demonstrate that communication between physicians, patients with advanced cancer, and their relatives is complex
- Physicians are often uncertain about their patients' values and preferences, and relatives may feel stressed, uncertain, and reluctant to relinquish treatment aimed at sustaining life, even if cure is no longer possible

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Advance care planning (ACP)

- Formalized process of communication between patients, relatives and professional caregivers
- A voluntary process of discussion and review enabling individuals to express, and, if they wish, record views, values and specific treatment choices to inform their future care (often in case of incompetence)
- It promotes the documentation of patients' preferences in their medical file, the communication of these preferences to family and friends, and the periodic review of preferences as circumstances change

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- Phase III multicentre cluster-randomized clinical trial (2014-2019)
- Intervention: “care as usual” and *Respecting Choices* ACP intervention
- Control: “care as usual”

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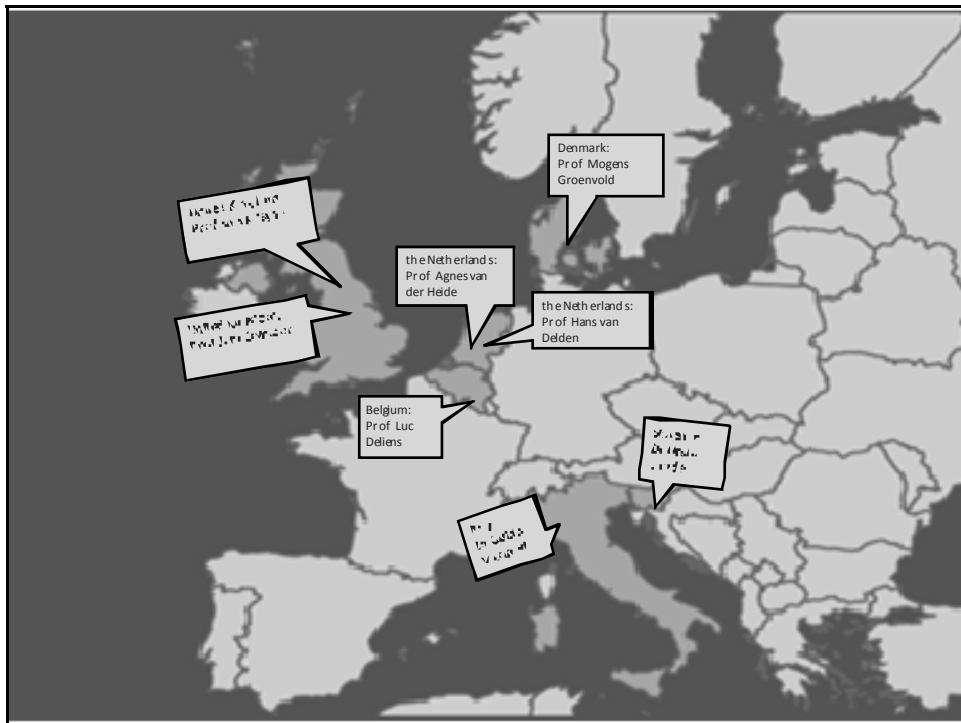
Respecting Choices

- Developed in the US (La Crosse, WI)
- In ACTION adaptations to
 - Oncology
 - European setting
 while maintaining core elements
- 1-2 structured interview sessions patient and relative (by facilitator)
 - Education about ACP
 - Goals of care and “living well”
 - Preferences for CPR and other decisions about care and treatment
 - Appointing healthcare agent
 - Filling in “my preferences” form

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A photograph showing two starfish on a sandy beach. One is a dark, five-pointed starfish, and the other is a white, five-pointed starfish. They are positioned diagonally across the frame.

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Main objective ACTION

Primary Research Question:

- To assess whether ACP improves the quality of life of patients with advanced cancer

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ACTION Secondary objectives ACTION

Effects of ACP on:

- quality of life in subgroups
- received care in line with patients' preferences, patient activation, decisional conflict, satisfaction with care, satisfaction with intervention, coping and relatives' wellbeing

Cost effectiveness

Patient experiences with ACP

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ACTION Setting and study population

6 European countries
20 hospitals
1360 adult patients
advanced lung or colorectal cancer
(50% or less one-year survival rates)

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Inclusion criteria

Inclusion criteria	Exclusion criteria
Lung cancer: - small cell - extensive disease/ stage III or IV - non-small cell - stage III or IV Colorectal cancer: Stage IV	Age < 18 years
Written informed consent to participate	Unable to provide consent
WHO performance status of 3 or under	Unable to complete questionnaire in country's language
	Less than 3 months anticipated life expectancy

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Data collection

Questionnaires at:
Baseline
2.5 months
4.5 months

In case patient dies within 1 year: bereaved carer questionnaire (3 months after death)

Medical files at 1 year follow-up
 use of medical care
 survival
 "indications" of ACP

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



Qualitative study

Qualitative analyses of experiences of patients, relatives, facilitators, and health care professionals

- * Interviews and focus groups (HCPs)
- * Patients outside the main trial


Qualitative analyses of Respecting Choices intervention sessions





Questionnaire data


Measured by questionnaire	Measures
Quality of Life	EORTC QLQ-C30, 4 items emotional functioning EORTC item bank, EF shortform, 6 items
Symptoms	EORTC QLQ-C15 PAL, 15 items
Decisional quality	Decisional Conflict Scale, 9 items
Patient Activation	(APECC) Decision-making Participation Self-Efficacy Scale, 5 items
Satisfaction with care	EORTC IN-PATSAT32, 7 items
Coping	COPE questionnaire, 12 items
Satisfaction with intervention	Dignity Therapy Patient Feedback Questionnaire, 2 items Self-developed (8 items)
Relatives' wellbeing	HADS Revised Impact of Event Scale



ACTION

Gemstracker

- A central database located in Erasmus MC in the Netherlands will be constructed with the use of the innovative tool 'GemTracker'
- Multi-language web based software package for (complex) distribution of questionnaires and forms during clinical research in healthcare
- GemTracker will be used to uniformly collect and store the data
- Open source
- Extensive security possibilities



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Planning

2014: preparation trial

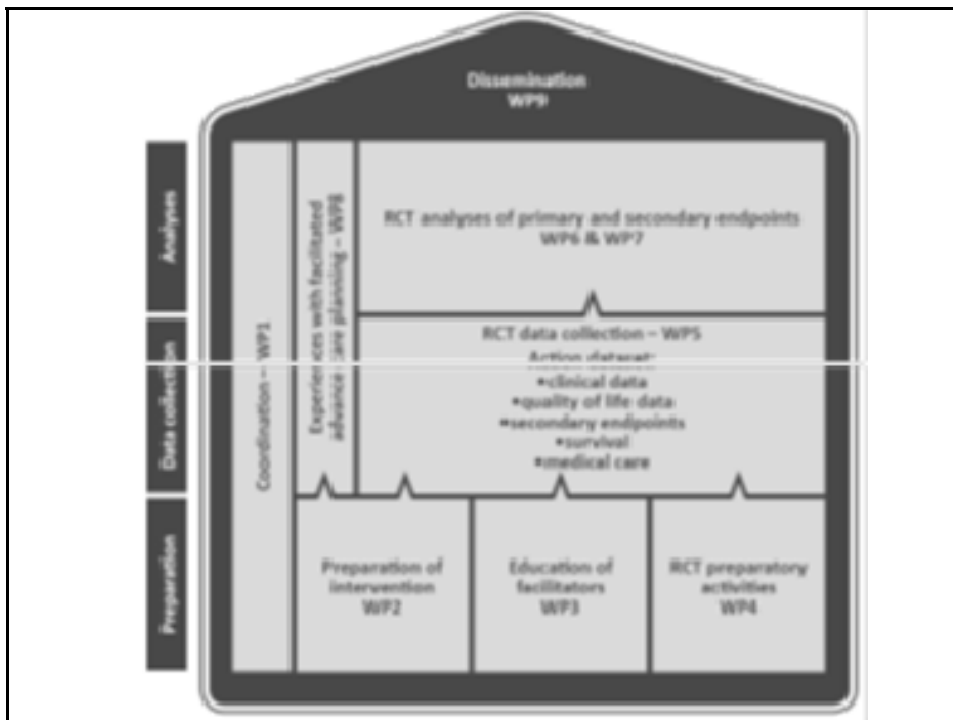
- Ethics procedures
- Development & translation intervention
- Questionnaire development
- Training facilitators
- Nov, Dec: feasibility study

2015 and 2016: inclusion

- 1 year follow-up

2017-2018: analyses

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Thank you!

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