

Bringing palliative care for dementia patients into agreement with their wishes and needs: development and evaluation of Decidem

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Netherlands

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Bringing palliative care for dementia patients into agreement with their wishes and needs: development and evaluation of Decidem

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ZonMw

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3.0

The project/programme is most relevant to:

Alzheimer's disease & other dementias

Keywords

Research Abstract

Patients with dementia have limited access to palliative care. At the end of their lives, aggressive and unwanted interventions like resuscitation and hospitalization regularly take

place. Physical symptoms in patients such as pain or dyspnea and neuropsychiatric symptoms and depression in both patients and family caregivers are often undertreated. This threatens the quality of life of dementia patients and their family caregivers. Therefore an innovative intervention in dementia care combining the strengths of advance care planning (ACP) and shared decision making (SDM) called Decidem will be developed. The research aim of this project is to evaluate its effects on care, patients and caregivers, and costs. We hypothesize that Decidem will bring actual care into agreement with patients' and caregivers' wishes/preferences and needs. This patient-centered, personalized intervention may increase their satisfaction with care, decrease caregivers' burden and increase quality of life. Decrease of under- and over treatment, of hospitalizations and of unplanned visits may reduce costs.

Methods: This project will use the MRC framework for development and evaluation of complex interventions as a guide. However, we will introduce a methodological novelty by assessing barriers and facilitators prior to the development of the intervention. Hereby we aim to avoid implementation failure: bad adherence to the intervention leading to negative trial outcomes. The work plan consists of the following steps:

1. Theory development
2. Modeling (Exploration of facilitators and barriers and Development of Decidem)
3. Evaluation of Decidem

Decidem's effects will be studied in a cluster-randomized controlled trial in 30 general practices and about 150 dementia patients with a follow-up of six months. Primary outcome is whether a patient's wishes are known and respected. Secondary outcomes are patients' quality of life and depression; caregivers' satisfaction and burden; and health care professionals satisfaction with the intervention. For the economic evaluation of Decidem, a traditional cost-effectiveness analysis will be performed in which utilities are generated with the EQ-6D and resources are measured using the Recourse Utilities in Dementia (RUD). A mixed methods process evaluation will evaluate its feasibility.

Lay Summary

Further information available at:

Types:

Investments > €500k

Member States:

Netherlands

Diseases:

Alzheimer's disease & other dementias

Years:

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Database Categories:

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