

# Effects on quality of life and family caregiving experiences by the Namaste Care Family program for advanced dementia

Gepubliceerd: 23-03-2016 Laatste bijgewerkt: 18-08-2022

Implementation of the Namaste Care Family program will improve lives of Dutch nursing home residents with advanced dementia and their families

<b>Ethische beoordeling</b>	Niet van toepassing
<b>Status</b>	Werving nog niet gestart
<b>Type aandoening</b>	-
<b>Onderzoekstype</b>	Interventie onderzoek

## Samenvatting

### ID

NL-OMON22922

### Bron

Nationaal Trial Register

### Verkorte titel

Namaste Care Family

### Aandoening

Dementia-related impairments

## Ondersteuning

**Primaire sponsor:** VU University Medical Center, EMGO+ Institute for Health and Care Research, Department of Public and Occupational Health, Amsterdam, the Netherlands

**Overige ondersteuning:** ZonMw The Netherlands Organisation for Health Research and Development grant number 733050302 and Fonds NutsOhra grant number 1405-181

## Onderzoeksproduct en/of interventie

## **Uitkomstmaten**

### **Primaire uitkomstmaten**

Patients' quality of life and families' positive caregiving experiences. These are measured with the Dutch translation of the Quality of Life in Late-Stage Dementia (QUALID) scale, the Dutch Positive Experiences Scale (PES) and the Dutch translation of the Gain in Alzheimer care Instrument (GAIN)

## **Toelichting onderzoek**

### **Achtergrond van het onderzoek**

Quality of life of people with advanced dementia in the Netherlands can be improved. People may be isolated as they cannot participate anymore in the activities that are offered. Some present challenging behaviors, and families may be frustrated with limited contact with their loved ones.

A US program called Namaste Care aims to increase quality of life and comfort specifically for these people. It incorporates person-centered and palliative care approaches and includes end-of-life care. Loving touch, presence of others, and engaging people in meaningful activities, such as gentle personal grooming, are central. Evidence accumulates that the program successfully changed the lives of people and their families in US, UK, and Australian nursing homes. In particular, it improved behavior, reduced use of psychotropic medications and did not increase health care costs.

With the committed support of the developers, experts, and an End-user Panel with families and volunteers, we propose to modify the program to sustainably fit it into the Dutch health care landscape. The adapted Namaste Care Family program will emphasize family and volunteer involvement, and end-of-life care.

In 16 nursing homes, a cluster-randomized controlled trial will assess if the Dutch Namaste Care Family program improves outcomes in a cost-effective manner. We will match pairs of homes on ongoing psychosocial and family programs before we randomize to the intervention or control conditions. The primary outcomes are patients' quality of life and families' positive caregiving experiences. These are measured with the valid Dutch version of the Quality of Life in Late-Stage Dementia (QUALID) scale, and the validated Dutch Positive Experiences Scale (PES) and another instrument because pilot data collected in 2015 indicate

psychometric properties are not fully satisfactory. Assessments are at baseline and multiple times over 12 months and also include an after-death assessment up to after 24 months, for efficient longitudinal analyses of data of 192 patients enrolled at baseline. Secondary patient outcomes, all measured with valid Dutch-version instruments, are (dis)comfort, behavior, health problems, and psychotropic medications. Secondary family outcomes are caregiver burden, (pre)grief, and perceptions of caregiving role. Costs from a societal perspective are measured with the Dutch standardized TOPICS-MDS. Semi-structured qualitative interviews with families, volunteers, nurses and managers will assess feasibility, accessibility, and sustainability.

We will adapt and (pilot)test the program also in the community, anticipating more people with advanced dementia staying there and the importance of helping family caregivers to achieve the best possible quality of life and positive caregiving experiences.

To assess effects and the most effective components (elements) of the program, we will perform longitudinal mediation Structural Equation Modeling (SEM) analyses. Based on literature and experiences with Namaste elsewhere, we refine the testing of effects in three ways. First, we test mediation through increased person-centeredness, patient engagement, and family visits. Second, we will test if the degree to which program elements are implemented at the individual level affect outcomes, also separately for touch and non-touch activities. Third, we will test if effects differ for subgroups (moderation) such as male patients, those with agitation or apathy, in pain (for moderating patient outcomes) and by family caregiving burden at baseline (for family outcomes).

An economic evaluation will relate the difference in societal costs to the difference in quality of life and positive caregiving experiences attributed to Namaste Care Family. Both a cost-effectiveness and a cost-utility analysis will be performed. Statistical uncertainty will be estimated using bootstrapping, and results presented using cost-effectiveness planes and cost-effectiveness acceptability curves.

Regarding sustainability, any resources such as supplies lists and an instructional video will be translated or developed, and improved for an accessible toolkit for further implementation. We will train “champion” families and volunteers to become trainers themselves. Mediation, moderation, and cost effectiveness analyses allow for informed limiting of the future intervention to the most cost-effective elements for patient subgroups (e.g, those with apathy), and activities planning (e.g., if touch approaches were most effective).

## **Doel van het onderzoek**

Implementation of the Namaste Care Family program will improve lives of Dutch nursing home residents with advanced dementia and their families

### **Onderzoeksopzet**

The primary outcomes are assessed at baseline, 1, 3, 6, and 12 months after the start of the intervention, and after death if the patient dies within the period of data collection

### **Onderzoeksproduct en/of interventie**

The Namaste Care Family program

## **Contactpersonen**

### **Publiek**

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### **Wetenschappelijk**

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## **Deelname eisen**

### **Belangrijkste voorwaarden om deel te mogen nemen (Inclusiecriteria)**

Nursing home residents with dementia who cannot initiative meaningful activities themselves. They cannot participate in the activities a nursing home usually offers. People will typically have advanced dementia. Others may have moderate dementia and challenging behaviour or they are particularly responsive to touch, and therefore they are expected to benefit from the program

### **Belangrijkste redenen om niet deel te kunnen nemen**

## (Exclusiecriteria)

Family does not give permission for the resident to participate in the program and the research

## Onderzoeksopzet

### Opzet

Type:	Interventie onderzoek
Onderzoeksmodel:	Parallel
Toewijzing:	Gerandomiseerd
Blinding:	Open / niet geblindeerd
Controle:	Placebo

### Deelname

Nederland	
Status:	Werving nog niet gestart
(Verwachte) startdatum:	01-09-2016
Aantal proefpersonen:	192
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
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NTR-new	NL5570
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NTR-old	NTR5692
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Ander register VU University Medical Center, EMGO: WC2014-048 : ZonMw: 733050302

## Resultaten

### Samenvatting resultaten

none yet