POWER: family-centered rehabilitation

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Family Group Conferences will improve disability-management self-efficacy and participation in patients with amputation, acquired brain injury and spinal cord injury and their relatives

Ethische beoordeling	Positief advies
Status	Werving gestopt
Type aandoening	-
Onderzoekstype	Interventie onderzoek

Samenvatting

ID

NL-OMON22723

Bron
Nationaal Trial Register

Verkorte titel
POWER

Aandoening

Leg amputation (beenamputatie), acquired brain injury (niet-aangeboren hersenletsel) and spinal cord injury (dwarslaesie)

Ondersteuning

Primaire sponsor: Center of Excellence for Rehabilitation Medicine, University Medical Center Utrecht and De Hoogstraat Rehabilitation, Utrecht, the Netherlands
Overige ondersteuning: Fonds NutsOhra, RevalidatieFonds, ZonMw

Onderzoeksproduct en/of interventie

Uitkomstmaten

Primaire uitkomstmaten

Disability-management self-efficacyv
Participation

Toelichting onderzoek

Achtergrond van het onderzoek

Background and objectives:
Empowerment of patients and their families, meaning enhancing their ability to handle the consequences of their condition adequately to participate in society, is an important goal of rehabilitation. However, for several reasons these efforts do not reach their goals. Research consistently shows that many patients and their families feel insufficiently equipped for their new life and perceive a discontinuity of care. The general aim of the POWER study is to improve upon current rehabilitation concerning empowerment of patients and their significant others. The specific aims of the study are to: (1) to develop and evaluate a systematic screening on risk factors in patients and their relatives(usually but not necessarily spouses) for long-term adjustment problems; (2) to evaluate a Family Group Conference (FGC) for families at risk on long-term adjustment problems, with at least two structured follow-up contacts with the family.

Paticipants:
Dyads of patients with recent onset of brain injury, amputation or spinal cord injury and their relatives.

Methods:
There is a comprehensive assessment of risk factors for long-term adjustment problems in patients and relatives in the first two weeks of admission. The assessment battery will cover the domains of mood, personality, coping strategies, psychological resources, lifestyle factors, existing social network and support and pre-injury social participation. The assessment battery functions as a screening instrument for ‘high risk’ families. The FGC intervention will only be implemented in ‘high risk’ families in the intervention centers. The FGC is an intervention consisting of three contact moments in which the family, supported by the social worker of the rehabilitation team, and relevant members of their social network (e.g., children, friends, colleagues) will come together to discuss the possible impacts of the condition on activities and participation of the family, to set priorities for support and to make action plans on how to achieve these priorities. The conference will be prepared by the social worker and the family together. Topics to be addressed and persons to be invited will be family-specific. The intervention will be evaluated in a parallel group trial. ‘Low risk’ families and families in the control centers will receive care as usual. All participating patients and their relatives will complete four questionnaires: at admission, at discharge, and after three and six months after discharge.

Outcomes:
It will be evaluated if the FGC will enhance empowerment, operationalized as disability-management self-efficacy, and participation of patients and relatives. In addition, the assessment battery of potential risk factors will be evaluated.

Doel van het onderzoek

Family Group Conferences will improve disability-management self-efficacy and participation in patients with amputation, acquired brain injury and spinal cord injury and their relatives

Onderzoeksopzet

Shortly after clinical admission in the rehabilitation centre, at discharge, 3 months after discharge and 6 months after discharge

Onderzoeksproduct en/of interventie

Patients and informal caregivers in the intervention centres who score low on self-efficacy (high-risk families) will receive the Family Group Conference, consisting of three meetings organised by social work. Aim of the Family Group Conference is to enhance disability-management self-efficacy and participation of the patient and the informal caregiver, with help of their social network. Patients and informal caregivers who score high on self-efficacy and the participating patient and informal caregiver dyads in the control centres receive regular care.

Contactpersonen

Publiek

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Wetenschappelijk

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Deelname eisen

Belangrijkste voorwaarden om deel te mogen nemen (Inclusiecriteria)

- Recent onset of spinal cord injury, acquired brain injury, or (leg) amputation

- Expected clinical admission stay in the rehabilitation centre of at least 4 weeks

- Age at least 18 years

- For intervention participation: the patient and/or the informal caregiver has a below-average self-efficacy score (46 or lower on the ALCOS-12)

Belangrijkste redenen om niet deel te kunnen nemen (Exclusiecriteria)

- Full recovery or nearly full recovery of the patient is expected

- No expected return to the home situation

- It is expected that outpatient treatment is in a different rehabilitation centre than the clinical treatment

- Patients cannot mention an informal caregiver / 'significant other'

- No informed consent of both the patient and the informal caregiver

- High degree of cognitive or intellectual problems (unreliable measurements);

- Participation in other intervention research.

- Limited life expectancy due to metastases

Onderzoeksopzet

Opzet

Type:	Interventie onderzoek
Onderzoeksmodel:	Parallel
Toewijzing:	Niet-gerandomiseerd
Blindering:	Open / niet geblindeerd
Controle:	N.v.t. / onbekend

Deelname

Nederland

Status:	Werving gestopt
(Verwachte) startdatum:	08-04-2016
Aantal proefpersonen:	328
Type:	Werkelijke startdatum

Voornemen beschikbaar stellen Individuele Patiënten Data (IPD)

Wordt de data na het onderzoek gedeeld: Nee

Toelichting
N.a.

Ethische beoordeling

Positief advies

Datum:	09-02-2016
Soort:	Eerste indiening

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	NL5414
NTR-old	NTR5742
Ander register	Dossiernumber ZonMW : 60-63000-98-110

Resultaten

Samenvatting resultaten
Hillebregt CF, Scholten EWM, Ketelaar M, Post MWM, Visser-Meily JMA. Effects of Family Group Conferences among high-risk patients of chronic disability and their significant others: Study protocol for a multicentre controlled trial. BMJ Open. 2018;8(3):E-pub.