

Het ontwikkelen en testen van een online ondersteuningsprogramma voor ouders van kinderen met een chronische nierziekte

Gepubliceerd: 23-09-2014 Laatste bijgewerkt: 13-12-2022

The aim of the pilot trial is to: 1. evaluate the potential effectiveness and effect size of the e-support program for parents of children with a chronic kidney disease; 2. to identify outcome measures most likely to capture potential patient...

Ethische beoordeling	Positief advies
Status	Werving nog niet gestart
Type aandoening	-
Onderzoekstype	Interventie onderzoek

Samenvatting

ID

NL-OMON21239

Bron

Nationaal Trial Register

Verkorte titel

e-Powered Parents

Aandoening

Chronic kidney disease (children).

Ondersteuning

Overige ondersteuning: De Nierstichting (The Dutch Kidney Foundation)

Onderzoeksproduct en/of interventie

Uitkomstmaten

Primaire uitkomstmaten

We will use five different questionnaires:

1. Parental Stress will be assessed with the Pediatric Inventory for Parents-short form (PIP-SF; Streisand et al. 2001).

2. The child's quality of life will be assessed using the Dutch version of the Child Vulnerability Scale (Forsyth et al. 1996).

3. Self-management of parents will be assessed with the Dutch version of the Family Management Measure (FAMM; Knafl et al. 2009).

4. Self efficacy in the communication with healthcare professionals will be assessed with the Dutch version of the Perceived Efficacy in Patient- Physician Interactions (PEPPI-5; ten Klooster et al. 2011).

5. Fatigue among parents will be assessed using the Dutch version of the Multidimensional Fatigue Inventory (MFI-20; Smets et al. 1995).

Toelichting onderzoek

Achtergrond van het onderzoek

BACKGROUND - In children with chronic kidney disease, parents have a key role in managing their child's disease and consequences for both child and family. However, while parents struggle with many health and life problems, well-developed self-management support for parents is lacking.

AIM - To develop, deliver and preliminary test e-POWERED PARENTS, an e-support package for parents managing their child's chronic kidney disease and its consequences for child and family.

APPROACH - We will use Intervention mapping, a systematic approach to intervention development that combines theory, research evidence and experience, while facilitating a collaboration of the target group, researchers and health professionals. A development group of 4 parents, a paediatric nephrologist, a specialised nurse practitioner, a psychologist, a dietician, a social worker and two project staff members will work collaboratively throughout the development process. Intervention Mapping (IM) will include:

- 1) Needs assessment; including a scoping review of the literature and focus groups with parents to provide an overview of parents' needs and relevant determinants;
- 2) Definition of proximal programme objectives by the development group;
- 3) Selection of theory and evidence based methods and practical strategies;
- 4) Production and piloting of programme components;
- 5) Anticipating adoption and implementation and;

6) Preliminary evaluation of the e-POWERED PARENTS programme versus usual care in an early randomised clinical trial (in parents of 2x60=120 children) to estimate effects on parents' self management, parental stress, and childrens' quality of life.

Doel van het onderzoek

The aim of the pilot trial is to:

1. evaluate the potential effectiveness and effect size of the e-support program for parents of children with a chronic kidney disease;
2. to identify outcome measures most likely to capture potential patient benefit;
3. to evaluate continued participation or dropping out of the e-support program.

Onderzoeksopzet

Baseline data collection will start in November 2014, follow-up will be at six months. Data will be collected using web based questionnaires (see outcomes), which take parents a maximum 30 minutes to fill in.

Onderzoeksproduct en/of interventie

Control group = Care as usual = all parents in this study receive the usual care, consisting of regular care and treatment for their child at the Radboud university medical center for paediatric nephrology in Nijmegen

Intervention: Additionally, the parents in the intervention group will have the opportunity to use the e-support program for six months. Parents can use this program voluntarily and can decide by themselves how often and long they 'visit' the program.

The program is developed using the Intervention Mapping (IM) method, the current standard for systematic development of health promotion interventions (Bartholomew et al, 2011).

The program consist of a communiy where parents can find information about kidney diseases and treatments. Moreover parents have the opportunity to chat with each other and ask their questions on the forum. Futhermore there are four online trainings: 1) Stress management, 2) Saying 'no', 3) Coping with your child's disease, 4) Communication. Each e-module consists of information, peer testimonials, tips and tricks of peers and healthcare professionals and exercises. Parents can use these modules on a privacy protected e-health platform: they will receive a login code and password.

Contactpersonen

Publiek

Junior onderzoeker/ PhD candidate

IQ healthcare

Radboud Universitair Medisch Centrum

Postbus 9101

W. Geense
Geert Grooteplein 21 (route 114)
Nijmegen 6500 HB
The Netherlands
(024) 3616538

Wetenschappelijk

Junior onderzoeker/ PhD candidate

IQ healthcare

Radboud Universitair Medisch Centrum

Postbus 9101

W. Geense
Geert Grooteplein 21 (route 114)
Nijmegen 6500 HB
The Netherlands
(024) 3616538

Deelname eisen

Belangrijkste voorwaarden om deel te mogen nemen (Inclusiecriteria)

The parents of children with a chronic kidney disease who receive treatment and care at the Radboud university medical center for paediatric nephrology in Nijmegen. We will include five subgroups of parents of children:

1. in the pre-dialysis stage of the chronic kidney disease,
2. on dialysis,

3. after transplantation,
4. with a hereditary kidney disease,
5. suffering from nephrotic syndrome.

Belangrijkste redenen om niet deel te kunnen nemen (Exclusiecriteria)

Parents who are not able to speak Dutch

Onderzoeksopzet

Opzet

Type:	Interventie onderzoek
Onderzoeksmodel:	Parallel
Toewijzing:	Gerandomiseerd
Blinding:	Open / niet geblindeerd
Controle:	Actieve controle groep

Deelname

Nederland	
Status:	Werving nog niet gestart
(Verwachte) startdatum:	15-10-2014
Aantal proefpersonen:	120
Type:	Verwachte startdatum

Ethische beoordeling

Positief advies	
Datum:	23-09-2014
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	NL4639
NTR-old	NTR4808
Ander register	: 2014/302

Resultaten