

Effectiveness of an online self management training for young adults with Juvenile Idiopathic Arthritis

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

Samenvatting

ID

NL-OMON25968

Bron

Nationaal Trial Register

Aandoening

Juvenile Idiopathic Arthritis (eng)

Juvenile Idiopathische Artritis (jeudgreuma) (Nederlands)

Ondersteuning

Primaire sponsor: Projectleiders:

Prof. Dr. J.W.J. Bijlsma, reumatoloog

i.s.m.

Prof. Dr. B.J. Prakken, kinderarts Immunologie

UMC Utrecht

Uitvoerder:

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UMC Utrecht

Overige ondersteuning: UMC Utrecht, afdeling Reumatologie & Klinische Immunologie

Onderzoeksproduct en/of interventie

Uitkomstmaten

Primaire uitkomstmaten

Self-efficacy

Toelichting onderzoek

Achtergrond van het onderzoek

Like adults, young adults with a rheumatic disease also have to deal with the physical and psychological consequences of having this disease.

The management of the disease is complex; young adolescents with JIA have to develop more tools and actions to incorporate their illness in daily life, in order to avoid complications within shorter and longer time. Not seldom these actions intervene negatively with individual needs of the young adolescents. The appeal on parents and their role in assisting

chronically ill children change over time as the child grows up into adulthood. The young adolescents must be more in charge. He is encouraged to ask questions, to take responsibility, to discuss the implications of

the given advices, to be a self manager. For this, the young adolescent is guided at the transition outpatient clinic which is developed in 2002 at the University Medical Hospital in Utrecht and at the transition outpatient clinic of the Erasmus MC of Rotterdam since 2009. Here, the

young adolescent is being prepared in taking an active part in his treatment and care process. A team of pediatricians, rheumatologists and a clinical nurse specialist (better known as transition coordinator) focus on the medical treatment and improving adherence.

To improve self-management skills, an online self-management training is developed. The training is lead by expert patients – trainers, young adolescents in the age of 20-30 years, suffering from a rheumatic disease themselves. Two moderators (a coach of a coaching agency, a clinical specialist or a communication advisor of the UMC Utrecht) will assist the trainers. The young adolescent is asked to logg in at least twice a week and to join the weekly chat. The amount of time the young adolescent spend on the training varies. Some exercises are mandatory (reading, practicing, and reflection, approximately 20 minutes per week) some are optional (depending on needs and questions, approximately 10 minutes per week). In this study the effectiveness of the online program is being studied.

Doel van het onderzoek

The objective of this research is to study the effectiveness of the online self-management training ReumaUitgedaagd! by young adults with Juvenile Idiopathic Arthritis (JIA) who are treated at the transition outpatient clinic of the departments Rheumatology and Rheumatology & Clinical Immunology of the University Medical Center Utrecht and the transition outpatient clinic of the departments Rheumatology of the Erasmus MC of Rotterdam.

Onderzoeksopzet

Before randomisation (T0, after three months (T1) and six months (T2). The participant will be asked to fill in online assessments (questionnaires) and to answer text messages.

Onderzoeksproduct en/of interventie

The control and intervention group will receive usual care. The intervention group will be asked, in addition to the usual care, to follow the six weeks online selfmanagement training.

Contactpersonen

Publiek

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Wetenschappelijk

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Deelname eisen

Belangrijkste voorwaarden om deel te mogen nemen (Inclusiecriteria)

Young adults with Juvenile Idiopathic Arthritis, diagnosed by a pediatrician or rheumatologist, age 16-25 years old

Belangrijkste redenen om niet deel te kunnen nemen (Exclusiecriteria)

- young adults who are not able to read and write in the Dutch language
- young adults who have no access to the internet
- young adults who have not a mobile phone
- young adults who have participated earlier in a online self managementtraining

Onderzoeksopzet

Opzet

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

Deelname

Nederland	
Status:	Werving gestart
(Verwachte) startdatum:	01-02-2012
Aantal proefpersonen:	72
Type:	Verwachte startdatum

Ethische beoordeling

Positief advies

Datum: 08-07-2014

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	NL4536
NTR-old	NTR4679
Ander register	NL38074.041.11 : METC UMC Utrecht

Resultaten