

Healthy living for young people with a chronic illness: finding the balance

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Ethical review	Approved WMO
Status	Recruitment stopped
Health condition type	Glucose metabolism disorders (incl diabetes mellitus)
Study type	Observational non invasive

Summary

ID

NL-OMON35574

Source

ToetsingOnline

Brief title

Young people with chronic illness in balance

Condition

- Glucose metabolism disorders (incl diabetes mellitus)
- Neuromuscular disorders
- Lifestyle issues

Synonym

diabetes, muscular disease

Research involving

Human

Sponsors and support

Primary sponsor: TNO

Source(s) of monetary or material Support: ZonMw,TNO

Intervention

Keyword: art of living, chronic illness, life skills, young people

Outcome measures

Primary outcome

The research variables are:

- participants' descriptions of having a good life
 - participants' descriptions of factors that contribute to having a good life
- and to finding a balance between a good life and taking care of their illness;
- this will mostly concern skills, competencies and character traits.

Secondary outcome

Not applicable

Study description

Background summary

Many young people with a chronic illness have difficulty in following medical prescriptions and regimes and in finding a balance for a healthy and good life. Adolescence is a developmental period characterized by many and fast changes, among which a strive for autonomy. Research indicates that many young people with a chronic illness struggle in this turbulent developmental period to find a balance between their illness and the life they want to lead (Holmbeck, 2002). For instance, adolescents with diabetes as a group have the worst glycemic control of all age groups (Morris et al., 1997). Health care professionals indicate they have great difficulty in keeping young people on the 'right track' with respect to the treatment of their illness. However, professionals also indicate that there are young people who succeed in finding a balance and in adequately integrating their illness into their daily life. In this study, we want to learn from this latter group of young people.

Study objective

The objective of this study is to learn from young people with a chronic illness (diabetes or progressive muscular disease) who have found a balance

between taking good care of their illness and having a good life. This study examines how these adolescents define a good life and sets out to identify which factors (skills, competencies, life style) contribute to leading a good life in the face of disability posed by illness and treatment.

Study design

This qualitative study consists of two parts. In part 1, online focus groups are held with 60 adolescents with a chronic illness: 30 adolescents with diabetes (3 groups of 10 participants) and 30 with progressive muscular disease (3 groups of 10 participants). These illnesses were selected because they differ in disease burden and in opportunities for personal and social development (school career, leisure activities): muscular disease has a more disabling effect on functioning than diabetes. The focus groups will focus on the adolescents' opinions about the following themes: how would you define a good life? why do you feel your life is good? how do you stay in control over your life? which choices do you make concerning your illness and treatment? which skills or qualities help you lead a good life?

The approval of the METC for the second part of the study will be sought later in the study. In part 2, the adolescents from part 1 participate in a photo workshop and a drama workshop. As the focus groups in part 1 fully rely on written language, the new methods in part 2 are used to complement the results of part 1 by making use of other modes of expression. Prior to the photo workshop the adolescents are asked to take pictures that are relevant to the central themes of the study (which things/people/events make you feel good about your life: what helps you cope with your illness? who or what makes you feel stronger?). In the photo workshop, the participants present their pictures and jointly reflect on their experiences and perspective. In the second workshop drama is used to actively involve the participants in further providing insight into their experience and perspective, for example by playing typical situations and brainstorming helpful responses (e.g., thought processes) to these situations.

Study burden and risks

Participation does not hold risks and does not take much time. From their personal computer at home, participants take part in online focus groups on three consecutive days (about 1,5 hour per focus group). In addition, they are expected to participate in a photo workshop and a theatre workshop, which are held on one day and will each take three hours; for this part of the study we will seek the approval of the medical-ethical committee at a later stage in the project.

The questions posed will not be intrusive, and participants can refrain from answering. Also, there is no intervention and participants will not be subjected to a particular way of behaving. A benefit for the participants may

be that their opinions are being asked and valued and that, at a later stage (in a potential follow-up project), the results may be used for developing interventions for young people with a chronic illness who have not yet found a balance between taking care of their illness and having a good life.

Contacts

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Trial sites

Listed location countries

Netherlands

Eligibility criteria

Age

Adolescents (12-15 years)
Adolescents (16-17 years)
Adults (18-64 years)
Elderly (65 years and older)

Inclusion criteria

Participants who

- either have diabetes (type 1 or 2) or a progressive muscular disease (Duchenne; SMA spinal muscular atrophy type 2; or HMSN hereditary motor and sensory neuropathy)
- are 12 to 18 years old

- according to their physician take care of their disease at least reasonably well and/or have a constructive attitude towards living with their disease
- indicate that they are at least reasonably happy (Affective evaluation). At least report mark 6 on the item: All things taken together, how happy or unhappy are you?
- indicate that they are at least reasonably satisfied with their life (Cognitive evaluation). At least report mark 6 on the item: Considering your life as a whole, have you achieved the most important things you want in life?

Exclusion criteria

- not meeting the above inclusion criteria
- non-availability of a computer with internet access at home

Study design

Design

Study type: Observational non invasive

Masking: Open (masking not used)

Control: Uncontrolled

Primary purpose: Other

Recruitment

NL

Recruitment status: Recruitment stopped

Start date (anticipated): 01-09-2010

Enrollment: 60

Type: Actual

Ethics review

Approved WMO

Date: 02-06-2010

Application type: First submission

Review commission: METC Leids Universitair Medisch Centrum (Leiden)

Study registrations

Followed up by the following (possibly more current) registration

No registrations found.

Other (possibly less up-to-date) registrations in this register

No registrations found.

In other registers

Register	ID
CCMO	NL29214.058.10