

Duchenne from the third Decade (3D) Functioning, quality of life and needs of health care in adults with Duchenne Muscular Dystrophy and their informal caregivers.

Published: 06-02-2007

Last updated: 10-05-2024

The main research questions are:1a. What are the functional status on all levels of ICF and quality of life of adults with DMD?1b. What are determinants of functional status and quality of life?2a. What are burden of care and quality of life of...

Ethical review	Approved WMO
Status	Recruiting
Health condition type	Neurological disorders congenital
Study type	Observational non invasive

Summary

ID

NL-OMON30601

Source

ToetsingOnline

Brief title

Duchenne from the third Decade (3D)

Condition

- Neurological disorders congenital

Synonym

Duchenne muscular dystrophy; Duchenne

Research involving

Human

Sponsors and support

Primary sponsor: Erasmus MC, Universitair Medisch Centrum Rotterdam

Source(s) of monetary or material Support: Johanna Kinderfonds; Stichting Kinderrevalidatiefonds Adriaan Stichting; Stichting Erasmusfonds Pijnbestrijding

Intervention

Keyword: Duchenne Muscular Dystrophy, Informal caregivers, Level of functioning, Quality of life

Outcome measures

Primary outcome

Functional level of adults with DMD

Quality of life of adults with DMD

Determinants of functional level and quality of life

Burden of informal caregivers of adults with DMD

Quality of life of caregivers of adults with DMD

Determinants of burden and quality of life

Needs of care of adults with DMD

Secondary outcome

a.o. prevalence co-morbidity

Study description

Background summary

Life expectancy of boys with Duchenne Muscular Dystrophy has increased greatly since the introduction of mechanical home ventilation. Over half of these patients now reach an age over 25.

This implies a totally different perspective for this group of patients and their parents than several decades ago, when average life expectancy was about 20 years. Children with DMD nowadays must be prepared for a meaningful adult life with considerable physical limitations; they will now require intensive

daily care for a much longer period, implying a much greater burden for informal caregivers, notably parents. In the new group of adults with DMD new health issues arise, posing new challenges for health care professionals. Patient organisations stress the need for guidelines and coordination of care for adults with DMD and support for their caregivers. Until now there has been little research into functioning and quality of life of adults with DMD and their caregivers.

Study objective

The main research questions are:

- 1a. What are the functional status on all levels of ICF and quality of life of adults with DMD?
- 1b. What are determinants of functional status and quality of life?
- 2a. What are burden of care and quality of life of informal caregivers of adults with DMD?
- 2b. What are determinants of burden of care and quality of life?
- 3a. What are the needs and utilisation of health care services of adults with DMD in relation to their functional status? Are there unmet needs?
- 3b. Do adult DMD patients experience they have made a successful transition from paediatric rehabilitation care to adult care? What were success factors or obstacles?

Study design

Cross-sectional, observational

Study burden and risks

In two home visits by the researchers, both lasting a maximum of two hours, participants will be subjected to a limited physical examination (estimation of joint contractures, hand function, weight/length), interviews and questionnaires. Part of the questionnaires will be filled out by participants in the period between the two home visits.

Caregivers will be asked to fill out a questionnaire.

Participation is without risk.

Contacts

Public

Erasmus MC, Universitair Medisch Centrum Rotterdam

Postbus 2040
3000 CA

Nederland
Scientific
Erasmus MC, Universitair Medisch Centrum Rotterdam

Postbus 2040
3000 CA
Nederland

Trial sites

Listed location countries

Netherlands

Eligibility criteria

Age

Adults (18-64 years)

Elderly (65 years and older)

Inclusion criteria

Confirmed diagnosis of DMD (Criteria Emery)

Age over 19

Exclusion criteria

None

Study design

Design

Study type: Observational non invasive

Masking: Open (masking not used)

Control: Uncontrolled

Primary purpose: Health services research

Recruitment

NL

Recruitment status: Recruiting

Start date (anticipated): 01-06-2007

Enrollment: 230

Type: Actual

Ethics review

Approved WMO

Date: 06-02-2007

Application type: First submission

Review commission: METC Erasmus MC, Universitair Medisch Centrum Rotterdam (Rotterdam)

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

CCMO

ID

NL14284.078.06