The meaning of living with myotonic dystrophy for couples

Published: 12-05-2009
Last updated: 05-05-2024

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

Summary

ID

NL-OMON33153

Source
ToetsingOnline

Brief title
Living with myotonic dystrophy

Condition

- Neurological disorders congenital
- Muscle disorders
- Family issues

Synonym
muscular disease, myotonic dystrophy

Research involving
Human

Sponsors and support

Primary sponsor: Nationaal Revalidatie Fonds
Source(s) of monetary or material Support: Nationaal Revalidatie Fonds

Intervention

Keyword: muscular dystrophy, myotonic dystrophy, qualitative research

Outcome measures

Primary outcome

the stories and experiences of persons with myotonic dystrophy and their

partners

Secondary outcome

nvt

Study description

Background summary

Myotonic dystrophy type I is the most common type of muscular dystrophy in adults. This hereditary progressive neuromuscular disorder has been recognized as a multisystemic disorder with various impairments, especially in the muscular, respiratory, cardiac, central nervous, endocrine and ocular systems. Typical symptoms of the disease include myotonia and progressive loss of muscle strength, usually distal to proximal, and also weakness of facial and anterior neck muscles. Other symptoms include cataracts, frontal boldness, dysarthria, fatigue and daytime somnolence. Also cognitive decline and specific personality traits are related to myotonic dystrophy. Myotonic dystrophy often results in restrictions in the performance of daily activities and participation in social roles. By comparison with other types of muscular dystrophy, persons with myotonic dystrophy have the greatest functional disabilities and lower social participation. When learning about the disease, persons are told that it is hereditary, progressive and that there is no treatment. Often, the problems in the performance of daily occupations increase until work is not possible anymore and the lifestyle becomes increasingly passive. Persons with the disease often avoid talking to others about their problems and have the impression that professionals cannot help and have little knowledge about the disease. The worst part is lack of understanding by other people.
A chronic disease like myotonic dystrophy also has major consequences for the life of the next of kin. Worries and sorrow, a reduced social network and emotional loneliness with the added burden of having to do the practical tasks are some of the experiences of the next of kin. Often there is a need to renegotiate and reinterpret family roles and responsibilities, including those

commonly associated with gender. Husbands, more often, restrict their involvement to a problem-solving role and do not seem to take on the same emotional burden compared to wives. Clearly the illness becomes, to a great extent, integrated into the life of the next of kin. When one lives close to someone with a slowly progressive disease like myotonic dystrophy, adjustments are made constantly over time, often without reflection. Both the person with the disease and their next of kin go through a process of learning to live within new limits and adapting to the changes. More attention for partner relationship was mentioned as an important topic for research among persons with neuromuscular diseases and their partners. An example included problems associated with daytime sleepiness and impaired initiative, which has major impact on the person having the disease, their next of kin and for both as a couple.
Despite the impact of myotonic dystrophy on both the person having the disease and the partner, these couples hardly complain and do not easily make use of rehabilitation services. One of the reasons may be that they have been told that the disease cannot be cured and that they have the impression that nothing can be done. Also the feeling that doctors know awfully little and generally people do not understand may contribute to the fact that they don*t ask for help or support. Professionals and others often focus primarily on the problems and needs of the person with myotonic dystrophy and overlook the support needs of next of kin.
In order to effectively target the interventions to promote participation and enhance quality of life, it is necessary to understand the unique meaning of participation in everyday occupations for a person and the impact of the disease on the participation. Because a chronic disease like myotonic dystrophy also has impact on the life of the next of kin, and for the couple, these perspectives also need to be understood. This understanding cannot be observed, but can only be acquired by listening to the persons telling about it.

Study objective

The purpose of this study is to increase our understanding of the meaning of myotonic dystrophy for both the person having the disease as well as for the next of kin as for both as a couple. An additional aim is to gain understanding of how these persons, as a couple and individually have adapted to the changes as a result of living with myotonic dystrophy. This understanding will contribute to improve the rehabilitation for couples with myotonic dystrophy.

Study design

Design: a qualitative study with in-depth interviews based on grounded theory as well as hermeneutics.
Three interviews are planned with each couple, the first interview with the person with myotonic dystrophy and the next of kin separately and a follow up interview with the couple together. Interviews are conducted with the aid of an

interview guide. Preceding the interviews, small talk and an explanation of the purpose and format of the interview will enable the interviewer and interviewee to become acquainted with each other. By way of introduction, the participants are asked to describe an ordinary day and their satisfaction with the current routines. Other topics include the roles and relations, context of performance, changes in occupational performance resulting from disease progression, the meaning of these changes and the adaptations to these changes in roles and routines and thoughts about the future. Each interview wil lasty one to a maximum of two hours. Following the interviews the interviewers writes memos on the impressions and reflections of the interview.
Initially a pilot interview will be conducted with a couple. The experiences are used to adapt the interview guide. Then two other couples are interviewed. The interviews are audio taped with the permission of the participants and then transcribed in full for qualitative analysis. Audiotapes and memos are used for preliminary analysis of each interview. The results of this preliminary analysis are used to guide interviews with three more couples. Ideally the data collection continues until saturation. In this study five couples will be interviewed and whether or not saturation was reached will be addressed.
Data-analysis: data from the transcribed interviews and memos are analyzed according to the constant comparative method. Concepts will be in vivo codes as well as sensitizing concepts. The following analytical procedure will be carried out: multiple readings of interview transcripts to gain understanding of each participant*s experiences, codes and meaning units are identified and related to the research questions (open coding), grouping and categorization of meaning units will enhance understanding of the participant*s experiences (axial coding), and core categories will be looked for by comparing, reorganizing and interpreting (selective coding). Finally new insights will be uncovered.
MaxQDA computer software will be used to assist in organizing the data (www.MAXQDA.com).

Study burden and risks

nvt

Contacts

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Trial sites

Listed location countries

Netherlands

Eligibility criteria

Age
Adults (18-64 years)
Elderly (65 years and older)

Inclusion criteria

- Couples living together for at least 5 years of which one of them has myotonic dystrophy type I and the partner is healthy
- Myotonic dystrophy has much impact on daily life of both
- the couple is able to and happy to share their experiences in two interviews
- both person with myotonic dystrophy and partner have given informed consent

Exclusion criteria

- couples living together for less than 5 years
- couples hardly experiencing problems in activities and participation
- One of the partners does not want to participate

Study design

Design

Study type: Observational non invasive

Masking:	Open (masking not used)
Control:	Uncontrolled

Recruitment

NL

Recruitment status:	Recruitment stopped
Start date (anticipated):	13-05-2009
Enrollment:	10
Type:	Actual

Medical products/devices used

Registration:	No

Ethics review

Approved WMO

Date:	12-05-2009
Application type:	First submission
Review commission:	CMO regio Arnhem-Nijmegen (Nijmegen)

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	NL26868.091.09