Responsiveness of the PRPP (Perceive-Recall-Plan-Perform System of Task Analysis and Intervention) in children with mitochondrial disease

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Exploring the responsiveness of the PRPP-Assessment in children with mitochondrial disorder

Ethical review	Approved WMO
Status	Recruitment stopped
Health condition type	Inborn errors of metabolism
Study type	Interventional

Summary

ID

NL-OMON51052

Source
ToetsingOnline

Brief title
PRPPchange-mito

Condition

- Inborn errors of metabolism

Synonym
mitochondrial disease

Research involving
Human

Sponsors and support

Primary sponsor: Radboud Universitair Medisch Centrum
Source(s) of monetary or material Support: NWO Promotiebeurs voor Leraren

Intervention

Keyword: assessment, everyday activities, mitochondrial disease, occupational therapy

Outcome measures

Primary outcome

PRPP-Assessment

Secondary outcome

COPM

GAS

Study description

Background summary

Engagement in everyday activities is seen as an important determinant for health, well-being and perceived quality of life. Children with mitochondrial disorder experience limitations in daily activities. On the basis of previous research, we know which activities children with mitochondrial disorder (want to) perform and what they find important. The variation in daily activities is large, which requires a personal approach tailored to the child's level. In order to make personal care possible, it is necessary to implement a measuring instrument in daily (care) practice that makes the quality of performance of a child's personally relevant activities measurable. There is one known instrument that has the potential to serve as a generic instrument for this complex group: the "Perceive, Recall, Plan and Perform (PRPP) System of task analysis". The PRPP is a criterion-referenced observation instrument with which the performance of activities is observed according to an objective scoring system. Since 2018, the PRPP has been part of the Mitoroute, in which parents provide videos of their children carrying out activities. These videos are analyzed by a PRPP{rained occupational therapist and discussed during the occupational therapy consultation and the multidisciplinary consultation within the Mitoroute. As a result of the recently conducted design study, the implementation of the PRPP within Mitoroute was optimized. The

manual for the use of the PRPP on the
Mitoroute is currently being finalized. This manual can also be used for other target groups and care paths in which the
PRPP is used by means of video recordings (instead of real-life observations). The psychometric properties of the PRPP have been studied in various target groups, but not for the target group of
children with mitochondrial diseases. Preliminary results are promising concerning reliability and validity. In order for
the PRPP to (continue to) be part of the regular care process and for application in clinical research, it is necessary
to know whether the PRPP is suitable for measuring the course of the disease. The instrument should measure
differences related to the severity of the disease at the level of functioning and be responsive to interventions.

Study objective

Exploring the responsiveness of the PRPP-Assessment in children with mitochondrial disorder

Study design

Multiple case series design with 5-8 children.
There will be a T0, waiting list period, intervention and T1. The intervention consists of a 6-week home-based video-coaching of parents in which they are coached how to guide their child so that the child learns to perform the activity better.
Data will be collected with the PRPP-Assessment, the COPM and the GAS. Descriptive statistics and correlations are used to compare change scores.

Intervention

Home-based video coaching consisting of the PRPP-Intervention aimed at coaching parents how to guide their children in learning the activity

Study burden and risks

It is a very minimal burden for children; only the pre- and post- interview is 'extra'; the activity is now filmed and practiced, but would otherwise be done. For parents, the burden is slightly greater (they film the activities, have a short conversation with the researcher, and are in weekly contact with an occupational therapist for 6 weeks for coaching on how to support the child in learning the chosen activities).
There are no risks.

Contacts

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Trial sites

Listed location countries

Netherlands

Eligibility criteria

Age
Adolescents (12-15 years)
Adolescents (16-17 years)
Children (2-11 years)

Inclusion criteria

- Genetically confirmed mitochondrial disorder
- Perform activities they would like to improve (learn to do better, faster, etc)
- Age between 2 and 18 years

Exclusion criteria

- Children with non-genetically confirmed mitochondrial disorder
- Children who participate in the medication-trial

Study design

Design

Study type: Interventional

Masking:	Open (masking not used)
Control:	Uncontrolled
Primary purpose:	Diagnostic

Recruitment

NL

Recruitment status:	Recruitment stopped
Start date (anticipated):	17-08-2021
Enrollment:	8
Type:	Actual

Ethics review

Approved WMO Date:	29-06-2021
Application type:	First submission
Review commission:	CMO regio Arnhem-Nijmegen (Nijmegen)
Approved WMO Date:	21-04-2022
Application type:	Amendment
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	NL77169.091.21

Study results

Date completed:	25-04-2022
Actual enrolment:	6