Sustainability of Work for Persons with Neuromuscular Diseases

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1. Hindrances in OT treatment
2. Little Scientific Literature
3. Client Perspective?
Neuromusculaire aandoeningen

Spierziekten

- Myotonic Dystrophy (MD)
- Facio Scapulo-Humeral Dystrophy (FSHD)
- Hereditary Motor and Sensory Neuropathy (HMSN)

Hereditary Motor and Sensory Neuropathy (HMSN)

Facio Scapulo-Humeral Dystrophy (FSHD)

Myotonic Dystrophy (MD)
Individual level
Organizational level
Societal level

‘The ability to adapt and self-manage.’
(Huber, 2011)

‘The importance of having an occupation for human health, well-being and justice.’
(Polatajko, et al. 2007)
1. Health
   - Type of NMD
   - HMSN & MD
   - Physical functioning
   - Muscle functions

2. Environmental factors
   - Absent

3. Personal factors
   - Age
   - Gender
   - Level of education

Work related factors
   - Type of job
   - Interest in work
1. Health
   - Type of NMD
   - HMSN & MD
   - Physical functioning
   - Muscle functions
   - Concentration
   - Activity level

2. Environmental Factors
   - Absent

3. Personal Factors
   - Age
   - Gender (man)
   - Level of education

Work Related Factors
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Secondary analyses: N=591 Fatigue and NMD
Fatigue ≠ NMD

• Significant differences in levels of fatigue between employed and not employed.

• All reported severe fatigue

• Fatigue no predictive factor
Analysis of client files (n=102)

- 86 (100%) files included
- 68 (80%) info on work status
- 37 (43%) at work
43% (n=37) Paid Work

76% Used adaptations
- Yes: 76%
- No: 24%

97% Received direct advice
- Advice: 97%
- No advice: 3%

87% Still problems
- Still problems: 87%
- No problems: 13%

54% Need additional support
- Yes: 54%
- No: 46%

Client files
1. Health
   - Type of NMD
   - HMSN & MD
   - Physical functioning
   - Muscle function
   - Concentration
   - Activity level

2. Environmental Factors
   - Task content
   - Terms of employment
   - Working conditions

3. Personal factors
   - Age
   - Gender
   - Level of education

Work Related Factors
   - Type of job
   - Interest in work
Themes identified

- Experiences regarding the meaning of work
- Solving problems oneself
- Reaching a turning point
- Taking environmental aspects into account
1. ‘Work is belonging.’

2. ‘I am not going to tell.’

3. ‘I have to be realistic.’

4. ‘I can understand both sides.’

Interviews
1. Health
- Type of NMD
- HMSN & MD
- Physical functioning
- Muscle functions
- Concentration
- Activity level

2. Environmental Factors
- Task content
- Terms of employment
- Working conditions
- Relationships at work
- Macro-economic circumstances

3. Personal Factors
- Age
- Gender (man)
- Level of education

Work Related Factors
- Type of job
- Interest in work
Recommendations for practice

• Development of patient platforms
• Easy accessible guide books & websites
• Implement existing guidelines
• Physicians’ awareness of the impact of NMD on work
Recommendations for practice

• Work sustainability in clients at risk as part of history taking of physicians.

• No diagnosis that leave open other possibilities.

• Secrecy? Ask the client permission to communicate if its in favour of his/her job retention.
Recommendations for practice

• Tailored and timely referral to (independent) occupational physicians and/or job coaches

• Referral to a multidisciplinary team, occupational therapists, rehabilitation physicians with employment expertise
  – Analysis of job concerns
  – Providing information
  – Formulate a job retention plan
Client perspective

**Strong**
- Building good relationships at work
- Information on job retention needed
- Websites & peer info
- Training in self-management

**Weak**
- No timely diagnoses
- Making irreversible decisions
- Anxiety to talk
  “I am not going to tell.”
Shared decision making

• Shared decisions regarding job retention possibilities
  – client/employee – employer
  – client/employee – occupational physician
  – client/employee – health professional
GOOD PRACTICE EXAMPLES

• Referral to the Hospital OT who can bridge the gap between health care and occupational care

• Self-management courses developed for persons with chronic or slow progressive neurological diseases (Varenkamp I; Detaille S, Hunting N)

• Referral to the hospital occupational physician who acts as an independant advisor
Future Research

• Replenish an SR with qualitative research since QR studies provide more insight in the actual problems involved.

• QR taking into account stakeholders with an occupational background

• Effect studies to prove the effectiveness of interventions recommended.
References:

MAH Minis; JS. Kalkman; RP Akkermans; JA Engels; PA Huijbregts; G Bleijenberg; RAB Oostendorp, BGM. van Engelen. Employment Status of Patients with Neuromuscular Diseases in relation to Personal Factors, Fatigue and Health Status: a secondary analysis. *J Rehabil Med* 2010;42:60–65
