Designing a vocational rehabilitation service in MS
Outcomes measured and achieved

Joanna Sweetland
Research Occupational Therapist
Institute of Neurology & the National Hospital for Neurology and Neurosurgery, Queen Square, London
Content

• Describe our research to date

• How we have developed a patient reported outcome measure
The problem

- At onset (nearly) all are in employment
- Within 20 years of onset only 20% remain in work
## Unemployment rates in MS

<table>
<thead>
<tr>
<th>Location (Reference)</th>
<th>Number</th>
<th>Mean age</th>
<th>Duration of MS</th>
<th>EDSS</th>
<th>Employment rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Saxony, Germany (Poser 1981)</td>
<td>92</td>
<td>N/A</td>
<td>18.4</td>
<td>N/A</td>
<td>30%</td>
</tr>
<tr>
<td>New York, US (Larocca 1982)</td>
<td>312</td>
<td>43</td>
<td>13</td>
<td>4.6</td>
<td>23%</td>
</tr>
<tr>
<td>Tromso, Norway (Gronning 1990)</td>
<td>79</td>
<td>30</td>
<td>N/A</td>
<td>N/A</td>
<td>49%</td>
</tr>
<tr>
<td>Vancouver, Canada (Jackson 1991)</td>
<td>210</td>
<td>45</td>
<td>N/A</td>
<td>N/A</td>
<td>24%</td>
</tr>
<tr>
<td>Ontario, Canada (Aronson 1997)</td>
<td>697</td>
<td>48</td>
<td>12</td>
<td>N/A</td>
<td>32%</td>
</tr>
<tr>
<td>Northern Ireland (McDonnell 1998)</td>
<td>111</td>
<td>53</td>
<td>13.6</td>
<td>6.0</td>
<td>14%</td>
</tr>
</tbody>
</table>
Duration of MS (years)

Proportion of patients still employed

0.0 0.2 0.4 0.6 0.8 1.0

0 5 10 15 20 25 30 35 40 45
Why work?

“Not everyone wants to be employed, but almost all want to ‘work’, that is to be engaged in some kind of valued activity that uses their skills and facilitates social inclusion.”
(College of Occupational Therapists 2007)

“Everyone has the right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment.”
(UN Declaration of Human Rights (article 23) 1948)
What is vocational rehabilitation?

- Vocational rehabilitation (VR) is the concept of enabling individuals with either temporary or permanent disability to access, return to, or remain in, employment.
  (British Society of Rehabilitation Medicine 2003)

- No formal VR in the UK although pockets of VR nationwide
Research questions

- Why do people with MS stop working?
- What would help?
Research problems

• Vocational rehabilitation is a ‘complex intervention’

• ‘The greater the difficulty in defining precisely what, exactly, are the “active ingredients” of an intervention and how they relate to each other, the greater the likelihood that you are dealing with a complex intervention’.
**Theory**

Explore relevant theory to ensure best choice of intervention and hypothesis and to predict major confounders and strategic design issues.

**Preclinical**

Identify the components of the intervention and the underlying mechanisms by which they will influence outcomes to provide evidence that you can predict how they relate to and interact with each other.

**Phase I**

**Modelling**

Describe the constant and variable components of a replicable intervention and a feasible protocol for comparing the intervention with an appropriate alternative.

**Phase II**

**Exploratory trial**

Compare a fully defined intervention with an appropriate alternative using a protocol that is theoretically defensible, reproducible, and adequately controlled in a study with appropriate statistical power.

**Phase III**

**Definitive randomised controlled trial**

Determine whether others can reliably replicate your intervention and results in uncontrolled settings over the long term.

**Phase IV**

**Long term implementation**

*Continuum of increasing evidence*
Cochrane Review 2009

‘Effectiveness of vocational rehabilitation intervention on the return to work and employment of persons with multiple sclerosis’

• Objectives: To evaluate the effectiveness of VR programs and to evaluate the cost effectiveness of these programs.

• Results:
  • There was 'insufficient evidence' for VR programs.
  • No evidence could be assimilated for cost-effectiveness.
Pre-clinical: Literature Review

- Completed as part of the DoH and BSRM guidelines for NSF for LTNC: Quality Requirement 6
- Search terms: MS + employment, unemployment, vocational rehabilitation, occupational health, job, work adjustment
- Number of papers: 412
- Cut down to: 95
Pre-clinical: Literature Review

- Little written about the delivery and outcomes
- Most government sponsored programmes focus on return to work not work retention
- Vocational rehabilitation is being delivered largely ad-hoc
- Health care professionals with expertise in MS report themselves poorly equipped to manage work related issues
What factors lead to unemployment for people with MS?

- Disease related factors
- The working environment
- Work demands
**Preclinical**

Explore relevant theory to ensure best choice of intervention and hypothesis and to predict major confounders and strategic design issues.

**Phase I**

Identify the components of the intervention and the underlying mechanisms by which they will influence outcomes to provide evidence that you can predict how they relate to and interact with each other.

**Phase II**

Describe the constant and variable components of a replicable intervention and a feasible protocol for comparing the intervention with an appropriate alternative.

**Phase III**

Compare a fully defined intervention with an appropriate alternative using a protocol that is theoretically defensible, reproducible, and adequately controlled in a study with appropriate statistical power.

**Phase IV**

Determine whether others can reliably replicate your intervention and results in uncontrolled settings over the long term.

**Continuum of increasing evidence**
Phase I: Modelling - Focus Groups

• Aims
  – to identify what people would want from a service
  – to confirm data already published as to what the barriers to working with MS are

• Four groups 24 participants
• Interview guide developed from a literature review
• Groups audiotaped, transcribed and analysed
Focus Groups - What are the obstacles to working with MS?

- Physical impact/barriers
- Psychological Impact/barriers
- Lack of knowledge
Focus Groups

“if you think your whole world is unraveling, if you can work, even in a compromised way, it’s fantastically important...because you feel useful as a human being”
Focus Groups

“You are constantly having to prove yourself because people don’t understand”
Focus Groups

“it’s difficult for me because I had my own company... which I had to sell because I couldn’t particularly carry on and I’ve gone back to really boring part-time job that I had before.

Really because I thought “Well who’s going to employ me?” you know, I’m 53, I’ve got MS, I think I’ve got lots of talent within my design field but, you know, who’s going to employ me?

So I’ve gone back to a rather boring part-time job”
Focus groups - What do people with MS want from a vocational rehabilitation service?

- Managing performance
- Managing Social and Personal Expectations
- Early intervention
- **Theory**: Explore relevant theory to ensure best choice of intervention and hypothesis and to predict major confounders and strategic design issues.
- **Modelling**: Identify the components of the intervention and the underlying mechanisms by which they will influence outcomes to provide evidence that you can predict how they relate to and interact with each other.
- **Exploratory trial**: Describe the constant and variable components of a replicable intervention and a feasible protocol for comparing the intervention with an appropriate alternative.
- **Definitive randomised controlled trial**: Compare a fully defined intervention with an appropriate alternative using a protocol that is theoretically defensible, reproducible, and adequately controlled in a study with appropriate statistical power.
- **Long term implementation**: Determine whether others can reliably replicate your intervention and results in uncontrolled settings over the long term.

**Continuum of increasing evidence**
Phase II: Exploratory trial

- Vocational rehabilitation service developed for Phase II
- Outcome measures chosen
- Interviews to be completed on discharge
Participants

• Inclusion criteria

• Participants
  – 23 people (mean age 40 years, range 24-63 years, 16 female)
  – 15 participants RRMS, 2 SPMS, 6PPMS
  – Mean duration MS 6.3 years
  – 15 of the patients were university educated
Intervention

Occupational Therapy led service consisting of:

- Fatigue management
- Education: Disability Discrimination Act and legal rights
- Support with disclosure
- Referral to and support with Access to Work applications
- Work Site visits:
  - environmental and ergonomic assessment
  - meetings with employers/Human Resources/Occupational Health
Intervention continued

• **Work planning** (changing hours, planning for the future, disengaging from work)
• Teaching of compensatory techniques for managing memory deficits
• Referral on to other agencies:

  MS nurses, Physiotherapy, Speech & language therapy, Neuropsychology, Dietetics, Continence nurse advisor, Consultant neurologist, Cognitive behavioural therapy, Social Service OT, Benefits advisor, Access to Work team
Cost data

• Contact and non-contact time was recorded
• The cost of the intervention was calculated
Outcome measures

• There is no one outcome measure for vocational rehabilitation
• Selection of outcome measures chosen:
  – Work productivity and Activity Limitation Questionnaire
  – Work Limitations Questionnaire
  – MS Work Instability Scale
  – Work assessment Scale for people with MS
  – Self Report Barthel
  – Occupational Wellbeing Questionnaire
  – MSWS12 (MS Walking Scale)
  – MSIS (MS Impact Scale)
  – SF36 (Short Form Health Survey)
  – GHQ (General Health Questionnaire)
  – A transition question
  – Assessment of Motor and Process Skills (AMPS)
Outcomes – physical and psychological measures

- Physical status remained stable
- Psychological status showed significant gains
  - MS Impact scale (MSIS-29) psychological p<0.001 ES 0.84
- Specific ‘work’ showed little change
The results

Distribution of time spent by the occupational therapist
The results

The distribution of occupational therapy time
Cost

Mean total intervention time was 16 hours costing a median £730 per patient

Compares favourably with the cost of intravenous methylprednisolone (Chataway 2006)
Results

• Following the intervention 17 / 23 participants felt that their ability to cope with the demand of the workplace had improved

• The vocational rehabilitation intervention resulted in improvements in psychological status whereas measures of physical status showed no change

• All participants maintained their working roles some with accommodations in place; one participant was supported to retire from paid work to a voluntary role
Interviews & outcome measure development

- Every participant leaving the service was interviewed by an Occupational Psychologist.
- Interviews transcribed and analysed.
- Themes used to:
  - capture participants experience to feed back into service development.
  - develop an outcome measure to capture change in a VR service for people with MS.
Themes from interviews

Impact of vocational rehabilitation intervention on
• symptom management
• emotions particularly anxiety and worry
• self-worth
• self-efficacy
• the workplace
  – Employers
  – Colleagues (work-place culture)
• adjustment

• The role of the expert
Themes from interviews

Impact of vocational rehabilitation intervention on symptom management - fatigue

'I didn’t understand what this fatigue was really....I kept getting told that I would have to manage it but what do you mean manage?'

'She sort of made me more aware.... you have to fill in a questionnaire which is saying about how tired you get ...so filling it in you realise that you are quite exhausted half of the time and you don’t really think about it ... so basically she sort of took different things and suggested things you could do to make it better'.
Themes from interviews

Impact of vocational rehabilitation intervention on self worth

'I wasn’t feeling particularly self confident at the time. I needed I suppose reassurance as well that I could actually do my job that I had been doing for years, that I knew I could actually do but I needed somebody to almost show me. Yes, you can actually continue to do it and there is no real reason to have this lack of confidence.'
Themes from interviews

Impact of vocational rehabilitation intervention on work place

'She came with me and met with my manager and she discussed the expectations from... She wasn't intruding too much but at the same time from a professional point of view I really liked the fact that she was there because it meant, not that they wouldn't believe me but it helped and my manager actually said afterwards that she was really glad she was there so that she had met her. And it just gave it a different edge her being there and made it real. Gave it that sense of seriousness and without making it a massive issue. I don't want to stand out... but at the same time I do have specific needs that need to be recognised'
Phase II: Lessons learnt

• Patients often not disabled at home however disabled in the work place by high level performance difficulties and anxiety

• Some patients present disabled with cognitive problems – however in a familiar work place and familiar role can manage their work

• The importance of looking at the social environment as well as the physical environment
Phase II: Lessons learnt

- The importance of understanding the demands of the corporate world on employers who often want to support but are restricted by financial demands – a balance needs to be met between your client and the employer

- Evident from interviews that the outcome measures used do not fully capture change…
Theory

Explore relevant theory to ensure best choice of intervention and hypothesis and to predict major confounders and strategic design issues

Preclinical

Modelling

Identify the components of the intervention and the underlaying mechanisms by which they will influence outcomes to provide evidence that you can predict how they relate to and interact with each other

Phase I

Exploratory trial

Describe the constant and variable components of a replicable intervention and a feasible protocol for comparing the intervention with an appropriate alternative

Phase II

Definitive randomised controlled trial

Compare a fully defined intervention with an appropriate alternative using a protocol that is theoretically defensible, reproducible, and adequately controlled in a study with appropriate statistical power

Phase III

Long term implementation

Determine whether others can reliably replicate your intervention and results in uncontrolled settings over the long term

Phase IV

Continuum of increasing evidence
Phase III: Definitive Randomised Control Trial

• Initial OT session with ongoing sessions if required, or rapid response if difficulties arise

• Early intervention:
  – education about DDA and legal rights
  – support with disclosure
  – advice on ‘invisible’ symptom management (e.g. fatigue)
  – meetings with employers (education on MS)
  – information about points of support (e.g. Access to Work, Disability Law Service)

• Proactive working
Phase III: Randomised Control Trial

Outcomes
• Powered using the MSIS-29
  – 100 in each arm

• Cost benefit data

• New outcome measure developed from data collected in qualitative interviews the PERFORMS
Evaluation: Randomised Control Trial

- PERFORMS: the Performance in Employment Role for people with MS
  - symptoms
  - emotions
  - adjustments
  - self efficacy
  - colleagues/culture
  - line manager support (understood, willing, able to help)
Evaluation: Randomised Control Trial

- Currently recruited 80 participants
- Aim to recruit 150
- Plan for five year follow up
Dissemination and implementation

- Part of a steering group working on a project with the MS Society (funded by DWP) to develop a website to provide information for people working with MS and their employers

- Close working with Employers’ Forum for Disabilities (wwwefd.org.uk)

- BSRM/DoH/JobcentrePlus guidelines – Vocational rehabilitation for Long term Neurological Conditions
Next steps

• MS Society – Funded new study looking at employers’ needs
• Project to start April 2010
Thanks to:

- Dr Diane Playford – Consultant Neurologist
- Dr Stefan Cano – Psychometrician, ION
- Bronwyn Jellie - Occupational Psychologist, Commonwealth Rehabilitation Service, Australia

Funding from:
- MS Society
- College of Occupational Therapists
Vocational rehabilitation: role maintenance

  “…preventing a person losing a job because of their disability merits further attention as it seems more efficient than providing assistance and support after this has happened.”
References

Bronwyn J, Sweetland J, Riazi A, Cano SJ, Playford ED. The experiences of people with MS who have undergone a vocational rehabilitation intervention to retain employment Submitted to Disability and Rehabilitation 2009.
Khan F, Ng L, Turner-Stokes L. Effectiveness of vocational rehabilitation intervention on the return to work and employment of persons with multiple sclerosis. Cochrane Database Syst Rev 2009;(1)