Vocational rehabilitation for people with MS

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

- Who works with people with MS?
- Who offers a vocational rehabilitation service to their clients with MS?

The problem

Evidence from the Department of Work and Pensions shows that 92% of people who left work because of their disability or impairment felt that they could have stayed in their job had interventions been made. However, they were not offered any adaptations, aids or adjustments.

Keeping a newly disabled person in employment has a cost benefit of at least 2.5 times an employer’s investment. (Vocational Rehabilitation: The business case for retaining newly disabled staff and those with a long term health condition/ RNIB 2011)

The problem

- Most individuals with MS have an employment history and many are working at the time of diagnosis (Rumrill 2009)
- Unemployment rates increase steadily with longer duration of MS (O’Connor et al 2005)
- Around 15 years after the onset of MS between 60% - 80% of people with MS will have lost their jobs (Zwibel 2009)

MS patients in full time and part time employment by degree of disability

![Graph showing employment by EDSS](image)

![Graph showing duration of MS and employment](image)
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'.

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 ‘Vocational Assessment and Rehabilitation for People with Long-Term Neurological Conditions: Recommendations for Best Practice’
(British Society of Rehabilitation Medicine 2010)

- Search terms: MS + employment, unemployment, vocational rehabilitation, occupational health, job, work adjustment
- Number of papers: 412
- Cut down to: 95

What factors lead to unemployment for people with MS?

- Disease related factors (Person)
- The working environment (Environment)
- Work demands (Activity)
**Canadian Model of Occupational Performance**

**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 helps people with MS remain in the work?**
- Specialist vocational rehabilitation services with access to a MDT
- Early intervention, open access, responsive and personal services
- Support managing work performance
- Liaison with employers to ensure work-place accommodations and redeployment
- Education and support
- Support to re-enter to the work-place

**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 - What do people with MS want from a vocational rehabilitation service?**
- Managing performance
- Managing Social and Personal Expectations
- Early intervention
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

**Education:** Disability Discrimination Act 2005 (now the Equality Act 2010) and legal rights
- MS is a named condition under the DDA as protected at the point of diagnosis
- you do not have to disclose your diagnosis (few exceptions)

Useful place of support:
Disability Law Service [www.dls.org.uk](http://www.dls.org.uk)

Intervention

**Fatigue management**
Most common symptom experiences by PwMS
- Education about why fatigue occurs and different types of fatigue
- Advice on implementing fatigue management strategies into weekly routine and work schedule

(Used the COT Fatigue Management pack)
Intervention

Referral to and support with Access to Work (AtW) applications
- self referral to AtW
- advice on what AtW can offer:
  - Taxi to work
  - Support worker
  - Buying equipment (e.g. voice activated software)

Intervention

Work Site visits
- environmental and ergonomic assessment
  - any work place physical barriers? (e.g. revolving doors)
  - any work place emotional barriers? (e.g. bullying)
  - understanding the demands of the job – do they match the skills offered by the employee?
  - ergonomic assessment (often completed by AtW)

Intervention

Work Site visits
- meetings with employers/Human Resources/
  Occupational Health
- education on MS (fear of making MS worse)
- advice on reasonable adjustments
- work place adjustment agreement
(Employers’ Forum on Disabilities www.efd.org.uk)

Intervention

Work planning discussions around:
- changing hours
- planning for the future
- disengaging from work

Intervention

Teaching of compensatory techniques for managing memory deficits
- use of Dictaphone
- diary use

Useful website: www.stayingsmart.org.uk

Intervention

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
Intervention
Linking with Employers’ Forum on Disabilities
- members list
- connect service

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
  - Self Report Battery
  - Occupational Workload Questionnaire
  - MSW12 (MS walking scale)
  - NRS Total Scale
  - NRS (MS impact scale)
  - GHSQ (General Health Questionnaire)
  - A transition question

Outcomes – physical and psychological measures
- Physical status remained stable
- Psychological status showed significant gains
  - MS Impact scale psychological p<0.001 ES 0.84
- Specific ‘work’ outcomes showed little change

The results
Distribution of time spent by the occupational therapist

The distribution of occupational therapy time
Cost

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

Results

• Following the intervention 17 / 23 participants felt that their ability to cope with the demand of the work place 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

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…
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
  - 75 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

- Only recruited 90 patients
- Data still being collected
- Plan for five year follow up

Dissemination and implementation

In the National Hospital for Neurology and Neurosurgery:
- more referrals for work related problems from all neurologists
- Developed a specialist VR Clinic with OT/ Neurologist / Neuro-psychologist
- Established links with Employers Forum for Disabilities (sharing resources and working closely)
- Part time DEA in outpatients
Dissemination and implementation

- Extended VR input into Neuro-oncology – initially a one year scoping exercise with good results now extended indefinitely with part time band 7 OT in post.
- A VR competencies framework has been developed for use in the OT service to ensure safe and good practice – currently being trialled in the service.

Dissemination and implementation

- Vocational Assessment and Rehabilitation for people with long-term Neurological Conditions: Recommendations for Best Practice published by the BSRM 2010.

Dissemination and implementation

- Part of a steering group working on a project with the MS Society (funded by DWP) that developed a website to provide information for people working with MS and their employers plus professionals www.myworkinglife.com
- launced at end of 2010.

Life homepage

Main navigation

Useful links

Case study button

Tag cloud

Partner boards

My working life page

Living with workplace injury. Free advice and support is just a click away.

Advice for employers

Advice for employees

A day in the life of a workplace injury survivor

Living with workplace injury. Free advice and support is just a click away.

Advice for employers

Advice for employees

A day in the life of a workplace injury survivor
**Dissemination and implementation**

- A ‘tool kit’ written for employees with MS - the aim is to educate, equip and facilitate work maintenance through information and work sheets
  - [http://www.mssociety.org.uk/node/1716](http://www.mssociety.org.uk/node/1716)

- Updated version of MS and Work – practical information about staying in work or returning to work
  - [http://www.mssociety.org.uk/node/1714](http://www.mssociety.org.uk/node/1714)
  - (recently was ‘highly commended’ in the BMA Patient Information Awards.)

**Next steps**

- Collecting enough completed outcomes of the PERFORMS so that Rasch analysis can be completed and outcome refined and published

**Dissemination and implementation**

- In the process of writing a bid for a full time VR OT to be based in outpatients at the NHNN

**Next steps**

- MS Society – Funded new study looking at employers’ needs
  - Will involve 20 interviews with employers/employees with MS
  - Creation of a tool kit to support employers
  - 50 evaluations of tool kit by employers
  - 15 interviews to establish use of tool kit
  - Publication of tool kit
Next steps

- MS Society – Funded new study developing a return to work service for people with MS
- Job to be advertised shortly

Summary

To encourage...
- small study
- patient involvement to design a service
- can change practice

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 2011.

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