Preventing job loss in people with multiple sclerosis

Section 1 – Project Details:

Rationale:
Multiple sclerosis (MS) is a chronic, incurable condition, affecting over 100,000 people in the UK, with around 5,000 people being diagnosed annually (MS Society, 2016). MS is the leading cause of disability amongst young adults (NIH, 2013). It is frequently diagnosed between the ages of 20-30, a time in life when people are starting their journey in the world of employment, seeking independence and financial security (Compston and Coles, 2008). Therefore, the question of whether and for how long a person can continue to work (or remain in education) is an important one.

Work is important not only for socio-economic reasons but also for health and wellbeing (Waddell and Burton, 2008) and as a central tenet of a person's identity (Sayce, 2011). Ensuring people with MS have the best chances of remaining in work is a recognized health outcome and a role for health services (DH, 2015), yet all too frequently, the management, advice and support necessary to ensure they can work is sub-optimal. Many people with MS exit the workforce prematurely, often within three years of diagnosis (MS International Federation, 2010).

Optimal medical management may improve a person’s ability to sustain work (Wickstrom et al., 2012), but this alone is not enough. Work is a contextually complex. Personal, social, political and organizational factors also affect a person’s chances of remaining in work. A mis-match between the person’s physical function and or cognitive abilities and the demands of their job may result in work instability (Gilworth et al., 2003; Mcfadden et al., 2012). Hidden disabilities such as mild cognitive or visual impairment, low mood or fatigue, especially if undisclosed, may negatively impact on the person’s own or team work performance. Unfortunately, the person with MS may fail to acknowledge the impact of these problems at work or to recognize the signs of work instability, often seeking support only once a crisis develops or their job becomes unstable (Rumrill et al., 2004).

Vocational rehabilitation (VR) is defined as a process whereby those disadvantaged by illness or disability can access, maintain or return to employment. It involves assisting those who are in work but having difficulty or supporting career progression in spite of illness or disability (Frank, 2016).

Finding ways of improving people’s work outcomes through optimum medical management plus early VR may result in more people with MS being able to work for longer and withdraw from the workplace at a time to suit them. VR may comprise: identifying factors that threaten to de-stabilise work, early disclosure and communication with employers to implement timely workplace accommodations, fatigue management, physical and environmental adaptations, changes in working hours or equipment to facilitate home working.

However, the effectiveness and cost-effectiveness of such multidisciplinary VR in combination with medical management need to be evaluated.

Aims and methodology:

The aim of this project is to refine a job/education retention intervention for people with MS – where continued work/education is what the person with MS wants, based on extant literature and stakeholder input. We then want to test the feasibility of delivering the intervention in addition to usual care and measuring its clinical and cost-effectiveness at reducing sickness absence and preventing job loss or dropout from education at 6 and 12
months post-randomisation when compared to usual care alone. The acceptability of the intervention and of usual care will be explored qualitatively with patients and employers, and barriers to sustainability and implementation will be explored with service providers and commissioners in the NHS, Department of Work and Pensions (DWP) and charitable sector.

**Proposed methodology:**

*Phase 1:* (months 1-5) Realist review of vocational rehabilitation (VR) approaches in MS (and other neurological conditions – if we do not have sufficient number of MS-specific studies). The realist review will enable us to determine which intervention works best for which patient under what conditions. There are various VR interventions available, but most have similar ‘ingredients’. We will base our intervention on Sweetland (2010), but update it based on more recent research.

*Phase 2:* (months 6-9) Qualitative study – stakeholder consultations to refine the intervention produced as a result of Phase 1.

*Phase 3:* (months 9-30) Single-centre feasibility trial with embedded post-trial qualitative interview studies with patients and expert stakeholders in the health, DWP and charitable sectors further refine the intervention and explore its acceptability and usefulness and barriers to its longer term sustainability, and determine the design of the definitive trial.

**Benefits and suitability as a PhD project:** We believe this to be suitable as a PhD project as it offers the PhD student the opportunity to develop expertise in different methods including systematic review, trials, qualitative interviews and implementation research. This is a cross-divisional and interdisciplinary research project. Because the topic area has the support of the MS Society, it will also form the basis for a postdoctoral grant application to the MS Society.

**Key References:**

https://www.mssociety.org.uk/sites/default/files/MS%20in%20the%20UK%20January%202016_0.pdf

US department of health and human services (2013) NIH Factsheets: Multiple Sclerosis


Multiple Sclerosis International Federation (2010). MSIF survey on Employment and MS.


Frank A (2016). Vocational Rehabilitation: Supporting Ill or Disabled Individuals in (to) Work: A UK Perspective.


Section 2 – Training Provision:

Embedding this PhD within a group of researchers/students working on projects on long term neurological conditions and related MS Society-funded projects will provide the PhD candidate an opportunity to work collaboratively with a multidisciplinary group of researchers with expertise in rehabilitation, complex intervention, vocational rehabilitation and MS research, and learn through them how large-scale multi-centre RCTs are conducted. This will equip the candidate to produce high impact outputs and place them at an advantage when applying for a postdoctoral fellowship to pursue a career as an independent researcher.

Prof dasNair, a clinical psychologist and neuropsychologist, has expertise in psychological interventions, and RCT, systematic review, and qualitative methods. He will train the student in these methods, guiding the research processes, and methods of analysis. Dr Radford is an occupational therapist with expertise in vocational rehabilitation and in conducting large-scale trials to evaluate these interventions. Neurologist, Dr Evangelous, will provide input into the medical aspects of MS, as an advisor.

The student will be based within the IMH and the Centre for Doctoral Training (CDT) in Rehabilitation and Healthcare Research. The CDT has a core training module in complex interventions and mixed methods research. They will attend courses offered by the Graduate School, and will receive appropriate formal training from relevant courses from the School of Medicine, and statistical advice from the statistics drop-in clinics. Health economics support will be offered by the Swansea Centre for Health Economics. We already have a PPI group set up to advise and support MS-related projects.