Institution: BRUNEL UNIVERSITY (H0113)

Unit of Assessment: 03 – Allied Health Profession, Dentistry, Nursing and Pharmacy

Title of case study: Living with Multiple Sclerosis: development and use of effective self-management strategies

1. Summary of the impact (indicative maximum 100 words)

Primary research with people with multiple sclerosis and their carers, led by Brunel, has had positive impacts on service user and government organisations internationally; research has improved practice in relation to the nature and effect of self-management strategies of people with Multiple Sclerosis, as well as enhancing therapy for the condition and raising awareness of the needs of carers. The research has shaped evidence-based guidelines, consensus papers, reports and policies, which have in turn enhanced the effectiveness of professional practice and service delivery. Through developing the evidence base and sharing best practice the research has resulted in improved health and welfare benefits for people with multiple sclerosis and their carers.

2. Underpinning research (indicative maximum 500 words)

Professor Lorraine De Souza, the lead academic of the research group, has held the post of Professor of Rehabilitation at Brunel University throughout the REF research and impact periods. Also employed at Brunel University, in academic or research posts, were Reynolds (2002-13), Prior (1994-13), O’Hara (1995-2000) Cadbury (1997-2000) Ide (1993-2003) Cassidy (2002-13) Rone-Adams (2004-9). Karen Baker, senior physiotherapist, National Hospital for Neurology and Neurosurgery, was a clinical collaborator. The Brunel studies were funded through three grants awarded to De Souza.

The first grant was awarded from the NHS R & D National Programme for Physical and Complex Disabilities, to undertake a three phase study, to investigate the efficacy of professionally guided self-care in people with Multiple Sclerosis £189,100 (1997-2000). The first phase of this research used a Delphi method to identify self-care practices used by people with multiple sclerosis [3.1]. The research found widespread self-care practices that covered all aspects of community living; these activities formed a key and subjectively beneficial part of the lives of people with multiple sclerosis.

In the second phase, a self-care intervention was designed with service users that could be provided under the guidance of a professional (nurses or therapists); it utilised the priorities identified by the service users as well as offering choices of self management interventions; each individual would need to be able to tailor the intervention to their own needs and preferences. In the third phase the guided self-care intervention was tested through a randomised controlled trial with community dwelling people with multiple sclerosis [3.2]. It was found that the intervention significantly improved aspects of quality of life and helped to maintain independent living in the community in people with multiple sclerosis. Although improvements in health status were small, at six month follow up the intervention group had significantly better mental health and vitality scores on the Short Form-36. In addition the intervention group had maintained levels of independence in activities of daily living while the control group’s levels had significantly declined.

Members of the research group have also undertaken qualitative in-depth studies to investigate specific sub groups of people’s self-management strategies. One such study, which focused on women's self-management strategies for negotiating an acceptable quality of life, exposed a variety of strategies and relationships, which evolved with the progression of the illness [3.3]. The research was able to reveal how women in the study used meaningful roles and occupations to enable them to engage in positive, enabling self-management strategies. The research uncovered the complexity of living with multiple sclerosis; the strategies used by the women were used to interweave the co-existing positive and negative experiences of living with multiple sclerosis.

The programme of research next moved to examine the needs of care givers of people with multiple sclerosis. The Physiotherapy Research Foundation funded de Souza and colleagues to research the needs of lay carers of people with multiple sclerosis £49,000 (2001-03) The research into care giving in a community sample of people with multiple sclerosis found that care was most likely to be provided by family rather than health or social care professionals in all domains including personal care, mobility, household tasks, leisure and employment [3.4]. It showed that many people with moderate to severe disability failed to receive assistance from community care services and the 'burden of care' had to be taken up by family members. The research drew specific attention to the NICE Guidelines recommendation that the needs of carers of people with multiple sclerosis should be addressed through assessment of need and professional support.

In addition to research on the self-management strategies of people with multiple sclerosis, and the burden on their carers, the research team also pursued primary research into effective therapy approaches. The research group focused on investigating the benefits of a standing and exercise intervention programme delivered in the home for people with multiple sclerosis who were wheelchair dependant. The study was a randomised single-blind cross-over trial with "30 minutes standing" being compared to "home exercises". Significant improvements in range of movement of the hip and ankle were found and were determined to be due to the standing component of the intervention rather than the exercise component [3.5]. The research also concluded that there was a need to build up tolerance to sustain therapeutic supported standing in people with severe disability who were wheelchair dependent in order to promote range of movement.

Due to the volume of research evidence on multiple sclerosis, to which the Brunel research significantly contributed, the first national guidance was produced (NICE 2004). The Multiple Sclerosis Society awarded De Souza a Multiple Sclerosis Network Research Studies Grant (2005-6) £23,114 to research and develop promotion of good practice in multiple sclerosis care and facilitate an integrated care based on the principles of the NICE guidelines.

3. References to the research (indicative maximum of six references)

3.1. O'Hara L, De Souza L, Ide L. (2000) A Delphi study of self-care in a community population of people with multiple sclerosis. Clinical rehabilitation; 14(1):62-71. http://dx.doi.org/10.1191/026921500666135189

3.2. O'Hara L, Cadbury H, De Souza L, et al. (2002) Evaluation of the effectiveness of professionally guided self-care for people with multiple sclerosis living in the community: a randomized controlled trial. Clinical rehabilitation; 16(2):119-28. http://dx.doi.org/10.1191/0269215502cr478oa

3.3. Reynolds F, Prior S. (2003) "Sticking jewels in your life": exploring women's strategies for negotiating an acceptable quality of life with multiple sclerosis. Qualitative Health Research [Special Issue: Care of Self]; 13(9):1225-51. http://dx.doi.org/10.1177/1049732303257108

3.4 O'Hara, De Souza LH and Ide L (2004). The nature of care giving in a community sample of people with multiple sclerosis. Disability and Rehabilitation 26(24); 1401-1410. http://dx.doi.org/10.1080/09638280400007802

3.5 Baker K, Cassidy E, Rone-Adams S (2007) Therapeutic standing for people with multiple sclerosis: Efficacy and feasibility. International Journal Therapy and Rehabilitation 14(3): 104–109 Available at http://www.ijtr.co.uk/cgi-bin/go.pl/library/abstract.html?uid=23523

4. Details of the impact (indicative maximum 750 words)

Some of the impact sources cited pre-date 2008, however the impact has continued past the 2008 threshold, for example the NICE Guidelines (2004) are still the guidelines which relate to current clinical practice.

Impact 1. Impacts on therapists, people with multiple sclerosis and their carers and governments through the evidence based guidance and policies disseminated by international multiple sclerosis organisations.

Our research has been used to directly inform national and international best practice guidelines for the care and support of people with multiple sclerosis and other long-term conditions. Both the Delphi study [3.1] and the qualitative evidence [3.3] produced by our research extensively informed the development of an international consensus paper, developed by the Multiple Sclerosis International Federation (MSIF) on the 'principles to promote quality of life of people living with multiple sclerosis' [5.1]. Our research informed the sections relating to empowered decision making [3.3], access to health services and the range of services that should be available [3.1], the provision of quality information to sufferers [3.1, 3.3], nutrition and physical fitness [3.1], the provision of family and relationship counselling, parenting support, employment support and post retirement support [3.3]. Similarly our research on therapeutic standing [3.5] has informed practice documents for health professionals relating to exercise and multiple sclerosis internationally; for example guidelines for therapeutic activity have published by the Multiple Sclerosis Society of Canada [5.2], underpinning the recommendation to consider therapeutic standing as a potential exercise choice. Our findings related to the value of therapeutic standing for wheelchair users with severe disability has also impacted on therapeutic interventions for people with other clinical conditions for example R82, a Danish private company, used our evidence [3.5] to support use of therapeutic standing to prevent contractures in children with disability [5.3].

Multiple Sclerosis Australia produced 2 reports for the Australian governments Senate Community Affairs Committee and Senate Finance & Public Administration Committees regarding the national pharmaceutical benefits scheme policy [5.4] and the Commonwealth State disability agreement [5.5]. Both reports were produced to guide and inform government policy with regards healthcare provision for multiple sclerosis. In these reports our research [3.3] was used to illustrate the profound biographical disruption caused by multiple sclerosis and the challenge to patient's lives presented by the unpredictability of the condition. Clinical Psychologist Dr Gary Fulcher has advocated the importance of our findings related to the burden of caring on spouses [3.4]; he has published this in an article in a prominent multiple sclerosis patient's magazine in Australia [5.6].

Our RCT [3.2] was cited by The Multiple Sclerosis Trust and the group Therapists in multiple sclerosis in a publication [5.7] that offered a set of proposals for the future of service commissioning for this condition. Specifically it was used to establish a role for the therapist in facilitating self-management, and allowing patients to remain at home or in community care settings and to define the role of the therapist in multiple sclerosis.

Impact 2. Impacts on practitioners and services internationally: key guidelines and evidence-based sources have been shaped by the research.

Our RCT [3.2] has been used to develop best practice guidelines for this condition. It was the sole RCT used to inform the National Collaborating Centre for Chronic Conditions' guidelines for multiple sclerosis (affiliated with NICE) guidelines [5.8]; the research trial findings directly underpins the recommendation related to encouraging self-management and autonomy. The funded research which developed the Multiple Sclerosis Network supported the national implementation of these NICE guidelines: impacts on practice were achieved through the creation of a bespoke website www.mssociety.org.uk/join-the-professional-network which has brought together 3000 practitioners to support effective services for people with multiple sclerosis. Workshops were undertaken across national locations to develop and adopt evidence based toolkits to implement best practice. A practitioner has provided a detailed statement demonstrating the impact of these workshops which concludes saying

'Without the involvement and active engagement of the patient groups and Brunel University at the critical first development stages of this journey, none of the listed outcomes and lasting impacts would have been possible to achieve just by service providers or commissioners alone.'

In addition the research trial was used to inform the self care section of the evidence-based markers of good practice produced by the Department of Health's National Service Framework for Long-term Conditions [5.9]. Finally our research trial findings were used in a consensus paper on how to deliver high-quality, patient-centred, cost-effective care [5.10], which was produced by the Kings Fund together with 10 leading health and social care organisations to support their recommendations for self care. The recommendations provided through these influential guidelines, evidence-based markers of good practice and consensus papers present clear evidence of how primary research conducted at Brunel has been used to on evidence based practice. Practitioners, commissioners and service providers use these documents to enhance practice and with the goal of improving the lives of service users.

5. Sources to corroborate the impact (indicative maximum of 10 references)

5.1 MSIF Consensus paper VI (2008) Principles to promote the quality of life of people with multiple sclerosis. http://www.msif.org/about-us/advocating-and-awareness-raising/quality-of-life-advoacy-tool.aspx (Our research cited in sections 1.5, 2.1.1, 2.1.2, 2.3.2, 4.1, 4.2, 5.4, 5.5, 7.1, 7.5)

5.2 Multiple Sclerosis Society of Canada (2009) MS Active Now: A Health Professionals Guide to Understanding Exercise and Multiple Sclerosis. www.mssociety.ca/alberta/pdf/Active/MS_ActiveNOW-HP_Book2009.pdf (Our research cited page 25, ref #141)

5.3 R82 Caribou Clinical & Therapeutical folder. http://ipaper.ipapercms.dk/R82/UK/CaribouClinicalTherapeuticfolder/ our research cited page 5

5.4 Multiple Sclerosis Australia. Submission to the Senate Finance & Public Administration Committees. Our research cited page 2, Ref #4) http://www.mssociety.org.au/media-archives.asp

5.5 Multiple Sclerosis Australia (2006) Senate Community Affairs Committee. Inquiry into the Commonwealth State Disability Agreement (Our research cited page 3, ref #7) http://www.mssociety.org.au/media-archives.asp

5.6 Fulcher G (2008) Enhancing the care giver/ care receiver relationship. In Touch. The official magazine of Multiple Sclerosis Australia. Summer 2008 http://www.mssociety.org.au/documents/intouch/intouch_summer08.pdf (our research cited p. 8)

5.7 The Multiple Sclerosis Trust, Therapists in Multiple Sclerosis (2006) THERAPISTS IN MS delivering the long-term solutions. http://www.therapistsinms.org.uk/resources/publications/therapists-in-ms-delivering-the-long-term-solutions/ (Our research cited on pages 11 & 22 reference #42)

5.8 The National Collaborating Centre for Chronic Conditions (2004) Multiple sclerosis. National clinical guideline for diagnosis and management in primary and secondary care. http://guidance.nice.org.uk/CG8/Guidance/pdf/English (our research cited on page 22 (reference #27)

5.9 DoH Long term Conditions NSF Team (2005). The National Service Framework for Long term Conditions. https://www.gov.uk/government/publications/quality-standards-for-supporting-people-with-long-term-conditions (our research cited on page 23, ref #67, Point 5)

5.10 The Kings Fund (2010) How to deliver high-quality, patient-centred, cost-effective care. Consensus solutions from the voluntary sector. http://www.kingsfund.org.uk/publications/articles/how-deliver-high-quality-patient-centred-cost-effective-care (our research cited on page 8)

5.11 Corroborating statement for Impact 2 - Letter received from Improvement Manager, National Institute for Health Research Collaboration for Leadership for Applied Health Research and Care; the contact confirms the research impact on raising awareness of the need of community service, which led to a successful funding for a MS specialist Nurse for Hounslow; establishing informal network which won the MS Society's Partnership Award and Measuring Success Award; and encouraging patients to form a sub-group of the network.

5.12 Contact to corroborate Impact 1: Clinical Lead Therapist for Stroke, Infectious diseases and Oncology at Chelsea and Westminster NHS Foundation Trust.