‘Move it or lose it’: perceptions of the impact of physical activity on multiple sclerosis symptoms, relapse and disability identity

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ABSTRACT

This study explores the roles which individuals with multiple sclerosis (MS) ascribe to physical activity (PA). PA is becoming more heavily promoted by health care providers to individuals with MS due to the evidence of improved health outcomes with PA participation. However, there are possible negative outcomes with the medicalisation of PA (e.g. increased guilt over inactivity, constrained views of PA) that may be compounded by the uncertain nature of having MS and negotiating a disabled identity. Framing disability and impairment within a social-relational model of disability, we undertook an interpretative phenomenological analysis (IPA) of 15 semi-structured interviews conducted among adults with MS who had recently experienced a relapse. Our purpose was to understand how persons with MS describe the roles of PA and exercise as part of daily life with MS, relapses and disability identity. Our analysis indicated that PA occupies several roles related to MS and relapse. These roles were categorised into three main themes: PA has a paradoxical role in MS relapse; PA has a role in guilt and empowerment; and PA as defiance of disability. The roles that exercise/PA take may inform the negotiation of disability identity for individuals with MS by providing ambiguous control 'over' MS relapses and over impairment/disability. When not engaging in PA, our participants described feelings of guilt, worrying that increased impairment/disability would be their 'fault.' Because of this, PA should be promoted carefully as it occupies many important and sometimes conflicting roles in the life of an individual with MS.

Introduction

Multiple sclerosis (MS) is a neurological disease of the central nervous system (CNS) with an approximate prevalence of 2.5 million people worldwide (National Multiple Sclerosis Society 2005). This disease results in a wide-range of consequences including loss of mobility, muscle spasms, weakness, sensory deficits, fatigue, sexual dysfunction, cognitive disturbances and mood disturbances (Compston and Coles 2008). MS is typically episodic in nature where relapsing-remitting MS (RRMS) involves periods of relatively stable symptomology interspersed with relapses that are characterised by acute disease activity (i.e. inflammation) and increased functional and symptomatic burden (Vollmer 2007). That is, individuals with MS experience ongoing and unpredictable changes in impairments over the course of this disease brought on by acute inflammation, despite medical management (though not all individuals with MS choose to use medical therapies (Apel, Greim, and Zettl 2005)).