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Adjustment to Multiple Sclerosis: application of the Fennell Four Phase Model and identification of effective social support

Gabrielle Berea
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**Adjustment to Multiple Sclerosis: Application of the Fennell
Four Phase Model and Identification of Effective Social
Support**

A thesis submitted in partial fulfilment of the
requirements for the award of the degree

Doctor of Psychology (Clinical)

from

University of Wollongong

by

Gabrielle Berea

BPsych(UwS)

Department of Psychology

2010

Thesis Certification

I, Gabrielle Bera, declare that this thesis, submitted in partial fulfilment of the requirements for the award of Doctor of Psychology (Clinical), in the Department of Psychology, University of Wollongong, is wholly my own work unless otherwise referenced or acknowledged below. The document has not been submitted for qualifications at any other academic institution.

Gabrielle S. Bera

April 2010

Abstract

This thesis investigated the specific aspects of support which people with Multiple Sclerosis (PwMS) perceive as helpful and unhelpful. While social support in general has been found to enhance adjustment, assist emotional wellbeing and maintain quality of life (QoL) for PwMS, the Multiple Sclerosis (MS) research does not provide a comprehensive understanding of the specific aspects of social support which are helpful and unhelpful. This thesis also tested the relevance of the Fennell Four Phase Model (FFPM) for adjustment to MS and explored whether perceptions of helpful and unhelpful social support differed according to adjustment levels. Many models of adjustment to chronic illness do not consider the support network and focus on only the psychological aspects of adjustment. The FFPM (Fennell, 1993; Fennell, 1995; Fennell, 2003a) is a multistage model which maps the adjustment process of chronic illness by addressing the physical/behavioural domain, social/interactive domain and psychological domain. Most importantly the model acknowledges the importance of the support network in adjusting to chronic illness. Two studies were carried out. The initial study investigated social support and took into account not only different categories of support but also different sources of support. Twenty individuals with MS were interviewed regarding the specific actions they found helpful and unhelpful from various potential support providers. Results provided a comprehensive behavioural understanding of what PwMS experience as helpful and unhelpful from key support providers. Specifically, emotional support was considered crucial in intimate relationships. Other PwMS were uniquely helpful by providing informational support, optimism, hope and emotional support. Results indicated the importance and need for greater informational assistance from medical professionals. The second study investigated the adjustment process for PwMS through the FFPM

and aimed to examine if individuals in different phases of adjustment had different perspectives of helpful and unhelpful support. Results supported the relevance of the four phases (Crisis, Stabilisation, Resolution and Integration) of the model for PwMS. No significant findings were found among phases in perceptions of helpful and unhelpful social support, indicating that regardless of levels of adjustment PwMS have similar social support needs. Individuals in each of the phases were found to have significant differences in emotional states, ways of coping, satisfaction with life and self reported moodiness, anxiety, QoL and coping levels. Findings indicated that regardless of an individual's level of adjustment to MS, certain types of supportive and unsupportive behaviours continued to be relevant. The FFPM appears to accurately map the journey and struggles of PwMS. Results from this research can be used to enhance social support with interventions and educational programs for key support providers and also to understand a patient's current adjustment phase, implement appropriate treatment strategies and support.

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Abbreviations

CBT	Cognitive-Behaviour Therapy
CFS	Chronic Fatigue Syndrome
DASS-21	Depression, Anxiety and Stress Scale-21
df	Degrees of freedom
F	F-ratio – test statistic for ANOVA
FFPM	Fennell Four Phase Model
FPI	Fennell Phase Inventory
GP	General Practitioner
MS	Multiple Sclerosis
n	Number of scores in a subset
NSW/VIC	New South Wales/Victoria
PwMS	People with Multiple Sclerosis
QoL	Quality of life
r	Effect size
RRMS	Relapsing remitting Multiple Sclerosis
SD	Standard deviation
SEFT	Supportive emotion focused therapy
SWLS	Satisfaction with Life Scale
TTM	Transtheoretical Model
<i>U</i>	Mann-Whitney U
WOCQ	Ways of Coping Questionnaire
η^2	Partial Eta Squared – effect size
χ^2	Chi-square
Z	Z-approximation of <i>U</i> (corrected for ties)

Key Terms

Adjustment: a process of adapting to chronic illness which signifies that an individual has been able to continue to grow and develop despite having a chronic illness (Marks & Millard, 1990).

Behavioural descriptions: a subjective description of a person's experiences when they are interacting with others and how they perceive this interaction.

Chronic illness: health conditions which continue indefinitely and may take many different forms (Lubkin & Larsen, 2006).

Fennell Four Phase Model: a model which maps the process of adjustment to chronic illness within four phases and focuses on stigma, illness traumatisation, the physical/behavioural and social/interactive domains, and the socio-cultural influences at each phase (Fennell, 2003a, Fennell, 2003b; Jason, Fennell, Klein, Fricano & Halpert, 1999).

Phases of model

Crisis: when an individual moves from the onset of illness to an emergency period (Fennell, 1993; Fennell, 2003a; Fennell & Bateman, 2005; Jason et al, 1999).

Stabilisation: when an individual begins to recognise and understand his or her symptoms and have a greater sense of control over their lives than patients in Crisis (Fennell, 1993; Fennell, 2003a; Fennell & Bateman, 2005; Jason et al, 1999).

Resolution: when a patient begins to acknowledge that his or her previous life will not return and struggles with life defining questions. Patients in this phase are beginning to also acknowledge the chronic

nature of their condition (Fennell, 1993; Fennell, 2003a; Fennell & Bateman, 2005; Jason et al, 1999).

Integration: when an individual has a blended pre-illness and post-illness self and has been able to find new ways to express a new “personal best” (Fennell, 1993; Fennell, 2003a; Fennell & Bateman, 2005; Jason et al, 1999).

Multiple Sclerosis: is a chronic and progressive neurological disease which leads to lesions to the brain white matter resulting from demyelization of nerve fibres and many different neurological abnormalities such as numbness, visual abnormalities, fatigue, mobility difficulties and cognitive dysfunction (Eeltink & Duffy, 2004).

Social support: the ways in which interpersonal relationships support individuals against the negative effects of stress (Cohen & McKay, 1984).

Types of social support

Esteem/emotional support: verbal and nonverbal communication of caring, concern, love, empathy and security (Helgeson & Cohen, 1996; House, 1981; Lafreniere & Cramer 2005; Schaefer, Coyne & Lazarus, 1981).

Informational support: the supply of information such as advice or guidance (Helgeson & Cohen, 1996, House, 1981; Schaefer et al, 1981).

Tangible support: the provision of direct aid such as money or transportation, or providing a service (Helgeson & Cohen, 1996; House, 1981; Schaefer et al, 1981).

Support network: people who are associated with, and care about, us and are able to provide assistance and support during times of stress (Vaughan & Hogg, 2002).