

Negotiating midlife with a chronic illness: Experiences of Canadian women diagnosed with multiple sclerosis

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Introduction

Multiple Sclerosis (MS) is a progressive neurological disease, typically experienced by women leading to functional limitations, reduced activity engagement and participation restrictions. Currently in Alberta, Canada there are reported rates of MS which are higher than the national average. Whilst MS does not reduce life expectancy, women with MS often have to devise a 'balancing act' in order to negotiate midlife whilst coping with a chronic illness.

Objectives

To obtain an in-depth understanding of the lived experiences of women with MS as they transition through midlife, in particular the physical, social and psychological changes experienced, the coping strategies used and suggestions for support services to assist them to engage and participate in occupations which are meaningful to them.

Methods

Twelve women volunteers from the local hospital MS clinic were surveyed using a semi-structured interview. The qualitative data were analyzed thematically. Some demographic information was also obtained

Results

Participants were on average 50.6 years (range 43-61 years) and had been diagnosed with MS for a mean of 14 years (range 1-30 years). The majority had the relapsing/remitting type of MS, lived with another person, had completed their high school education, and were not working. Thematic analysis revealed the identification of four discrete themes; confusion about the interaction of midlife with MS; impending fears of the future (due to functional changes, role loss and reduced activity involvement); coping and influence of social network); and support services required.

Conclusion

Results showed that midlife women with MS face many challenges (physical, functional, social and psychological). There is scarce general information available to women about midlife transitions (more than just about menopause) resulting in much confusion for this population which actually heightened their fears regarding the progression of the disease. Participants perceived that whilst health personnel needed to have up-to-date knowledge about MS they also should be cognisant of midlife issues.

Contribution to the practice/evidence base of occupational therapy

These results indicate the need for occupational therapists to familiarize themselves with the range of issues faced by women in midlife. This will assist in devising appropriate intervention strategies to enable effective transition through midlife with a chronic illness.