

The effectiveness of self- management programs in improving daily living for people with Multiple sclerosis

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CLINICAL SCENARIO:

Multiple Sclerosis is a chronic CNS disorder .Those with MS must learn to deal with daily symptoms of the disease, specifically with fatigue (Fraser et al, 2002). Self- management programmes teach those with MS the skills and knowledge needed to manage their condition so it does not take control of their life. The use of this intervention can “minimize the negative features of a chronic, potentially disabling disease such as MS” (Martz & Livneh, 2007, p.300). Occupational therapists are firm believers in using programs like this with patients to help them gain knowledge and control over their condition.

FOCUSSED CLINICAL QUESTION:

For those with Multiple Sclerosis does the participation in self- management programmes improve management of symptoms of MS?

SUMMARY of Search, ‘Best’ Evidence’ appraised, and Key Findings:

Self- management programmes for MS were difficult to find and there was limited research on this topic. A number of studies had a cost to access or related to self-management for conditions other than MS. The studies by Ward & Winters (2003) and Stapleton & Mulholland (2004) were not used as they were difficult to interpret and did not have a definitive methodology. In particular the article by Stapleton & Mulholland (2004) which used a quantitative method to gather data however data was presented in a qualitative form. The most useful articles regarding the topic at hand were found using Google scholar, PubMed and CINAHL. Six articles were found that were of particular relevance to the topic

The two articles chosen (Barlow et al 2009 & Kos et al, 2007) directly related to the clinical question proposed and met all inclusion criteria set.

The key findings of this appraisal were that self-management courses can be a source of new skills and a reinforcer of old self-management skills for those with MS and relaxation, goal setting and pacing are particularly useful. However the idea that gender differences can impact on educational preferences requires further research (Barlow et al, 2009). Furthermore the Multi Fatigue Management Programme has minimal impact on fatigue and is best used as an introduction to fatigue management (Kos et al, 2007).

CLINICAL BOTTOM LINE:

Self-management programs can be a beneficial way to introduce fatigue management to those with MS and when techniques like goal-setting, relaxation and pacing are used the individual's confidence and self-efficacy can be improved.

Limitation of this CAT:

This critical appraisal has been peer reviewed by one lecturer as part of an assignment for Otago Polytechnic, School of Occupational Therapy. The breadth of the review has also been limited by the assignment requirements (ie. 2 articles only were reviewed).

SEARCH STRATEGY:

Databases used; CINAHL, Joanna Briggs Institute, ProQuest nursing and allied health, PubMed Central (PMC) and Google Scholar. Key phrases used in the search were; 'fatigue management' OR 'fatigue programme' OR energy conservation' OR 'fatigue intervention' OR 'fatigue strategies' AND 'Multiple sclerosis' OR MS.

INCLUSION and EXCLUSION CRITERIA

- Inclusion:
 - ✓ Quantitative studies
 - ✓ Qualitative studies
 - ✓ Systematic reviews

- ✓ Included some form of self- management program for MS
 - ✓ Included Multiple Sclerosis as condition the program was directed towards
 - ✓ Published in English language
 - ✓ Male and female
 - ✓ Article in full text available on database or through Robertson Library
- Exclusion:
 - Informal case studies
 - Opinion pieces
 - Literature reviews
 - Publication not available in English
 - Articles that cost money to access
 - Articles from Cochrane database

Study Design/ Methodology of Articles Retrieved	Level	Author (Year)
<i>Qualitative</i>	5	<i>Barlow, Edwards & Turner (2009)</i>
<i>Qualitative</i>	5	<i>Bowcher & May (1998)</i>
<i>Qualitative</i>	5	<i>Ward & Winters (2003)</i>
<i>Quantitative (RCT)</i>	1	<i>Kos, Duportail, D'hooghe, Nagels & Kerckhofs (2007)</i>
<i>Quantitative (Pilot study)</i>	3	<i>Stapleton & Mulholland (2004)</i>

BEST EVIDENCE

Barlow, J., Edwards, R., & Turner, A. (2009, December). The experience of attending a lay-led, chronic disease self-management programme from the perspective of participants with multiple sclerosis. *Journal of the European Health Psychology Society*, 24(10), 1167-1180.

This article was selected because it directly relates to Multiple Sclerosis and self-management and as Taylor (2007) states qualitative research can generate “deeper, richer data (p.87) than quantitative research.

Kos, D., Duportail, M., D'hooghe, M. B., Nagels, G. & Kerckhofs, E. (2007). Multidisciplinary fatigue management programme in multiple sclerosis: a randomized clinical trial. *Multiple Sclerosis*, (39), 996-1003.

This article was selected because it is quantitative research which is a higher level of evidence than the qualitative research and because we needed another form of research other than qualitative.

Both articles included RCT's which are one of the most appropriate types of evidence to use when researching effectiveness of interventions (Taylor, 2007).

SUMMARY OF BEST EVIDENCE

Quantitative article (Kos et al, 2007)

Title: Multidisciplinary fatigue management programme in multiple sclerosis: a randomized clinical trial

Aim of study:

The aim of the study is to establish the short and long term efficacy of the multidisciplinary fatigue management programme (MFMP) in reducing the impact of fatigue on those individuals with MS.

Study Design: Quantitative, single blind randomized placebo-control with matched pairs.

Setting: The setting was not clearly stated.

Participants:

51 participants were recruited by flyers and personal invitations through the Belgian National MS Society and some participants were referred by the treating neurologist. Stratified random sampling occurred. Participants included had MS-fatigue symptom that scored 3 or more on the Guy's Neurological Disability Scale, lived in the community and able to walk 100m without aid. Participants were excluded if they had attended a rehabilitation programme, received energy management programmes and were receiving psychiatric

treatment for depression. After screening one participant was excluded. The end sample contained 40 participants, reasons for dropouts were; relapse and lack of interest.

Method:

Participants were put in pairs which were based on the results from the Modified Fatigue Impact Scale (MFIS), age, gender and MS-FC score. Participants identifying numbers were put into an envelope with the other pair member. A research assistant separated each pair and divided the individuals into two groups by random draw. Both the MFMP and placebo intervention programme consisted of 4 sessions each lasting 2 hours, spread over 4 weeks. Details regarding who and where the programmes were administered were not stated.

MFMP intervention session:

The instructor provided information involving strategies to manage fatigue, followed by participants discussing strategies.

Placebo intervention session:

Topics were chosen of interest but unrelated to fatigue, for example general information about MS.

Control group:

Participants do not attend any interventions.

Primary outcome measures:

MFIS evaluated the impact fatigue had on physical, cognitive and social activities. MFIS has been reported to have high reliability and good validity in participants with MS.

Secondary outcome measures:

The Fatigue Severity Scale (FSS) evaluates the severity, frequency and impact of fatigue. FSS has good reliability and acceptable validity. The Multiple Sclerosis Self-Efficacy (MSSE) scale has good reliability and validity. Other assessments used were; the Impact on Participation and Autonomy scale and the Mental Health Inventory.

Results:

Between the baseline MFIS scores and the scores after 3 weeks and 6 months after the MFMP in the control group there was a significant decrease between the means in MFIS (3weeks $p=0.091$ and 6months $p=0.015$). The baseline showed no significant differences between the intervention (group A) and placebo intervention (group B) groups as at 3weeks

after $p=0.06$ and at 6 months after $p=0.685$. There is a significant difference between the post-scores from the recent intervention group (B) after 6 months and the control group (A) after 6 months ($p=0.03$). This was shown by the difference calculated between 6 months and 12 months after group A's MFMP where 0% of the group found an improvement in fatigue. Six months after group B's placebo intervention and 6 months after the MFMP only 31% of the group found an improvement. No significant effect was found in secondary outcome measures. P-value has to be 0.05 or less to be a significant change (Kos et al, 2007).

Original Authors' Conclusions

The author concluded that the MFMP did not decrease the impact fatigue has in daily life compare to the placebo intervention in individuals with MS. It was indicated that the sample size was too small and both programmes may have been too similar. Six months after the MFMP there was little improvement of the impact of fatigue when compared to no intervention. Future research "should include a placebo intervention and a control group to confirm results" (Kos et al, 2007, p. 1002). Individuals newly diagnosed with MS may use MFMP to introduce fatigue management.

Critical Appraisal

Validity

Focused issue:

The study stated the aim clearly. No research question was stated. In a brief introduction the authors noted the reason for the study; that former studies had "not reached a consensus concerning the best fatigue strategies" and that fatigue has a large impact on people with MS (Kos et al, 2007, p. 996).

Sampling:

The study was a single blind randomized placebo-controlled design. Single blind eliminated the chance of the participants being influenced by knowing they are the intervention or placebo group. The sample process was poorly described as it contradicted the study design stating, "Due to the nature of the intervention, blinding of participants was not possible" (Kos et al, 2007, p. 997). A placebo trial was required to present the effectiveness of the MFMP was due to the influence of participants being in a discussion group and knowing of the intervention (Taylor, 2007). A stratified randomised sample was taken so there was no

significant difference between the two groups. Both groups were treated equally apart from the interventions.

Ethical issues:

The study was approved by the ethics committee of the Vrije University Brussel. Supported by a study suggesting 51 participants were adequate for best results; however the end results only included 40 participants. Reasons for this change were stated clearly. No ethical issues were stated.

Results:

The primary outcome measure used had high reproducibility and good validity. Secondary outcome measures had good reliability and validity. These measures were explained in detail. The software package SPSS for Windows Standard Version 13.0.1, 2004 was used to analyse results. Differences between the groups were measured by the ANOVA, Mann-Whitney and chi-square tests; these are all common standardised tests. Results showed no significant difference between the MFMP group and the placebo group. There was a significant difference between the post-MFMP scores and no intervention after 6 months ($P=0.03$). The criterion for statistical significance was p -value less than 0.05. The study identified factors that could have influenced the results.

Summary/Conclusion:

Results have shown that the MFMP has little effect on managing the impact of fatigue. Clinical decisions should not be based solely on this study; other researches should be used to support the decision. This study had many factors that may have influenced the results and as the authors stated "future studies with larger sample sizes may be needed to provide" a better representation of the population (Kos et al, 2007, p.1002). The study would be difficult to replicate and with programmes two hours long would be unrealistic for individuals struggling with fatigue.

Qualitative Article (Barlow et al, 2009)

Title: The experience of attending a lay-led, chronic disease self- management programme from the perspective of participants with multiple sclerosis.

Aim:

To determine whether the Chronic Disease Self-Management Course (CDSMC) is effective for people with MS, in terms of improving self-efficacy, self-management behaviours, health status, and healthcare utilisation.

Study Design:

Qualitative (RCT)

Setting:

Community based

Participants:

There were ten participants, 7 females and 3 males. Participants were recruited via MS Society membership information, MS Society website and local media sources. Participants were randomized to attend a course straight away or to alternatively participate in a course 4 months later. The 10 participants that participated in this study were purposively selected from the 40 Intervention group participants who had indicated their willingness to be interviewed. This ensured a variety of ages and disease duration could be represented in the given study.

Participants ranged from 35 to 60 years of age and their disease duration ranged from 4 to 19 years. All participants had MS and were recruited in community settings and all participants consented to participate in the study.

Method:

Participants were interviewed by phone before attending the CDSMC. Aims and objectives of this study were explained to participants prior to a phone interview. These telephone interviews lasted half an hour to an hour and were completed by two researchers. Verbal consent was requested at the beginning of each interview to record interviews and also to include the participant's data in the study. Topics covered in the first interview included: the meaning of the term 'self-management', motivation to attend the CDSMC and current use of self-management strategies. A four month follow up was done in the form of an interview

which focused on participants views regarding the CDSMC; any changes made since attending and suggested improvements. Interviews were tape recorded and transcribed verbatim. Data were analysed using framework analysis. Two researchers analysed the transcripts and a third researcher analysed a random sample of transcripts. Themes that were consistent were identified by the researchers.

Findings:

The findings consisted of a number of themes as follows:

1. Learning and reinforcing self-management techniques.

Participants felt that “the CDSMC reinforced existing knowledge” (Barlow et al, 2009, p.1172). Relaxation and pacing were seen as useful in managing fatigue and goal setting helped them to feel “empowered, build confidence and increase positive affect” (Barlow et al, 2009, p. 1172).

2. Meeting similar others

Participants felt sharing with others helped alter their perspectives in a positive way and helped decrease feelings of isolation. Participants also found lay tutors sympathetic and easy to relate to as the tutors also had MS.

3. Concerns /suggested improvements to CDSMC

Views expressed were mainly positive however negative comments included it was seen as “Americanised”, forced social interactions were viewed negatively, many felt the course manual would be best given at the end of the course, and some felt course tutors could not answer all questions asked.

4. Gender differences

Male participants were more critical of the course and women valued the interactive processes. There is a suggestion that some “male participants may find it difficult to engage with group interaction on emotive topics” (Barlow et al, 2007, p.1175).

Authors Conclusions:

The author's concluded that those with MS found the CDSMC a valuable source of new skills and a reminder of previously learned self- management strategies. Relaxation, pacing and goal setting were particularly useful however it is important to acknowledge gender differences when delivering information regarding these strategies. Achieving goals can be

linked to increases in confidence and these interventions may have a future role to play in the maintenance of self- management techniques for individuals suffering from MS.

Critical Appraisal:

The four criteria of trustworthiness as proposed by Taylor (2007) were used to critique this research.

Trustworthiness:

Credibility:

-This study was qualitative therefore using interviews was an appropriate way to gather data. Qualitative is an appropriate methodology to use as the study is aimed at exploring the perspectives of those with MS.

- There was no clear illustration of how in-depth the interviews were and the structure of them was not well explained. It would have been beneficial to have an overview of the questions that were asked; however the process is described well. Member checking did not occur however interviews were transcribed verbatim which improved credibility.

-Participants were also willing to participate which may mean their perceptions of the course may differ to those that would not be willing to do the course which may question the credibility of this study.

Transferability:

-The setting in which the study took place was not well described, purely being described as community based therefore this may make it difficult to transfer this study to other situations.

-Purposive sampling was also used to ensure there was there was a mixture of ages and disease duration in the study increasing transferability of this study as this sampling identified participants which could give meaningful data (Taylor, 2007).

Dependability:

-Procedural rigour was at a high standard as the procedures done to complete this study were easy to understand and clearly described by the authors which means the study has improved dependability.

-Framework analysis was used to analyse data gathered which was explained well and appropriate as it “is flexible enough to allow other themes to emerge” (Barlow et al, 2009, p. 1171).

-Analytical rigour was something that was good as the data was organized into clear themes that helped understand the study's main findings.

Confirmability:

-Three researchers were used to analyse data which worked to enhance the confirmability of this study by reducing bias within the research (Taylor, 2007).

-Member checking would have been beneficial in confirming information gathered from interviews.

Summary/Conclusion:

It can be concluded that those with MS can generate benefits from self-management programmes like that of the CDSMC and the procedural rigour of this study means it can be easily transferred into other contexts. A number of valuable themes emerged but may have been affected by the participants' willingness to participate. The majority of the strategies used in the CDSMC are currently utilised by Occupational Therapists for use with patients with varying conditions and the fact that this study demonstrated the many benefits of the use of these strategies is promising regarding its future use for Occupational therapists.

IMPLICATIONS FOR PRACTICE, EDUCATION and FUTURE RESEARCH

After reading both articles we believe that they differ greatly in relation to how useful they may be. Barlow et al (2009) presented clear findings that were explained well whereas the article by Kos et al (2007) presented results in various tables however these results were not clearly explained. In regards to the programme/course used in each study Barlow et al (2009) discussed the CDSMC well in regards to how the course can improve various aspects of participants' lives whereas Kos et al (2007) focused mainly on fatigue and its impact. Both studies used purposive/stratified random sampling to gain the best representative sample required for the aim of the studies. These studies also identify the

effect of the interventions on the individuals' lives by following up on participants in four or more months' time.

A variety of background research was discussed and used by Barlow et al (2009) to justify the completion of the study which we believe gave validation for the completion of this study. It had a high level of trustworthiness and refers to occupational interventions including the use of pacing and goal setting which are all very relevant to the practice of Occupational therapy. Procedural rigour and analytical rigour were also demonstrated by Barlow et al (2009) which produces a more trustworthy study which has a high chance of being replicated in future. Useful evidence is produced by Barlow et al (2009) regarding the use of a self-management program to help those with MS to reduce the impact of symptoms on their daily lives. On the flipside Kos et al (2007) did not explain in great detail what was involved with the program and its relevance to the practice of occupational therapy was lower. Processes were also unclear and as a result it may be difficult to replicate this study in the future. Furthermore weak evidence was provided in regards to the effectiveness of the MFMP in those with MS.

Numerous factors affected the study done by Kos et al (2007) including the progressive course of MS which meant participants with a chronic progressive course of MS benefited more than those with relapsing-remitting course of MS. The differences between male and females in relation to the way they prefer to participate in self-management courses requires further research as Barlow et al (2009) states "some male participants may find it difficult to engage with group interaction on emotive topics"(p.1175). The way topics were handled by the tutor might also be factor. We feel that further research needs to be done to address these factors which impacted on the studies.

To conclude Barlow et al (2009) proved the CDSMC was an effective way to learn new skills and to reinforce previous learned self-management skills. It also explores the subjective experiences of participants attending the course which provided more useful information. On the other hand, Kos et al (2007) showed that the MFMP had little effect on the improvement of fatigue in individuals with MS. With this in mind any changes to Occupational therapy practice can be based on the Barlow et al (2009) study.

CRITICAL OVERVIEW OF USING EVIDENCE IN OCCUPATIONAL THERAPY

Using evidence in occupational therapy like the study's completed by Barlow et al (2009) and Kos et al (2007) can be a challenge for the practice. Lack of funding to complete research is often a barrier and as Occupational therapy is a relatively new practice Occupational therapists are often not skilled in researching. Although the study done by Barlow et al (2009) provided some valuable results regarding the value patients can get out of self-management programs, qualitative research like this is often disregarded due to it not having the statistics behind it like quantitative research does. As Taylor (2007) states "numbers and anything that can be quantified, are acceptable as 'scientific' facts and, therefore as evidence" (p. 87) whereas qualitative studies are often viewed as lacking validity and reliability.

However it is this research which may be more beneficial to Occupational therapists as qualitative research looks into the perspectives of the participants and values the context the study takes place in which are all important to the profession of Occupational therapy. RCT's in particular reduce biased results as they are randomized and therefore produce more trustworthy and reliable research. However the inclusion criteria can restrict the sample of complex cases that occupational therapists deal with every day.

The value of research to Occupational therapy is dependent on the trustworthiness/validity and relevance of the research to the context. If a study is done like the one by Barlow et al (2009) it would be appropriate to use it as evidence for the use of future courses with patients struggling to deal with Multiple sclerosis as it has good procedural rigour and participants perceived many benefits from the course. The study done by Kos et al (2007) specifically looks at the MFMP and therefore is unlikely to be replicated in other areas of occupational therapy. Due to this and because of its poor validity it is not useful for the practice of occupational therapy. The study does show it would be beneficial to use group interventions with individuals with MS as participants showed improvement in fatigue management as a result of group discussions. Barlow et al (2009) demonstrates research that can be easily replicated and which can be of benefit to occupational therapists when using self-management programmes with people with MS.

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