

Occupational therapists online: Equity of access to fatigue self-management

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Fatigue is one of the most common and debilitating symptoms experienced by people with chronic conditions. Between 50 and 95% of people with chronic neurological conditions report fatigue and mostly name it as their worst or one of their worst symptoms (Fisk, Pontefract, Ritvo, Archibald, & Murray, 1994; Kraft, Freal, & Coryell, 1986). Fatigue has a known impact on quality of life and health status (Benedict et al., 2005; Benito-Leon et al., 2003). It results in major life changes. For example fatigue is reported as a central cause of people with multiple sclerosis (MS) being unable to maintain full-time employment (Smith & Arnett, 2005).

How do we support people to manage their fatigue?

Although the literature suggests different approaches to treatment of this pervasive symptom, there is no single, comprehensive and well-supported guideline to manage fatigue. Management includes pharmacological and non-pharmacological interventions. Systematic reviews show that most pharmacological interventions result in severe side-effects and risk becoming refractory to treatment (Brañas, Jordan, Fry-Smith, Burls, & Hyde, 2000; Solari et al., 2008). The literature also suggests a range of non-pharmacological solutions from cooling therapy to cognitive behavioural therapy, yoga, exercise and so on.

One of the only standardised interventions well supported by the literature is Managing fatigue: A six week course for energy conservation (Packer, Brink, & Sauriol, 1995). The efficacy of the program has been tested by several independent researchers (Mathiowetz, Finlayson, Matuska, Chen, & Luo, 2005; Mathiowetz, Matuska, Finlayson, Luo, & Chen, 2007; Sauter, Zebenholzer, Hisakawa, Zeitlhofer, & Vass, 2008).

This face-to-face fatigue program includes six weekly sessions. Each is highly structured and includes an education session, practice activities, discussions and a homework assignment. All content (topics: the importance of rest, communication, body mechanics, re-arranging activity stations, setting priorities and standards, and balancing a schedule), worksheets, handouts and homework assignments are standardized in a manual for facilitators. Based on self-efficacy theory (Bandura, 1997) each session incorporates strategies known to increase confidence in the ability to engage in specific behaviours. Facilitators support participants to develop problem solving skills, set goals and to take action to meet these goals. The facilitators are most often occupational

therapists; their specialized knowledge of occupation, expertise in task analysis and group facilitation skills are ideal competencies to facilitate the program.

Problem: Not many people have access to face-to-face programs

Despite its effectiveness, most people with fatigue have limited access to this self-management program. Those who live in rural and remote areas, have transportation difficulties, work full-time or are confined to the house due to disability are often denied access to the face-to-face version of the program.

Solution: An online fatigue self-management program

There is sufficient evidence that in many countries including Australia and Canada many people have access to the Internet every year (Australian Bureau of Statistics, 2006; Statistics Canada, 2010) therefore, delivering programs online is a way to increase equity of access to programs such as the fatigue self-management program.

The online program mimics the face-to-face protocol developed by Packer and colleagues (1995). A research team in the Centre for Research into Disability and Society at the School of Occupational Therapy and Social Work, Curtin University, Western Australia undertook deconstruction of the face-to-face program and reconstruction into an online prototype and then followed with three pilot tests. Content, activities and discussion topics from each of the six weekly sessions were captured and transferred to the alternative medium (Ghahari, Packer, & Passmore, 2009). During and after the pilot tests, feedback from users and facilitators was sought and electronic program records scrutinised. Collected information was used for quality improvement. The end result was a standardized online fatigue self-management program, user-friendly for people with basic computer skills.

The program:

- includes all aspect of the face-to-face program including weekly information, activities and group discussions;
- is guided by self-management principles. For example, to facilitate behaviour change based on vicarious learning and social persuasion, 'blogs' from previous participants in face-to-face programs (an expert panel) are included in the weekly content;

- is seven-weeks long. An extra week solves technical problems and allows participants to meet each other and become familiar with online navigation;
- provides opportunity for participants to share information and experiences, express their ideas or feelings and offer advice and support to one another through a discussion forum;
- is easily accessible and user-friendly for participants with limited computer knowledge and literacy (defined as the ability to use the internet for simple searches and send/receive emails);
- uses asynchronous participation, such that participants can log on and remain online at their convenience;
- expects a weekly commitment of approximately 2–3 hours per week (facilitator and participants), similar to participation in the face-to-face version; and
- requires individual usernames and passwords to enter the online program.

Occupational therapists online

Facilitators for the online program are usually occupational therapists experienced in working with people with neurological conditions, experienced in group facilitation and with knowledge of self-efficacy and self-management theory and practice. They receive specific training on the technical aspects of the platform and instruction on online facilitation. Facilitators log on daily, respond to participant entries, pose questions and provide encouragement.

Is the online fatigue self-management program effective?

The program was tested on 105 individuals with multiple sclerosis, Parkinson's disease or post-polio syndrome in Australia (Ghahari & Packer, Under review; Ghahari, Packer, & Passmore, 2010). The participants were allocated to four groups: face-to-face, online, information only and a no intervention control group. The results of the study suggest that both the face-to-face and online versions of the fatigue management program effectively helped people with neurological conditions to manage their fatigue. Both groups showed significant improvement in their fatigue over time. However, while the face-to-face group significantly decreased the fatigue level in comparison to the control group, the online fatigue self-management group helped people to manage depression and stress and improved their self-efficacy in comparison to the control group. Further, the online program reached people with poorer baseline scores; participants in the online fatigue management program had lower activity levels

and higher fatigue levels than the participants who had access to the face-to-face program. Therefore, providing services using two delivery mechanisms appears to increase access and decrease known inequities, particularly between metropolitan and rural and remote areas.

The participants of the online fatigue self-management program reported that the program was easy to follow, completing the activities online was straightforward and interesting and that the most popular part of the program was the group discussions.

Conclusion

Although fatigue is a common problem for people with neurological conditions, to our knowledge, this online fatigue self-management program is the first of its kind. Through the application of a fatigue self-management program, occupational therapists and other health professionals can expect that the participants will learn self-management skills, make corresponding behaviour changes and experience a reduction in the effect of fatigue on their lives. Occupational therapists, with their specialized knowledge of occupation and expertise in task analysis, have the skills required to help people with chronic conditions manage their fatigue and improve their lives.

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