

Patient Self-Management in Multiple Sclerosis

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This White Paper represents the consensus of the professionals who comprise the Consortium of Multiple Sclerosis Centers. We encourage your comments, suggestions, or questions. Visit the Consortium at www.mscares.org.

Patient Self-Management in Multiple Sclerosis

Introduction

Health education and disability management research supports the efficacy of self-management programs related to health outcomes in populations of people with chronic illness. The focus here is on actual patient self-management activity vs. health systems intervention or patient education (Barlow et al., 2002). The central premise behind such programs is that day-to-day management of chronic illness rests in the hands of the patient, as opposed to medical providers, and wellness management skills are a necessary teaching focus in order to mitigate disability and improve outcomes (Lorig & Holman, 2003).

Current Practice: Literature Review

The substantive portion of literature in the area of self-management intervention is based upon the work of Lorig and colleagues at the Stanford Patient Education Research Center (Jordan & Osborne, 2007). Within that literature, the primary tasks taught in self-management are threefold: 1) medical symptom management, examples of which include taking medication, adhering to special diet, or using medical devices (i.e., inhaler); 2) role management, which refers to maintaining, changing, and creating new meaningful behaviors and life roles (adopting new recreational activities, changing responsibilities in household, etc.); and 3) emotional management, such as adjusting to situation-induced emotions including

anger, fear, sadness, depression, or grief (Corbin & Strauss, 1988; Holman & Lorig, 2004).

Within this framework, patients are taught specific skills. These include problem-solving, decision-making, resource utilization, formation of patient-provider partnerships, action planning, self-tailoring (making plans based on learned principles of behavior change), and self-management (Lorig & Holman, 2003). This social learning approach appears most common while others include self-management models based upon stress coping or readiness to change (Newman, Steed, & Mulligan, 2004).

Self-management programs have primarily been conducted in a group face-to-face format with a specific number of scheduled sessions. Lorig's group initially developed a condition-specific program, the Arthritis Self-Management Program (ASMP), based upon needs assessment research conducted with rheumatologists and their patients (Lorig, Ritter, & Plant, 2005). It should be noted that telephone intervention is lesser utilized with very few web-based programs.

Across multiple studies, the ASMP has been found to improve health and disability outcomes, including reduced pain (despite increasing levels of functional disability), depression, number of physician visits, and improved levels of self-efficacy. These changes are immediate within one month of intervention and have been found to be sustained in study groups up to four years post-intervention (Lorig et al., 2005). The Chronic Disease Self-Management Program (Lorig, Gonzales, & Laurent, 1999) was developed to accommodate individuals with various symptomatic chronic conditions such as heart disease, lung disease, stroke, and type 2 diabetes and

utilizes the same format and skill areas as the ASMP and results have been similarly successful.

Barriers to Progress

Although there are a number of very positive results to these research efforts, there are also a number of caveats that require consideration, including: insufficient data to evaluate intervention modalities, type of self-management intervention, the frequent lack of needs assessment underlying developed interventions, inadequate session variable analysis – group size, number of sessions and intensity, type of leadership, key patient variables, benefits retention, inadequate statistical evaluation of impact, and impact on health care utilization among others (Newman et al., 2004). One stringent review of the literature isolated only the variable of face-to-face contact as being associated with improved outcomes (Warsi et al., 2004).

Application to MS Healthcare Community

Multiple sclerosis (MS), a chronic, unpredictable disease of the central nervous system, is primarily thought to be an autoimmune disorder and is treated by disease modifying therapies and multidisciplinary rehabilitation. Currently, approximately 400,000 people in the U.S. and 2.5 million worldwide are known to have MS, with incidence estimates at 1-5 per million worldwide (National Multiple Sclerosis Society [NMSS], 2006; Noseworthy et al., 2000). In addition to a multitude of physical effects such as fatigue, numbness, gait and coordination disturbance, bladder and bowel dysfunction, sexual dysfunction, vision problems, and pain, many

people with MS experience changes in cognitive and emotional function as well (i.e., complex attention, memory, information processing, and mood, NMSS, 2006). MS is a chronic, multi-system disease that truly deserves comprehensive self-management programs.

The self-management literature and research in multiple sclerosis is, however, limited (Devins & Shnek, 2000). Stuifbergen et al (2003) reported on an eight session wellness intervention program for women which was chiefly focused on health and physical functioning, with two sessions dealing with stress management and relationships/intimacy. Multiple outcome measures indicate that participants realized significant improvements in self-efficacy, health behaviors, and selected dimensions of quality of life (QOL). Using a multidimensional instrument designed to evaluate self-management behavior among people with MS (Bishop & Frain, 2007), researchers demonstrated that self-management is strongly associated with perceived control and that both perceived control and self-management mediate the relationship between the physical and emotional impact of MS and QOL (Bishop, Frain, and Tschopp, 2008). Mohr and colleagues (2000, 2005) have shown the benefits of telephone-delivered cognitive behavioral therapy in reducing depression and are completing current research on the benefits of a cognitive behavioral psychoeducational program in stress management. Other self-management programs are narrowly targeted toward specific areas such as fatigue or energy conservation (Finlayson & Holberg, 2007), medication adherence (Medco, 2003), or diverse programs relating only to physical conditioning provided by the National MS Society, the MS Foundation, etc. To date, self-management programs have not addressed the constellation of multi-system symptoms and secondary conditions that occur for the majority of persons with MS. Intervention

modalities have fluctuated, as have research analysis methods. Clinical interventions targeting MS symptom self-management too often rely solely upon patient education without the other core components of successful self-management (e.g., skill acquisition, rehearsal of skills, problem-solving, or resource acquisition). From the perspective of comprehensive intervention, self-management research in multiple sclerosis rehabilitation has been chiefly overlooked, particularly from a comprehensive needs-based context.

There are limited comprehensive patient self-management programs available to MS professionals. Available programs tend to be narrowly focused or require the MS professional to use more generic chronic disease self-management models, which may not accurately address the unique needs of persons with MS.

Best Practices and Consortium of Multiple Sclerosis Centers (CMSC) Recommendations

It is incumbent upon the MS professional community to establish effective self-management programs for MS that meet the unique, fluctuating needs of patients dealing with this complex, chronic condition. These interventions must be comprehensive and take into account the constellation and variable, unpredictable nature of the disease and symptoms.

Given that self-management is, by definition, consumer centered, the involvement of consumers in the development, evaluation, and dissemination of self-management interventions is essential. Recently a participatory action research approach (PAR) was used to design and test a self-management intervention for persons with limb loss entitled,

“Promoting Amputee Life Skills” (PALS: Wegener, MacKenzie, Ephraim, Ehde, & Williams, 2009). Stakeholders, including the Amputee Coalition of America, individual consumers, and an advisory board comprised of experts in the field of limb loss, were active in all phases of the research, including the development, implementation, and evaluation of the intervention. A randomized controlled trial evaluating the PALS self-management intervention showed it to be efficacious in reducing depression and functional limitations, and in increasing positive mood and self-efficacy. From the sustainability perspective, the PALS program is now “owned” by the Amputee Coalition of America (ACA). This organization is now overseeing the training of group leaders program, implementation, dissemination of materials, and quality control. It is now part of the ACA portfolio of services and, as such, is sustained beyond the research project.

CMSC Recommendations

- a. Raise awareness for the need of self-management within the MS professional community.
- b. Conduct assessment of the unmet needs in MS from both patient and professional perspectives.
- c. Promote research to evaluate not only the specific components of self-management programs that are most critical/useful to consumers with MS, but also how self-management programs are best delivered (e.g., in person vs. phone, type of leadership, number of sessions, etc.).
- d. Eliminate practice barriers to self-management by involving consumers in all stages of the process-development of intervention(s), implementation, testing via research, dissemination, and sustainability.
- e. Develop evidence based practice to encourage financial support of self-management.
- f. Encourage the CMSC-NARCOMS registry to promote self-management among their registrants.

- g. Leverage health plans to financially support strategies for self-management which will lead to cost savings.
- h. Encourage members of the CMSC and the broader MS community to promote self-management in collaboration with the National MS Society, the National Multiple Sclerosis Foundation, the Multiple Sclerosis Association of America, and other relevant organizations.

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