A critical look at the role of self-management for people with arthritis and other chronic diseases

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Received 26 October 2007
Accepted 17 January 2008
Published online
26 February 2008
www.nature.com/clinicalpractice
doi:10.1038/ncprheum0765

Chronic disease can affect every aspect of a person's day-to-day life. Although the individual adapts to these effects over time, health-care systems could do more to provide patients with necessary skills and resources. Self-management programs have been designed to help fill this void, and are in an early stage of development. Given that encounters between health-care professionals and patients with chronic conditions are sporadic, and their overall impact on patient wellbeing is small, the potential capacity of patient self-management has been viewed as large but underdeveloped. There is a range of influencing factors, however, that might impact on the effectiveness of self-management programs for patients with long-term conditions; these influences relate to the personal and social resources patients are able to access, the response and role of clinicians, and the workings of the broader health-care system.

A distinction can be made between 'self-management' and 'self-management support'. Self-management is a normal part of daily living, and involves the actions individuals take for themselves and their families to stay healthy and to care for minor, acute and long-term conditions. Self-management support is the facility that health-care and social-care services provide to enable individuals to take better care of themselves. The onus in recent times has been on delivering training for self-management skills to individuals through a range of interventions.[1]

Self-management support encompasses information, awareness campaigns, devices and medical education, provided through a wide range of delivery processes (Supplementary Table 1 online). Patient information, effective engagement, communication and shared decision making are likely to generate more-effective self-management practices; however, routine application of these resources might be hindered by contemporary clinical environments. Difficulties also arise when patients have poor 'health literacy' and, therefore, lack the capacity to seek, understand and utilize information to participate fully in decisions about their care.

For arthritis, the dominant approach to self-management support has been the implementation of community-based group programs, which tend to be isolated from clinical practice, without review or follow-up.[2] This approach has the potential to undermine the clinical encounter in two ways: it negates the self-management support that clinicians deliver, as the patient might receive mixed messages, and little account is taken of the routine ways in which people accommodate their chronic condition, as well as how they seek and utilize services for support.[3] Self-management programs should, therefore, be closely linked to clinical practice. Comprehensive research into the needs of patients is required, particularly with regard to the nature and level of information and resources patients require to support and enhance life with a chronic condition. There also needs to be improved understanding of how these resources can be best applied across the interface between clinical practice and the community to optimize patient outcomes. This is necessary because, although these programs have a modest impact on knowledge and the sense of empowerment, the lasting educational or behavioral impact has not been substantial to date.[4–6]

Clinical outcomes have been the predominant yardstick for measuring the effectiveness of self-management programs. For arthritis, meta-analyses of randomized controlled trials of a limited range of programs have demonstrated minimal or no effect on reducing pain and disability.[7,8] This is not surprising, given the apparent discrepancies between program content, patient expectations and outcome measurement. Furthermore, self-management programs focus on improving patients' skills and their capacity to deal with daily life, including maintaining quality of life despite having chronic pain. These outcomes, in addition to provision of opportunities to reduce social isolation and increase access to social networks, might be more relevant than clinical outcomes for the measurement of an individual's ability to manage their condition.[2,9] Investments in future clinical-practice-linked self-management programs should consider key indicators of successful self-management, rather than pain and disability that have resulted from specific pathology and structural changes.[9]

Programs that focus on self-efficacy (the confidence to undertake self-management activities) as the primary marker of improved self-management are in danger of ignoring the social environment and reality of living with a chronic condition. Individuals with chronic diseases often have poor functional capacity, and many live in socially disadvantaged circumstances; however, existing recruitment and engagement strategies are often biased towards those who already perceive themselves to be 'good' self-managers and to those from white, middle-class backgrounds.[10] More-marginalized groups arguably have the most to gain from self-management programs, and the existence of social inequalities among patients with chronic illness should be considered when developing new programs. For example, group-based programs rely on social comparison for mediating self-efficacy; however, social comparison can have a negative effect if positive comparisons by individuals cannot be made. Being poor and ill brings with it the possibility of shame and insecurity.[11] This, combined with the debilitation of suffering a chronic condition, might generate a vicious circle of insecurity, depression and social isolation, rather than improved self-efficacy and better self-management practices. A suite of condition-specific programs with varied content and delivery modes needs to be developed and tailored to the needs of communities.

Although emphasis has been placed on the content and delivery mode of self-management programs, the method of program implementation and integration into the patient environment, clinical settings and the broader health-care system is of equal importance. From the patient's perspective, there are many physical and emotional barriers to participation in self-management programs (Supplementary Box 1 online), which in part explains why many organized programs have struggled for viability, coverage and integration. There are also many needs and concerns of health-care professionals, as well as risks for health-care managers and policymakers, that need to be addressed before self-management programs can be successfully implemented (Supplementary Table 2 online).

The development and implementation of self-management programs requires attention to the environment in which a person with arthritis and other chronic conditions lives, and to how they interact with the health-care system. We know that many patients desire to fit in with what is expected of them, and that systems (i.e. referrals and availability of services), as well as patient demand, drive the utilization of services. To enhance the utilization and sustainability of a program, it is crucial that development and implementation strategies engage patients, clinicians and policymakers. The key consideration when developing new programs, or adapting established programs, is the extent to which the self-management program will be workable for both patients and health professionals.

Supplementary information in the form of two tables and a box is available on the *Nature Clinical Practice Rheumatology* website.

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Acknowledgments
RH Osborne is funded in part by a National Health and Medical Research Council Population Health Career Development Award.

Competing interests
The authors declared no competing interests.