Patient education and self-management programs in arthritis

Richard H Osborne, Jean M Spinks and Ian P Wicks

ABSTRACT

- Arthritis self-management programs (ASMPs) are integrated into many clinical practice guidelines and policies, and are the core business of Arthritis Foundations.
- Australian Arthritis Foundations are embarking on a National Quality Assurance Program which should raise awareness and improve confidence in such programs.
- ASMPs aim to empower people, improve quality of life while living with chronic disease, increase healthy activities and improve self-monitoring — each of which can assist with clinical management, but can be difficult to evaluate.
- Although there is modest high-quality evidence of traditional "clinical outcomes" from ASMPs, these programs are strongly endorsed by consumers, are being used as a vehicle for healthcare reform, and have the potential to substantially improve public health.
- Coordinated national delivery of patient education programs has the potential to improve healthcare and outcomes for people with arthritis.

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FOR FUNDERS OF HEALTHCARE, the allure of patient education and self-management programs includes the promise of reduced costs alongside higher patient satisfaction. This has placed self-management on to the agenda of local and international health authorities. Local authorities are currently discussing whether large-scale organised self-management programs should be implemented in Australia.[1] This agenda is consistent with the goal of the World Health Organization's Bone and Joint Decade that "... the informed and empowered patient must be a critical part of any therapy".[2] Furthermore, international clinical practice guidelines recommend that self-management be part of routine clinical practice.[3] Despite this enthusiasm for self-management, the potential benefits of such programs may not be immediately apparent for healthcare professionals and their patients.

What is patient education and self-management?

There are a variety of models of both formal and informal self-management. However, the core concepts involve engagement in self-care, improved self-monitoring, interactions with healthcare professionals and coping with disease (Box 1). The dominant model in Australia is the Stanford University School of Medicine chronic disease self-management program (Box 2). This course runs for 2.5 hours per week over 6 weeks and is led by peers or health professionals. The arthritis self-management program (ASMP) is the core business of the Australian Arthritis Foundation (www.arthritisfoundation.com.au).

Outside the research setting, self-management programs are mostly provided to people with arthritis and other chronic diseases through community organisations such as Arthritis Foundations (see Box 3). In the United States, courses are also sometimes available to members of Health Maintenance Organisations (HMOs), and are reputedly highly endorsed.[4] In the United Kingdom, the Stanford model is being used as a vehicle for healthcare reform through the Expert Patients Program.[6] This program is designed to integrate user-led self-management courses for people with chronic diseases into the existing National Health Service (NHS) frameworks. Over 150 Primary Care

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1: Core concepts of patient self-management

- Engagement in activities that promote health, build physiological reserve, and prevent adverse sequelae
- Interacting with healthcare providers and adhering to recommended treatments
- Monitoring physical and emotional status, and making appropriate management decisions on the basis of the results of self-monitoring
- Managing the effects of illness on a patient's ability to function in important roles and on emotions, self-esteem, and relationships with others[1]

2: Content of the 6-week Stanford University chronic disease self-management course delivered by Arthritis Foundations in Australia[4]

- How to manage pain and fatigue
- The benefits of physical activity
- Understanding medication use
- Managing anger, fear and frustration
- Solving health-related problems
- Better communication with doctors

3: National and international community-based models of self-management course delivery

Australia[5]

- Community-based course delivery (Arthritis Foundations) with referral to courses by peers or health professionals

United States[4]

- Community-based course delivery (Arthritis Foundations) with referral to courses by peers or health professionals
- Health Maintenance Organisation (HMO) members obtain access to self-management courses through their workplace

United Kingdom (Expert Patients Program)[6]

- User-led (peer) self-management courses available within Primary Care Trusts funded by the National Health Service (NHS). Required to meet NHS-prescribed throughput

Trust sites across England are currently taking part, and an estimated 20 000 patients will receive training in this initial phase. From 2004 to 2007, it is proposed that the program will become part of mainstream services throughout the NHS.

Evidence for the effectiveness of self-management

Existing evidence for the "clinical" effectiveness of self-management is summarised in Box 4, using information from two recent meta-analyses.[7,8] While many studies have been published, they can be difficult to interpret for several reasons:

- many of the intended benefits do not fit into the traditional medical model and are difficult to measure and qualify (eg, "empowerment");
- many trials include "chronic diseases" without disease-specific subanalyses (ie, for arthritis);
- patients studied are often from selected subpopulations; and
- self-management interventions are delivered in addition to usual care (which is often of a very high standard in clinical research centres).

The meta-analyses for both rheumatoid arthritis and osteoarthritis indicate small average benefits for clinical outcomes (Box 4). Larger benefits have been reported for "illness distress" and "self-efficacy" (confidence in undertaking healthful behaviours), which are critical components of quality of life for patients with a chronic disease.[4,5,9] Most controlled trials have a relatively short follow-up period, as participants are usually randomly allocated to wait-list control groups who receive the intervention within 4–6 months.[4,9] Our 2-year longitudinal study of people with arthritis attending the ASMP found that the benefits that were apparent at 6 months (eg, less pain and fatigue, increase in physical activity) were still apparent at 2 years.[5]

The association between self-management and health service use is more complex. As patient education and self-management programs aim to improve the efficiency and quality of the healthcare process, it may be unrealistic to expect a reduction in doctor visits, hospital attendances or medication use. For some individuals, an improved healthcare process could include more *frequent* use of services because of improved compliance. In addition to better compliance, a better "mix" of healthcare resources might eventuate, including reduced use of unplanned services (eg, emergency presentations). Healthcare use outcomes from controlled trials of self-management reflect this complexity, with somewhat inconsistent outcomes for attendances at GPs, emergency presentations, and medication use.[4,5-10]

Potential benefits of a widely applied self-management program

"Program logic" assists in conceptualisation of complex programs, and helps to identify measurable targets in the "causal" chain.[11] Through workshops with stakeholders, we have developed a program logic of how the outputs of self-management, if delivered widely across the community, might lead to effects on individuals, the healthcare system and the population (see Box 5). Immediate effects involve education and patient empowerment, including improved collaboration within the healthcare system (see Box 2). These are the most basic effects, consistent with course content and are the most easily measured. Standardised indicators are being developed (see below), and will assist in ascertaining whether course participants actually receive these benefits. The difficulty of demonstrating outcomes increases as one progresses down the model (eg, clinical outcomes such as pain, quality of life and disability). Some of these outcomes can be measured reliably by questionnaire (see the non-italicised components in Box 5). Benefits to communities and ultimately to public health are the most difficult to demonstrate, and such outcomes are highly dependent on the coverage of the program in patient groups most likely to benefit.

In an attempt to standardise the quality of patient education programs, the National Arthritis and Musculoskeletal Conditions Advisory Group[12] has funded the development of a national quality assurance program. A standardised questionnaire to measure outcomes, the Health Education Impact Questionnaire (HEI-Q), has been developed to assess eight proximal indicators — positive and active engagement in life, health behaviour change, skill and technique acquisition, constructive attitude shift, self-monitoring, healthcare service navigation, social integration, and emotional wellbeing. These indicators were developed through consultation with stakeholders and workshops. In

4: Summary evidence of the effectiveness of self-management education programs for people with osteoarthritis and rheumatoid arthritis

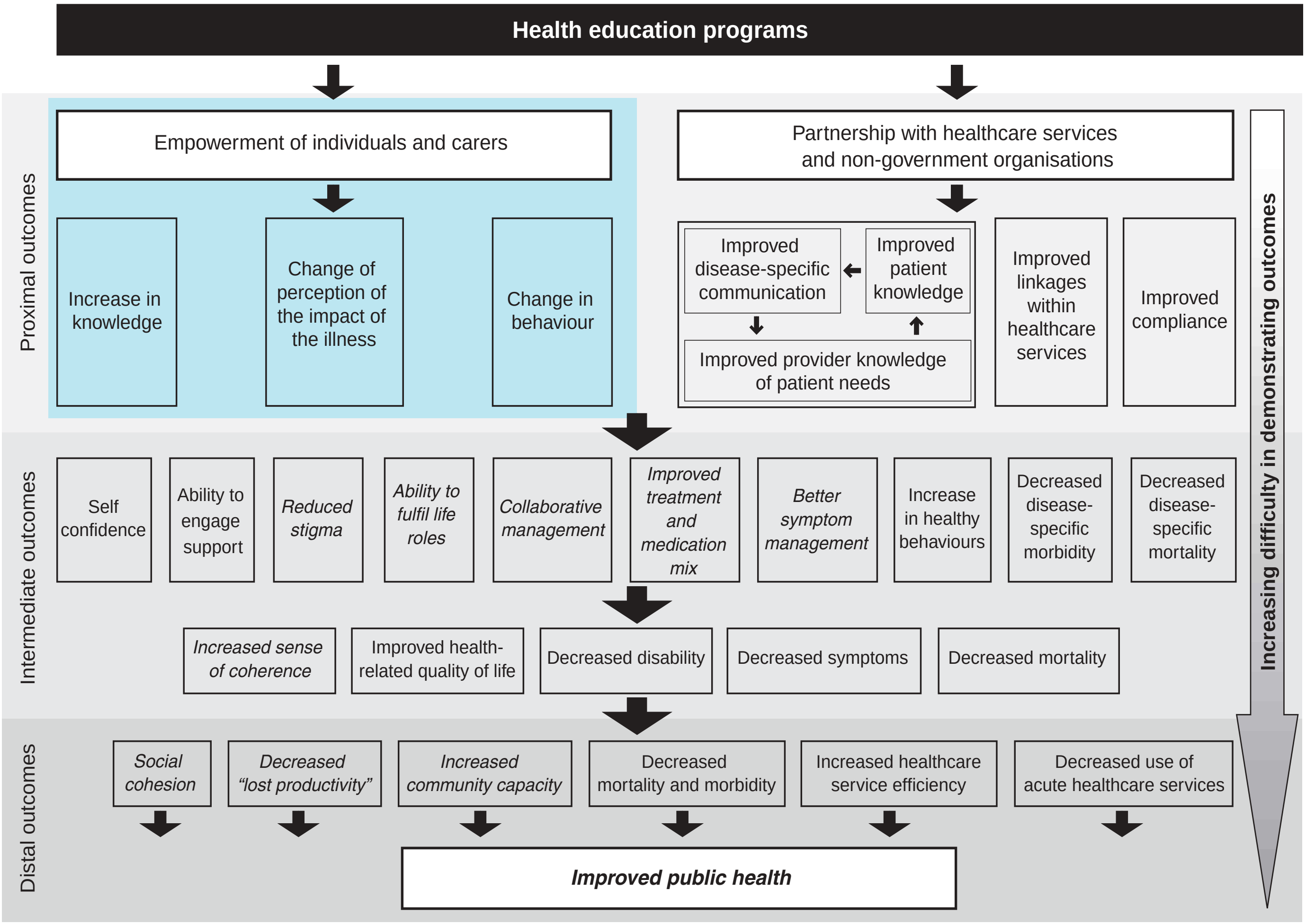
Rheumatoid arthritis — Cochrane Review[7]

- Small beneficial effects on disability, number of swollen and tender joints, patient global assessment, psychological status and depression

Osteoarthritis — meta-analysis[8]

- Small beneficial effects on pain and disability
- Effects on factors such as illness distress, self-efficacy and depression have not been subjected to meta-analyses

5: A program logic model of how health education programs for people with chronic conditions might lead to improved outcomes for individuals, benefits for the community and enhanced public health*



* Boxes with italics indicate outcomes that are not easily measured because they are difficult to define and/or no standardised outcome measures are available.

addition to data on course quality, the HEI-Q will provide systematic data on where and to whom self-management programs are being delivered.

Australian initiatives

In Australia, there is interest in the potential value of patient education and self-management programs, particularly the ambitious UK Expert Patients Program.[1] This program (Box 3) is a lay-leader model; it is unknown whether program quality will be maintained or whether it will reach those who might benefit most. A current Australian policy initiative is the Commonwealth Sharing Health Care Initiative,[13] which is part of the Enhanced Primary Care (EPC) package. Over 4 years, $14.2 million was allocated to the development and implementation of a variety of chronic disease education models, including self-management. This program is implemented through the Divisions of General Practice, various non-government health organisations, academic centres and some state and territory health authorities. The first stage of this program should be completed during 2004 and will yield data on the applicability of a range of models in a variety of Australian settings and health conditions, including people with Aboriginal or Torres Strait Islander backgrounds. A further $21.8 million over 4 years was provided by the Federal Government in the 2003–2004 Budget to further integrate chronic condition self-management into the Australian healthcare system.

Preliminary Australian work on 2-year outcomes in 452 people attending ASMPs shows that, in a self-selected population, most individuals are female and educated.[5] Our current nationwide studies are designed to be sensitive enough to identify a broad range of small intervention effects using new, sensitive questionnaires for community-based interventions. We have found that only about 6% of referrals to self-management courses come from GPs or hospitals. These studies, as well as the findings of the 12 demonstration projects in the Commonwealth Sharing Healthcare Initiative,[14] will provide much-needed data to inform any future integration of patient education programs in Australia.

Conclusion

The EPC package recognises that there is a growing proportion of the population with chronic conditions. These people have complex and continuing needs, and the acute healthcare approach is not appropriate. There may be unrealistic expectations of what medical care can deliver in these illnesses, partly fuelled by increasing media coverage. Self-management and patient education principles have the potential to militate against these problems. Furthermore, it is likely that many patients underestimate the value of active participation in their own healthcare, and that doctors underestimate the value of education in patient compliance. For patients to become empowered and informed partners in the doctor–patient relationship, well-directed education is required. In addition to specific disease-related information, general information on the boundaries of healthcare and how mutual collaboration can facilitate better care is an important component of these programs. A standardised and monitored network of locally provided patient education programs might improve rates of referrals from clinicians. A program that includes disadvantaged groups would contribute to a more equitable healthcare system. Whether such a national program improves public health may be difficult to prove in the short term, but, with appropriate tools, effects on individual and specific disease states can be assessed. Healthcare resources are precious. Any widespread application of patient education programs in Australia must be subject to rigorous evaluation of short-term and long-term benefits.

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Competing interests

None identified.

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