Chronic disease self-management support: the way forward for Australia

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ABSTRACT

- We examined research and implementation activities presented at the Centre for Rheumatic Diseases 2007 Conference and other selected literature to identify common themes and posit some "next steps" required to develop self-management programs in the Australian context.
- Self-management and self-management support are key aspects of optimal chronic disease care, and are effective if implemented appropriately.
- Health literacy is the foundation for self-management programs and should be fostered within the whole population.
- We should invest in research and evaluation of self-management because the evidence base is under-developed and inherently difficult to expand.
- Because patient, carer, clinician and organisational engagement with self-management and self-management support programs are uneven, we need to prioritise activities designed to engage known hard-to-reach groups.
- We should strive to improve integration of self-management into clinical, educational and workplace contexts.
- Education and psychological theories can help guide self-management support.

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Self-management is integral to good chronic disease care.[1] Various self-management and self-management support programs are effective, particularly when combined with other system-level interventions, such as modifying delivery system design.[2-5] Examples of programs with proven cost-effectiveness include the Expert Patients Programme in the United Kingdom, which has demonstrated a cost-effective increase in self-efficacy and energy levels (see Rogers and colleagues in this supplement, *page S21*);[6] the "education and action-plan" approach, which reduced the "use of health care in asthma";[3] and group education in self-management interventions targeting patients with diabetes, which reduced the need for diabetes medication.[7]

Australian research has examined generic[8] and disease-specific[9] self-management programs. In Australia, self-management programs have been implemented in clinical[8] and primary care[10] settings, and others have used population health approaches.[11]

We consider some recurring themes within these research and implementation activities and those found in other published material addressing self-management and self-management support. We then propose some "next steps" in the Australian context that are required if self-management and self-management support activities are to fully realise their potential in delivering enhanced health outcomes to people with chronic diseases and meeting government policy objectives.

Methods

We identified themes through consideration of the material presented during the Centre for Rheumatic Diseases 2007 Conference[12] and articles in this supplement. In addition, two recent books focusing on chronic disease and summarising research led by the European Observatory were used as sources.[2,13]

Common themes

Health literacy: a foundation for self-management

The terms "health literacy", "self-care", "self-management" and "self-management support" are commonly used. Although a clear consensus on the meanings of these terms remains to be achieved, there is movement towards agreement. The constructs are all related and overlap. Recently, the relationships between self-care (taking responsibility for health of self, children and family), self-management (active participation of patients in their treatment to minimise impact of their condition) and self-management support (patient, health care practitioner, and health care system interventions designed to increase self-management behaviour) have been described.[14] In this supplement, Jordan and colleagues stress the importance of patients having the capacity to participate in self-management and self-management support, capturing the connections between these constructs (*page S9*; Box 4).[15] Patients with chronic disease must be health literate — have the capacity to seek, access, comprehend and use health information and services.[16]

Challenges in building the self-management evidence base

Researchers and evaluators encounter many challenges when assessing the effectiveness and cost-effectiveness of self-management programs.

Methodological challenges arise because of the complex and multifactorial nature of self-management interventions. Pragmatic randomised controlled trials can be undertaken, as illustrated by the evaluation of the Expert Patients Programme,[17] but these are resource-intensive. Brand notes the "black box" nature of self-management interventions (*page S25*; Box 3).[9] Although there are common elements in interventions across studies, there are also unique elements. Which elements contribute to any observed efficacy may be unknown. However, some elements are effective. Harris and colleagues report that patient education, distribution of educational material and motivational counselling are effective, and note that delivery in group settings enhances effectiveness (*page S17*).[10]

Study designs need to account for comorbidity. In Australia, about 55% of people aged 65–84 years have five or more long-term conditions.[18] Excluding these patients from self-management trials may reduce the generalisability of results; however, including them compounds the complexity of studies.

Study designs also need to account for the complex and dynamic interplay between factors related to patients, clinicians, the health system and those outside the health system, which bear

on chronic disease management. For example, optimal chronic disease care delivery may be frustrated by a public transport timetable preventing access to an activity aimed at enhancing a patient's self-management capacity.

In keeping with any trials of interventions designed for long-term use, self-management studies must consider the degree to which any observed effect at the end of the trial is sustained. Does a result observed at 6 months allow claims of efficacy to be extrapolated to 1 or more years?[3] They also need to consider potential harms. Studies may not be powered to assess harms, with only observational data collected on these, if collected at all. Redman comments:

> there is virtually no evidence about harms to individuals and groups, even obvious ones such as those occurring from lack of patient competence in patient self-management clinical judgements and skill.[19]

Once implemented, self-management programs should be evaluated with reliable and valid tools.[19] The Health Education Impact Questionnaire (heiQ), which was developed in Australia, is one such tool suitable for applications for quality improvement purposes within a program and/or comparison of effectiveness between programs.[20] Ongoing evaluation with such tools strengthens the evidence base.

Challenges engaging patients, clinicians and organisations

Achieving engagement of patients, clinicians and organisations with self-management programs is challenging.

Particular patient groups are less engaged. For example, people with low levels of health literacy, of low socioeconomic status, or who are members of culturally and linguistically diverse communities may all struggle to engage with "standard" programs. Frail older people, with or without cognitive impairment, rely heavily on others for their daily activities. Engagement of their carers and families is important,[21] but much of the focus of self-management programs to date has been directed at patients.

Self-management programs have often developed and/or been implemented in parallel to the direct provision of clinical services. For example, programs may be driven by research groups (eg, the AFV Centre for Rheumatic Diseases at the University of Melbourne) or by organisations such as Diabetes Australia.[22] This may contribute to clinicians' lack of awareness of programs, with the consequence that referrals from clinical practice are infrequent and non-systematic.

This parallel development contributes to problems at an organisational level as well. As Harris and colleagues point out, many Divisions of General Practice have contractual responsibilities with the Australian Government Department of Health and Ageing for the delivery of self-management programs.[10] Similarly, various state and territory governments have specific self-management programs. For government and Division employees, there are clear accountabilities for the delivery of these programs. However, for both, the connections with other parts of the system are voluntary. For example, general practices usually run as private entities with no direct lines of accountability to Divisions or governments. This lack of clear accountability contributes to non-engagement.

Lack of integration

From the patient perspective, obtaining chronic disease care from the health system often highlights areas of fragmentation. Consider the case of a person with type 2 diabetes, ischaemic heart disease and low socioeconomic status. The general practitioner and practice nurse are located in one health facility with appointment systems in place. The podiatrist, diabetes educator, dietitian and ophthalmologist are often each located in a separate health facility with separate appointment systems; pathology services and pharmacies are also separate. Information and communication systems are disjointed, and data entry is duplicated. Funding streams to support these activities are drawn from different public and private sources.

Jordan and colleagues report there has been a tendency for self-management programs and self-management support programs to develop as standalone activities, rather than as integral parts of the system.[15] Harris and colleagues note this as a particular issue within primary care.[10] Self-management programs are in danger of becoming another fragment in an already fragmented system. Self-management should be one component of service delivery within a broader framework of service redesign.[9] This would require critical reflection on current approaches to health care delivery and re-engineering of workplace practices to facilitate the delivery of chronic disease care, including self-management support, while ensuring that other important activities, such as acute care, screening and review are not compromised.

Should there be increased efforts to integrate self-management support activities within other sectors? School curricula could be the focus for more material relevant to chronic disease prevention, management and the health system. For example, an asthma program in schools could be expanded to illustrate best use of the health system, contrasting the respective roles of general practice and emergency departments in asthma care. The workplace is another site in which self-management support activities could be developed. The Australian WorkHealth Program is piloting activities within the workplace aimed at enhancing self-management for arthritis.[23]

Insights from education and psychology

Health-literate patients' active participation in their own care is central to good chronic disease care. Patients should gain increasing autonomy from "teachers" as they become more expert in self-management judgements and decisions. One might expect self-management pedagogical approaches to emphasise adult learning characteristics and developmental teaching principles in which the focus "is on the development of learners' thinking, reasoning, and judgement".[24] However, didactic educational approaches have come to the fore in the development of self-management interventions.[3] There are significant hurdles to overcome in order to achieve best educational practice self-management programs. For example, in already full curricula, clinicians will need specific educational training. Clinical settings will need to be designed to facilitate educational activities as well as clinical activities.

Self-management educational activities are directed at achieving behavioural change. It is not just educators who can contribute to achieving this goal. Psychological theories informing approaches to self-management have been identified,[2,3] but there remains scope for their further development and better integration with educational, clinical and health services research.

The way forward

There are no simple answers to the question: What could be done to better implement self-management and self-management support? Multiple activities at all levels of a complex system are

needed, including those directed at patients, carers, self-management support programs themselves, health professionals, the health system and government.

We suggest the following five areas of focus to take self-management forward:

Develop health literacy within the whole population. Health literacy is the foundation on which self-care, self-management and self-management support are built. Patients with chronic disease must be health literate. Strong policy direction supporting the development of health literacy is therefore critically important, and should be seen as a whole-of-government issue rather than just a health issue.

Invest in research and evaluation. Active support of research and evaluation activities will build the evidence base. Research funding bodies should stimulate interdisciplinary and inter-sectoral research. Reliable and valid tools for research and evaluation in self-management should be further developed. Minimal datasets gathering information on programs should be encouraged and used for quality assurance and evaluation purposes. Regular opportunities for exchange of information between groups working in self-management should continue.

Increase engagement of patients, clinicians, and organisations with self-management programs. Priority should be given to developing programs that engage hard-to-reach patient groups, busy clinicians, and relevant organisations, so that effective self-management support is available for all people with chronic diseases, including patients who are younger, older, marginalised, culturally and linguistically diverse, from low socioeconomic groups, or who have multiple comorbidities, and carers. Policy leadership is necessary for this and could be provided through frameworks such as the National Primary Health Care Strategy.

Drive integration of self-management into clinical, educational and workplace contexts. Maximise the opportunities for integration of relevant aspects of self-management into these contexts through national and organisational policy leadership.

Optimise self-management programs through incorporation of best educational practice and insights from psychological sciences. Programs should develop greater capacity to assess learners and tailor educational responses accordingly. System supports should increase access to programs, and flexible delivery of programs. Clinician training should include motivational interviewing approaches, with incorporation of self-management support into relevant curricula across the continuum of health professional education.

Competing interests

Nicholas Glasgow was a co-author of one chapter in each of the two books examined.[2,13]

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References

1 Wagner EH, Davis C, Schaefer J, et al. A survey of leading chronic disease management programs: are they consistent with the literature? *Manag Care Q* 1999; 7: 56-66.
2 Nolte E, McKee M, editors. Caring for people with chronic conditions: a health system perspective. Maidenhead, UK: McGraw Hill Open University Press, 2008.
3 Newman S, Steed L, Mulligan K. Self-management interventions for chronic illness. *Lancet* 2004; 364: 1523-1537.
4 Dennis SM, Zwar N, Griffiths R, et al. Chronic disease management in primary care: from evidence to policy. *Med J Aust* 2008; 188 (8 Suppl): S53-S56.
5 Jordan JE, Osborne RH. Chronic disease self-management education programs: challenges ahead. *Med J Aust* 2007; 186: 84-87.
6 Rogers A, Kennedy A, Bower P, et al. The United Kingdom Expert Patients Programme: results and implications from a national evaluation. *Med J Aust* 2008; 189 (10 Suppl): S21-S24.
7 Deakin T, McShane CE, Cade JE, et al. Group based training for self-management strategies in people with type 2 diabetes mellitus. *Cochrane Database Syst Rev* 2005; (2): CD003417. doi: 10.1002/14651858.CD003417.pub2.
8 The "Flinders Model" of chronic condition self-management. Adelaide: Flinders Human Behaviour and Health Research Unit, 2008. http://som.flinders.edu.au/FUSA/CCTU/self_management.htm (accessed Jul 2008).
9 Brand CA. The role of self-management in designing care for people with osteoarthritis of the hip and knee. *Med J Aust* 2008; 189 (10 Suppl): S25-S28.
10 Harris MF, Williams AM, Dennis SM, et al. Chronic disease self-management: implementation with and within Australian general practice. *Med J Aust* 2008; 189 (10 Suppl): S17-S20.
11 Buchbinder R. Self-management education en masse: effectiveness of the Back Pain: Don't Take It Lying Down mass media campaign. *Med J Aust* 2008; 189 (10 Suppl): S29-S32.
12 The way forward: chronic disease self-management in Australia. Centre for Rheumatic Diseases 2007 Conference; 2004 Jul 26-27; Melbourne. Melbourne: AFV Centre for Rheumatic Diseases, University of Melbourne, 2007. http://www.crd.unimelb.edu.au/news/archive.html#conference (accessed Sep 2008).
13 Nolte E, Knai C, McKee M, editors. Managing chronic conditions — experience in eight countries. Copenhagen: European Observatory on Health Systems and Policies. In press.
14 Rijken R, Jones M, Heijmans M, et al. Supporting self management. In: Nolte E, McKee M, editors. Caring for people with chronic conditions: a health system perspective. Maidenhead, UK: McGraw Hill Open University Press, 2008: 116-142.
15 Jordan JE, Briggs AM, Brand CA, Osborne RH. Enhancing patient engagement in chronic disease self-management support initiatives in Australia: the need for an integrated approach. *Med J Aust* 2008; 189 (10 Suppl): S9-S13.
16 US Department of Health and Human Services. Healthy People 2010: understanding and improving health. Washington, DC: US Government Printing Office, 2000.
17 Kennedy A, Reeves D, Bower P, et al. The effectiveness and cost effectiveness of a national lay-led self care support programme for patients with long-term conditions: a pragmatic randomised controlled trial. *J Epidemiol Community Health* 2007; 61: 254-261.
18 Australian Institute of Health and Welfare. Chronic diseases and associated risk factors in Australia, 2006. Canberra: AIHW, 2006. (AIHW Cat. No. PHE 81.)
19 Redman BK. Accountability for patient self-management of chronic conditions; ethical analysis and a proposal. *Chronic Illn* 2007; 3: 88-95.
20 Osborne RH, Elsworth GR, Whitfield K. The Health Education Impact Questionnaire (heiQ): an outcomes and evaluation measure for patient education and self-management interventions for people with chronic conditions. *Patient Educ Couns* 2007; 66: 192-201.
21 Mountain GA. Self-management for people with early dementia: an exploration of concepts and supporting evidence. *Dementia* 2006; 5 (3): 429-436.
22 Diabetes Australia [website]. http://www.diabetesaustralia.com.au/ (accessed Jul 2008).
23 Australian WorkHealth Program. The Australian WorkHealth Program — Arthritis. http://www.workhealth.org.au/project_background.html (accessed Jul 2008).
24 Arseneau R, Rodenburg D. The developmental perspective: cultivating ways of thinking. In: Pratt DD, editor. Five perspectives on teaching and higher education. Malabar, Fla: Kreiger, 1998.

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