Self-management: its place in the management of chronic illnesses

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Abstract

Self-management programs are now regarded as important facets in the overall care of people with chronic illnesses. They are seen as producing long-lasting benefits both to participants and to the health system in terms of reduced hospitalisations and reduced lengths of stay, as well as decreasing medication usage. In this article we examine what constitutes self-management and the evidence supporting the views that the benefits are unequivocal. We argue that greater attention to research design is required before the benefits can be assessed. We also argue that greater attention must be paid to access issues for people from culturally and linguistically diverse backgrounds (CALD) and lower socioeconomic status.

Introduction

In Australia, chronic diseases are seen as having reached epidemic proportions (AIHW 2001). Chronic diseases or illnesses range from seasonal hay fever through to serious life-threatening illnesses. While most people with chronic illnesses are elderly, there are also younger people with congenital illnesses as well as those who have become ill following serious traumas, including those caused by road accidents. They are estimated to be 80% of the total burden of disease, mental problems and injury, measured in disability-adjusted life-years (AIHW 2001).

Recently, Australian policymakers realised the value of integrated models of care for chronic illnesses, where a multidisciplinary or systematic approach is adopted (Dept of Human Services 2000). Wagner et al (1996) considered the distinctive characteristics of chronic illness and identified the core attributes required in any models developed to address the needs of people with chronic illnesses. These include the adoption of care plans, allocation of more time by the medical practitioner and resources to reflect the needs of individuals with chronic illnesses, and access to information and programs that address behaviour change including self-management programs.

Most people with chronic illnesses report that their illnesses have a profound effect on their lives (Place 1993; Charmaz 2000; Millen and Walker 2002). Many of them experience negative reactions from their communities and workplaces and this in turn may impact on their beliefs in their ability to assist themselves, as well as producing a level of depression that paralyses them. A disempowering medical system may also contribute to a loss of confidence (Trostle 1997). Other people, for a variety of reasons, including cultural beliefs concerning an illness, may have little expectation that they could improve their ability to function by changing their own behaviour.

Chronic illnesses are by definition experienced over an extended period, if not a lifetime. The interaction between physical symptoms, beliefs and attitudes, feelings and behaviour influence the way people manage the

consequences of chronic illness. Following Wagner et al's (1996) seminal article, self-management is considered an important component in the overall management of chronic illnesses. Other things being equal, more effective self-management allows people with chronic illnesses such as asthma, arthritis, diabetes and epilepsy to feel better and to participate more fully in everyday life. To do this successfully requires a "learning" approach where the individual adopts various strategies to assist them maintain a healthy lifestyle.

Self-management and related concepts

Much of health care is self-managed with little direct involvement of health professionals. Even when health professionals are involved, self-management remains a significant component of care and treatment for most health conditions. A review of the literature shows that there are a number of terms employed to describe self-management including self-care, self-monitoring, self-help and social support. Often these are used interchangeably.

Broadly, self-management approaches focus on teaching skills so that individuals better manage chronic illness. They emphasize programs to (1) engage in activities that promote health, build physiologic reserves and prevent adverse sequelae; (2) improve interactions with health care providers and adherence to treatment protocols; (3) monitor physical and emotional status and make appropriate management decisions on the basis of self-monitoring and (4) manage the effects of illness on the person's ability to function in important roles and on emotions, self esteem and relationships with others (Van Korff 1997).

The narrow emphasis on compliance with specific treatment recommendations has been replaced with a broader focus on a range of educational self-management programs where a person learns more about their own illness, its treatment, and a range of coping strategies (Lorig et al 1993; 1999a; 1999b; 2000, Gonon 1999; Barner et al 1999; Lahdensuo 1999). These approaches include information, developing action plans, self-monitoring, undertaking exercise where appropriate, adapting emotionally to changed circumstances, interacting with health professionals and accessing services and support. Lorig et al (1993) contribute to the view that self-management refers to formal processes of learning, by arguing that effective self-management enables people to adapt to their circumstances through newfound skills. Self-management programs aim to improve health outcomes through supporting, rather than replacing, medical care.

On the other hand, self-help is the term more likely to be used by those writers who emphasize the value of psycho-social support and the benefits gained through self-governing groups (COSHG, 1998). Self-help is often associated with support groups formed when people's needs are not met by health professionals (COSHG 1998). Two main characteristics of self-help groups are that members share a life condition or situation that gives rise to shared needs, and control of the group remains in the hands of group members (Thorman, 1987, quoted in ACCV 1992). While providing mutual support in its widest sense, they may also run formal self-management courses and employ the services of health professionals to deliver them. They may provide ongoing self-management in the form of information days, health professionals as guest speakers and exercise sessions (COSHG 1998, WISH 1998, ACCV 1992).

Theoretical basis for the introduction of self-care, self-management and social support

Self-management approaches which focus on teaching skills to better manage chronic illness generally have their origins in value expectancy theories (e.g. Edwards 1954, 1961). These include the Theory of Reasoned Action (Ajzen & Fishbein 1969), the Health Belief Model (Maiman & Becker 1974) and social learning theory (Rotter 1954; Bandura 1986). The likelihood of effective self-management is seen as a function of the person's current experience of their illness and their knowledge, attitudes and beliefs (i.e. values and expectancies) about any self-management action they might take. In effect, current values and expectancies mediate the likelihood of future behaviour and the impact of behaviour when it occurs either confirms or contradicts current values and expectancies. This reciprocal process leads individuals to develop generalized expectancies about their capacity to manage their own chronic illness. Individuals who have a greater expectation that they can manage are seen as having greater 'self-efficacy' (Bandura 1986).

Value expectancy theory has also been influential in developing strategies to directly address the effects of pain and discomfort associated with chronic disease. Pain and discomfort often lead to negative appraisals, inaction and feelings of hopelessness and depression. Value expectancy theory predicts that techniques which change negative thoughts will lead to more positive feelings, greater use of coping strategies and increased perceptions of self-efficacy, control or empowerment.

Programs to improve self-management of chronic illness therefore focus on enhancing perceptions of selfefficacy and control. This is done through persuasion, observational learning and direct experience (practice). Persuasion involves the presentation of knowledge, information and argument about the relationship between chronic illness symptoms and their effects and strategies to better manage them. Observational learning occurs when individuals observe how others with whom they identify manage chronic illness. This often involves peers modeling successful coping strategies and providing feedback on the effectiveness of these strategies. Individuals can also gain direct experience of particular self-management strategies through carefully planned, reinforcing practice. As individuals successfully adapt strategies for their own circumstances their perceptions of selfefficacy, control and empowerment increase and they are more likely to apply and generalize the skills and techniques they have learnt in their everyday lives.

The most widely researched approach to self-management has been developed by Lorig et al (1993, 1999a and 1999b) who apply Bandura's theory of self-efficacy to build up levels of personal control (or as she prefers, self-efficacy). All people, they argue, are self-managers, but there are better ways to manage than others. Which strategies and skills a person adopts are up to them individually but "what you do may not be as important as the sense of confidence and control that comes from successfully doing something you want to do." (Lorig et al, 2000: p11). Further, Lorig divides self-management into tasks to develop the skills to build up levels of personal control. Skills are required to (a) manage health care activities; (b) undertake daily activities (c) and manage the emotions associated with having a chronic illness.

Peterson and Stunkard (1989) have included the concepts of self-efficacy and mastery under the composite concept of personal control. They argue the strong correlation between health and personal control has useful applications in designing interventions for health promotion programs. A program will only produce successful health outcomes if the participants believe that the steps they follow produce those outcomes "and they have the capacity to follow them" (Peterson and Stunkard, 1989: 824).

Evidence base for self-management

Advocacy for the systemic introduction of self-management approaches as part of health care delivery rests on the evidence that self-management improves social, psychological, functional and clinical outcomes associated with chronic illness and reduces the utilization of health services. There is now a considerable literature on the impact of self-management programs on these outcomes.

With respect to functional outcomes, increased physical activity has been a focus of self-management programs. Increased physical activity is seen as having a beneficial effect on physical health and in reducing the psychological impact of chronic illness. A number of studies has demonstrated that self-management can increase physical activity for people with chronic illness. For example, Harland et al (1999) carried out a randomized controlled trial to evaluate the effectiveness of physical activity in primary care. Their results demonstrated that the more intensive interventions that linked financial incentives (vouchers to the local leisure centre) and motivational interviewing were the most effective in the short term. However, over a year these lifestyle changes were not maintained.

Another randomized controlled trial evaluated a home-based exercise program in terms of its cost-effectiveness and benefits to the client group in New Zealand (Robertson, 2001). This study found that an exercise program could be delivered by a community nurse and resulted in the reduction of falls among a high-risk group of elderly clients. It also demonstrated that its delivery by a community nurse was very cost-effective.

Lorig, in her evaluation (1999a), found that there were specific benefits such as improved exercise minutes, management of cognitive symptoms, self reported distress and fatigue, and improved social functioning. She has also demonstrated that her program can be generalized across a range of different illnesses.

Interestingly, the use of peers to model and teach self-management has become a feature of self-management programs. In the United Kingdom the Living With Long Term Illness (LILL) project implements Bandura's self-efficacy theories through lay-led self-management programs based on Lorig's programs (Cooper, 2001). When the skills are taught through modeling the behaviors, the LILL project team considers the outcomes are more powerful. Lorig's (1999a and 1999b) evaluations also support lay-led programs since her results show that positive role models increase patients' self-efficacy and confidence to manage their illness.

Not surprisingly, policy makers are particularly interested in the impact of self-management programs on health services utilization. A number of studies has examined this issue (Thoonen et al 1999; Gonon et al 1999; Lahdensuo, 1999; Fries et al 1998). Fries et al (1998) cite a range of studies including Lorig's (1993;1999a) randomized controlled trials which demonstrate that self-management has the potential to significantly lower service use. Other system benefits concern the improved coordination of services (Koontz et al 1991) and greater adherence to treatment regimens (Gallefoss and Bakke, 1999). Another claim made is that self-management will be cost effective (Thoonen et al 1999), for example, by reducing days lost through sickness (Gonon et al 1999 and Fries et al 1998).

In summary then, research largely reports positive benefits arising from self-management programs for individuals in terms of their psychosocial responses and clinical outcomes. Systems benefits such as reduced days off work and reduced service utilisation are also claimed. However, it should be noted that interventions that aim to construct more supportive social environments also produce similar results. "Social support appears to protect individuals from a variety of physical and psychological symptoms as well as contributing to benefits around mortality and morbidity...A meta-analysis of nine major cohort studies, showed that the magnitude of the effect of social support variables on cardiovascular mortality was similar to variables such as blood pressure and exercise in middle-aged white males (Olsen 1992, quoted in Martin 1998). A protective social network has been shown in several studies to be protective for cardiac recovery in both emotional and physical recovery from myocardial infarction". Research in the area of social support suggests that such consistently favourable results for self-management programs may be due to the self-selection of the participants. These methodological problems deserve further attention.

Research limitations

Many studies that have evaluated the effectiveness of self-management do not meet rigorous evaluation criteria. Lawlor and Hopker (2001) identified a number of methodological problems including the methods of recruitment used, the maintenance and sustainability of results, problems with randomization and self selection and small sample sizes that affect generalization of results.

Research designs also vary in their capacity to compare different approaches to self-management. Some studies have compared a particular program to a control group. Others have compared the effectiveness of a set of interventions with one another and with a control group. Control groups vary. In some cases controls understood they were to receive usual care. In others they understood they were on a waiting list (e.g. Lorig 1999a). In most cases, "usual care" and waiting lists were not described, making it impossible to replicate the research. Many of the studies employing randomization were too small to effectively conceal the identity of the participants from the researchers so that it was impossible to argue that results were uncontaminated. The small numbers also meant that the studies were not statistically meaningful. Nor have studies systematically examined the extent to which process variables (e.g. peer leader training, program content, program format) affect outcomes.

There are also concerns about the measurement of outcomes. For example, Lawler and Hopker (2001) considered that those studies relying on participants to self-measure outcomes (usually by questionnaire) were of low quality. Only one of the 14 studies they examined carried out blind assessment. Measurement by questionnaire is the most prevalent form. Lorig (1993; 1999), Solomon et al (2002), Harland et al (1999), Fulcher (1997) all use this form of data collection for measurement.

Although the evidence suggests that self-management principles are broadly applicable across different chronic conditions, questions about their robustness across diverse socioeconomic, ethnic and cultural settings and

groups remain. Lorig and her colleagues have developed programs for the Vietnamese and Spanish-speaking communities of the US. There are Chinese programs in Shanghai and programs proposed in Italy. Programs developed for specific cultures report similar results to other self-management programs. This requires more investigation, given that there are some major variables impacting on the health status of ethnic groups, not the least of which is the interplay between culture and health (O'Neill 2000). Social, cultural and economic factors probably have a complex impact on the effectiveness of self-management programs. This relationship has not yet been well studied in Australia.

Conclusions

Despite methodological gaps, the literature consistently reports favourable social, psychological and functional outcomes across self-management programs. Unfortunately clinical outcomes are not usually tested and functional outcomes are viewed as surrogates for clinical outcomes (e.g. pain and fatigue). There is emerging evidence that self-management programs may reduce utilization of particular health services. As a result, there is growing interest in the systemic incorporation of self-management programs into the mix of health services for people with chronic illness.

In Australia, self-management programs are available in all states. Nationally, the Commonwealth Government has recently initiated chronic disease prevention and management demonstration projects to foster self-management. Other projects have been funded by State Governments and research schemes such as the National Health and Medical Research Council. But implementation is still at the trial stage. Moreover, many of the programs currently being tested are offered on a self-selecting basis and positive results therefore will need to be interpreted cautiously.

There is a need for studies that examine the effectiveness of chronic illness self-management programs as part of the overall system of ongoing treatment and support for people with chronic illness. Studies need to examine the impact and outcomes of self-management in more diverse cultural, social and economic settings. In particular, research should now begin to examine the sustainability of self-management programs in local health systems, the processes associated with ongoing success and the impact self-management programs have on relationships between service providers and consumers.

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