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Self-Management of Chronic Conditions: Everybody's Business

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Introduction

The National Chronic Disease Strategy (NCDS)[1] is due for release in October 2005 after being presented to federal, state and territory health ministers within the Australian Health Ministers' Advisory Council (AHMAC). The strategy comprises four action areas, one of which is self-management, and this is integrally linked with the other action areas of prevention, early detection, and integration and coordination. This paper provides a definition of chronic condition self-management (CCSM) as it applies to the individual, the clinician and the health system. It also discusses the role of GPs and other health workers in using a population health approach to provide self-management support for people with an established chronic condition and people at risk of developing chronic conditions.

Self-management is viewed as a key element in the prevention and early intervention of chronic conditions, and can be applied to individuals, families, communities and populations. It fits well with public health models of prevention and the population approach. It also acknowledges that social determinants of health have a powerful influence on lifestyle behaviours and perceived choices, so that attempts to prevent and minimise the impact of chronic conditions must focus not only on individuals but also on the social determinants of health which influence their behaviours. This is everybody's business, and particularly that of the health service systems, which often shape and influence how a person responds to and manages their chronic condition.

Rationale for self-management as part of a public health approach

The leading chronic conditions (cardiovascular disease, cancer, chronic lung disease, and diabetes) share several key risk factors (tobacco use, poor diet, lack of physical activity, and alcohol use) and are strongly influenced by social determinants of health such as poverty, education, mental health and unemployment. Self-management programs offer a key strategy that can be used to prevent and better manage the range of chronic conditions and their risk factors, as well as taking into account the underlying determinants of health. Hence, population health strategies that shift towards primary intervention are crucial for the prevention and management of chronic conditions.[2]

However, existing health care systems tend to provide episodic care services in response to patient demand, often in association with acute health events, and do not necessarily encourage self-management. Currently, attempts to address many of the risk factors noted above occur within administrative and bureaucratic silos, with each developing its own strategy in isolation. A person must usually seek help from a single health professional, or else be forced to navigate a labyrinth of services provided by health professionals within a fragmented and disjointed system. Diverse and divergent structures and cultures offer few clearly established communication pathways that enable information to be shared. This often leads to duplication and waste, and ignores the possibility of a holistic approach to the person's health and wellbeing, or to the realities of their psychosocial environment.

The current system of health care focuses heavily on treating individual chronic conditions and delivering specialised disease management programs through specialist clinics. Under these circumstances of fragmented patient care, health professionals may under-treat or overlook other related (or unrelated) disorders, with deleterious consequences for the person's morbidity and mortality.[3] The person with the chronic condition is also more likely to feel disempowered within such a system, and less likely to learn effective self-management. Evidence from research on compliance and adherence supports the idea that health professionals need to change the way they interact with consumers of health services.[4] Such research has found that 30-50% of people do not comply with their treatment (medical or behavioural lifestyle changes) irrespective of disease, prognosis or setting. This suggests that health professionals need to consider and understand the person's viewpoint and potential barriers to managing their health, rather than simply dictating the treatment and expecting the person to follow it largely without question.[4]

The person's perspective

When a person develops a chronic illness and is first given a formal diagnosis, this constitutes a critical life event for them. Such a crisis has well defined characteristics.[5,6] Put simply, it is a time of emotional disequilibrium, and one that needs resolution through the learning of new skills to cope with the challenge that is presented. Once the challenge is confronted, dealt with and overcome, the person can achieve a sense of mastery, and self efficacy can grow.[7] This is the first step in developing an effective self-management approach to any clinical condition. The person's experience of chronic illness is subjective, interpersonal and social.

Self-management tasks involve an understanding of, and the ability to distinguish between, the experience of illness, levels of distress, perceived loss of wellbeing, illness behaviour, and the impaired functioning observed by others. They serve to reduce the effects of the condition or disease on the person, such as social stigma and exclusion, and decreased levels of participation in family and community, and aim to promote full personal and social wellbeing.

Similarly, the perspective of a chronically ill person's carer is unique. Caring for someone with chronic illness has a significant impact on the carer's role, and on their interpersonal relationships with the person and with others, as well as causing inevitable changes in their own careers and lives.[8]

A cognitive behavioural (CBT) approach to CCSM, as used in the Flinders model, enables the health professional to use a motivational approach in support of self-efficacy and change, as part of their interaction with a chronically ill person. It is linked with a crisis intervention model which recognises that crisis offers a unique opportunity for the person to make positive changes.[9] It also involves an important personal, emotional, social and psychological adjustment, progressing towards self-management beyond the limits of bio-psychosocial understanding,[10,11] and is therefore more meaningful for the person with the chronic condition.

Medical practitioners and allied health workers are critical partners for people faced with the diagnosis of any chronic condition. At this time, the person, their carers and family, doctors and health workers must join together as "partners in health" to develop complementary roles in the total management of the condition. Central to this is agreeing on what CCSM means and how responsibility for self-management and self-management support is shared.

Definitions of self-management

People with chronic conditions need (and want) to live effective lives in spite of their symptoms and limitations, if they are to make the most of their lives with the least possible disability and optimum health outcomes. Central to this is good mental health and wellbeing to foster positive coping skills and independence rather than dependence. Together with these goals, any definition of CCSM needs to encompass the broad spectrum of chronic conditions and to support a generic focus for action. It needs to recognise that personal risk factors for health, CCSM and health promotion are part of the same strategy.

CCSM is about how the person, the health workers and the system share knowledge and responsibility and work together to support the achievement of better health and wellbeing, as defined by the person, not by the professional. It acknowledges social, psychological, and biological impacts on self-management ability, and sets all this within a cultural context that recognises and respects the beliefs and values of the person.

Self-management is therefore a set of attributes of the *individual* who:

- has knowledge of their condition and treatment
- follows a treatment plan (care plan) agreed and negotiated with their health professionals, carers/family and other supports
- actively shares in decision-making with health professionals, carers/family and other supports
- monitors and manages signs and symptoms of their condition
- manages the impact of the condition on their physical, emotional and social life and has good mental health and wellbeing as a result
- adopts a lifestyle that addresses risk factors and promotes health by focusing on prevention and early intervention
- has confidence in their ability to use support services

This occurs within a *health system* that provides ready access to appropriate systems of self-management support which are:

- evidence-based
- adequately resourced
- endowed with staff who are adequately trained, culturally sensitive to the person's needs and who support the belief in the person's ability to learn self-management skills

Hence, for definitional purposes, *self-management* is what the person with a chronic condition (or at risk of a chronic condition) does, and *self-management support* is what the health professional and the health system do to support the person in achieving optimal self-management.

The professional assists the person with a range of tasks that promote effective self-management, based on the person's goals, wishes and capacities, by addressing and encouraging the person's participation in the key

skills of knowledge-building, problem-solving, decision-making, and confidence-building. This is achieved by addressing central tasks regarding role, emotional management, and medically related tasks, using a client-centred, holistic approach that builds on the person's capacity, strengths, resilience and dignity. CCSM involves the identification of issues, setting of goals, and commitment to action components. Hence, progress and outcomes are measurable via action plans that can be reviewed over time for process and impact by the person, helping professionals and other supports. We argue that a self-management care plan must be client-owned and client-driven in order to be effective.

We also suggest that this care plan can be incorporated into current GP chronic disease care planning arrangements,[1] as the means of promoting collaboration and partnership between the person, their GP and other health professionals, and alleviating the fragmentation of services and communication between these self-management support providers.

Conclusion

For chronic condition self-management to become an accepted and established part of health care in Australia, a range of support structures and relationships need to be developed or enhanced. Fundamentally, this also requires a shift towards building self-management capacity in the individual with the chronic condition, and placing them at the centre of action and knowledge. This involves a significant change in the behaviour of health professionals who have traditionally viewed themselves as experts. Increasing the capacity of the primary (as well as secondary and tertiary) and acute health care sectors to provide timely, coordinated and integrated chronic disease management support is essential. Promoting a partnership approach to self-management care planning is needed, with the person as an equal partner with each and all of those providing support. It also involves raising awareness in the community about managing, promoting and maintaining health and wellness, and minimising health risks as part of a population-wide approach.

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