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THE CONTRIBUTION OF CONSUMER HEALTH ORGANISATIONS TO CHRONIC DISEASE SELF MANAGEMENT IN THE CONTEXT OF PRIMARY CARE

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POLICY CONTEXT

As Australia's health system confronts the challenge of increasing rates of chronic disease, self management has gained health policy prominence. Initiatives designed to enable people to engage in active self management hold much promise for the health system and for the many individuals and families affected by chronic illness, but current approaches must be expanded to ensure self-management is supported and embedded in social, community and health system contexts. A range of community-based approaches is required – no single or uniform approach will suffice if policy is to respond to the diversity of needs and maximise health, wellbeing and knowledge outcomes.

Consumer health organisations (CHOs) constitute an existing and relatively low-cost community resource which has the potential to meet information and support needs that people with chronic illness frequently express as being unmet in the formal health system. Key national (NHPAC, 2006) and international (WHO, 2007) policy statements call for stronger integration of these organisations in primary care to build a patient-centred health system. Yet, CHOs remain under-utilised and referral pathways to them are largely non-existent. Within the context of current discussion surrounding chronic disease, self management and primary care, it seems timely to consider an argument for better integration of these organisations into the primary health care system. Our research sought to investigate the potential of CHOs as part of a comprehensive approach to self managment support in chronic disease. The overarching question was: could more people with chronic disease use and benefit from CHOs? If so, how might contact with CHOs be increased?

KEY FINDINGS

STUDY ONE, a survey of 323 people living in south east Queensland who made contact with chronic disease related CHOs, found:

- People who contacted CHOs tended to be older women of middle socioeconomic status and not in the paid workforce. Other subpopulations were less well represented.
- Patterns of CHO contact were markedly different for diabetes and arthritis, the two major chronic diseases addressed in the study. Compared with arthritis, those with diabetes contacted the CHO sooner following diagnosis and were more often referred by a health professional. The diabetes CHOs also had a higher representation of men and people from lower socioeconomic backgrounds. These differences appear to reflect the greater integration of the diabetes CHO into the health system that has occurred as a result of the Australian Government subsidy of services and products (National Diabetes Services Scheme, NDSS).
- General practice referral to CHOs was limited, with the exception of diabetes where pathways to the organisation were more clearly established.
- People who contacted CHOs did so mainly to gain information about their condition and how to manage it and to access services such as exercise classes and medical aids.
- CHO users reported that their contact with the organisation prompted them to take positive health-related behaviours: almost half said they had started to exercise or changed their diet as a result of contacting the CHO and one-third reported that CHO contact had led them to seek advice, assessment or treatment from a doctor.
- People who contacted CHOs were likely to have higher levels of patient activation (knowledge, skills and confidence to manage their chronic condition) than found in the general community. Those who had been in contact over a longer period of time tended to have greater levels of activation than those in contact for the first time.

STUDY TWO, a randomised control trial of a print-based intervention package designed to increase awareness of and access to a relevant CHO among 276 general practice patients with chronic disease, found:

- At baseline, around one in four patients with chronic disease recruited through general practice had ever contacted a CHO relevant to their condition. Patients with diabetes contrasted markedly with those with other chronic conditions: 81% had contacted a diabetes CHO at some time compared with 11% for other conditions.
- Tentative results support the delivery of the intervention package to general practice patients with chronic disease. Those with conditions other than diabetes who received the package were significantly more likely to make some form of contact with a CHO than those who did not receive the package: 41% compared with 21%. "Low intensity" contact such as reading the newsletter and discussing information received from the CHO with others were the most commonly reported forms of CHO activity.
- The intervention package did not lead to greater CHO access among patients with diabetes, most probably because of already high levels of CHO contact.
- The intervention package received strong endorsement from patients. The intervention package ultimately "reached" about half the intended audience: 54% said they had received it, recalled it and read its contents. Almost all who read it thought it would be a good idea for doctors to give the intervention package to their patients, and almost half would have liked to have received it sooner. Two thirds reported that they kept the package 12 months later.
- Receiving the intervention package did not lead to changes in chronic disease related outcomes measured in the study. Those who received the intervention package and

those who did not had similar scores in terms of mental and physical health and patient activation at all data collection points.

- Two main attitudinal barriers seem to stop people contacting CHOs. The first is the perception that their doctor provides all the care and information they need. The second is that they are currently managing and have no additional need for support or information. Among those who had never contacted a CHO, there was a commonly held view of CHOs as a "last resort". They would only be motivated to contact a CHO if they became substantially more unwell or at their doctor's direction.

POLICY OPTIONS

CHOs are a health system resource that people with chronic disease access for information, services and support with managing their condition. The potential value of CHOs is seen in the context of current health system constraints, including the standard fifteen minute medical consultation, during which GPs have limited opportunity to provide all the information, support and skills management that patients require. CHOs are very well-regarded by those who do make contact, and CHO users report engaging in key health behaviours following their contact.

Integration of CHOs in the health system, as seen in Diabetes Australia via the NDSS, appears to have helped establish referral pathways between primary health care and CHO settings. Strategies to embed other chronic disease focused CHOs in the health system are required if the benefits associated with CHO contact are to be extended to include people who are recently diagnosed, disadvantaged groups and subpopulations that typically experience barriers in accessing health care. Ensuring self-management interventions and resources are well-integrated with the formal health system is essential to maximising access, appropriateness and sustainability.

A print based intervention package to refer patients with chronic disease from GP settings to CHOs has potential with further refinements. This strategy is likely to be most efficacious in relation to chronic disease types in which there is normally little routine referral from the medical profession into CHOs such as arthritis, asthma and kidney disease.

Strategies to embed CHOs in the health system should be cognisant of the widely held perceptions that CHOs are viewed as a "last resort" and that managing health is something that takes place mainly in the doctor's consultation room. This points to an underlying disparity between current health policy orientations and community perceptions, that is, between policy advocating community supported self management initiatives and community attitudes regarding pathways in managing a chronic health condition. Any such strategy must also take into account the practicalities and constraints of the general practice setting and ensure there are clear benefits for both health professionals and patients from any referral process that is prescribed in health policy directives.

METHODS

The study involved two parts. In Study One we surveyed 323 people who had recently contacted a CHO in relation to their own or someone else's health. Our emphasis was on the reasons for, nature and perceived benefits of CHO contact with regard to people's capacity for chronic disease self management. Study Two involved a randomised control trial to evaluate a print based intervention designed to enhance access to CHOs among general practice patients with chronic disease. General practitioners recruited 276 patients who completed computer assisted telephone interviews at baseline and then 4 and 12 months later to evaluate the intervention package. The study also provided the opportunity to gain insights into why relatively few people with chronic disease make use of CHOs.

For more details, please go to the full report

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