

Information for guided chronic disease self-management in community settings.

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Abstract

The World Health Organisation's framework for innovative care of chronic diseases identifies self-management support as part of the building blocks for effective health care organisations (World Health Organisation, 2002). This project reports on initial research involving interviewing key stakeholders on attitudes to Guided Chronic Disease Self Management (GCDSM) as a step towards developing an information architecture to support guided patient self-management of chronic disease.

Few chronic disease sufferers are provided with care plans and there are few means for monitoring compliance. Self-management programmes that exist tend to be focused on specific diseases with no common information architecture and few means of sharing information across carers and between clinicians, carers, patients and their families. As patients age and accumulate co-morbidities they need to interact with the various different means that information providers have to assist them. This research-in-progress aims to identify requirements for a generic architecture for chronic disease guided self-management to assist the elderly in particular in accessing often critical information in a timely and targeted way to assist self-care.

To date consultations have been held with key stakeholder organisations and is reported here. Further research will involve patients, their carers and families,

Key-words: chronic illness, self-management, information systems

Background

Australia, like much of the world, is facing increasing health pressures with its ageing population, shortages of family and professional carers and increasing costs. Attendant with ageing is an increase in chronic illness and demands on health and aged care services. Almost everyday media carry reports of healthcare systems that are struggling. The ageing of Babyboomers is yet to significantly impact; as this cohort moves into their 60's and beyond, health and aged care services will come under even greater pressures.

Chronic illness such as asthma, dementia and coronary heart disease are the leading cause of disability and mortality (Australian Institute of Health and Welfare, 2008). There has been growing interest over several decades in CDM (Chronic Disease Management) (National Health Priority Action Council, 2006), and more recent attention to patient self-management (Australian Department of Health and Ageing, 2008). GCDSM is of particular interest for its potential to help people who are aged 65 and above with chronic illness to manage more effectively in the

community settings. The interest is associated with expectations of the likelihood of benefits including:

1. Better partnerships between patients, their carers and clinicians in the management of their conditions
2. Better guidance for patients to ensure the right information is provided at the right time and place to guide self-management
3. Clinical outcomes including a slowing of the advance of chronic conditions
4. Earlier and more timely interventions with clinical and economic benefits
5. A reduction in unplanned hospital attendances and admissions
6. A reduction in health expenditure on patients with chronic illness.

This research-in-progress involves patients, their families and care providers to identify what patients need to better manage their own conditions as well as what their clinicians and carers identify is needed for guided self-management. The stage reported on in this research involved consultation with care provider entities. The project design has been informed by earlier consultations with stakeholders.

The longer-term aim is to develop and evaluate a prototype interactive information system to assist patients to access relevant, timely and quality information to meet their needs for effective self-management.

Ageing

The proportion of the population aged 65 and over is predicted to increase from 12% to 25% by 2051 in Australia with comparable increases in the percentages of the elderly in the populations of most other countries. The numbers in this age group are predicted to grow very fast, from 2.2 million in 1997 to about 4.0 million in 2021 and about 6.3 million in 2051. Ageing is related to health issues such as declining health status, and increased costs of care (Australian Department of Health and Ageing, 2000). About one-quarter (23%) of all people aged 65 years and over have a profound or severe core activity limitation and chronic illnesses such as dementia, hypertension, asthma and diabetes are common conditions (Australian-Institute-of-Health-and-Welfare, 2007). More than fifteen million Australians are directly affected by at least one chronic disease (Australian-Institute-of-Health-and-Welfare, 2006). If these are not managed effectively in primary and community care they can progress to produce acute care episode with impacts and cost implications. Poorly managed chronic illness can progress to severe episodes resulting in premature death or blindness and amputations in the case of diabetes.

In order to respond to the rapidly increasing global burden of chronic disease, the Australian Health Ministers' Advisory Council has developed a national strategic policy approach to chronic disease prevention and care. This approach includes the National Chronic Disease Strategy and five supporting National Service Improvement Frameworks which cover the national health priority area of asthma, cancer, diabetes, heart, stroke and vascular disease, osteoarthritis, rheumatoid arthritis and osteoporosis (National-Institute-of-Health, 2000).

Self-management

Self-management has been an expectation for individuals with a chronic disease for much of the past century although the dominant model of care is one where the clinician, particularly the physician, provides advice for patients to follow. There are disease-specific associations and programmes such as for asthma, diabetes, stroke and many others that provide information and

other services for sufferers of chronic disease. There are also CDM programmes provided by community health services, Divisions of General Practice and others to better manage conditions and slow the progress of disease. There is no common approach to providing this information and it is often provider rather than consumer-driven. Social marketing is also used by health departments to encourage behaviour change and current media programmes address diabetes, obesity, alcohol abuse, smoking and gastric reflux. There is some evidence to suggest that patients with effective self-management skills make better use of health care professionals' time and have enhanced self-care (Jordan and Osborne, 2007).

The concept of self-management and its practice is changing. The availability of health information on the internet is an indication of the interest people have in independently searching for information to help them understand and cope with their health conditions. A more proactive self-management role is being promoted rather than a health care provider giving instructions and hoping the patient will adhere to them. The UK has introduced the Expert Patients Program that recognizes this change (National-Health-Service, 2007). The Expert Patients Programme is a lay-led self-management programme that has been specifically developed for people living with long-term conditions. The aim of the programme is to support people to increase their confidence, improve their quality of life and better manage their condition.

There are also devices, prostheses and assistive technologies to help people and their carers manage conditions in home and community. Telecare typically provides links with a call centre to provide an immediate response for pre-defined events. There is increasing use of telehealth either between patients and their clinicians or between clinicians such as remote or general practice clinicians and specialists for advice. Many of the technology developers have focused on the technology itself and there is an ever more sophisticated range of products available as evidenced by innovations available through the largest body in this field CAST (Center for Aging Services Technologies) in the USA (www.agingtech.org).

An essential component that has not as yet been addressed is defining a model for the information that patients need and to develop a model for capturing, managing and transmitting that information. Much of the self-management support available has been for specific conditions although many people, particularly as they age, suffer from multiple co-morbidities.

Guidance

Self-management needs to be guided to be effective and to guard against patients being misinformed or influenced by much of the poor quality information available through the Internet. Research has indicated that successful self-management is dependent on the engagement of health care professionals and failure to communicate benefit to health professionals has resulted in difficulties in engaging the community in self-management (Jordan and Osborne, 2007). Thus, frequent face-to-face contacts with the health professional are required to achieve the therapeutic goals. This is an expensive and unrealistic practice. Therefore, the substituting conventional appointments with telecare were utilized and assessed in recent years (Meneghini, Albisser, Golberg, and Mintz, 1998; Piette, Weinberger, Kraemer, and McPhee, 2001). The effectiveness of self-management by using modern technology has been indicated to be of value in reducing health expenditure (Handley, Shumway, and Schillinger, 2008), providing better disease management (JansÃ , et al., 2006) enhancing quality of care as well as reduce hospital admissions (Coye, Haselkorn, and DeMello, 2009) and providing better psychosocial support (Weinert, Cudney, and Hill, 2008).

Data gathering and results

The initial findings stem from an in-progress, qualitative research conducted in Queensland. Data was collected by interviews and will be further explored in focus groups. This phase of data collection activities involved semi-structured interviews with representatives of key stakeholder community care provider organisations. This paper provides preliminary findings of the responses of community care providers. The issues explored and the responses are listed below:

1. Awareness of federal government initiatives for GSMCI?
There was awareness of the existence of government initiatives although little awareness of the details
2. Attitudes to GCDSM?
There was strong support for example “It is about time”.
3. Barriers to GCDSM?
Barriers identified included a need for more education and for there to be better availability of information. Current CDM was hampered by infrastructure for team work and collaboration between General Practitioners, specialists and other health professional in community settings concerned with the care of a patient
4. Potential positives?
Potential benefits identified included reduced hospitalization and better disease prognosis through improved case management.
5. Risks?
Cost was identified as a major risk to GCDSM happening
6. What should happen for it to work?
A need was identified for better education for all stakeholders. A model needs to be developed of how it can work involving doctor and other clinicians. Patients need to be included in the information loop about their own care.

Discussion

The research found strong support for GCDSM amongst managers in the care provider community who were consulted. There is a paradox in that care providers are supportive of GCDSM; yet there is as yet little progress in developing national approaches for the community-based information infrastructure that will be essential to support the health professionals, carers and the patients. The Internet is a major source of information and has a plethora of health-related information however some of this can be confusing, inaccurate or even dangerous. There was a sentiment that we enjoy on-line control over many aspects of our lives including ready access to other databases that assist us but little access to our own information. An information infrastructure would facilitate exchange of information between patients and their informal and professional carers. Carers could guide patients in accessing both evidence-based information about their condition as well as aspects of their own health history so that they can develop targets and monitor indicators such as weight, exercise, blood sugar levels and spirometry.

Research has indicated that self-management needs to be guided as a partnership between patients and their care team members. This will be a challenge in community settings where there is currently little infrastructure to support case management or collaboration between providers. There are few directories of community providers, little means for electronic referrals or ensuring a carer receives all relevant details to plan and deliver appropriate care.

Further research

To date only care provider organisations have been contacted. The next stage will involve broader research with providers, other stakeholders and most importantly with patients, informal carers and families. Patient participants will be recruited to the project and a similar number will be in a control group. Invitations to participate will be issued to patients over 65 randomly identified from the registers of the community health unit of the participating Health district.

Conclusion

There has been growing interest in GCDSM and the recent development of national strategies. The research reported in this paper indicates there is support on the part of care providers for GCDSM. For national initiatives to be successful there will be a need to raise awareness, to educate both providers and patients, and to develop a means for electronic sharing of information and providing the needed guidance for patients.

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