

Multi-morbidity: a system design challenge in delivering patient-centred care

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The National Chronic Disease Strategy provides a framework to improve ‘chronic disease prevention and care across Australia’.¹ It is framed around single chronic illnesses. However, multi-morbidity is increasingly common in our ageing population. In 2010 ~13.6% of Australians were aged between 65 and 85 years and over half of these are known to have had at least five chronic conditions.² The top five co-existent conditions in Australia are cardiovascular disease, diabetes, chronic obstructive pulmonary disease (COPD), obesity, kidney disorders and cancers. By the year 2050, more than one-quarter of Australians will be aged over 65 years and consuming over 66% of the projected increased health funding.³ Is the rise in multi-morbidity prevalence the ‘elephant in the room’ that, if ignored in shaping tomorrow’s health system, will play havoc with the financing and performance of that system?

Multi-morbidity increases the complexity of both medical management and self-management. Findings of the Serious and Continuing Illness Policy and Practice Study (SCIPPS) provide evidence of the effects of multi-morbidity on self-management and suggest urgency for the development of policies that account for these effects.

SCIPPS gathered data on the lived experience of community-dwelling Australians with co-morbid chronic heart failure, complicated type II diabetes mellitus and COPD.⁴ The 52 participants aged between 45 and 85 years with these conditions and 14 informal carers lived in western Sydney and Canberra. Eighty-seven percent of participants had multi-morbidity, a figure exceeding the 70% of older Australians known to have multiple chronic conditions.²

Self-managed care or the ‘active participation by people in their own health care’ is central to the National Chronic Disease Strategy that assumes the involvement of family and/or other carers in the process of achieving ‘better patient outcomes and improved health’. However, SCIPPS findings suggest that some groups of patients, particularly those with multi-morbidity, may not achieve these goals. Additional time required to manage

illnesses, along with increased dependency on others, caused patients to reduce or neglect some health needs. Multi-morbidity, particularly with comorbid depression, jeopardised participants’ capacity to modify lifestyle factors such as reducing alcohol intake or increasing daily activity levels, the capacity to recognise the signs and symptoms of a single illness that affected the participants’ decision making and help-seeking behaviours, and the capacity to manage multiple medications.⁵ The interactions between various chronic illnesses multiplied the complexities of self-management to the degree that in some cases self-management may have been detrimental to the participant’s health. Reduced capacity to self-manage frequently resulted in depression and the interplay of symptoms sometimes caused patients to withdraw from otherwise helpful programs.

Effective self-management may contribute to secondary prevention. Participants with multiple chronic illnesses, particularly older participants and migrants, were frequently overwhelmed by the requirements of self-management, and experienced increased confusion and additional costs related to self-management.^{5–7}

Economic hardships associated with self-management of multiple chronic illnesses arose through the accumulation of related out-of-pocket expenses.^{6,8} A single chronic illness, type two diabetes mellitus for example, might require lifestyle changes such as dietary modification and exercise, neither of which are covered by financial rebates, and might not of themselves cause undue financial pressure. However, compounding incidental expenses associated with the self-management of several illnesses, such as home oxygen in the case of comorbid COPD, the out-of-pocket costs multiply. The Medical Benefits Scheme, Pharmaceutical Benefits Scheme and Medicare rebates do not cover all expenses, leaving some patients with challenging out-of-pocket expenses.⁸

Although informal family carers minimise the financial and workforce pressures on the public health system, this comes at a cost to the carer. Fifty-seven percent of the SCIPPS carers were managing their own chronic condition and 71% of the carers were

the spouse. Increased dependence among spouses through undertaking a caring role sometimes resulted in resentment and marital stress.⁷ Carer self-neglect and conflict arising between the carer and the care recipient added further tension to the already demanding situation of caring for a family member. SCIPPS found that some policies designed to support carers did not actually meet their goal.⁷ One example of this is the Carer Eligibility and Needs Assessment (Revised), which overtly assesses the carer's needs arising through the caring process. However, the assessment is based on the care recipient's needs in the first instance and therefore continues to overlook the carer's needs.

Current related policy assumes that the existence of family members equates with capacity to undertake an informal carer role. SCIPPS found that in some cases, family members had to leave the workforce or reduce their paid working hours in order to assume the caring role.⁸ As this burden is incompletely compensated by Centrelink, some participants reported resulting economic hardship^{5,8} and frustration caused by role and financial adjustment, compounding the pressures inherent to the carer role. Geographic distance between family members contributed to escalating stress levels as family attempted to care for patients *in absentia*. This situation provides another example of co-existent yet mismatched health and social policy failing some Australians with multi-morbidity. Synergetic health and social policy have a greater chance of resulting in effective protocol that is beneficial to those whom it is intended to serve.

Psychological distress arises through progressive loss of independence, self-esteem, self-identity and sense of agency as chronic illnesses increase in number and progress in severity. Several SCIPPS participants reported co-morbid depression that was exacerbated by the loss of sense of agency and reduced capacity for self-management. The potential melee resulting from some of the complexities of self-management of chronic illness is magnified with each additional illness as they and their effects interrelate one with the other. Where sufficient appropriate and accessible support is unavailable in a timely manner the generally positive concept of self-management can quickly turn sour.

Towards a solution

The National Chronic Disease Strategy recognises the role of the community in self-management and in the support of people with chronic illness, but little mention is made of the additional and complex needs of patients with multiple chronic illnesses. The SCIPPS findings have shown the importance of the interrelatedness of health literacy within a supportive community, primary healthcare services and the complexities of multi-morbidity. In addition, SCIPPS findings contribute to the evidence base underpinning policy development in the area of self-management for people living with multiple chronic illnesses and their families. Effective policy is the first step in addressing the complexity of related issues.

The infancy of Australian Medicare Locals provides a timely opportunity to develop pragmatic solutions to the growing complexity of self-management for people (and their families) with multiple chronic illnesses, into effective policy.

As they 'tackle local health care needs and service gaps ... and drive improvements in primary health care ... to meet the needs of local communities',⁹ Medicare Locals will encounter the challenges presented by people from disadvantaged groups such as those with multi-morbidity. These groups engage less with clinicians and support services for several reasons; however, their constituents remain within the Medicare Local community and continue to experience multiple and ongoing complex needs. The development of collaborative partnerships is essential for Medicare Locals to succeed in their pursuit of health improvements specific to their individual community.

The evidence-based, patient-centred Wagner Chronic Care Model (CCM)¹⁰ presents itself as a possible framework for Medicare Locals in their establishment period. After a decade of implementation in several collaborative healthcare settings around the world, a systematic literature review of the CCM¹¹ revealed that as an integrated framework, the CCM has delivered improved patient care and better health outcomes – the same goals as for self-managed care within the National Chronic Disease Strategy – across a variety of chronic illnesses including diabetes, asthma, cancer and co-morbid depression.

The CCM maintains that effective chronic illness care (the health professional contribution) and self-management (the patient contribution) results from a functional relationship between motivated patients (including the family and other caregivers), healthcare professionals and a collaborative healthcare system that articulates with active community supports and resources.¹⁰ If all elements of the CCM were applied within a community, the CCM would see a patient (with the family and carers where indicated) self-managing within a community-based support system while accessing professional medical and health services prudently. However, with its focus on single chronic illness care, the CCM falls short of addressing the real issue: many patients actually have multi-morbidity.

The bottom line to successful self-management of multi-morbidity lies in patient centredness – not a mindless parroting of the term, but a genuine commitment to putting a particular patient presenting at this point in time in the centre of what shapes management for that patient. The patient has intimate ownership of the understanding of their needs and goals, and these within their own unique multi-morbid, cultural and social milieu. These unique factors of an individual patient need to find their way into the self-management plans for that individual patient. It is not enough to complete a standard template of a care plan for a patient with diabetes and another standard template for the same patient's COPD. The interaction between the clinician and the patient must elucidate those aspects of evidence-based care for both conditions that can be incorporated into a single self-management plan tailored for that patient.

Although the collaborative approach of the CCM potentially presents part of the solution, development of this model to take specific account of multi-morbidity is required. This is no simple task, but it is something that the Medicare Local network could take an interest in. There are common patterns of multi-morbidity. Medicare Locals could take existing evidence-based guidelines for single chronic diseases and, using the multidisciplinary expertise within the Medicare Local, synthesise these to arrive at some expressions of the CCM that take account of multi-morbidity. This would be practical recognition of a patient-

centred approach to self-management. It would also be a meaningful initiative for the Medicare Locals. However, Medicare Locals have no statutory or financial authority over their member service providers and their source of funding was not as a consequence of bipartisan agreement at a federal level. A change of government could threaten the future of Medicare Locals unless they begin to exert their influence through collaborative approaches recognised as being of benefit to their members. Multi-morbidity is something all members will recognise as being relevant to their daily work. Poised for action, Medicare Locals are well placed to champion this approach.

Disclosure

The authors declare there are no competing interests.

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