

## **Co-Morbidity and the Reform Context**

In response to the escalating burden of chronic illness in Australia, the Council of Australian Governments instigated the Better Health for All Initiative<sup>1</sup> in line with the 2005 National Chronic Disease Strategy (NCDS).<sup>2</sup> Central to these changes is the promotion of patient self-management and better preventive care through increased patient support to act on risk factors.<sup>3,4</sup> State and territory governments have developed policies consistent with this.

At federal, state and territory government levels, policy initiatives are primarily single-illness oriented and this is reflected in many aspects of organization, planning and delivery of health services.<sup>5</sup> While this is the case, the prevalence of multi-morbid chronic illness was estimated at 25.5% of the Australian population in 2005 and 29% of people who attended a general practitioner (GP) during that year.<sup>6</sup>

A notable omission of current chronic disease policies in Australia is the acknowledgment that patients with chronic illness tend to have co-morbid conditions, the prevalence of which increases with age.<sup>7,8</sup>

## **The Serious & Continuing Policy & Practice Study**

The Serious and Continuing Illness Policy and Practice Study (SCIPPS) is a five-year National Health and Medical Research Council funded study which commenced in 2006 with the following aims:

- to improve the health outcomes of those suffering from chronic illness,
- to reduce unnecessary hospital admissions of this group, and
- to develop more effective preventive strategies.

Stage 1 of SCIPPS involved a qualitative study of patient (and carer) experience of living with and managing, and health professional experience of managing, chronic illness. Patients recruited to the study were aged 45 – 85 and had one or more of the following chronic conditions – chronic heart failure (CHF), diabetes, and chronic obstructive pulmonary disorder (COPD).

This research was supplemented by epidemiologic reviews of the index conditions within the Australian environment and literature reviews of the experience of people living with CHF, as well as a policy diffusion study.

Stage 2 of SCIPPS built on results of the qualitative study and included surveys of older adults living with chronic conditions, evaluations of models of chronic disease management, and a study focusing on Indigenous Australians living with chronic conditions.

## **SCIPPS Findings**

Findings discussed in this section are detailed in the following publications:

- Jowsey T, Jeon Y-H, Dugdale P. Glasgow NJ, Kljakovic M, Usherwood T. Challenges for co-morbid chronic illness care and policy in Australia: a qualitative study. *Aust New Zealand Health Policy* 2009; 6: 22.
- Jeon Y-H, Essue B, Jan S, Wells R, Whitworth JA. Economic hardship associated with managing chronic illness: a qualitative enquiry. *BMC Health Serv Res* 2009; 9: 182.
- Yen L, Gillespie J, Jeon Y-H, Kljakovic M, Brien J, Jan S, Lehnbohm E, Pearce-Brown C, Usherwood T. Health professionals, patients and chronic illness policy: a qualitative study. *Health Expect* 2011; 14(1): 10-20.
- Essue B, Jowsey T, Jeon Y-H, Mirzaei M, Pearce-Brown C, Aspin C, Usherwood T. Informal care and the self-management partnership: implications for Australian health policy and practice. *Aust Health Rev* 2010; 34: 414-422.
- Yen L, McCrae I, Jeon Y-H, Essue B, Herath P. The impact of chronic illness on workforce participation and the need for assistance with household tasks and personal care by older Australians. *Health Soc Care Community* 2011 19(5): 485-94.

### ***Patients and Informal Carers Managing Chronic Illness - Challenges Posed by co-Morbidity***

Fifty-two patients and 14 family carers participated in the SCIPPS qualitative study into the experience of living with chronic illness. Most of the patients interviewed by SCIPPS had co-morbid conditions; several carers did, too. Of the 52 patients interviewed, 45 patients (87%) indicated they had more than one chronic illness. Furthermore, without being prompted 55 of the 66 patients and informal carers interviewed raised co-morbidity as a complicating factor in their experience of chronic illness; in response to prompting, a further 2 patients discussed co-morbidity as a complicating factor. Focus group discussions of health care professionals (n=63) found that health care professionals thought co-morbidity was a major determinant of the capacity of patients to self-manage their chronic illness.

Patients, informal carers and health care professionals found that co-morbidity influenced the capacity of patients to self-manage their chronic illness by impacting on patients' capacity to:

**1. act on risk factors** - patients and informal carers reported co-morbidity created barriers to patients acting on risk factors (defined as variables known to increase a person's risk of illness or deterioration). Many patients found it difficult to maintain a healthy diet. Clinical depression was a common co-morbid condition that reduced patient motivation to follow a healthy diet or exercise. For some patients co-morbid conditions such as arthritis delayed completion of rehabilitation programs or caused them to withdraw from the program.

Health care professionals reported that co-morbid conditions reduced the usefulness of rehabilitation; premature withdrawal of patients from rehabilitation programs due to co-morbid conditions was costly, as was extended participation in programs, which was perceived as creating further resource restraints explained in a system already under considerable strain.

This perception explained why health care professionals deterred people with multiple conditions from staying in rehabilitation programs

**2. recognise the signs and symptoms of illness and of exacerbations** - co-morbidity made it difficult for patients to recognise signs and symptoms of the index condition, especially early warnings of an exacerbation. Learning about the features of both their index condition and co-morbid conditions took much longer and was much more complicated than simply learning about the features of a single condition. Patients indicated they learnt how to recognise signs and symptoms of exacerbation by applying information gained through various sources (written sources, conversations with health professionals, friends and family) to their personal experience in a process of trial and error.

Health care professionals agreed with patients and informal carers and thought the difficulty recognising signs and symptoms of exacerbations was a particular problem for people with limited health knowledge. They added that when patients did correctly identify new symptoms they did not always know how to respond and so ended up in hospital or suffered unnecessarily at home. For example, when a patient with both heart disease and lung disease develops swollen ankles they have to decide if they think this symptom is due to their heart condition or their lung condition, and then what to do about it - should they call the doctor, should they do nothing and watch and wait, or should they go to hospital?

**3. manage medication** – of the 45 patients with co-morbid conditions, 38 received treatment with medication for at least one of their conditions and 20 patients were prescribed seven or more medications, each with their own daily regimen. Patients found managing medication for their numerous conditions to be complicated, time-consuming, inconvenient and confusing, and they raised concerns of insufficient knowledge about drug-interactions and side effects. Many patients had limited knowledge and understanding of their medication and were not able to differentiate between them. However, patients noted the complex process of finding suitable medications to manage their conditions often required good communication with health care professionals, which in turn depended upon patient awareness of signs and symptoms of their numerous conditions.

Health care professionals raised other elements influencing medication compliance (patient honesty or recall/forgetfulness about medications they were actually taking; financial constraints and the cost of filling scripts). Several health care professionals indicated that medication management and non-compliance were particular problems with patients with mental illness. Health care professionals also suggested that lack of awareness by health care professionals and patients concerning risks involved in using multiple medication brand names could lead to patients unknowingly taking doses higher than prescribed or doubling up unawares, taking the same drug prescribed using a different brand name.

## **Recommendations**

To facilitate self-management, patients will benefit from increased access to information that addresses the links between co-morbid conditions.

Health care professionals suggested that better access to mental health care providers could improve medication management for patients with co-morbid mental health problems.

Patients, informal carers and health care professionals suggested that the capacity to manage medication could be improved through increased education, patient engagement and good communication between patients and their health care professionals.

### **Confirmatory or Novel?**

#### **1. Co-morbidity diminished patients' ability to act on risk factors - CONFIRMATORY**

**This finding has been noted in the literature.**<sup>9-11</sup>

##### **Recommendations**

Future management strategies and guidelines should be informed by dialogue between patients and professionals as well as lessons learnt in studies addressing specific comorbidities clusters.<sup>12-15</sup> One solution to the challenge of maintaining an exercise regimen would be for cardiac and pulmonary rehabilitation programs to undergo redesign, catering to the needs of COPD and CHF participants with common co-morbid conditions such as arthritis.

Policy interventions that offer incentives to rehabilitation programs could effectively initiate the required changes to increase the programs' capacity to meet more common combinations of comorbid conditions. The success of this solution will depend on the increased understanding of comorbidity among health care professionals and increased communication among specialities.<sup>15</sup> Existing initiatives such as the Chronic Disease Management Medicare items facilitate communication among specialties and increasing their uptake will benefit patients with co-morbid illness.<sup>16</sup>

#### **2. Co-morbidity made it difficult for patients to identify signs and symptoms of an exacerbation of an index condition – CONFIRMATORY BUT NOVEL REASON**

Kerr, Heisler, and Krein et al. (2007) found complications occurred when patients prioritised the self-management of one condition over another.<sup>11</sup> However, our findings suggest it is the complexity of the knowledge required and the confusing nature of the symptoms that prevent patients from recognising physical and psychological changes.

##### **Recommendations**

The ability to recognise signs and symptoms of each illness is an important aspect of self-care and care planning<sup>17,18</sup> and patients may benefit from policy that promotes patient health knowledge through self-management planning. Much written patient information provided in primary care settings is disease-specific. Many non-government organisations are orientated towards single diseases or organs (e.g. Diabetes Australia or the National Heart Foundation). Recent policies such as the 2005 NCDS<sup>2</sup> focus on common single conditions rather than co-morbidity. All these observations reflect the dominant disease silo orientation of current Australian policy and practice.<sup>17,19</sup>

#### **3. Co-morbidity interfered with patient capacity to manage their medications and adhere to medication regimens – CONFIRMATORY**

This was made worse by polypharmacy, poor medication literacy or confusion about regimens, and financial pressure.<sup>20-23</sup>

### **Recommendations**

Patients may benefit from medication education and services that address these complications.<sup>22,24</sup> In Australia this has been addressed through a pharmacist in-home patient medication review as part of a GP care plan called the Domiciliary Medication Management Review (DMMR). This review has had slow uptake across Australia because of pharmacist workforce shortages, pharmacists needing to be accredited before they can access the item, insufficient financial incentives for doctors, insufficient collaboration between pharmacists and GPs and insufficient promotion of the item.<sup>25</sup> These factors need to be addressed to support the needs of patients who have co-morbid conditions.<sup>25,26</sup> None of the participants in our study mentioned the DMMR, which might reflect the initiative's shortfalls.

**Research is now needed** to address how best to manage specific combinations of illnesses that are known to be co-morbid and highly prevalent. This kind of research may suggest modifications to the existing chronic care models and will inform policy initiatives at national and state levels that aim to improve patients' capacities to act on risk factors, knowledge of signs and symptoms, and capacity to manage medication.

### ***Economic Hardship Exacerbated by co-Morbidity***

Patients (n=52) and informal carers (n=14) experienced ongoing financial pressure due to high costs involved in the treatment and management of chronic illness (ie out-of-pocket costs) as well as the affordability of additional necessities required for the management of the illness, such as healthy food, exercise and gym memberships and joining social activities. Patients and informal carers commonly expressed the view that maintaining a healthy lifestyle is more expensive.

Our analysis found that a number of factors influenced economic hardship, one of which being the presence of 'co-morbidities' or 'multi-morbidities'. Put simply, economic hardship was exacerbated when patients had co-morbidities or multi-morbidities with the cost of illness management increasing as more illnesses were being managed.

### **Confirmatory or Novel? NOVEL**

This study adds to previous research by identifying a potential risk group for whom the impact of economic hardship on their management of chronic illness was reported as greater relative to others in this study. The groups most at risk included those who are: not in paid employment; on multiple medications; experiencing co-morbidity; from culturally and linguistically diverse (CALD) or Indigenous backgrounds; and/or not eligible for government subsidies and financial support (e.g., low income employees or an income bracket neither sufficiently low for government subsidy eligibility nor high enough to afford necessary expenses; or self-funded retirees without good cash reserves).

### ***Compliance Failures and the Ability of Patients to Follow Recommended Treatment and Self-Manage – Health Care Professionals Views***

Focus groups of doctors, nurses, allied health staff and pharmacists (n=88) investigated health professionals' reactions to patients' and informal carers' perceptions of health issues which related to the difficulty managing their chronic illness in three areas: economic hardship;<sup>27</sup> the complexity associated with managing co-morbid conditions;<sup>28</sup> and multiple competing demands inherent in balancing illness and its management with the desire to lead a normal life.<sup>29</sup>

Health care professionals often described the patient experience as a series of failures relating to compliance or service fragmentation, and while some thought this was a result of individual shortcomings, most identified structural and attitudinal issues.

When discussing compliance, all groups of health care professionals recognized that patients often received inconsistent and contradictory advice from the health professionals involved in care. GPs described their frustration managing co-morbidity when other professionals give patients alternative information and strategies, and nurses and allied health professionals identified the confusion felt by people with multiple conditions when they received conflicting or different advice from professionals.

### ***The Effect of co-Morbidity on Workforce Participation***

A survey of a random sample of 10 000 National Seniors Australia members carried out by the SCIPPS team in August/September of 2009 asked respondents about their chronic illnesses along with their age at diagnosis. Additionally, participants were asked about their need for assistance with everyday household tasks and personal care.

#### Chronic Illness, Co-Morbidity, and Age at Retirement

The SCIPPS survey found that people with more chronic illnesses prior to retirement were more likely to retire earlier and more likely to retire due to ill health: 12.0% of retirements among those with no chronic disease were due to ill health, while among those with three or more chronic diseases 34.2% of retirements were due to ill health. Each additional chronic illness present at the age of 50 reduced working life by a year, and each present at age 60 by 0.7 years. Diabetes, arthritis and depression were significantly related to earlier retirement.

#### Chronic Illness, Co-Morbidity, and Part-Time Work

Furthermore, an examination of the subset of respondents working part-time aged under 70 (26% of all respondents under the age of 70) found that as the number of chronic conditions increased, more people working part time chose to do so because of their health: 6.5% of people with one chronic condition worked part time because of ill health but 47.7% of people with five or more conditions who worked part time due to ill health.

Almost all respondents aged over 70 (89.2%) were retired so they were not included in the analysis.

#### Chronic Illness, Co-Morbidity, and Need for Assistance with Household Tasks and Personal Care

When participants were asked to specify categories of assistance they needed (personal care, getting around, prepare meals, shopping, house work, gardening), we found that number of diseases,

adjusted for confounders, was positively related to all categories of assistance needed except personal care.

### **Confirmatory or Novel?**

#### **Chronic Illness, Co-Morbidity, and Age at Retirement and Part-Time Work - CONFIRMATORY**

The study confirms the findings of earlier studies<sup>30-32</sup> showing people with chronic illnesses are less likely to be in the paid workforce. It also shows that people with chronic illness are almost three times as likely to retire because of ill health as people without a chronic illness. In contrast to previous studies where neither the chronic diseases nor overall health status of the respondents necessarily relate to time prior to retirement, this study more closely links the time of diagnosis to the decision to retire.

This study explicitly collected information on the age at retirement and age of identification of chronic illnesses, and while it is not possible to prove causality between the presence of a chronic illness and age of retirement, the argument for the causality is stronger as the illness was known to be present when the retirement decision was taken.

Despite this caution, this study shows not only that chronic illness is linked to earlier retirement, but that each additional chronic disease diagnosed prior to age 50 leads, on average, to a 1-year reduction in working life, and for those experiencing a chronic disease before age 60, each additional disease leads to 0.7 years reduction in working life. Broadly, as the number of chronic conditions increases, so does the likelihood of being out of the workforce.<sup>30,33</sup> For the surprisingly small percentage of respondents who moved to part-time work because of ill health, the pattern remained: the greater the number of chronic conditions, the more likely it was that the person had chosen part-time work for health reasons. While the study sought information about decisions to work part time, it did not explore whether respondents had moved to less demanding, but still full-time, work.

#### **Chronic illness, Co-Morbidity, and the need for assistance with household tasks and personal care – NOVEL IN AUSTRALIAN CONTEXT**

The study showed people with more chronic diseases had a greater need for assistance in their day to day lives, and while few needed assistance with personal care matters like eating and cleaning teeth, five times as many needed help with shopping and 10 times as many needed help with housework. Furthermore, the dominant load carried by partners in these situations lends further support to ensuring that partners in particular are adequately supported to carry out care-giving roles. **While the direction of the results may not be surprising, to our knowledge this is the first Australian study to measure these effects.**

#### **Depression/anxiety**

Depression/anxiety was strongly related to both earlier retirement and to the need for assistance with everyday tasks. While people with diabetes were likely to retire earlier, they did not have similar needs for assistance. This may illustrate differences in type of need associated with each illness, but as depression is both a chronic illness and an acknowledged co-morbidity for many other chronic

illnesses, further work is needed to understand its independent or related impact on self management capacity.

#### Impact of Caring on Workforce Participation

These results support the view that chronic illness may affect paid work participation for people other than the person with chronic illness. Women in particular retire earlier to care for others. A 2009 House of Representatives standing committee report on carers, "Who Cares", suggests that many carers want to enter or remain engaged in the workforce. Carers stated that employers' commitment to work life balance evaporated when faced with requests for flexible work to care, particularly for older carers or when caring for older people.

#### ***The Effect of co-Morbidity on Informal Carers***

Analysis of interviews of informal carers (n=14) show that informal carers assume a number of roles in the self-management partnership with their care recipient. These were: home helper; lifestyle coach; advocate; technical care manager; and health information interpreter.

#### *Emphasized Informal Carer self-neglect*

The aforementioned roles of caregiving often combine to create a demanding and exhausting 'job' for informal carers, with the demanding and exhausting nature of caregiving contributing to informal carers neglecting their own needs. The presence of co-morbidity or multi-morbidity leads to emphasized informal carer neglect.

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