



# The experiences of patients and carers living with multimorbid, non-communicable diseases



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## Background

Non-communicable diseases (NCDs) are increasing in prevalence and straining health systems globally. This creates a so-called 'burden of disease', which can be traced in terms of fiscal health system matters and in terms of quality of life and lived experiences of people with NCDs. The United Nations has called for a global agenda to manage NCDs and reduce their burden.

## Objectives

The purpose of this article is to summarise key findings from the Serious and Continuing Illness Policy and Practice Study concerning patients' and carers' experiences of multimorbid NCDs in Australia. We focus on the relevance of findings for policy and general practitioners in Australia.

## Discussion

We suggest that a complex multimorbidity policy is needed to contextualise and guide single-illness NCD policies. Our research suggests that specialist NCD nurses and allied health professionals could have important roles in improving care coordination between general practices and community health centres.

**NON-COMMUNICABLE DISEASES** (NCDs), such as coronary heart disease, stroke, cancer, musculoskeletal disorders and mental illness, among others, are increasing worldwide and account for 63% of deaths worldwide.<sup>1</sup> In Australia, the prevalence of comorbid and multimorbid NCDs is high.<sup>2</sup>

The origins of NCDs lie deep within the social, political and economic structures of society. International concern led the United Nations (UN) General Assembly to convene a high-level meeting on the prevention and management of NCDs in September 2011.<sup>3</sup> The UN's only previous discussion on health was on acquired immune deficiency syndrome (AIDS) in 2001.

The UN General Assembly set out to 'adopt a concise, action-oriented outcome document that will shape the global agendas for generations to come'.<sup>4</sup> The outcomes document was a political statement, which, although not binding, is a powerful tool for achieving international cooperation and action. The UN directed the World Health Organization (WHO) to implement its resolutions. The WHO identified three principal fields for action – cultural, economic and educational<sup>1</sup> – and established goals, targets and monitoring mechanisms. However, the challenge is almost overwhelmingly difficult. Indeed, when preparing for the 2018 high-level meeting to assess progress, a WHO report in November 2016 noted:<sup>5</sup>

*Globally, premature mortality from these four main NCDs [cardiovascular diseases, cancers, chronic respiratory diseases*

*and diabetes] declined by 15% between 2000 and 2015. These improvements are estimated to be mainly due to reductions in cardiovascular and chronic respiratory disease mortality. Under a business-as-usual scenario (without scaling up efforts significantly) this rate of decline is insufficient to meet the [goal to] reduce premature mortality from NCDs by one third [by 2030]. This is the key message to frame the discussions during the preparatory process leading to the third UN High-level Meeting on NCDs in 2018.*

Prevention is difficult because it requires action regarding the social determinants of health. Additionally, organising care for patients with NCDs is complex and costly. Multimorbidity adds another layer of complexity. Here, we refer to complexity in terms of layers of complications and the difficulties it brings to the patients' or carers' experiences, rather than complexity theory, despite their obvious similarities in terms of non-linearity and change.

The complexity around organising care for patients with NCDs is reflected in NCD multimorbidity literature. Part of the complexity is often framed as a result of the sheer number of illnesses, each with its own management regimen.<sup>6-11</sup> The number of illnesses almost certainly influences overall lifestyle and management capacity.<sup>12</sup> Harrison et al suggest that a person with three or more discrete NCDs is likely to have complex care needs.<sup>7</sup> They proposed the term 'complex multimorbidity' to differentiate between such patients and those with two NCDs, or with NCDs in the same 'system'

or 'domain' (see below) and with less need for complex care. Because the number of chronic conditions increases with age, the average Australian aged 75 years with an NCD can expect to have illnesses in three or four domains.<sup>6</sup>

Another layer of complication presents as NCDs that are commonly reported in physiologically unexpected specific comorbidities, such as heart failure and depression.<sup>9,12</sup> Such pairings are referred to as being within the same 'system' or 'domain',<sup>6</sup> and as being either concordant (ie diabetes and obesity, diabetes and chronic kidney disease) or discordant (ie diabetes and asthma, diabetes and depression).<sup>13,14</sup>

Finally, the complexity is detailed in literature concerning patients' experiences<sup>15-17</sup> and the impact of multimorbidity on quality of life.<sup>18</sup>

### Serious and Continuing Illness Policy and Practice Study

In 2008, the Menzies Centre for Health Policy at the Australian National University and University of Sydney embarked on a study to examine the experience of patients with NCDs in Sydney's western suburbs and Canberra. The Serious and Continuing Illness Policy and Practice Study (SCIPPS), funded by the National Health and Medical Research Council, sought to explore the major challenges to patients and their informal (usually family) carers in managing and living with a chronic disease. The purpose of this article is to summarise key findings from the SCIPPS around patients' and carers' experiences of multimorbid NCDs in Australia, and to discuss their relevance for general practitioners (GPs) and policy.

In designing the study, patients with chronic respiratory problems and/or cardiovascular disease (especially heart failure) and/or diabetes were invited to participate. Data from more than 60 interviews provided detailed insights into the:

- physical and emotional demands on patients and carers
- economic consequences of chronic illness, where patients and carers had necessarily ceased paid employment

and where social security benefits did not cover the full costs of care

- misery and social isolation resulting from limited mobility, pain, breathlessness and weakness.

Most participants had more than one NCD. Many of those who lived at home were cared for by family members or friends who, themselves, suffered from one or more NCDs.

### Specific troubles raised by multimorbidity

Eighty-seven per cent of respondents had more than one NCD.<sup>19</sup> Having more than one NCD made it more difficult for respondents to control contributory factors and health-preserving behaviours, especially exercise.<sup>20</sup> In addition, having more than one NCD complicated the recognition of early symptoms or signs of deterioration of each condition (eg swollen ankles, indigestion), and managing multiple medications was not always easy.<sup>15</sup> Almost half of those with more than one NCD reported being on >20 prescribed medications, each with its own regimen, side effects, and dietary and other restrictions. Not surprisingly, they found medication management 'complicated, time-consuming, inconvenient and confusing'.

Some NCDs are particularly arduous. Respondents with chronic obstructive pulmonary disease (COPD) or diabetes spent more time managing their health than people with other NCDs.<sup>21</sup> The type of NCD seemed to be a better predictor of quality of life than the number of NCDs. This is illustrated with COPD, an illness that typically takes more time to manage than other NCDs, and which significantly diminishes a patient's quality of life.<sup>22</sup> The high level of multimorbidity in our study reflects the high level in the broader society, as shown in recent hospital separation data (Table 1).

### Policy implications

The SCIPPS spoke to more than 100 healthcare practitioners, in focus groups and round-table meetings, about participants' experiences, and the associated management and policy issues.

The healthcare practitioners suggested that efforts to support patients and carers must encompass all facets of the impact of multimorbidity on lifestyle.<sup>23</sup>

Although chronic diseases often share common features, patients' needs differ with specific disorders and often require special care (eg diabetes, compared with chronic respiratory illness).<sup>20</sup> In planning models of care for patients with NCDs, differences and commonalities must be considered.

In Australia and New Zealand, policies for NCD management are oriented towards single illnesses.<sup>24</sup> Because most people with NCDs suffer from more than one NCD, we endorse the proposal of Harrison et al that single-illness oriented NCD policies be housed under an overarching multimorbid 'umbrella' policy – the 'complex multimorbidity' policy.<sup>7</sup>

Careful thought (and money) is needed to turn this aspiration into effective policy. Insofar as policy is the mechanism of allocating resources to achieve goals, judicious financial planning is imperative. First, appropriate models of care need to be defined and worked through with the involved professional groups, including GPs, community health workers, hospital staff and others.<sup>25-27</sup> Multimorbidity calls for different configurations of the healthcare profession, which previously served the community well in eras dominated by acute illness and episodic care. Studies concerning health service interventions<sup>28</sup> and polypharmacy<sup>29,30</sup> may also shed light on the best way forward.

Second, the resource implications of this re-fit approach must be hammered out in the larger context of general health policy and overall resource allocation. This would require political action federally to obtain appropriate attention from the federal Department of Health.

### Implications for Australian GPs

Those determining current policy and resource allocation seem not to know, or prefer not to know, what is happening on the frontline. GPs have to negotiate the divide between treating single illnesses and the needs of patients with multimorbid NCDs. GPs manage the latter

**Table 1. Patient and hospital separations with multimorbidities, Western Sydney Local Health District residents, >18 years, 2014–15**

Multimorbidities	WSLHD		
	n	%	Rate
Diabetes and COPD	441	3.5%	0.2%
COPD and cardiovascular	1,185	9.4%	0.5%
Diabetes and cardiovascular	10,358	82.0%	4.0%
Diabetes, cardiovascular and COPD	645	5.1%	0.2%
Separations with selected morbidities	12,629	100.0%	4.8%
Total number of separations (>18 years )	261,303	–	–

Source: Admitted Patient, Emergency Department Attendance and Deaths Register, NSW Ministry of Health, Secure Analytics for Population Health Research and Intelligence – courtesy of Helen Achat  
COPD, chronic obstructive pulmonary disease; WSLHD, Western Sydney Local Health District

by relaxing their specific management goals and striving to ‘maintain the status quo’.<sup>31</sup> Tackling the accompanying polypharmacy remains difficult for GPs and pharmacists, but is crucial in order to achieve better outcomes for patients. There are many publications that address polypharmacy in patients with multimorbidity, especially older people. These publications encourage regular reviews of medication, and provide evidence of surprisingly little consequence from judiciously stopping drug treatment of non-life threatening illnesses.<sup>32</sup>

One bright spot for GPs was identified in the second phase of SCIPPS. This was the possibility of improving care coordination between general practices and community health centres, where specialist NCD nurses and allied health professionals (ie nutritionists, dietitians, occupational therapists, podiatrists, others) care for patients with multimorbidities.

A SCIPPS evaluation of a New South Wales Ministry of Health program, which was designed to better coordinate such care through a specialist liaison nurse role, showed promise.<sup>33,34</sup> GPs, community health centre staff and management all reported improved coordination of services, and better integrated health and social care.<sup>35,36</sup> Defined, but flexible, policy aims and objectives assisted in establishing and meeting local needs

and priorities. These, in turn, fed into the observed improvement. Patient and practitioner satisfaction increased. The complex Australian health system, geared, as it is, towards the provision of single, acute episode care is, however, resistant to isolated attempts at local-level integration and threatens sustained long-term change.

## Conclusion

Although we have the attention and goodwill of the UN, through the WHO, to make a positive difference in NCD prevention and management, the reality remains grim for the lifestyles of many patients with multimorbidity and their carers. Advocacy on their behalf, combined with growing awareness of the inefficiency of using episodic services for a purpose for which they were not designed, could lead to change. At the heart of any proposed change should be the experience of each patient and their informal carer. It is the patients’ lives, their lifestyles and their quality of life that must be afforded primacy in any proposed way forward.

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