Financial Pressure and Economic Hardship and the Reform Context

The costs to individuals living with chronic illness in Australia and their families of treatment, management and care of their condition or conditions are cushioned ostensibly by publicly-funded health care and social security arrangements.

There is, however, growing evidence that despite substantial efforts to publicly fund essential care and support, out-of-pocket spending is financially stressful for chronically ill patients and their families, particularly those with lower incomes.¹

We know from previous work that out of pocket costs increase with additional chronic illnesses and that the poorest members of the community both have more chronic illnesses and spend a greater proportion of their income on health-related costs.²,³

Furthermore, social disadvantage is known to be associated with less access to allied health and this is thought to be related to the cost of these services.⁴,⁵ For many of individuals living with chronic disease and their families the ongoing costs lead to economic hardship.

In the context of health reforms, the final report of the National Health and Hospitals Reform Commission was sensitive to the matter of out-of-pocket costs for health care. The Report, for example, recognised that people at times do not seek necessary dental care because of cost.⁶

Additionally it recommended a review of the Medicare Safety Net arrangements and the scope of services contained under a ‘universal service entitlement’. Nothing was said about the effect of co-payments on medication compliance, however.⁶

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:


**Ongoing Financial Pressure due to Treatment and Management of Chronic Illness**

Interviews of patients living with chronic illness (n=52) and their informal carers (n=14) showed that they experienced ongoing financial pressure due to high costs incurred as a result of the treatment and management of chronic illness (i.e. out-of-pocket costs) and the purchase of additional necessities required for the management of the illness such as home modifications and assistive devices.

**Affordability of treatment**

Financial pressure resulted in patients having a limited capacity for health-related decision making and for engaging in other desired pursuits. For example, participants were often unable to follow their management plans or actively engage in secondary prevention activities due to financial constraints. Some patients prioritised essential treatment options and/or medications (i.e. some prescriptions were not filled or compliance with medication regimes was compromised).

**Affordability of other things**

The affordability of additional necessities required for the management of the illness, such as healthy food, exercise and gym memberships and joining social activities, was also raised as a concern by patients and carers interviewed. A common view among participants was that maintaining a healthy life-style is more expensive when they have a chronic problem. Consequently, participants reported limiting discretionary spending, cutting back on more expensive, healthier foods and reducing participation in regular exercise programs at a gym.
Factors that influenced economic hardship

Several factors influenced the level of economic hardship experienced by participants in the management of their chronic illness. These were:

- Eligibility for pensions and other government subsidies or allowances and access to concession cards
- Eligibility criteria of health services
- ‘Co-morbidity’ or ‘multi-morbidity’
- The health literacy of patients and carers
- Knowledge of self-care.

Eligibility for pensions, other government subsidies or allowances (e.g., pension, carer allowance, health care card or Department of Veterans' Affairs Gold Card, oxygen subsidy scheme), and/or a concession card (for additional discount rates for electricity, water and other home care services) influenced whether participants experienced economic hardship. While participants eligible for pensions or other government subsidies were grateful for these schemes, a subset of these individuals were unable to overcome economic hardship despite this support, and any additional costs not covered by Medicare or other support measures posed an economic burden on their life. Individuals ineligible for pensions or government subsidies, often due to their means-tested income exceeding the eligibility criteria, felt economic hardship severely and it was reported to impact significantly on their illness management.

Further to this, a lack of flexibility in health care services influenced whether participants experienced economic hardship because eligibility criteria were not always inclusive of those most in need. For example, to be eligible for an oxygen subsidy scheme (free, limited, oxygen support for people with COPD) patients have to be a permanent resident of the ACT or NSW.

Hardship was exacerbated when patients had 'co-morbidities' or 'multi-morbidities' with the cost of illness management increasing as more illnesses were being managed.

The level of health literacy, in terms of patients' and carers' awareness of the system and services, also played an important role in the ability to access subsidies, income support or other available benefits (e.g., free oxygen, community transport or taxi vouchers). Lack of knowledge of self-care added economic hardship, costing both the participants and the health care system.

Consequences of Economic Hardship

Participants reported the need to be extremely vigilant with expenses and to limit physical and social activities in order to minimise economic hardship and maintain capacity to act on lifestyle risk factors and balance their life and illness management requirements.

Confirmatory or Novel? – NOVEL IN AUSTRALIAN CONTEXT
This study is the first Australian qualitative inquiry that explored the economic impact of common chronic illnesses (COPD, CHF and diabetes) based on the perceptions of patients and family carers and confirms findings of earlier qualitative studies of chronic illness experiences regarding the kinds of economic hardship associated with managing chronic illness. These include the individual’s compromised ability to afford not only essential treatment and medication but also to maintain a health lifestyle and quality of life.

Moreover, in the 2008 Commonwealth Fund International Health Policy Survey, 36% of Australian participants (n=593) reported access problems (accessing physicians, filling prescriptions, or getting recommended test, treatment or follow-up) because of cost.

The NOUS-Menzies Centre for Health Policy’s national survey (n=1,200) conducted in 2008 confirmed these findings: those reporting financial stress were more likely to skip a medical test or treatment recommended by a doctor, were more likely to fail to collect a prescription or skip doses of medicine, and were less likely to access dental services when necessary.

This study adds to previous research by identifying risk groups 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 include 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).

Furthermore, our study suggests that the problems associated with economic hardship are not geographically specific and are not restricted to locations known to have higher concentrations of residents with lower socioeconomic status.

Participants discussed coping strategies to manage their ongoing economic hardship. One strategy discussed was prioritising essential treatments or living expenses, including those related to their care and management. However, participants still had to make a choice between purchasing essential treatments and medications and paying for basic living expenses as most could not afford both.

Recent Australian studies provide similar results. Hynd et al. (2008) investigated the impact of a co-payment increase for dispensing Australian Government-subsidised medicines and found a significant reduction in the patient's ability to afford essential medicines following the initiative.

Internationally there are an increasing number of studies which report often catastrophic economic consequences associated with chronic illness in low and middle income countries. Xu and colleagues in their examination of data from household surveys in 59 countries, argue that middle and
low income countries in particular ought to address gaps in their health policy in terms of available health services, health insurance, out-of-pocket payments and financial risk protection to minimise catastrophic health expenditures and potential consequences of impoverishment.16

Recommendations
The findings in this study indicate the need for further research on the nature of catastrophic health spending among people with chronic, complex conditions and its relationship with health policies in developed countries such as Australia in which such phenomenon is often overlooked. Policies should be developed that take account of the economic impact of chronic illness on sufferers and their supporters.

FUTURE RESEARCH
This research provides a platform for further research into strategies to improve the affordability of illness management, particularly self-management activities, given the significant role they play in controlling the progression of illness. In addition, it highlights a need to critically appraise current health, social and welfare policy in order to identify possible options for alleviating hard-ship. This will require the following:

1. A detailed investigation of the different dimensions of economic hardship experienced by households affected by chronic illness to measure the scope and scale of the hardship, the coping strategies employed to manage and, where possible, to overcome the hardship.

2. An economic evaluation of subsidising supportive prevention measures (e.g., food, exercise and transport) with additional funding for medical costs (e.g. medication, oxygen and health care equipment), in comparison with health care services provision for those who end up in hospital due to failures in existing primary care and social support arrangements.

3. A review of current eligibility criteria for health and social care and other support policies associated with funding subsidies for people with chronic illness, in particular those with multi-morbidity.

The findings of this study underscore the need to consider the cost of lifestyle changes required as part of chronic disease management in developing future policy to address economic hardship among people affected by chronic illness.

Further research is necessary to explore the ways in which people cope with economic hardship and prioritise conflicting demands to balance between managing chronic illness and living a normal life. Future research should focus on developing an understanding of health care decisions that are likely to cause less than optimal health outcomes and result in increased costs to the health system.

For health care practitioners these insights are fundamental to providing appropriate and flexible care for chronically ill patients and support for their families. The findings highlight the need to examine in-depth, and even to challenge, common perceptions of the economic impact of chronic illness with respect to geographic or government jurisdictional boundaries. Future policy needs to be multi-sectoral, focusing not only on clinical issues but also on the individual, their household and economic capacity to manage chronic illness.
Costs Associated with Treatment and Management of Chronic Illness Lead to Compliance Failures – 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;\(^{17}\) the complexity associated with managing co-morbid conditions;\(^{18}\) and multiple competing demands inherent in balancing illness and its management with the desire to lead a normal life.\(^{19}\)

Health care professionals often saw the patient experience as a series of failures relating to compliance or service fragmentation. Their comments on compliance failures had particular relevance to economic hardship and the ability of patients to follow recommended treatment and to self-manage.

While health care practitioners saw personal priority-setting as a key compliance factor, the view of most health care professionals was that medication and other treatment costs were prohibitive and it was widely believed that these costs lead to compliance problems with patients rationing their treatments, selectively filling prescriptions, storing partly used courses of medication for later use and, at times, sharing medications with relatives and friends.

Cost was also seen as a factor in patients’ abilities to effect lifestyle changes. Most focus groups identified the prohibitive costs of individually-focused preventive health, such as gym membership and weight loss programs. Nurses and allied health staff saw patients making choices between rival necessities: tradeoffs between paying essential bills, buying good quality food and paying for medicines. They and hospital specialists recognized that these difficulties were made worse by the perceived higher cost of purchasing recommended healthy and special food.

Health Professionals Linked Compliance to Health Literacy.
Health professionals linked compliance to health literacy – the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.\(^{20}\) They saw formal learning as crucial to the patient’s ability to make appropriate management decisions.

Confirmatory or Novel? CONFIRMATORY

All but a small group of health care professionals, irrespective of background, identified social and economic issues as key elements in patients’ compliance. Most of the professionals believed that compliance would improve with more adequate pensions and safety net arrangements for pharmaceuticals and necessary aids. The international literature on chronic care recognises the effect of these financial barriers.\(^{21}\)

Economic Hardship associated with Chronic Obstructive Pulmonary Disorder

All patients enrolled in the Respiratory Ambulatory Care Service in Western Sydney between 1 January 2001 and 31 August 2008 were surveyed to examine the household economic consequences associated with out-of-pocket spending for the care and management of chronic obstructive
pulmonary disease (COPD). The household economic consequences were measured in terms of economic hardship indicators, based on the response to two questions:

1. the household’s inability to pay at least one living or medical expense in the previous year; and
2. the household’s use of financing coping strategies in order to pay a living expense in the previous year.

Hardship was a dichotomous variable, codes as either present or not.

Of the two hundred and eighteen respondents who completed questionnaires on behalf of their household (RR = 38%), virtually all had at least one other chronic illness apart from COPD. One hundred and sixty nine respondents (78%) experienced economic hardship while managing their illness. Of all respondents, just over a quarter (27%) reported being unable to pay for medical or dental expenses; the same proportion were unable to pay rent or mortgage; 1 in 5 (18%) were unable to pay for medication; and 1 in 5 (19%) were unable to pay utility bills.

In addition, 141 (65%) households reported using at least one financial coping strategy in the past year to pay a living or medical expense. Drawing on savings was the commonest coping strategy (60%), followed by borrowing money (17%), seeking assistance from a charity organisation (13%), selling assets (10%) and, least commonly, moving house (2%).

In a comparison of respondents who indicated they experienced economic hardship and those who did not, respondents experiencing economic hardship paid more out-of-pocket overall (=AUD$544 versus =AUD$280; t148=-2.03, p=0.04) and for medications and oxygen specifically (=AUD$247 versus =AUD$125; t83=-3.98, p<0.0001). They also paid more for homecare assistance (=AUD$218 versus =AUD$156) and illness related transport (=AUD$202 versus =AUD$104). 56 (46%) respondents had catastrophic levels of out-of-pocket spending which made them 7.5 times more likely to experience economic hardship (95% CI: 1.2-46.3). Out-of-pocket burden was categorized as catastrophic when OPP costs for a period were greater than 10% of a household’s income for the given period.

**Novel or Confirmatory? CONFIRMATORY**

Despite a universal health care system in Australia, it is clear from this study that patients with COPD experience high levels of out-of-pocket spending which can impact their ability to maintain necessary living and medical expenses: 78% of patients in our sample reported some form of economic hardship and 46% were experiencing catastrophic health care expenditure. These findings support concerns raised elsewhere that the treatment for COPD and chronic illness management generally are increasingly becoming less affordable.22, 23

Higher levels of OOP spending are partly due to the presence of co-morbidity – each additional chronic condition can increase individual health care expenditure by as much as 6%.24 Co-morbidity is now the rule, not the exception,25 as seen in this study.

Within this context, worsened by increasing co-payments for medical care and medications – which have risen faster in Australian than in any other OECD country25 - and inadequate coverage for
essential self-management supports (e.g. transport, medical equipment), we have the makings of a serious social problem.

There are safety nets to cap individual levels of spending on medical care and prescribed pharmaceuticals but households often struggle well before they meet these minimum levels of spending and as a result, forego treatment. One source of out-of-pocket spending is over-the-counter medications which impose a large cost burden because they are routinely used but are rarely subsidised. In addition, substantial variation in the eligibility criteria, funding and subsidisation of domiciliary oxygen therapy across jurisdictions in Australia can result in high out-of-pocket costs for home oxygen users, as reported in this study.

While concessions for basic living and medical expenses are enshrined in the social security system, they may not be enough. Here we found that possession of a concession card (e.g. Pensioner Concession Card; Commonwealth Senior’s Health Card; Health Care Card) did not protect households from experiencing hardship or a high out-of-pocket burden. This calls into question the adequacy and breadth of support provided by these programs, particularly for those who are retired and those with low incomes – both of whom are over-represented in this study.

The development of a Health Care Card specifically for the chronically ill, not income tested, may better meet the diverse needs of this low-income sub-group.

Identifying the particular types of expenditures that contribute most to the high out-of-pocket burden experienced by the chronically ill will also point to options for improving the available support.

A household’s first response to high health care costs is often to mobilise savings, followed by a combination of selling assets, borrowing money and labour substitution within the household. Dealing with catastrophic health expenditure can cripple a household’s economic wellbeing and diminish their ability to cope with future health shocks.

Policy interventions must strengthen protections for the household unit, especially low income groups such as the retired. They should support households to cope with the double jeopardy that chronic illness often poses: increasing health expenditure at a time when individuals are also experiencing a reduction in productive labour.

References


