

The Cost of Chronic Illnesses for Rural and Regional Victorians

**Christine Walker and Jo-Anne Tamlyn
Chronic Illness Alliance 2004**

Funded by the Reichstein Foundation

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Executive summary

This report presents the findings of the 'The Cost of Chronic Illnesses for Rural and Regional Victorians' project. The project was conducted in two stages. The first stage was a series of public consultations in regional Victoria. The results of the public consultations were used to develop a questionnaire survey that was used in the second stage of the project.

The project was unique because it examined *all* the health costs associated with having family members with chronic illnesses.

The questionnaire survey results represent the experiences of 381 rural and regional households with at least one member with a chronic illness. The households comprised 1626 people, of whom 507 had chronic illnesses.

The results showed that households with chronic illnesses in rural and regional Victoria:

- **pay for their health needs regardless of income**
- **experience considerable poverty and financial distress**
- **believe they are worse off under the new tax system**
- **benefit greatly from having concession cards if they use a large range of health and support services**
- **spend more on Pharmaceutical Benefits Scheme and over-the-counter medications than any other health-related item**
- **greatly value access to bulk-billing GPs**
- **need access to better information, and allied health and support services**
- **find the costs of travel, telephone and utilities onerous.**

Recommendations

'The Cost of Chronic Illnesses for Rural and Regional Victorians' project clearly showed that rural and regional households caring for people with chronic illnesses experience considerable hardship and distress. Developing policies and services that acknowledge and address the reality of living with chronic illnesses would alleviate much of that hardship and distress.

All households with chronic illnesses

Many of the findings of this project reiterated the findings of the Chronic Illness Alliance's earlier 'A Concession Card for People with a Chronic Illness' project, because they apply equally to metropolitan and rural and regional households. Therefore, the following recommendations apply to all households with chronic illnesses.

- Governments, service providers and state-based health organisations should acknowledge that households with chronic illnesses are at risk of life-long poverty that decreases the quality of life of all household members. They should develop comprehensive policies and services to prevent such situations arising, and stop increasing co-payments for health-related services.
- Governments, service providers and state-based health organisations should acknowledge that poverty contributes to chronic illness by limiting access to health services, education and employment.
- Governments should address the relationship between poverty and chronic illness by ensuring that all health policies and services are based on needs rather than income. This approach would be more cost-effective than the present welfare-based approach.

Rural and regional households

In addition, specific policies and services need to be developed to cater for the particular needs of rural and regional households with chronic illnesses.

- The Australian Government should extend the availability of bulk-billing GP services in rural and regional areas.
- Governments should acknowledge that rural and regional households with chronic illnesses need access to regional allied health services and support services, and develop a comprehensive and co-ordinated system of appropriate services.
- Governments should revise all utility concessions, including energy and telephone, to take account of the additional costs faced by rural and regional households with chronic illnesses.
- The Victorian Government should revise the Victorian Patient Transport Assistance Scheme so it operates on the basis of need and improving access to health services rather than on welfare principles. It should also remove the travel co-payment and provide a realistic accommodation allowance.

- Governments should provide better information about health policies and services, such as the Pharmaceutical Benefits Scheme Safety Net and energy concessions, to people in rural and regional areas.
- Governments and service providers should provide better information about health-related support organisations, such as the Cancer Council of Victoria and Asthma Victoria.

Further research

Further research into the issues facing rural and regional households with chronic illnesses is needed to facilitate the development of better health policies and services. Immediate research is needed:

- to investigate the relationship between poverty and financial distress, and the real cost of health care for households with chronic illnesses
- to investigate the long-term social and financial effects on all household members of caring for family members with chronic illnesses
- to determine the 'poverty threshold' for households with chronic illnesses which takes into consideration the costs of chronic illness
- to determine the extent of the social and financial buffering effects of having access to a concession card on households with chronic illnesses
- to determine the buffering effects of better community integration through employment, community involvement and educational opportunities on households with chronic illnesses.

1. Introduction

1.1 Previous work

In 1997, the Chronic Illness Alliance (CIA) conducted its 'A Concession Card for People with a Chronic Illness' project ('Concession Card' project), which examined the cost of chronic illness for people who do not qualify for a concession card (CIA 1997). It found that some people on reasonable incomes lived in relative poverty owing to the cost of maintaining their health at an optimal level. Families were forced to budget on many household items in order to afford the illness-related costs of one or more family members. In those families where more than one member had a chronic illness, these costs accounted for more than 20% of total household expenditure. To cope with this, some families cut back on heating and cooking energy, or saved on food and clothing. Others shared medications or went without medications in order to afford other forms of care. It was not uncommon for parents to go without their own medications and other health needs in order to afford their children's health care needs. Most people budgeted on items, such as school camps, excursions, family outings and holidays, that other families regard as normal expenditure.

The project's findings indicated that many people with chronic illnesses live with financial distress (ABS 2002). The indicators of financial distress include seeking financial help from family and friends; going without items, such as food, clothing and utilities; not being able to afford special meals, family holidays and outings; and seeking assistance from welfare agencies. Financial distress is said to be present when two or more key indicators are present. When five or more indicators are present, the level of stress is said to be high. The Australian Bureau of Statistics (2002) estimated that one-third of Australian households experienced financial distress in 1998-99. It is likely that this figure included many people with chronic illnesses. Financial distress is usually a temporary problem for households with time-limited expenses, such as mortgages or school fees. However, for people with chronic illnesses, the costs are ongoing, so the financial distress is ongoing.

Since the CIA undertook the 'Concession Card' project, the Australian Government has introduced major tax reforms. The introduction of the Goods and Services Tax (GST) has affected people on low incomes. Furthermore, tax cuts to compensate people for the introduction of the GST have been of limited value to people with chronic illnesses on low incomes, whether the incomes be earned incomes, disability support pensions or both, because these people still face the additional costs associated with their illnesses. Many health services are GST free, but there are anomalies. Consumers who buy their own dressings in bulk are charged the GST, while GPs are not. Costs such as public transport and petrol are not GST free, even when associated with health care. Many people with chronic illnesses rely on over-the-counter medications, such as painkillers, which attract the GST.

1.2 This project

The CIA undertook this project, 'The Cost of Chronic Illnesses for Rural and Regional Victorians', to investigate how, in the context of the recent changes to the tax system, households in rural and regional Victoria were coping with chronic illness in their households. The project was funded by the Reichstein Foundation.

The project had two aspects. One focused on the costs of caring for people with chronic illnesses in rural and regional Victoria. The other focused on the impact of the changed tax system on households with at least one person with a chronic illness.

In the past, most surveys exploring health costs have used statistical data such as that supplied by the ABS Household Expenditure Survey, Health Insurance Commission and Pharmaceutical Benefits Scheme. People with chronic illnesses and their carers have consistently criticised this approach. It estimates *only* medical costs, that is, the cost of medical services and products. It does not estimate *all* the components of 'health' care, including the emotional and social costs. Consequently, people with chronic illnesses believe it underestimates the true cost of chronic illness (CHF 1997 p2).

This project is unique because it was based on the 'lived experiences' of rural and regional households with chronic illnesses, and it set out to estimate *all* the costs experienced by those households.

2. Background

2.1 Consumers' Health Forum study

In 1997, the Consumers' Health Forum (CHF) published its 'Cost of Chronic Illness and the Quality Use of Medicine' project ('Cost of Chronic Illness' project). The study (CHF 1997 p2) showed that recent changes to the Pharmaceutical Benefits Scheme (PBS) Safety Net and consumer co-payments had substantially increased the amount consumers spent before reaching the Safety Net. In addition, it took consumers longer to reach the Safety Net. People who had previously qualified in the first few months of the year now took several more months to qualify. While the purchase of medicines was a significant cost burden, the study also showed that a range of additional expenses were not recognised by the Safety Net and PBS provisions. Consequently, the study concluded that the cost of chronic illness was significant and underestimated.

The study found that the average expenditure of Australian households on health was \$27.14 per week. However, those on the lowest incomes spent an average of \$15.00 per week, which represented 10% of their income. When the additional costs, such as hospitalisation, aids and equipment, specialist consultations, allied health and transport, were included, people with chronic illnesses spent far more than Australians in general (CHF 1997 p13).

The study concluded that the expenditure of people with chronic illnesses went beyond their immediate medication and health care costs, and that such costs diminished the income available for other aspects of their lives. It also showed that government policies, such as those governing the PBS Safety Net and the availability of concession cards, played a crucial role in helping people to manage their chronic illnesses.

2.2 Specific illness studies

A study of the economic impact of multiple sclerosis (MS) on well-being (De Judicibus & McCabe 2001) revealed another aspect of the economic impact of chronic illness. The major financial impact of MS was the loss of earnings due to early retirement or reduced working hours. Two-thirds of participants were unemployed. The study also highlighted the need for spending on household tasks that participants were no longer able to perform, such as child care, cleaning, cooking and gardening. They also reported additional expenses due to impaired mobility.

The 'HIV Futures Study' (Ezzy *et al* 1998) investigated the long-term impact of living with HIV/AIDS and found that lost earnings reduced the capacity of people with HIV/AIDS to afford all their illness-related needs.

These two studies showed that long-term and serious illnesses reduced the capacity of families to cope financially, and were major contributors to emotional stress and long-term disadvantage.

2.3 Rural studies

Over the last three decades, many rural health studies have noted that the health of rural Australians is significantly worse than that of other Australians (Dixon & Welch 2000 p255). Rates of death from suicide, injury, motor car accidents, asthma, ischaemic heart disease and diabetes are higher in rural areas than in metropolitan areas. The reasons for these differences are not always clear, and claims that they may have been due to lifestyle differences and a lack of services need more investigation. However, rural health researchers (Bourke 2001 p2, Fitzgerald *et al* 2001 p231) have noted that the distances rural people travel, the lack of services in rural areas, and the economic downturn in many rural areas has affected rural health consumers negatively, and may have led to poorer health outcomes. Other factors that have affected rural health are shortages of GPs and other health professionals (Simmons 2001).

The Victorian study 'Caring for Children with a Disability: Experiences of Rural Families' (ACD-RCH 1998) explored the needs of rural families through case studies. It found that if more had been done by the Royal Children's Hospital to address the needs of rural families, it would have been easier for them to attend appointments at the hospital, and care for their children post-operatively at home. Issues such as accommodation in the city, travelling time and costs, outpatient appointment scheduling, discharge planning, and communication between rural practitioners and the hospital were all identified as barriers to parents accessing health care.

2.4 Impact of tax, health and welfare policies

All the above studies have recognised that Australian Government tax, health and welfare policies play an important role in determining access to health care. CHF's 'Cost of Chronic Illness' project (CHF 1997 p2) found that changes to the PBS Safety Net meant that, in 1992-1996, there was a six-fold increase in the number of households that had spent at least \$25.00 per week on prescriptions before reaching the general Safety Net. In addition, households that had previously reached the Safety Net in March now did so in June. Eligibility for concession cards also played an important part in accessing health care. Families with low incomes who were not eligible for concession cards spent a greater percentage of their income on health costs. In some cases, these families paid six times more for the same services than concession card holders.

Victorian Government programs have also affected the ability of families to access health services. The Victorian Patient Transport Assistance Scheme reimburses some of the costs of travelling to Melbourne and regional centres for treatment. Over the years, the amount reimbursed has decreased, the forms have become more complex to complete, and an increase in the threshold distance beyond the current 100 kilometres has been threatened frequently. Concession card holders are also eligible for concessions on household rates and utilities, such as water and power. Over the last few decades, these concessions have been reduced markedly.

Simmons (2001) found that the introduction of pro-competition policies and mechanisms has been a major challenge to the health system, particularly in rural areas. Occurring in an environment of rural economic downturn, they have led to further declines in the number of health professionals in rural and regional Australia, because they have made it harder for them to make a living in rural areas.

Recent changes to the tax system and the introduction of the Goods and Services Tax (GST) have affected all Australians. At this stage, little has been published on the effects of these changes on rural Australians, and the impact on rural and regional Australians with chronic illnesses has been ignored completely.

Landt and Beer (1998 p15) explored the changing burden of income tax on working families in 1982-1994. They showed that the average income of families increased in real terms but the distribution of incomes became more unequal. High income

families had large increases in income, while those of low income working families fell in real terms. The impact of income tax and family payments was progressive, with low income families receiving greater family assistance. It is possible that the GST, essentially a regressive tax, and the other tax changes introduced in July 2000 have eroded the benefits previously received by low income families.

2.5 Poverty levels

The study 'Financial Disadvantage in Australia 1990–2000: Persistence of Poverty in a Decade of Growth' (Harding *et al* 2002 p4) found that 13% of Australians lived in poverty. In 2000, the income below which a single income family with two children was said to be living in poverty was \$416.00 net per week, which was half the average weekly income of all Australians.

2.6 Conclusion

Information about the income and expenditure of rural and regional people with chronic illnesses is sparse. What we do know is that, in general, rural people have lower incomes, fewer health services, poorer health outcomes, and higher rates of illness. We also know that changes to the tax system have, at least superficially, applied equally to rural people. However, if rural people were already experiencing disadvantage and financial distress before the introduction of the new tax system, their disadvantage and financial distress may have increased in relative terms.

3. Methodology

3.1 Project stages

'The Cost of Chronic Illnesses for Rural and Regional Victorians' project consisted of two stages. The first was a series of public consultations that captured the views of people with chronic illnesses living in three rural regions: Bendigo, Geelong and Moe. The second was a questionnaire survey that surveyed households with chronic illnesses throughout rural and regional Victoria. The survey responses were then subjected to a series of statistical analyses. The two stage process means that the project's results and conclusions have been subjected to qualitative and quantitative validation. As a result, the Chronic Illness Alliance (CIA) believes they accurately reflect the experiences of households living with chronic illnesses in rural and regional Victoria.

3.2 Public consultation recruitment

Participants in the public consultations were recruited from a range of community groups, including CIA organisational members, support groups, church groups, community health centres and hospitals. Participants responded to notices in newsletters; flyers in churches, health centres and hospitals; and direct approaches from health workers.

3.3 Questionnaire survey distribution

The results of the public consultations provided the basis for the questionnaire used in the state-wide survey. The questionnaires were distributed by CIA organisational members that had networks in rural and regional Victoria. Seventeen organisations mailed out the questionnaires with their newsletters. In addition, over 30 individuals contacted the CIA to request a questionnaire.

3.4 Survey analyses

The survey response rate was four times greater than that anticipated. More than 400 rural and regional households returned a questionnaire. Of these, 381 questionnaires were able to be included in the analyses. This represents 381 households comprising 1626 people, of whom 507 had chronic illnesses.

In order to allow all responses to be included, the questionnaire responses were coded for analysis by SPSS rather than manually as originally planned.

Initially, simple percentages and frequencies were produced. These results appear in Chapter 5.

Later, the responses were analysed by income to allow comparison between income groups. These results appear in Chapter 6.

All results were checked and cross checked by academics with expertise in statistics.

3.5 Survey limitations

The questionnaire survey was an 'opportunistic' survey. Organisations with the capacity to recruit people through their newsletters or by personal contact were the ones most likely to help with the distribution of the questionnaire. Similarly, households with the greatest interest in the issues were the ones most likely to respond. Consequently, some illnesses are over-represented, and others absent. Of the households that responded, 12% had Crohn's disease and/or ulcerative colitis, 9% had cystic fibrosis, 12% had juvenile diabetes, and 10% had Meniere's disease. These illnesses are not representative of the illnesses most common in rural areas, namely, diabetes, heart and respiratory conditions.

The survey covered 381 households that comprised 1626 people, of whom 507 had chronic illnesses. No other published study has surveyed the health costs of such a large number of people in rural and regional Victoria (or Australia). The illnesses are not representative of the community burden of disease. However, the costs surveyed are representative of the illness costs of households living in rural and regional areas, as validated by the public consultations.

3.6 Terminology

The term 'concession card' refers to health care cards and pensioner concession cards.

Unless otherwise indicated, all incomes are gross annual incomes, be they earned incomes, disability support pensions, age pensions, or combined earned incomes and pensions.

4. Consultation results

4.1 Attendance

The attendances at Geelong and Bendigo were pleasing, with 25–30 participants at each session, but the attendance at Moe was disappointing, with only 10 participants. In total, 60–70 people provided their views and described their experiences. Their illnesses were as diverse as cancer, poliomyelitis, multiple sclerosis, epilepsy, asthma, diabetes, scleroderma, Fabry's disease, repetition strain injury, heart conditions, work place injuries, amputations, transplant recipients and mental illness. All participants had a chronic illness themselves, or were the carers or parents of a person with a chronic illness.

4.2 Key service issues

At each public consultation, the following lack of services was clearly articulated, reinforcing the view that the issues were Victoria-wide problems.

Lack of specialist services

Participants had to travel to Melbourne for almost all specialist services, even check-ups. Often, they spent many hours travelling back and forth for a 10-minute appointment. Sometimes, they also had to stay overnight to attend early morning appointments and tests.

Lack of local GP and ancillary services

Participants said shortages of GPs and ancillary services had resulted in long waits and dearer charges. New residents in Bendigo had to wait 3 months before seeing a GP for the first time. Up-front fees for health providers were common, while bulk-billing was uncommon. Out-of-hours visits were very limited. Ambulances often took too long, or had only one person available to drive and deliver paramedic services. One woman said she had had to drive an ambulance, while the driver attended to her husband in the rear cabin.

4.3 Major financial costs

Participants rated the following financial costs as the most imposing.

Medications and running medical equipment

The costs of medications and running medical equipment were rated very high in relation to total household spending, and were particularly expensive for those not on concession cards. One example was a pump for a person with diabetes that cost \$300 per month to run, and medications that were six times more expensive to buy without a concession card.

Transport

Transport costs were high because of the need to travel long distances to access services. Trips to Melbourne were the norm, with one participant reporting 75 visits per year. Petrol and parking were the most common expenses. These costs were compounded by the cost of meals and accommodation, and, particularly for families, the cost of snacks and beverages.

The Victorian Patient Transport Assistance Scheme was criticised for its laborious application procedures and inadequate reimbursements. Often reimbursements were forfeited because the effort outweighed the return.

Taxis were an expensive transport option, and participants thought the costs could be alleviated by easier access to the Multi Purpose Taxi Scheme. Fares were particularly expensive when needed to get to and from short-term unplanned hospital stays during crises. Again, distance aggravated the cost.

Employment

Employment costs were of two types. The first was the cost of having to give up work because of their own or another person's illness. The second was the cost of having to take unpaid time off work to attend appointments. One woman said visits to her Melbourne specialist had cost her \$300 per month in lost wages.

Telephone

Although expensive, telephones were seen as essential because of the distances to doctors, hospitals, and so on; and the distances between neighbours. Mobile telephones were deemed necessary because of the isolated and outdoor nature of rural living. In addition to being critical in emergency situations, telephones also enabled housebound people to have social contact, or, in the words of one participant, 'a social life'.

Complementary therapies

Complementary medicines and treatments were often regarded as unaffordable. One woman had used them to help her husband get off his rejection drugs following a transplant. It had cost them \$500 per month, which they could no longer afford.

Vitamins were also seen as too expensive. Some participants said they could not afford good quality fruit and vegetables, let alone vitamin supplements.

Lack of information

An indirect cost was lack of information, which resulted in fewer opportunities to access services. Participants felt they did not know how to find out about their entitlements, let alone benefit from them. In some cases, this meant that households had gone without services and welfare entitlements for years, because no-one had told them about the services available or their entitlement to them.

Medical equipment and aids

The availability of medical equipment and aids under the Victorian Aids and Equipment Program (A&EP), formerly the PADP scheme, was a concern for many participants. In some instances, people with chronic illnesses were not eligible for equipment under A&EP, because their illness was not considered a permanent disability, even though not having the equipment meant they could not function. A person who had had a limb amputated said that the government-based schemes offered vastly different benefits. For example, the Free Limb Scheme provides limbs up to \$2000 in value, while the Traffic Accident Commission provides limbs for road accident victims up to \$15,000 in value. Other complaints related to A&EP's limitations, long waiting times, and expensive excess fees. For example, wheelchair recipients are required to pay a \$700 excess fee. In addition to this, A&EP has limited funding, which periodically runs out.

4.4 Major emotional costs

In addition to the financial costs, participants voiced strong views about the emotional costs that came with the responsibilities and duties of being a carer.

Time

The parent of a severely disabled child outlined the costs to his family of caring for their child. He explained that caring full time for his daughter required great sacrifices in terms of his 'time': time with his wife, time with his other children, time with their extended family and friends, and time off work. As a result of their commitment and the installation of specialised equipment, they had reduced their daughter's hospital admissions from 20 to 4 per year, saving the government \$6000 for each two week stay averted. This case highlights the benefit to governments of caring for the carer. However, participants felt that governments were reactive rather than proactive in regard to carers, and did not reciprocate with support to cover their expenses.

Caring and burnout

Carers said that 24-hour caring was extremely stressful, and respite care difficult to access. In Portland, respite care was heavily rationed, and bookings had to be made months ahead. Others said that, because care was needed 24 hours a day, the cost of hiring someone to come into the home was not affordable. The lack of respite care and the around-the-clock demands of caring were, in the words of one participant, 'wearing this one out'. Other participants spoke about lack of sleep and depression, and said they were often sick and on medication themselves. They missed their relaxation time, and thought that the strain on their health and their families was unfair.

The strain was compounded by the need to battle bureaucracies, lobby members of parliament, and lobby hospital staff. Participants spoke of 'fighting every day for rights', something they 'don't need to be doing on top of everything else'. A follow-up email from the parent caring for his daughter quoted above expressed the same sentiment. He wrote:

'We have many stories to tell in relation to the small and large battles we have fought on our daughter's behalf ... We are proud of the many things we have achieved thus far and are probably better people for it, but it would have been far less stressful and less of a financial burden to have done without these never-ending problems, which at times of a weak moment appear insurmountable.'

Caring for children

Parents caring for ill children felt they were not seen in the same light as other carers, particularly those caring for elderly spouses. They felt they were 'out of the equation'. In other words, they felt that the government expected them to be full-time carers, regardless of the health and abilities of their child, and therefore not entitled to support until the child was 16 years of age. One woman had given up a salary of \$500 a week to stay at home and care for her child, yet she received no financial assistance from the government.

Loss of employment

Carers believed that ceasing work had had substantial social costs for them. They said they had made many friends at work, and the longer they were away from work the more disconnected they had become from those friendships. In addition, identities were lost and changed with employment status. Participants representing people injured at work said rates of depression and suicide were high in their constituencies. In view of this, the support given by family and support groups was seen as vital. Group meetings became social events, and ongoing networking between meetings provided great benefits to members.

4.5 Conclusion

Overall, participants were grateful for the opportunity to voice their concerns and opinions. Not all participants were dissatisfied with the health system and the costs they had incurred. However, the vast majority were, and they wanted more opportunities to get together and share experiences. They felt there were not enough local support and self-help organisations to provide support through group gatherings and exchanges, because such organisations were usually based in Melbourne or the large regional centres. The message from the public consultations was clear. Rural and regional Victorians do not have equality of health services compared with city people, and they experience greater financial and emotional hardships, often without professional and peer support.

5. Survey results

Chapter 5 presents the questionnaire survey data that was analysed to show how access to a concession card affects health costs. All 381 households were included in these analyses.

5.1 Demographics

Number of households

Three hundred and eighty one (381) households were included in the survey analyses. The households comprised 1626 people, of whom 31% (507) had a chronic illness, and 69% (1119) did not.

Table 5.1 Number of households that responded to the survey in each Victorian region

Region	Percentage	Number
Barwon-South	29.4	112
Loddon-Mallee	25.7	98
Grampians	14.4	55
Hume	13.9	53
Gippsland	13.6	52
Outer metro >50 km	2.9	11
Total	99.9	381

Number of people with a chronic illness per household

Seventy-two percent (276) of households had one person with a chronic illness; 23% (87) had two people with a chronic illness, and 5% (18) had more than two people with a chronic illness.

Table 5.2 Number of people with a chronic illness per household

No of people with illness in household	Percentage of households with illness	No of households with illness	Total no of people with illness in all households
One	72.4	276	276
Two	22.8	87	174
Three	4.2	16	48
Four	0.3	1	4
Five	0.3	1	5
Total	100.0	381	507

Age distribution of people with a chronic illness

Overall, 51% (258) of the people with a chronic illness were of working age, and 24% (124) were of school age.

Table 5.3 Age distribution of people with a chronic illness

Age (years)	Percentage	Number
0–16	24	124
17–45	29	145
46–60	22	113
61–75	22	109
76–87	3	16
Total	100	507

Chronic illnesses represented

The more common diseases represented in the study were diabetes (12%, 45), Crohn's disease and/or ulcerative colitis (14%, 54) and cystic fibrosis (9%, 35).

Table 5.4 Chronic illnesses represented as described by participants

Diabetes
Asthma
Cystic fibrosis
Hepatitis C
Hormonal disorder
Ulcerative colitis and Crohn's disease
Cardiovascular disorders
Meniere's disease
Renal failure
Multiple sclerosis
Musculo-skeletal disease
Lung disease
Mental illness (depression/anorexia)
Chronic fatigue syndrome/myalgic encephalomyelitis
Epilepsy
COPD
Multiple disorders
Other

Income distribution of households

Forty percent (152) of households had a gross income of \$25,999 or less, 36% (137) had an income of \$26,000–51,999, and 21% (80) had an income of \$52,000 or more.

Table 5.5 Income distribution of households

Income (\$AUD)	Percentage	Number
25,999 or less	40	152
26,000–51,999	36	137
52,000 or more	21	80
Missing	3	12
Total	100	381

5.2 Concession cards

Sixty-four percent (245) of households had access to a concession card. Of these households, 58% (141) had used it weekly or fortnightly, and 91% (222) thought it was extremely or very important. The remaining 34% (129) did not have access to a concession card.

Of the households with incomes of \$25,999 or less, 86% (132) had access to a concession card. Of these households, 61% (80) had used it regularly, and 92% (121) thought it was extremely or very important.

5.3 Medications

Eighty-seven percent (330) of households had bought medications covered by the Pharmaceutical Benefits Scheme (PBS). PBS spending ranged from \$1 to \$850 per month, the average being \$52 per month. The most commonly stated monthly amount was \$20. Of these households, 9% (31) had spent \$100 or more per month on PBS medications.

Sixty-seven percent (257) of households had bought medications not covered by the PBS. Non-PBS spending ranged from \$3 to \$1000 per month, the average being \$62 per month. The most commonly stated monthly amount was \$20. Of these households, 12% (31) had spent \$110 or more per month on non-PBS medicines.

Thirteen percent (50) of all households said the cost of medications caused them major financial problems. This rose to 20% (30) for households with incomes of \$25,999 or less. Thirty-eight percent (144) of all households said the cost of medications caused them moderate problems, and 47% (178) said it caused them minor or no problems.

'Problems for me include the cost of medication advised by my doctor but not on prescription, such as folic acid, vitamin D, Rhinocort and Voltaren.'

*'Prednisolone tablets have run out or become hard to get from chemists in ****, so now I have to ring around and drive around to get them. Apart from the inconvenience, this is very upsetting and worrying.'*

5.4 Impact of tax, health and welfare policies

Changes to tax system

Sixty-two percent (234) of households said changes to the tax system, including the Goods and Services Tax, had had a negative effect on their household finances. Of these households, 25% (59) said it had made a huge or big difference, while a further 55% (128) reported a noticeable difference.

Satisfaction with government assistance

When asked if they were satisfied with the amount of government assistance received, 48% (185) said they were not. The most dissatisfied were the non-concession card holders, of whom 63% (86) were not satisfied. Non-concession card holders wanted better access to concession cards and more help with the cost of medications, complementary medicines and supplements.

Government assistance

Fifty-eight percent (223) of households thought obtaining information about government assistance was hard to access. Of these households, 50% (111) thought it was difficult to obtain, and 22% (49) thought it was very difficult. Another 28% (63) said they did not know where to start.

'As a person with Crohn's Disease, I travelled to Melbourne for 10 years before I became aware in 2002 of the patient transport scheme.'

5.5 Medical services

Household spending on GP visits in the previous six months had ranged from \$5 to \$1000. Having a concession card would usually influence the cost of visiting GPs, so households were divided into two groups: concession card holders and non-concession card holders. The average amount spent by both groups was the same, \$19 per month. This finding highlights the households' lack of access to bulk-billing, and the impact that lack had on those most in need.

Sixty-four percent (245) of households had access to a concession card, but only 34% (130) of all households had access to bulk-billing GPs.

Household spending on specialist visits in the previous six months had ranged from \$5 to \$1000, the average being \$25 per month. Concession card holders had spent an average of \$24 per month, while non-concession card holders had spent an average of \$27 per month.

Household spending on tests and treatments in the previous six months, had ranged from \$6 to \$6000, the average being \$41 per month. Concession card holders had spent an average of \$38 per month, while non-concession card holders had spent an average of \$47 per month.

'As a result of living in a country area my illness took a long time to diagnose and was not properly treated until I was attending a specialist in Melbourne. Much of the medication I initially purchased had to be discarded as it was ineffectual.'

The difference between concession card holders and non-concession card holders was more noticeable for hospital stays. The average cost of hospital stays for concession card holders was \$60 per month, compared with \$101 for non-concession card holders. The total amount spent in the previous six months ranged from \$10 to \$5000, the average being \$76.

While some households had not visited doctors, undergone tests or stayed in hospital, all households had had some form of therapy, such as physiotherapy, speech therapy or homeopathy. Concession card holders had spent an average of \$6 per month on therapy, while non-concession card holders had spent an average of \$17 per month. The average amount spent was \$11 per month.

5.6 Medical equipment and aids

Medical equipment and aids were another cost for households. When the costs of medical equipment, daily living aids and personal aids were combined, 99% (378) of households had needed some form of physical aid. Aids included diabetic equipment, walking sticks, incontinence pads, and exercise equipment for people with obesity and cystic fibrosis. Concession card holders and non-concession card holders had spent much the same amount, around \$16 per month or \$190 in the previous 12 months.

5.7 Allied health services

Allied health services, such as dentists, opticians, dietitians and podiatrists, were grouped together, and once again there was universal usage. The average amount spent was \$11 per month. There was a large disparity between the low income households, which had averaged \$8 per month, and the higher income households, which had averaged \$25 per month, over three times as much. This suggests that increased income enables better access to allied health services such as dental care.

5.8 Travel

Over half (57%, 218) of the households had travelled to Melbourne for appointments and treatments, which had incurred additional costs. While 70% (153) of these households had travelled once every two months or less, the remainder had made more frequent trips, with 8% (17) travelling fortnightly or monthly, and another 4% (9) travelling even more frequently. In addition to travelling to Melbourne, thousands of kilometres had been travelled to regional medical centres, the nearest doctors and regional towns to attend appointments and collect prescriptions. The main travel costs were petrol, parking and meals.

Petrol

Concession card holders had spent an average \$37 per month on health-related travel, while non-concession card holders had spent an average of \$43 per month.

Parking

Thirty-eight percent (145) of households had spent an average of \$7 per month on parking. There was no difference between concession card holders and non-concession card holders.

Meals

The long distances travelled had required spending on meals, which were expensive. Even if meals had been taken from home or not needed, coffees and snacks bought along the way had added up. On average, meals had cost \$20–28 per month.

'It is costly enough for me to take time off work, husband to look after, other children at home, whilst one child is in hospital in Melbourne and I have to stay with her. There are the costs of food, petrol, accommodation and phoning home, entertainment equipment for the child in hospital and parking. Not to mention the emotional cost!'

'The unnecessary costs involved in going for check-ups. Travel three hours to Melbourne for a five-minute question time, no examinations, just 'How are you going? Then three hour's home. I lost a day's pay, the carer lost a day's pay as I was unable to drive. On top of this was the cost of food and the aggravation. They could have just phoned me!'

5.9 Household costs

Households were asked to estimate any other household costs they had incurred as a result of chronic illness. The estimates suggest that concession card holders needed more assistance and spent more time at home, which resulted in increased costs.

Telephone

Concession card holders had spent an average of \$32 per month on health-related telephone calls, while non-concession card holders had spent an average of \$28 per month.

Energy

Concession card holders had spent an average of \$51 per month on energy, while non-concession card holders had spent an average of \$42 per month.

Cleaning

Concession card holders had spent an average of \$66 per month on cleaning and gardening, while non-concession card holders had spent an average of \$57 per month.

House repairs and appliance servicing

Eight percent (30) of households had had to make substantial modifications to their homes, and in some cases had had to move house, which had incurred considerable additional expense. Some households had spent only hundreds of dollars, but others had spent thousands. Repair and servicing of appliances were other expenses that only a few (10%, 37) households had incurred, but which had added to the burden of chronic illness. Most households had spent an average of less than \$30 per month on such expenses, but some had spent more than \$200 per month.

5.10 Complementary therapies

Complementary products and services

Complementary products and services were very popular. Just over half (51%, 194) the households had used them often or all the time, 16% (61) had used them occasionally, and 22% (85) had never used them. Household spending on complementary products and services in the previous 12 months had ranged from \$10 to \$4800, the average being \$36 per month. There was little difference between concession card holders and non-concession card holders.

Complementary products are expensive, so households were asked if they had stopped using them because of cost. Of the 281 responses to this question, 20% (55) said they had. Another 16% (46) said that they had stopped using some or all such products, partly as a consequence of cost. The fact that more households responded to the question about cost and usage (73%, 281) than the question about current usage (51%, 194) suggests that more households would have used them if they could have afforded them.

Special foods

Seven percent (28) of households had bought special dietary foods, and found them very expensive. The average amount spent each month by these households was \$141. However, the high income households had spent considerably more, an average of \$187 per month, compared with the low income households, which had spent an average of \$115 per month.

5.11 Loss of work and wages

In thirty-nine percent (147) of households, at least one member had had to leave work indefinitely and forfeit their wages as a result of chronic illness. Of those that had left work, 60% (88) were the person with a chronic illness, 21% (31) were the carer, and 18% (27) were both.

Another 29% (112) of households had had to take unpaid time off work to attend appointments and tests as the consumer or carer. The time off work came at a great cost for many households, and as would be expected the cost increased with income. Those on incomes of \$25,999 or less had lost an average of \$2251 over the previous 12 months, and those on incomes of \$52,000 or more had lost an average of \$5523. These incomes were lost against a background of increased costs, so the households were doubly disadvantaged.

5.12 Carers

Twenty-nine percent (109) of households had a full-time carer in the home. We asked these households how they were coping. Thirteen percent (14) said they were not coping or barely coping. Forty-three percent (47) said they were coping moderately well (or OK), but would like more support. The rest said they were coping comfortably or very well. Support in the form of respite care would have helped many of these households, but 67% (73) said they never or only occasionally had access to respite care.

5.13 Conclusion

Non-concession card holders spent 67% more on PBS medications and 19% more on non-PBS medications. They also spent 68% more on hospital stays. They spent a little less on household costs, and had fewer concerns about finances. However, they were less satisfied with the amount of government assistance received. This suggests that, as in 1997, many households with chronic illnesses whose incomes were above the concession card threshold have costly and unavoidable health expenses.

These results also show that the concessional base of concession card holders has declined in recent years. Overall, they no longer benefit from bulk-billing, paying as much to doctors as non-concession card holders, and pay more in household costs. The higher power and telephone calls may be the result of not working and being housebound.

'Until very recently my frail aged mother was living with us, as she had for the last ten years. As her carer, I have scleroderma and rheumatoid arthritis, so I could no longer look after her and she went into a nursing home. We are now in a position where we have to find money for her pharmaceuticals and doctors' visits, which adds to the financial burden already oppressing us. She is also 40 minutes drive away. My partner who is also unwell, now works impossible hours to try and stay afloat, thus compounding his (health) problems.'

'I have had no carer costs but rely on my friends to help in ways they didn't need to prior to my illness, such as mow lawns or drive me to Melbourne.'

6. Income and the cost of chronic illness

Chapter 6 presents the questionnaire survey data that was analysed to show how income affects the capacity of households to care for members with chronic illnesses. Twelve households were excluded from the analyses, because they did not give details of their incomes. This left 369 households for analysis.

Some items, namely hospital stays, foods and household renovations, were excluded from the analyses. These items were reported by only a small number of households, so their inclusion would have skewed the results.

Table 6.1 Annual health costs of households by income

Cost items	<\$13,000 N=39		\$13–25,999 N=113		\$26–36,399 N=64		\$36,400–51,999 N=73		\$52–78,000 N=80	
	N	\$pa	N	\$pa	N	\$pa	N	\$pa	N	\$pa
GPs	22	206	62	188	51	237	61	237	67	254
Specialists	21	309	64	294	41	283	45	280	53	325
Treatment & tests	17	290	50	656	28	345	38	438	48	517
PBS medications	36	334	102	443	53	839	62	606	69	707
Non-PBS medications	30	570	75	804	47	885	49	654	51	867
Petrol	30	462	81	431	50	504	62	408	67	447
Parking	10	149	40	72	23	125	31	59	36	95
Meals	20	287	47	359	34	410	33	252	36	267
Telephone	24	517	47	379	29	331	31	292	40	345
Cleaning	13	663	31	580	13	1007	15	617	13	647
Complementary therapies	28	429	70	473	45	292	50	360	59	452
Lost wages	5	1680	23	1658	19	1495	22	999	29	5337
Therapy and allied health	11	742	37	541	23	665	27	507	39	863
Medical aids & equipment	11	563	36	426	33	360	37	587	31	525
Energy	28	526	49	630	28	650	28	550	25	404
Fares	16	192	16	206	9	384	16	239	7	373
Median income	<\$13,000		\$19,500		\$31,200		\$44,200		\$65,000	
Average total health costs	\$3,585 (based on 12,999)		\$3539		\$4356		\$3585		\$5767	
Percentage of median income	27.5%		18%		14%		8%		9%	

6.1 Health costs and poverty

Total health costs

Table 6.1 shows the average amount spent annually on 16 health-related items by the households in each income group.

When all the components of health care were taken into account, households had spent an average of \$4200 (\$3600–5800) on health costs. For the households with incomes of \$36,399 or less, the percentage of income spent on health-related items was 14–27.5%. These results are consistent with the Consumers' Health Forum's (CHF) 1997 'Cost of Chronic Illness' project (CHF 1997).

The 2000 poverty threshold for a couple with two children was \$416 per week or \$21,632 per year. Forty-one percent (152) of households in this study had incomes of less than \$21,000 per year after all their health costs had been deducted. Therefore, on the basis of the 2000 poverty threshold, they were effectively living in poverty. It is estimated that 12.2% of Australian couples with children live in poverty (Harding *et al* 2002), so the percentage of survey households living in poverty was three-and-a-half times that of Australians in general. The 1995 poverty threshold for single people was \$215 net per week (ABS 1996), so the figures also suggest that health costs forced households with incomes of \$13,000 or less, which were presumably largely single-person households, to live in near-third-world poverty. Current estimates suggest that 20% of single Australians live in poverty (Harding *et al* 2002).

The average amount spent on health costs by the income groups varied by only \$2182 (\$3585–5767), even though the variation in incomes was much greater. The variation between the amount spent by the lowest income group and the second highest income group was small. This suggests that households spend to take care of their health needs, regardless of their income. However, what households bought varied widely between income groups, and, presumably, between individuals.

Financial distress

The survey did not set out to gather information about financial distress. However, the issue emerged as a result of the comments many households wrote on their questionnaires. Households said they had experienced financial difficulties because of the health costs of family members with chronic illnesses.

One household said governments should help families by providing emergency or short-term financial support. Another said they had to continually ask extended family for financial help. Others said they saved money by going without medications and not keeping medical appointments.

Under normal circumstances, for most families, financial distress occurs at specific times in the family's life cycle. Typical times of financial distress are when the children are young and only one parent is working, or when money has been allocated to a mortgage or school fees. When these situations pass, the financial distress usually ceases. However, in families with chronic illness, the illness continues indefinitely, so the financial distress continues indefinitely too.

The total health cost figures suggest that many households had experienced severe poverty and financial stress, even if they had reasonable incomes.

One household with an income of \$52,000–78,000 per year said:

'We had no income for two weeks while our child was in hospital due to a new employer not paying the sole wage earner for time off work.'

Another household with a similar income stressed the ongoing costs:

'Transport and parking and ongoing costs for regional families to get to Melbourne and other appointments is just so expensive for families.'

'There are other major cash outlays to do with CF ... ie PEP masks and flutter valve purchases, syringe purchases, nebuliser pumps, exercise equipment, mini trampolines, exercise videos, exercise bikes, swimming lessons, chiropractor visits, naturopath visits, travel to large cities so you can find out about the latest physio, medication routines, etc. They all add up to the cost of trying to run a household and cope with chronic illness. Poor finances contribute to an already stressful lifestyle.'

'There is no way we can afford holidays or an extra haircut or something that is not a necessity-have had a visit to Bendigo for a free movie as our treat.'

6.2 Impact of tax, health and welfare policies

Changes to tax system

Two-thirds of households said recent changes to the tax system had had a negative effect on their household finances. The Goods and Services Tax (GST) was the most clearly identified factor.

Satisfaction with government assistance

Household satisfaction with government assistance was related to their access to concession cards. Households with incomes of \$13,000 or less were the most satisfied with government assistance (61.5%, 24). Almost all these households (92%, 36) had concession cards, so the satisfaction probably reflects the information and help that comes with a concession card. Of the households with incomes of \$13,000–25,999, 85% (96) had a concession card. Their satisfaction with government assistance fell to 42.5% (48). Of the households with incomes of \$26,000–36,399, 47% (30) had a concession card. Their satisfaction with government assistance was 34.5% (22).

Table 6.2 Satisfaction with government assistance

	<\$13,000 N=39		\$13–25,999 N=113		\$26–36,399 N=64		\$36,400–51,999 N=73		\$52–78,000 N=80	
	%	N	%	N	%	N	%	N	%	N
Yes	61.5	24	42.5	48	34.5	22	46.5	34	35.0	28
No	38.5	15	48.5	55	53.0	34	50.5	37	55.0	44
Missing	0	0	9	10	12.5	8	3.0	2	10.0	8

Government assistance

The Consumers' Health Forum (CHF) 1997 'Cost of Chronic Illness' project concluded that 'it appears that a concession card is a major factor in determining what impact health costs will have on low income households' (CHF 1997 p11–13). It found that households without concession cards had spent three times as much on health costs as those with concession cards.

The CHF conclusion remains relevant in 2004. Households in this survey clearly indicated that they believed concession cards were or would be critical in enabling them to cope with the costs of having a member with a chronic illness, and non-concession card holders wanted greater access to them. Households also wanted financial assistance in times of crises, so they could gain more control over their lives.

'Ineligible for a HCC but would like one just for the medications ...'

'I understand that my children are not disabled enough for an allowance but a HCC should not have been refused. The fact is that a person who has a chronic lifetime illness through no fault of their own, should be given a permanent HCC – regardless of income.'

'Over the past two years (financial years) we averaged \$4500–\$6000 out of pocket. People on higher incomes receive no assistance financially even though we are on one income and have a dependent student at university. Government bodies need to do more for all people with illnesses that require regular treatment.'

Carers

Carers said they needed more help, and indicated that they felt abandoned by governments. Some said they had spent considerable amounts of time and money while caring. Several said they had also spent much time travelling and had incurred considerable travelling costs while caring. However, their main request was for more respite care.

'We are unable to obtain assistance (that is a concession card) due to incomes. A HCC for medical only (not including concessions on electricity or car registration) would be great ... three years ago I became extremely ill and spent one month in hospital ... I had leave without pay from my job which we estimate cost us \$3500–4500 in lost income ... During all this time as hard as we tried we could not receive assistance ... We estimate that it took us over twelve months to recover financially, mentally and physically ...'

6.3 Medical services

'Sometimes when feeling so unwell, I have had to postpone a visit to the doctor due to lack of funds for the visit—can there ever be another way around it?'

Sixty to seventy percent of households in each income group had used GPs and medical specialists in the previous six months, and the amounts spent by each income group were similar.

Although the amounts spent by the households in each income group were similar, they would have been a much greater burden for the lower income households. Some households said that medical and hospital costs had contributed to their financial distress, and they believed that their inability to find local bulk-billing GPs was a key problem.

Table 6.3 Cost of medical services

	<\$13,000		\$13–25,999		\$26–36,399		\$36,400–51,999		\$52–78,000	
	N=39		N=113		N=64		N=73		N=80	
	\$	N	\$	N	\$	N	\$	N	\$	N
Average total health costs	\$3585		\$3539		\$4356		\$3585		\$5767	
Cost of GP services	208	22	188	62	237	51	237	61	254	67
Cost of specialist services	309	21	294	64	283	41	280	45	325	53
Total	517		482		520		517		579	
%age of average total health costs	14%		14%		12%		14%		10%	

6.4 Medications

Sixty to ninety-five percent of households had bought Pharmaceutical Benefits Scheme (PBS) and over-the-counter medications, which represented 25–40% of their total health costs. Households did not think that medications were an onerous expense. However, the survey results indicate they were the largest single cost item. In each income group, a smaller percentage of households had paid for GP and specialist services, and they had spent less on them. Nevertheless, households thought the cost of GP and specialist services were a greater problem than the cost of medications.

The importance of concessional medicines for households with chronic illnesses was amply demonstrated. Almost all (92%, 36) households in the lowest income group had concession cards, so they were eligible for medications at the concessional PBS rate. Medications accounted for 25% of their total health costs. In contrast, only 47% (30) of households in the \$26–36,399 income group had concession cards. Medications accounted for 40% of their total health costs.

The Australian Institute of Health and Welfare investigated consumers' pharmaceutical, dental, nursing home care and private hospital costs for 1997–98. It estimated that consumers had spent \$7000 million per year on these costs, and that pharmaceuticals had accounted for a third of the total (\$2245 million) (AIHW 2001).

Table 6.4 Cost of medications

	<\$13,000		\$13–25,999		\$26–36,399		\$36,400–51,999		\$52–78,000	
	N=39		N=113		N=64		N=73		N=80	
	\$	N	\$	N	\$	N	\$	N	\$	N
Average total health costs	\$3585		\$3539		\$4356		\$3585		\$5767	
PBS medications	334	36	443	102	839	53	606	62	707	69
Non-PBS medications	570	30	804	75	885	47	654	49	867	51
Total	904		1247		1724		1260		1574	
%age of average total health costs	25%		35%		40%		35%		28%	

6.5 Complementary therapies

MacLennan *et al* (1996) found that half (50%) of all South Australians had used alternative medicines, and one-fifth had visited alternative practitioners in 1992–93. They estimated that Australians had spent \$621 million on alternative medicines in that period. These figures are consistent with overseas studies, which have found that consumers spend at least as much on alternative medicines as they do on pharmaceuticals and hospital stays (Eisenberg *et al* 1993, Fisher & Ward 1994).

The 'HIV Futures Study' (Ezzy *et al* 1998) showed a relationship between the use of complementary therapies and the poverty threshold. It found that while 60% of participants with incomes above the poverty threshold had used complementary therapies, only 50% of those with incomes below the poverty threshold had done so.

More than half (53%, 252) the households in this survey had used complementary therapies all the time, much the same usage as that found in the two abovementioned studies. Complementary therapies included naturopathy and chiropractic services, nutritional supplements, vitamins and special foods. Between 60% and 70% of households in each income group had used complementary therapies, but the lower income groups had spent more on such therapies, and had spent a greater percentage of their income on them. In contrast to the 'HIV Futures Study', households in this survey had used complementary therapies regardless of income.

'Because of my food allergies, it is vital I use nutritional supplements, but because they are purchased "over-the-counter" I am unable to access any financial rebates or assistance either from health funds or government.'

'Special diet for coeliac disease and diabetes has impacted greatly on our weekly food bill. A lot of gluten-free products are not sold locally so we have to travel 70 km per month for supplies.'

Table 6.5 Cost of complementary therapies

	<\$13,000 N=39		\$13–25,999 N=113		\$26–36,399 N=64		\$36,400–51,999 N=73		\$52–78,000 N=80	
	\$	N	\$	N	\$	N	\$	N	\$	N
Average total health costs	\$3585		\$3539		\$4356		\$3585		\$5767	
Cost of complementary therapies	429	28	473	70	292	45	360	50	452	59
%age of average total health costs	12%		13%		7%		10%		8%	

6.6 Other expenses

Other expenses included all the other costs that households thought were essential to their health care. They included the cost of allied health services, travel, domestic help and household expenses, including energy costs to run medical equipment and control temperature. With the exception of parking, these costs were significant relative to medical and medication costs.

Table 6.6 Cost of other expenses

	<\$13,000 N=39		\$13–25,999 N=113		\$26–36,399 N=64		\$36,400–51,999 N=73		\$52–78,000 N=80	
	\$	N	\$	N	\$	N	\$	N	\$	N
Average total annual health costs	\$3585		\$3539		\$4356		\$3585		\$5767	
Petrol	462	30	431	81	504	50	408	62	447	67
Parking	149	10	72	40	125	23	59	31	95	36
Meals	287	20	359	47	410	34	252	33	267	36
Fares	192	16	206	16	384	9	239	16	373	7
Telephone	517	24	379	47	331	29	292	31	345	40
Cleaning	663	13	580	31	1007	13	617	15	647	13
Energy	526	28	630	49	650	28	550	28	404	25
Therapies & allied health	742	11	541	37	665	23	507	27	863	39
Medical aids & equipment	563	11	426	36	360	33	587	37	525	31

Petrol

Petrol was a significant cost for a substantial percentage of households in each income group. Although the percentage of households in each income group for whom petrol was a substantial cost increased with income, the lower income households did not use public transport more than the higher income households. This suggests that households rely on cars for health-related travel.

Meals

Meals bought during travel to and from treatment centres was another significant cost for some households in each income group. Households with members with diabetes and cystic fibrosis were more likely to record meals as an expense, which presumably reflects the need for these people to access special diets and pay accordingly.

Parking

Parking costs were small in terms of the amount spent and the percentage of total costs. This suggests that households were able to access free or cheap parking.

Telephone

While most households would not have claimed that they had a telephone only for emergencies, telephone calls were a significant cost for some households in each income group. The greater cost for households in the lowest income group, which were presumably largely single-person households, suggests that this group used the telephone more for maintaining their social networks and obtaining support than the other households.

Cleaning

Paying someone to clean, garden and do basic maintenance is generally seen as a luxury affordable only by high income earners. However, the survey results showed that households in all the income groups used these services, including one-third of those in the lowest income group. The results also suggest that some households in the lowest income group needed considerable help and could not have managed without it. Many of these households were single-person households, so it is likely that they needed more help because they did not have families around them to help with such tasks. They also probably had greater access to government home-help schemes at concessional rates.

Like De Judicibus and McCabe's (2001) study of the economic impact of multiple sclerosis, the results of this survey showed that other costs are significant costs for households with chronic illnesses. They also suggest that having a concession card is essential for accessing services such as cleaning, telephone and cheaper energy.

6.7 Loss of work

Lost wages

Having to take unpaid time off work was a major health cost for a small percentage of households in each income group. Even though the percentage of households in each income group was small, they comprised 26% (98) of all households. Typical reasons for having to take time off work were visiting doctors in Melbourne and regional centres, taking children to check-ups and treatment appointments, and caring for children. Other reasons included hospital stays, and recovering after hospital stays and flare-ups. The lost income was a contributor to financial distress. It was also a major contributor to poverty for the low income households. Although only 13% (5) of households with incomes of \$13,000 or less had lost income this way, the lost income made up 13% of their total income.

In 1999, the Epilepsy Foundation of America estimated that epilepsy had cost the United States of America \$10.8 billion in indirect costs (EFA 1999). Indirect costs were employment-related costs, such as lost wages and reduced earnings. The Epilepsy Foundation of Victoria argued that indirect costs, such as not being able to work, were also significant costs for Australians with epilepsy (EFV 2000). Similarly, Access Economics estimated that lost employment due to arthritis cost the Australian economy \$6.72 billion annually (Arthritis Australia 2001).

'People with illnesses find it harder to get even casual work, which puts more strain both emotionally and financially on the family.'

'Warragul has the closest doctor to me ... which is very costly. Costly in the fact I must take half a day from work and fuel the car, which adds up over time. I feel I am disadvantaged by living in the country.'

However, these estimates do not give the full picture. The 'NATSEM' study (Harding *et al* 2002) found that being employed did not always lead to better incomes, because of the growth of part-time and casual work. However, as the 'HIV Futures Study' also found, employed people were usually better off financially than those who were not (Ezzy *et al* 1998).

Little research has investigated the differences in employment status between metropolitan and rural and regional people with chronic illnesses. The Epilepsy Foundation of Victoria survey (2000) found that rural people were more likely to be concerned about the costs of living with epilepsy than metropolitan people. This suggests that incomes and the increased casualisation of the workforce have markedly affected rural people. This Chronic Illness Alliance study provides primary information about lost wages and employment that may not be available elsewhere.

Table 6.7 Cost of lost wages

	<\$13,000		\$13–25,999		\$26–36,399		\$36,400–51,999		\$52–78,000	
	N=39		N=113		N=64		N=73		N=80	
	\$	N	\$	N	\$	N	\$	N	\$	N
Average total health costs	\$3585		\$3539		\$4356		\$3585		\$5767	
Lost wages	1680	5	1658	23	1495	19	999	22	5337	29
%age of average total health costs	13%		8.5%		5%		2.5%		8%	

Loss of personal and social benefits

People with chronic illnesses usually prefer to work because of the associated personal and social benefits. Walker and Millen (2003) showed that people with chronic illnesses had higher self-esteem when they were in paid employment or working as volunteers. People also felt that their communities responded to them more positively when they were seen to be employed. The 'HIV Futures Study' (Ezzy *et al* 1998) showed that HIV positive people preferred to work. Even though they thought working would be difficult, most wanted to return to work and welcomed anti-viral medications as the means to help them do so. 'Just under half of PLWHA cited improved health as a reason for wanting to return to work, while more than half cited financial, psychological, emotional or social reasons for wanting to return to work.'

Like other people, rural and regional people with a chronic illness wanted to work for the intangible benefits it gave them, including higher self-esteem and a sense of belonging.

Disincentives to returning to work

Like metropolitan households, rural and regional households felt that some government policies were disincentives to working. When people with chronic illnesses return to work, they sometimes lose their concession cards and have to pay the full PBS rate for medications. In addition, they often lose other concessions, such as utility and public transport concessions. In some cases, the loss of concessions results in their disposable 'work incomes' being less than their disposable 'benefit incomes'. Some households thought this situation was punitive:

'The fact is that a person who has a chronic lifetime illness through no fault of their own should be given a permanent HCC – regardless of income.'

Others tried to work part time to obtain the psychosocial benefits of working. However, doing this was always a balancing act:

'Can only work part time in order to get HCC. Considered working full time but this results in loss of card. Wage would be spent on full price medications. The government does not provide incentive to work for those of us who hold a HCC. If you are not working at all or work minimal hours, you are allowed a HCC and can just manage to pay for your medications. However if I decided to take up full-time employment, which despite health issues I aspire to do, I cannot see how I could afford to pay full price for my scripts. Considering I take over 30 tablets a day, this would create a large chunk out of my wage.'

'I also want to work and don't want to appear "lazy" by taking advantage of my medical situation by saying, "Yeah, well I have a chronic illness and the government should provide for me and support me, so I don't have to work". I want to work and I do work, I just think it's not unreasonable that the government subsidises part of the costs of the medication so I'm not essentially spending my wage on keeping myself alive.'

6.8 Conclusion

Three points stood out in relation to income and health costs. Firstly, households took care of their health needs first, regardless of income. However, what households bought varied widely between income groups. Secondly, in many households, health costs contributed to increased poverty. In the lower income groups, the contribution was so great that it sometimes led to dire poverty. Thirdly, many households experienced ongoing financial distress that is largely unrecognised by governments and service providers.

Households believed they had been adversely affected by the introduction of the GST. However, satisfaction with government assistance was strongly related to having a concession card, which probably reflects the help and information that comes with a card. Having a concession card was the most important factor limiting the adverse effects of health costs, a fact widely recognised by the households in the survey. Carers expressed great dissatisfaction with government assistance, and said access to respite care was their greatest need.

While the costs of GP and specialist services were a source of great distress, PBS and over-the-counter medications were the largest single health cost for households. Medications made up a staggering 25% and 35% of the total health costs of the two lowest income groups. Many of these households used multiple medications, so the figures also illustrate the benefit of having a concession card.

Complementary therapies were used by households regardless of their incomes, and many households considered them as important as their prescription medications.

Petrol was a significant cost for all income groups, which reflects the distances travelled to and from regional and metropolitan treatment centres. The cost of telephone calls was more significant for people in the lower income groups, which probably reflects the greater health needs and social isolation of single-person households.

Lost wages was a significant cost for some households in each income group. Having to take unpaid time off work to travel to check-ups and treatments contributed to financial distress and poverty in the lower income groups. Households that had been forced to stop working because of illness wanted to work because of the social benefits. However, they were concerned about the possibility of losing access to concession cards.

7.0. Conclusions

7.1 Supports previous work

The findings of 'The Cost of Chronic Illnesses for Rural and Regional Victorians' project supports and extends the findings of the Chronic Illness Alliance (CIA) 'A Concession Card for People with a Chronic Illness' project ('Concession Card' project) (CIA 1997). It also supports the findings of the Consumers' Health Forum (CHF) 'Cost of Chronic Illness and the Quality Use of Medicine' project ('Cost of Chronic Illness' project) (CHF 1997). All three projects showed that people with chronic illnesses need a range of services beyond the strictly medical and pharmacological to maintain their health.

In 1997, the 'Concession Card' project estimated that people with chronic illnesses spend up to 20% of their annual income on health costs. However, that project involved only 18 households comprising less than 100 people. The 'Cost of Chronic Illness' project estimated that Australians spend an average of \$27.14 per week on health care. However, it also found that people with chronic illnesses spend far more than Australians in general. This survey found that households with chronic illnesses spent far more than that estimated by the 'Cost of Chronic Illness' project. However, it did include a wider range of items than that study.

The differences in the design and limitations of the three projects mean that it is not possible to conclude that the situation has worsened over the last six years (1997–2003). However, the Australian Bureau of Statistics gives some support for the view that consumers' out-of-pocket health costs have increased (a view held by many in this survey). It showed that health costs rose 7% as a percentage of the Consumer Price Index (CPI) in 2002–03.

7.2 Poverty and financial distress

This project provides a baseline for future studies investigating the income-related health costs of households with chronic illnesses. It showed that, while households spent similar amounts on health costs, they spent those amounts differently, and the amounts comprised very different percentages of their incomes. Consequently, they were left with very different amounts to spend on other aspects of their lives, and on the care of other household members.

The survey showed that health costs pushed many households – already in poverty because of chronic illness – to even greater poverty. The poverty of households in the two lower income brackets is a stark reminder of the vulnerability of households with chronic illnesses – whose ill health means they have no choice but to pay for a wide range of health care products and services. The lower income households needed more services, and could not have afforded those services without the concessions that come with a concession card.

The poverty of low income households with chronic illnesses means they are affected greatly by even small increases in co-payments. Often small increases in co-payments are justified on the basis that they are small, so they do not impinge on the incomes of those using the service. However, such increases do affect households living on or below the poverty threshold. The same argument applies to lack of access to bulk-billing. Even if they will be reimbursed, a household with a disposable income of only \$183 per week has little capacity to pay up-front fees, particularly if the amount claimable is a diminishing proportion of the total account.

Households documented their financial distress, even though the questionnaire did not set out to collect such information. The introduction of the Goods and Services Tax (GST), the lack of bulk-billing for GP services, and lost wages contributed to this distress. Additional costs, such as medications, complementary therapies and petrol, amplified the financial distress to general distress. Many households recorded their feelings about their additional health costs on their questionnaires, and emphasised that they were long-term commitments that stopped them doing other things. Concession cards were seen as a crucial support. Many households said that, if governments showed practical sympathy by reducing their costs and providing more information, the level of distress would be reduced. The claims expressed in the public consultations that health services had been cut back and privatised in rural and regional Victoria was also an expression of distress.

7.3 Medical services

Participants in the public consultations and survey were distressed by the lack of access to bulk-billing medical services. To access bulk-billing GPs, they had to travel long distances, and had to take time off work to do so. Participants in some regions said it took 6 weeks to get GP appointments, while others said that GPs in their areas were now 'choosy' about which patients they took on.

These views reflect the poor access to medical practice in rural Australia. The supply of primary care practitioners per head of population is 13% lower in regional centres than in capital cities, and the disparity increases with increasing remoteness (AIHW 2003 p83). In addition, rural GPs do more procedures, so the figures do not fully reflect the poor access to services. Uneven distributions of other health professionals and facilities compounds the lack of GP services, and result in poorer health outcomes (AIHW 2003 p83). The costs of health services are also a concern for rural Australians, and these costs have not been helped by economic rationalisation (Bourke 2001 p5).

7.4 Medications

The cost of medications was the biggest single health cost for all income groups, and was a significant cost for the lower income households. The buffering effect of concession cards was amply demonstrated in the lower income groups, who consumed more medications. Households that did not qualify for a concession card were well aware of its benefits of cheaper prescription medicines. Many of these households felt they should be eligible for a concession card, because their health needs, and consequently their health costs, were life long.

A comparison of medication use in rural and metropolitan areas would be valuable in determining if the medication use recorded in this survey was typical. However, little material is available. 'It's Different in the Bush' (AIHW 2001 p xv) found that simple analgesic and cardiovascular medications were prescribed less frequently in large rural areas than in metropolitan areas. However, antidepressants, hormones, anti-ulcerants and urogenital medications (such as diuretics) were prescribed more frequently in rural areas. In addition, GPs were less likely to offer counselling and advice about nutrition and weight control in rural areas. These differences in prescribing patterns suggest that there may be important differences in medication use and access between rural and metropolitan areas.

It is interesting to note that, although the Pharmaceutical Benefits Scheme Safety Net plays an important role in reducing health costs, it was not mentioned by any of the households in the survey. The lack of comment may be a result of the households not knowing about it. This is likely, because when similar discussions are held with people with chronic illnesses in metropolitan areas, the Safety Net is usually discussed.

7.5 Wider application

Many of the conclusions of this study apply equally to metropolitan households with chronic illnesses. Therefore, this survey has wider application than just informing people about the needs of rural and regional Australians with chronic illnesses. Nevertheless, some health-related costs are amplified by living in rural and regional areas, particularly travel costs. Travel costs include petrol, food and fares, as well as unpaid time off work by carers and consumers. Households also noted that they spent considerable time travelling to bulk-billing doctors and to Medicare offices for reimbursements. Cash strapped lower income households were not able to accrue their accounts and seek reimbursement all at once. Some households also had to travel to regional centres to buy special foods and complementary products. In addition, rural and regional households had substantial telephone costs, most of which were health-related long-distance calls to city and regional treatment centres.

This survey provides a detailed picture of the reality of living with chronic illness in rural and regional Victoria. It suggests that the lack of services in rural areas, and the costs of travel and communication exacerbate the poverty resulting from chronic illness. Apart from incentive schemes for GPs, governments have done little to temper these costs by providing better access to appropriate services. The complexity of the Victorian Patient Transport Assistance Scheme exemplifies a service that creates barriers rather than access.

Whether households live in rural and regional or metropolitan areas, access to a concession card, access to bulk-billing GPs, and the presence of government services and information about them is the difference between just surviving and having an optimal quality of life. A better understanding of these matters by governments and service providers would greatly enhance the lives of people with chronic illnesses.

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