Chronic illness and consumer inequality: the impact of health costs on people with chronic illnesses in rural and regional Australia

Christine Walker

Abstract

This paper presents the results of a survey undertaken in rural and regional Victoria in 2003 on the total costs faced by households caring for people with chronic illnesses. The impact of these costs for the households is discussed in the context of neo-liberal policy development by Australian governments and the effects of those policies on such households.

Aust Health Rev 2007: 31(2): 203–210

What is known about the topic?

While neo-liberalism assumes that all consumers are equal in the marketplace and can choose the products that best suit their needs, there have been many studies reporting increasing inequality in Australia.

What does this paper add?

This article provides results from a 2003 survey of rural households in Victoria, Australia. It demonstrates that chronic health needs expose people to poverty and financial distress which is further exacerbated by decreased government assistance.

What are the implications for practitioners?

It is likely that households with chronic illnesses will have to choose between food, heating and medications in the future. Practitioners and policymakers may have to consider broader issues, such as retaining social welfare programs, as part of the care of people with chronic illnesses.

SINCE 1984, when the Australian dollar was floated, neo-liberal ideologies have dominated both Australian government and opposition policy development.[1] In promoting their ideology neo-liberal protagonists argue that the marketplace empowers all consumers equally.[2,3] Neo-liberalism makes no distinction among consumers or the products they consume. Health outcomes and health care are viewed as consumables like any other product. People requiring health care are seen as consumers and by definition are free to choose those products that best suit them in the open market, in much the same way they would browse supermarket shelves for their favoured shampoo. This portrayal of health care neglects that for many people health care is essential and not optional.

This article presents research that demonstrates that caring for members with chronic illnesses reduces a household's disposable income, thus limiting households' abilities to participate in a market economy. The author argues that neo-liberal policies do not take into account that the costs of essential health care mean some people are already disadvantaged in their capacity to participate in a market economy.

Christine Walker, PhD, Executive Officer
Chronic Illness Alliance, Melbourne, VIC.

Correspondence: Dr Christine Walker, Chronic Illness Alliance, 818 Burke Road, Camberwell, Melbourne, VIC 3124. **christine@chronicillness.org.au**

Marketplace domination and the reduced role of government

Orthodox neo-liberal theory argues that private investment is encouraged when governments withdraw from markets, reduce interest rates and do away with regulated labour markets.[4] Wages will be determined by market forces.[5,6] These theories have been implemented by governments since 1984, with programs to sell state-owned enterprises such as Telstra and the Commonwealth Bank, to deregulate labour, reduce the

power of trade unions and to engage with deregulated markets internationally. Where health care is concerned, the US–Australia Free Trade Agreement marks one of the high points of deregulating the pharmaceuticals market,[7,8] accompanied by incentives to local manufacturing industry and the withdrawal of government from regulating pricing by turning the Pharmaceutical Benefits Pricing Tribunal into the independent Pharmaceutical Benefits Pricing Authority.[2,9] Other measures to open health care services to market forces relate to the dismantling of Medicare in favour of private health insurance.[10,11,12]

A cornerstone of neo-liberalism is the abandonment of the welfare state.[5,13] The welfare state, Navarro argues, hinders private enterprise by redistributing wealth from the wealthiest sectors to the poorer sectors. This increases taxes and in turn reduces the capacity of the wealthiest to save and to consume.[5] It also impedes consumption among the poorer sectors. One of the rationales for reducing the redistributive power of health policies such as Medicare and the Pharmaceutical Benefits Scheme (PBS) is that government will no longer be able to support the burden of the ageing population and that the private sector is more equipped to provide these services at a reasonable cost. While Navarro[5] maintains that this kind of rationalisation is class interest dressed up as policy, he acknowledges that most national governments maintain some element of redistributive capacity such as the Australian Medicare safety net and Britain's "third way". Lofgren and de Boer[2] describe the subordination of other policies to economic policy as "social policy shaped by economic objectives and industry competitiveness".

Consumers

In order to make health care a market, Australians must perceive themselves as consumers rather than recipients of a government service.[2] The Consumer Focus Collaboration operated between 1997 and 2001 with the stated aim to strengthen the focus on consumers in health service planning, delivery, monitoring and evaluation in Australia's health system.[14] This Collaboration assisted in reconstructing health care recipients as consumers and legitimised the shift away from citizenship and the welfare state to consumerism.[15] Importantly, the Collaboration argued that consumers required access to quality information in order to be able to choose health products.[14]

Government promotion of private health insurance as part of health care along with the accepted construction of health care users as consumers gives legitimacy to the view that those who purchase health care are stakeholders along with health care providers and government. In contrast, people using Medicare-funded services are welfare recipients who receive "free" health care as charity and are neither citizens nor consumers. The concept of "mutual obligation" as a feature of welfare policy in neo-liberal economics plays a role in further debasing those who use Medicare-funded services, by suggesting that they are not meeting their social contract in being productive consumers.[16]

As these conditions are cemented into health care in Australia, they will impact on people's lives. Neo-liberal rhetoric suggests that the impact is favourable, benefiting all consumers equally. "There is no doubt that the cost of the PBS will increase in future years, but so too will the benefits — both for the Australian economy and for Australians themselves".[17] A survey conducted by the Chronic Illness Alliance revealed that there are groups whose circumstances make it difficult for them to participate in the community and the market. Neo-liberal policy will place them at greater disadvantage. One of these groups, though by no means the only one, is rural households with chronic illnesses.

The impact of chronic illnesses on participation in the market

The Chronic Illness Alliance surveyed the costs of chronic illnesses to households in three rural areas of Victoria in 2003.[18] This survey was based on a table of costs that was earlier validated in consumer consultations with people with chronic illnesses in Geelong, Moe and Bendigo. The table

1 Annual overall costs of chronic illnesses to households, by income

	Annual household income ($ per annum)									
	<$13 000		**$13 000–$25 999**		**$26 000–$36 399**		**$36 400–$51 999**		**$52 000–$78 000**	
No of households	39		113		64		73		80	
Cost of illness-related services	**N**	**$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 and 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 and 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 annual overall costs	$3 585*		$3 539		$4 289		$3 585		$5 767	
Percentage of median income	27.5%		18%		14%		8%		9%	

* Based on $12 999. N = 369 as this number provided information re income; incomes were divided on the basis of incomes limits for pensions and concession payments in 2003.

comprises some 16 items, including travel, lost income, complementary therapies, medications and medical items. Apart from the survey items, respondents were asked to comment on the impact of tax reform and the information they received about government services. They also provided comments relating to their social and emotional circumstances.

Three hundred and eighty one households comprising 1626 individuals participated in the survey. There were 507 people who had chronic illnesses, 28% of whom had comorbidities. Forty percent of households had a gross income of $25 999 per annum or less, while 36% had an income between $26 000 and $51 999 per annum and the remaining households (24%) had an income exceeding $52 000 per annum. This meant that a large proportion of the households (64%) had access to health care cards and were eligible for concessions on a range of their health needs, including PBS medications and public transport. Households also required other items for which there were no concessions, including over-the-counter medicines, complementary therapies, meals and parking.

Box 1 shows the average amount spent annually on 16 health-related items by households in each income group. The results show that when all the components of health care were taken into account households spent an average of $4200

2 Cost of medications as a percentage of annual illness-related overall costs

	Annual household income ($ per annum)				
	<$13 000	$13 000–$25 999	$26 000–$36 399	$36 400–$51 999	$52 000–$78 000
No of households	39	113	64	73	80
Average annual overall costs	$3585	$3539	$4289	$3585	$5767
Average annual cost of medications	$747	$934	$1345	$954	$1162
Costs of medications as % of annual overall costs	21%	26%	31%	27%	20%

(range, $3600–$5800) on health costs. For households with incomes of $36 399 or less, the percentage of income spent on health-related items was 14%–27.5%. The average amount spent across all income groups varied by only $2182 ($3585–$5767), despite the variations in annual income being far greater. This suggests that all households spend on health needs regardless of their income, though what they buy varies between income groups and individuals.

Expenditure on health costs and poverty

On the results of this survey, lower income means that households caring for someone with a chronic illness are living in poverty. In 2000, the poverty threshold for a couple with two children was $416 per week or $21 632 per year. Forty one percent ($n = 152$) of households in this study had incomes of less than $22 500 per year after all their health care costs had been deducted. The percentage of households (41%) living in poverty in this study is three and a half times greater than the estimated 12.2% of the total of Australian couples with two children living in poverty.[19] Single income households in Australia are particularly vulnerable to poverty, with an estimated 20% living below $215 per week. In this study, when the costs of health care are deducted, those households living on $13 000 or less per year (most likely single people) are living near the level of poverty in a developing country.

Respondents wrote comments on their survey which demonstrated that some households experienced financial distress from the impact of health care costs on income. When households are not able to afford holidays, or pay the extra for school camps, or pay for repairs to a broken fridge or washing machine, they are said to be in financial distress.[20] Under normal circumstances financial distress occurs at specific times in a family's life cycle such as when the children are young and only one parent is working, or when a high mortgage or school fees account for a large proportion of the household income. Financial distress usually resolves with the passage of time, but when households care for people with chronic illnesses the situation is ongoing. In this survey, households recorded that they could only manage with financial help from extended families or that they saved money by going without medications or not keeping medical appointments. Financial distress was not confined to the lower income groups, since loss of wages is a contributor to distress, and this was greatest among the highest income group.

Health care items contributing to poverty and financial distress

The greatest contributor to both poverty and financial distress in this survey was medications costs. Eighty seven percent ($n = 330$) of all households had bought medications covered by the PBS with spending averaging $52 per month. Sixty-seven percent ($n = 257$) bought over-the-counter medications with spending averaging out at $62 per month. Thirteen percent ($n = 50$) of all households said that medications costs caused them major financial problems, but this rose to 20% among those households with incomes of $25 999 or less per annum. Thirty eight percent

3 Cost of complementary therapies as a percentage of illness-related overall costs

	Annual household income ($ per annum)				
	<$13 000	$13 000–$25 999	$26 000–$36 399	$36 400–$51 999	$52 000–$78 000
No of households	39	113	64	73	80
Average annual overall costs	$3585	$3539	$4289	$3585	$5767
Average annual costs of complementary therapies	$308	$293	$205	$246	$333
Complementary therapies as % of annual overall costs	9%	8%	5%	7%	6%

4 Cost of lost wages as a percentage of illness-related overall costs

	Annual household income ($ per annum)				
	<$13 000	$13 000–$25 999	$26 000–$36 399	$36 400–$51 999	$52 000–$78 000
No of households	39	113	64	73	80
Average annual overall costs	$3585	$3539	$4289	$3585	$5767
Average annual cost of lost wages	$215	$337	$444	$301	$1935
Lost wages as % of annual overall costs	6%	10%	10%	8%	33.5%

($n = 144$) of all households said that medication costs caused them moderate problems.[18]

Box 2 shows the costs of medications in terms of income groups. Both medications bought on the PBS and over the counter represented between 21%–31% of total health care costs and were the largest single-cost item. This demonstrates the importance of concessional medicines for households where there is chronic illness. Almost all households ($n = 36$) in the lowest income groups had concession cards and were eligible for medications at the concessional PBS rate, but nevertheless averaged 21% of their health costs on medications. Forty-seven percent ($n = 30$) of households in the $26 000–$36 399 group had concession cards, and medications accounted for 31% of their overall health costs.

Complementary therapies and lost income were two other reported costs associated with health care and poverty in households with chronic illness (Box 3 and Box 4).

Just over half ($n = 252$) of all households used complementary therapies all the time, while another 16% ($n = 61$) used them occasionally. Because complementary therapies are expensive, respondents were asked if cost was a factor. Of the 281 who responded to this question, 20% ($n = 55$) said they had stopped using them due to cost, while another 16% ($n = 46$) said they had cut back on use partly due to the costs. These findings are consistent with other studies.[21,22,23] These studies affirm that complementary therapies, including alternative medicines and alternative practitioners, are now integral to Australians' health care, but there are people who cannot afford them.

Lost income includes wages lost due to the time people took off work either as the consumer or carer to attend appointments, as well as income lost due to the need to cease work altogether as a consumer or a carer. Thirty nine percent of the households surveyed had members who had had to leave work indefinitely either because of their own illness or to care for someone else. In some households both consumer and carer had given up work. Still other households had to take time off work to keep appointments.

Lost income was a major contributor to poverty and loss of purchasing power. Even 13% ($n = 5$) of those on incomes of $13 000 or less, and presumably on government benefits, lost income in this manner. While the average cost of lost wages was only 3% of median income of the highest income group, it was a significant cost to a greater percentage of them. Thirty six percent ($n = 29$) of households with incomes above $52 000 lost income averaging $5337 per annum.

Impacts of government policy on households

Changes to the taxation system are one of the most visible aspects of neo-liberal policies. In this survey, respondents were asked about the impact of tax reforms. Most households (62%; $n = 234$) considered they were worse off since the introduction of the Goods and Services Tax (GST), with 25% of this number considering it had made a huge difference. Even so, most households were not able to quantify the degree to which they were worse off. In this survey it is more accurate to say that the GST contributes to financial distress than to measurable levels of income reduction.

Households were asked whether they were satisfied with the government help they received. Nearly half were dissatisfied, and the most dissatisfied were those without concession cards. The greatest source of their dissatisfaction was lack of help with the costs of medications, complementary therapies and food supplements. Most satisfied with the level of government assistance were those households with concession cards, and this probably reflects the information and help that accompanies a health care card.

Another question related to households seeking information from the government about health and benefits they were entitled to, and if they knew where to find it. Fifty-eight percent ($n = 223$) of households considered government information hard to find, with 28% ($n = 63$) of that number saying they did not know where to start. This suggests that the benefits of becoming informed consumers of an open market economy had eluded the respondents in this survey.

Discussion

This survey demonstrated that households in rural Victoria where there are people with chronic illnesses have varying levels of income as well as a considerable proportion of their incomes consumed by health care costs, placing some of them in poverty. Less spending power, combined with loss of earnings in some cases, also demonstrated that households where there are people with chronic illnesses have less money for other items, such as food, clothing, education, housing and holidays. Rural households where there are people with chronic illnesses clearly have different purchasing power and imperatives to their rural counterparts who are well, placing them at relative disadvantage. This disadvantage becomes clear when the items to be purchased relate to health care, without which household members' health may suffer.

The survey provided additional data for the emerging picture of rural health and wellbeing as significantly worse than other Australian areas.[18] Asthma, motor car accidents, suicide, injury and diabetes all result in higher death rates in rural Australia.[24] Higher unemployment, lower wages and lack of services in rural areas also impact on health outcomes for rural people.[25,26] Rural households with chronic illness consumed health care products within this structure of disadvantage. Neo-liberal policies claim that in providing consumers with information they are able to make informed choices about the health care products they consume. These households did not have information, suggesting their ability to participate as consumers was limited. Additionally, the costs of caring for people with chronic illnesses faced by these households meant that they did not have the disposable income of other households to participate in the market economy.

This survey demonstrated that not all consumers are equal. Rural consumers face health inequalities generally, while rural households where there are people with chronic illnesses face broader inequalities. Inequalities in health care and health outcomes are not new, neither are they limited to the rural–metropolitan divide but are part of the reproduction of inequalities

nationally. Such inequalities derive from income inequality. Whereas in the past governments provided assistance to ameliorate the situation, this is no longer the case. Quiggan[13] argues that neo-liberal policies where markets dominate have produced greater economic inequality in Australia, as well as in other countries. Distribution of income has become more unequal in developed countries since the end of the 1970s. Income growth in the US has accrued to the top 20% over the past 3 decades. Similar increases are reported in New Zealand and the United Kingdom.[13] In Australia there is mixed evidence regarding inequality, though an increase in inequality for wage earners has been evident since 1975. There is greater polarity, with the top 10% of workers earning greater income relative to median income and the lowest 10% having income falling even more sharply compared with the median.

Wicks[27] argues that official government statistics demonstrate that assertions that inequality is moderating are based on averages that disguise the unequal growth of incomes in the lower income groups, which have worsened due to regressive tax policies such as the GST. Quiggan[13] suggests that this is most likely due to neo-liberal policies that have removed the buffering effects of welfare services, or more specifically the redistribution of post-tax income, for the lower income groups. Further, inequality in labour markets has occurred where neo-liberal reforms have favoured higher skilled workers and removed the services that assisted lower skilled workers. Short-term contracts, competitive tendering and casualisation of the workforce have all led to increased inequality of both labour markets and incomes.[13] Coburn[28] argues that policies based on neo-liberal ideologies are associated with greater income inequalities, and greater health inequalities within nations. Like Quiggan, he argues that the reduction of welfare programs has played a part in greater inequalities, pointing out that those countries that retain welfare-support programs have better health than those that have pursued neo-liberal doctrines and policies.

Conclusion

Neo-liberal ideology promotes the view that when government withdraws from service provision such as health care, the new markets that are fostered by private enterprise will benefit all consumers alike. This ideology is based on the assumption that all consumers are free to choose from an array of products. In reality, this freedom of choice is greatly curtailed by the circumstances, such as health, income and place of residence, and means they enter any market with differing needs and differing means to pay. For households where there are people with chronic illnesses, choice is curtailed by the need to purchase health care before all else. As governments refuse to increase taxes to assist people in such circumstances through the welfare state, greater inequalities will emerge, and one group at greater disadvantage will be households where there are chronic illnesses.

Acknowledgement

A grant from the Reichstein Foundation, a philanthropic trust, was the source of funding for the original survey.

Competing interests

The Chronic Illness Alliance is a member of Consumers' Health Forum. Christine Walker represents CHF at meetings.

References

1 Aspromourgos T. Is zero government debt desirable? [revised version of an address to the Evatt Foundation's Breakfast Seminar — Who's afraid of public debt? Sydney; 2002 Nov 19.] Evatt Foundation, 2003. Available at: http://evatt.labor.net.au/publications/papers/64.html (accessed Jun 2005).

2 Lofgren H, de Boer R. Pharmaceuticals in Australia: developments in regulation and governance. *Soc Sci Med* 2004; 58: 2397-407.

3 Perkins D, Nelms L, Smyth P. Beyond neo-liberalism: the social commitment state? Social Policy Working Paper No 3; 2004. Brotherhood of St Laurence. Available at: http://www.bsl.org.au/main.asp?PageId=1978 (accessed Jan 2005).

4 Stillwell F. Different dimensions of debt. [revised version of the introduction to the Evatt Foundation's

Breakfast Seminar — Who's afraid of public debt? Sydney; 2002 Nov 19.] Available at: http://evatt.labor.net.au/publications/papers/66.html (accessed January 2005).

5 Navarro V. Neoliberalism, "globalization", unemployment, inequalities and the welfare state. In: V Navarro (ed). The political economy of social inequalities: consequences for health and quality of life. New York: Baywood Publishers, 2002.

6 Larner W. Neo-liberalism: policy, ideology, governmentality. *Studies in Political Economy* 2000; 63: 5-26.

7 Merson JA. Trojan horse? The US pharmaceutical industry's trade 'breakthrough'. Evatt Foundation, 2004. Available at: http://evatt.labour.net.au/publications/papers/122.html (accessed January 2005).

8 Drahos P, FaunceT, Goddard M, Henry D. The FTA and the PBS: submission to the Senate Select Committee on the US-Australia Free Trade Agreement. Doctors Reform Society, 2004. Available at: http://www.drs.org.au/articles/2004/FTA/Doc/DRS%20Website%20AUSFTA.htm (accessed Jan 2005).

9 Harvey K. The Pharmaceutical Benefits Scheme under threat. *Health Issues* 2002; 71: 11-15.

10 Dwyer J. Moving from a provider to a patient-focussed care system: the health reform imperative. *Health Issues* 2004; 81: 10-14.

11 Gray G. The politics of Medicare: who gets what, when and how. Sydney: UNSW Press, 2004.

12 Duckett S. The Australian health care system. Melbourne: Oxford University Press, 2000.

13 Quiggan J. Globalisation, neoliberalism and inequality in Australia. *Economic and Labour Relations Review* 1999; 10: 240-59. Available at: http://www.uq.edu.au/economics/johnquiggin/JournalArticles99/GlobalisELRR99.html (accessed Jan 2005).

14 Consumer Focus Collaboration. The evidence supporting consumer participation in health 2001. CFC, 2001. Available at: http://www.participateinhealth.org.au/clearinghouse/ (accessed Mar 2005).

15 Goggin G, Newell C. Reclaiming citizenship: biotechnology and the civil society. *Aust Health Consumer* 2003; 2: 12-13.

16 Spencer B. Another day, another dollar: the way welfare changes affect us all. *The Age* (Melbourne) 7 May, 2005: 25.

17 Schneemann K, Medicines Australia. Media release commending the federal government on the increase in PBS Safety Net. 10 May 2005. Accessed Jun 2005 at: www.medicinesaustralia.com.au/public.

18 Walker C, Tamlyn J. The costs of chronic illness in rural and regional Victoria. Chronic Illness Alliance Inc: Victoria, 2004. Available at: www.chronicillness.org.au/reports.htm (accessed Mar 2007).

19 Harding A, Lloyd R, Greenwell H. Financial disadvantage in Australia 1990-2000: persistence of poverty in a decade of growth. Discussion paper no 29. Canberra: Smith Family and National Centre for Social and Economic Modelling, University of Canberra, 2002.

20 Australian Bureau of Statistics. Australian social trends, 2002. Income and expenditure; households in financial distress. Canberra: ABS, 2002. (ABS Cat. No. 4102.0.)

21 MacLennan A, Wilson D, Taylor A. Prevalence and cost of alternative medicine in Australia. *Lancet* 1996; 347: 569-73.

22 Eisenberg D, Kessler R, Foster C, et al. Unconventional medicine in the United States: prevalence, costs, patterns of use. *N Engl J Med* 1993; 328: 246-52.

23 Fisher P, Ward A. Complementary medicine in Europe. *BMJ* 1994; 309: 107-11.

24 Dixon J, Welch N. Researching the rural-metropolitan health differential using the social determinants of health. *Aust J Rural Health* 2000; 8: 254-60.

25 Fitzgerald M, Pearson A, McCutcheon H. Impact of rural living on the experience of chronic illness. *Aust J Rural Health* 2001; 9: 235-40.

26 Bourke L. Australian rural consumers' perceptions of health issues. *Aust J Rural Health* 2001; 9: 1-6.

27 Wicks J. The reality of income inequality in Australia. Social Policy Issues Paper 1, 2005. St Vincent de Paul Society. Available at: http://www.vinnies.org.au/content.cfm?table=content_listitems&parentid=0&id=2539 (accessed Jun 2005).

28 Coburn D. Beyond the income inequality hypothesis: globalization, neo-liberalism and health inequalities. *Soc Sci Med* 2004; 58: 41-56.

(Received 25/06/06, revised 26/11/06, accepted 4/02/07) □