

Financial toxicity in clinical care today: a “menu without prices”¹

Out-of-pocket costs are rising rapidly and can influence treatment decisions and health outcomes

Australia delivers health outcomes that rank well internationally, with per capita spending demonstrably less than that of the United States. Of concern, Australia's out-of-pocket costs for health care are sixth highest among Organisation for Economic Co-operation and Development countries,² despite universal health insurance. These out-of-pocket expenses accounted for 57% of non-government health expenditure in 2011–12, or over 17% of all health care expenditure.³ Health care costs in Australia continue to rise well above the consumer price index. The net burden of costs are reported by clinicians to influence some decisions that patients make, with the potential for detrimental health outcomes for individuals and for Australia's health as a whole.

The average equivalised weekly disposable household income in 2013–14 was \$998, with a median of \$844.⁴ About half of all households therefore have a weekly net income of less than \$844, yet that income has to support out-of-pocket health expenses. There are also limits to what is covered under different aspects of the safety net. Further, many aspects of community-based care are associated with part or all of the cost being borne by the patient, in many cases with no safety net provisions (wound dressings, incontinence pads, community nursing and allied health visits).

In cancer care, patients often face tough decisions as new unsubsidised therapies become available. An ageing population, innovations (some with very marginal benefits) and the risk that some procedures are overused or harmful all contribute to unnecessary financial (and emotional) pressure on patients and their families. Procedures and interventions, at times with marginal health gains, are being promoted actively, frequently with high costs and little meaningful benefit in terms of quality of life or survival. In the context of ongoing outcome disparities based on socio-economic status, our aim must be timely access to world class care for all Australians, regardless of financial circumstances.

In the Australian context, financial disclosure is not only how much a procedure will cost but, crucially, whether there are alternatives that offer similar benefits at less cost to the patient. This may be as important to the patient as the side effects or risks of an intervention. Most starkly, the omission of information from a private clinician regarding options in the public sector reduces informed financial choice and increases the potential for significant financial and health disadvantages.

Failing to inform patients about comparative waiting times in public and private systems falls short of fully informed (financial) consent. Indeed, national data

demonstrate that public surgical waiting times for a sample of cancers are very short.⁵ Publicly available data on waiting times and service quality are critical for supporting informed treatment decisions, especially when out-of-pocket expenses can vary from zero to tens of thousands of dollars for the same procedure.

Value in health care is defined as outcomes relative to cost.⁶ In considering this from a patient's perspective, it is imperative to not only question outcomes but to understand the true cost for the whole episode of care — the out-of-pocket expenses, the contribution made by the community through Medicare, and any supplementary private insurance. Informed choice should be based on more than the costs charged by an individual practitioner and those incurred by related pathology, imaging and anaesthetics. Informed choice now needs also to account for the extreme variations in the prices charged by identically credentialed practitioners within Australia undertaking the identical procedure.⁷

International data suggest that the consequences of high out-of-pocket costs include the potential for poorer compliance with ideal care, including prescribed medications that are necessary for best outcomes.^{8,9} To make decisions about what is often a long treatment pathway across multiple modalities, patients need a comprehensive and early understanding of the financial impacts of treatment, time away from work and other costs, and the opportunity to seek financial advice and assistance early as needed. Indeed, in one survey, people only sought help when the financial burden was starting to cause significant difficulties.⁹

Arguably, failure by medical practitioners to disclose all of the financial costs affecting patients' decisions is a cause of avoidable suffering for tens of thousands of households across Australia each year.¹⁰ A new standard for financial disclosure is required — a standard that moves beyond disclosure of the costs of a single procedure to one that accounts for the costs of a full pathway of treatment and all the alternatives open to the patient. The issue of financial toxicity in Australian health care requires open debate supported by population- and individual-level data on rapidly rising out-of-pocket costs, and advocacy that places patients' outcomes at the centre of any debate about the profession's increasing demands on patients' wallets.

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David Currow
PhD, FRACP, FAHMS¹

Sanchia Aranda
PhD, MN, BAppSci²

¹ Cancer Institute NSW,
Sydney, NSW.

² Cancer Council Australia,
Sydney, NSW.

David.Currow@cancerinstitute.org.au

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