



# Paternalism in Medicine and High-Priced, Non-Subsidized Medications

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## INTRODUCTION

### Unsubsidized, expensive drugs

Most prescription drugs in Australia are subsidized by the government through the pharmaceutical benefits system. The Pharmaceutical Benefits Advisory Council, an independent expert committee comprised of medical practitioners and pharmacists, evaluates new pharmaceuticals that have been authorized by the Therapeutic Goods Administration for inclusion in the plan. Before selecting a medicine, the committee analyses numerous factors, including efficacy, safety, quality of life advantages, and cost effectiveness. The committee may impose limitations on the way medications are prescribed. It might take a long time for a new medicine to be approved by the Therapeutic Goods Administration and then included on the pharmaceutical benefits plan.

Other nations have experienced similar delays between permission and subsidization. The National Institute for Health and Clinical Excellence (NICE) in the United Kingdom has been accused of causing significant delays in making medications available through the NHS. Cancer BACUP, a cancer charity, has released a "dossier of delay," which details severe delays in the clearance of novel anticancer medications. Some drugs that have demonstrated to improve survival in big clinical studies may not be recommended by NICE for several years, rendering them unavailable to many patients. Other European countries, as well as Canada and New Zealand, experience similar delays.

### Practice of discussing unfunded drugs

Several cancer medications (chemotherapy and biological agents) have recently been tested in big phase III clinical trials and shown to be more effective than currently available therapies. Patients must pay the full cost of the new medications unless they are delivered by a public hospital because they are not on the pharmaceutical benefit system list. The costs may be substantial, averaging \$A1000 per week (£420, €600, \$730). For many people, such expenses would be a significant financial burden or outright prohibitive.

Clinical problems arise when discussing the use of non-subsidized medications with patients. Is it acceptable to expect a patient to cover the whole cost of their therapy when it is not covered by the government? Would it be immoral not to mention the possibility of using an unsubsidized drug? And how should an oncologist approach a patient or their family about the possibility of taking an unsubsidized drug?

We looked at how Australian medical oncologists felt about unsubsidized medications and what they did about it. We sent a survey to all 274 members of the Medical Oncology Group of Australia, outlining three clinical circumstances in which a hypothetical unsubsidized medicine was linked to a significant, objective benefit that had been established in big clinical trials. The case studies were based on therapies that had recently been published in medical journals (trastuzumab for women with breast cancer, imagined for treatment of gastrointestinal stromal tumours, and gemcitabine based treatment for people with advanced bladder cancer). The medications were not covered by the pharmaceutical benefit system at the time. Despite the fact that each is currently available, it took months or years for them to be included.

The poll received a 78 percent response rate (38 were ineligible; of the remaining 236, 184 returned questionnaires). Most oncologists said they would talk to their patients about the new treatment if it was covered by insurance (72 percent to 94 percent of eligible replies (128-169), depending on the circumstance). Oncologists were far less likely to offer treatment options if the medications were not subsidized (28 percent -41 percent (50-72), depending on the circumstance). "Knowing they wouldn't be able to receive this new treatment would be too stressful for the patient and their family," and "I would feel guilty recommending a prescription that the patient certainly can't afford" were the most often given reasons for not discussing the drug.

Our findings indicate that oncologists are worried about the psychological and emotional impact these interactions might have on patients and their families. These talks are also stressful for practitioners, according to the research. Nonetheless, we question

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if this practice is always in the best interests of the patient and whether such a paternalistic attitude is acceptable.

## CONCLUSION

There are no simple answers to the problem of obtaining new, pricey pharmaceuticals. Nonetheless, it is irrational to conceal information about any potentially beneficial treatment from a patient due to worries about financial ability, even if these talks are

challenging and distressing for some patients. Withholding such information is, in our opinion, immoral and paternalistic.

Additional issues include gaining early access to potential treatments and determining whether or not to publicly subsidize high-cost drugs. The general public will have to discuss how much responsibility the government should bear for individual health and well-being, as well as how limited healthcare money should be distributed.