

Overview: Cost of cancer to the patient

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The escalating financial cost of cancer to patients and their families is emerging as a global phenomenon. Despite diversely funded healthcare systems internationally,¹ cancer causes substantial financial burden to individuals in many different countries, including the USA, Canada and Ireland.² Australia is no exception and the articles in this Forum explore the many facets of financial costs in this context.

Although cancer remains a leading cause of death in Australia,³ survival rates have improved substantially over recent decades and more and more people are living longer following a diagnosis of cancer.⁴ Consequently, the prominence of research into the financial aspects of diagnosis, treatment and follow-up for individuals and their families has increased dramatically.⁵ Given the growing international body of evidence on the financial issues faced by people diagnosed with cancer,^{2,5} there is a need to understand more deeply the magnitude and consequences of financial challenges in the Australian setting to better maximise cancer care.

Christine Paul and colleagues provide an assessment of how patient expenses arise in the Australian healthcare setting despite the predominantly publicly-funded system.^{3,6} The review summarises local evidence on the burden, distribution and potential consequences of financial costs on patients and families faced with cancer and provides information on the financial assistance available. The authors also highlight the paucity of accurate, ongoing, system-wide information about the financial cost of cancer care experienced by patients and their families, and the absence of evidence on information needs and financial care.

Camille Schubert describes the key Australian Government regulatory bodies and funding schemes related to cancer care, including a summary of the different types of cost and economic and financial analyses required for evaluations of new cancer technologies.⁷ Camille concludes that Australian regulatory agencies and funding bodies consider patient costs. However, some types of cost are often omitted, potentially affecting affordability and access to care for individuals.

While local guidelines recommend including costs in economic analyses informing societal research and reimbursement decisions from a government funding agency, a healthcare and a societal perspective (all costs, including patient and family), in reality the latter seldom occurs.⁷⁻⁹ Placing greater emphasis on the societal perspective in this context will promote greater research into the cost of cancer to the patient and family. Robust and rigorous analysis will more fully inform decision makers and help to prevent cost shifting.^{10,11}

The financial burden of cancer care also falls on to informal (unpaid) caregivers, often family members. Demand for informal caregivers is rising,¹² although broad social changes such as smaller, dispersed families and higher divorce rates are reducing availability.¹¹ Afaf Girgis and Sylvie Lambert review the financial impact on this vital group of people who are integral to cancer care service provision.¹² The results of the review suggest informal caregiving represents as much as a third of the total financial cost of cancer.

Accurately measuring the costs of cancer to the patient for research purposes is challenging, as discussed by Sophy Shih and Rob Carter.¹³ Issues covered include methods of data collection, instruments specifically designed to collect costs incurred by cancer patients, questionnaire development, recall length, specificity, coverage and missing data. The authors suggest advances in information and mobile technologies may overcome existing barriers to robust measurement of resource utilisation and patient costs in cancer research, ultimately improving societal decision making.

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Two closely related articles by Louisa Gordon and colleagues and Bogda Koczwara tackle the concept of 'financial toxicity'.^{14,15} The former article defines financial toxicity, describes how financial toxicity is measured and reviews the prevalence of financial problems on the individual after a cancer diagnosis. As many as half of cancer survivors have been estimated to have experienced financial stress, a proportion that is even higher (73%) if objective or subjective questions are considered in addition to monetary measures alone.¹⁴

A major driver of financial toxicity, unemployment and reduced work participation, is discussed in more detail by Bogda Koczwara.¹⁵ The article outlines current knowledge on unemployment and reduced work participation after cancer, associated equity implications and evidence-based strategies to improve work participation, such as physical training and psycho-education. The role of the health care provider in financial wellbeing is raised, highlighting the need (yet again) for multi-disciplinary and multi-sectorial collaboration to improve patient care.

In advanced cancer, addressing financial issues is an important aspect of quality of life from palliative care patients' perspectives.¹⁶ Timothy Ford and colleagues further explore financial issues in this setting, in a review of the evidence of the relationship between financial concerns and advance care planning.¹⁷ The results suggest concerns about being a burden on others and financial worries can influence individual treatment decisions and may motivate and shape advance care plans. Further, the authors propose a useful conceptual model on the role of financial concerns, advance care planning and treatment decisions to guide future research.

Despite this body of research, to date, the actual rather than estimated financial cost of cancer to patients in Australia is largely unknown.^{6,14,15} Currently, work is underway by Cancer Council Queensland to investigate the financial impact of diagnosis and treatment through the Everyday Health Survey 'Health System Quality & Costs – How High is the Burden?' This state-wide survey aims to improve understanding of how the cost of cancer impacts patients and influences their access to healthcare services, treatment decisions and compliance with clinical advice. Further, Breast Cancer Network Australia, with the assistance of Deloitte Access Economics, has recently conducted a national survey to determine out of pocket costs of breast cancer patients. Results will be published later this year.

The articles in this Forum provide a valuable overview of the research into the cost of cancer to the patient and their families and highlight the need for more work into this emerging phenomenon to promote equitable, effective and efficient cancer care in Australia.

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