CANCER FORUM

Financial toxicity – what it is and how to measure it

Louisa G Gordon,[1,2,3] Katharina M D Merollini,[4] Anthony Lowe,[5,6] Raymond J Chan[2,7]

1. QIMR Berghofer Medical Research Institute, 300 Herston Rd, Herston Q4006, Brisbane, Australia
2. Queensland University of Technology, School of Nursing, Victoria Park Rd, Kelvin Grove, Q4059, Brisbane, Australia
3. The University of Queensland, School of Public Health, Herston Rd, Herston Q4006, Brisbane, Australia
4. University of the Sunshine Coast, Faculty of Science, Health, Education and Engineering, Maroochydore DC Q4558, Sunshine Coast, Australia
5. Prostate Cancer Foundation of Australia, St Leonards, NSW 2065, Sydney, Australia
6. Griffith University, Menzies Health Institute Queensland, Southport Q4215, Gold Coast, Australia
7. Royal Brisbane and Women's Hospital, Cancer Care Services, Herston Q4029, Brisbane, Australia

Email: louisa.gordon@qimrberghofer.edu.au

Abstract

The term 'financial toxicity' is broadly used to describe the distress or hardship arising from the financial burden of cancer treatment. In much the same way as physical side-effects of treatment like fatigue, nausea or blood toxicities, financial problems after cancer diagnosis are a major contributor to poorer quality of life, treatment non-adherence and delayed medical care. This article describes what financial toxicity is, how it is measured, how common it is and what the implications are for further research and clinical practice. A recent review shows a wide range of measures used to describe the financial burden of cancer. Using monetary measures, the magnitude of financial stress was between 28-48% in cancer populations. Possible solutions to reduce the family financial burden include mandating full disclosure of doctors' fees and charges related to treatment and strategies to empower patients to improve their treatment decision making. Furthermore, screening tools such as the COST-FACIT 11-item survey may assist health professionals to identify those patients at high risk of financial stress and refer them to support services. Minimising financial stress is important for patients and measuring financial toxicity helps to expose flaws in health systems and subsequently ensure that citizens receive quality cancer care.

For patients and their families with cancer, the financial impact of this disease can be devastating. Although this may also be a problem for patients with other serious diseases, patients with cancer are particularly vulnerable, in part due to the high costs associated with multiple components of care, advancements in technologies, new oncology pharmacotherapies and surgical techniques, increased use of imaging, and genetic testing.[1] Ancillary costs such as travel, parking, accommodation, medical aids, home help and child care can also mount up. Further, improvements in survival mean that most people with cancer are living longer, but with increased risk of functional decline and comorbidities causing substantial personal and societal burden.[2] As most health systems face ever-constrained budgets, there is increasing reliance on patients to make larger co-payments and financial contributions to their healthcare.[3,4]

Since all healthcare systems differ, their organisation and funding mechanisms largely determine the degree of financial hardship experienced by citizens when a major health shock occurs, such as a diagnosis of cancer. In low income countries, where affordability and access to healthcare is low, patients with cancer may not even present to health services when symptoms arise, or only present to a doctor when the cancer has spread and death is imminent.[5] Poor provision of a public health sector, strong cultural beliefs about illness and geographical barriers to receiving cancer treatment compound the problem.[6] In high income countries, patients with cancer often believe they are sufficiently

protected from high medical costs through their public health system or health insurance policies, only to discover inadequate coverage and subsequent 'bill shock' as invoices arrive.[7] Health systems claiming to have 'universal health coverage' in practice may not be truly universal. For example, Australians do not have access to free basic dental health services.[8] Additional patient out-of-pocket expenses are common even in countries where there is universal health care or when individuals purchase private health insurance.[1,4,8] High out-of-pocket healthcare costs have led to the recent conceptualisation of 'financial toxicity'. This paper outlines the notion of financial toxicity - a new term originating in oncology by Zafar and colleagues in 2013,[9] - and describes what it is and how it is measured. The popularity of this term has grown because of the clear link to patient loss of wellbeing, placing it in the same context as physical toxicities.

What is financial toxicity?

There is no standard definition of financial toxicity. Together with the terms financial hardship and financial burden, which are used interchangeably, the term is broad and non-specific. However, the occurrence of financial toxicity has two key contributors: 1) high medical payments by individuals/households; and 2) reduced income while being treated or recovering from cancer. Some physical and mental impairments of cancer treatment also lead to permanent work cessation.[10,11] The extent of financial burden is worse for individuals facing the dual problem of high out-of-pocket medical expenses or outgoings and concurrent loss of earnings or incomings. In some research studies, financial hardship has been captured as 'catastrophic spending', which is defined as spending greater than 30% of household income on healthcare.[5]

The ways that individuals cope with financial burden fall into two broad categories: raising income through seeking financial assistance, early return to work and increasing debt/borrowings and the like; or reducing spending by forgoing or delaying healthcare, choosing a less expensive option and similar steps. However, these strategies are not available to all individuals. A diagnosis of cancer can be very fearful for patients and questioning their health professional on fees is often a low priority.[3] Also, patients with cancer may not be informed of less expensive options unless they are confident and proactively search for this information. For example, in our research involving men with prostate cancer,[3] the choice of receiving brachytherapy treatment in private practice was offered to one man at an upfront cost of $15,000 for the brachytherapy seeds and a further $10,000 for the surgical procedure requiring three days in hospital. With further research, he was advised he could receive the same procedure at a public hospital at no cost. However, in the same study, another participant reported paying $16,000 for a prostatectomy by a private surgeon, later regretting his decision when he learned other less-invasive and less expensive options were relevant, but never discussed by his specialist. In economic terms, these scenarios are examples of 'asymmetric information' between the consumer and provider, partly influenced by the lack of market competition and demonstrating market failure in the healthcare sector. Market failure in healthcare has many sources, but generally describes the scenario where resources are not being allocated efficiently and it is possible that patients could be better off. Market corrections via regulations or government intervention are usually required. Strategies to empower patients to engage in optimal decision marking in healthcare are also important.[12]

Measuring financial toxicity

There have been numerous studies over the last 10 years specifically among individuals and families on the topic of the financial burden of cancer. Several reviews have been published covering selected aspects, for example, perceptions of cancer-related financial hardship or reported impact on quality of life.[13] In a recent systematic review,[12] the current extent of financial toxicity was assessed from studies published within the previous three years. Further, it described the latest measures or tools researchers employ to understand this occurrence.

The measures of financial toxicity varied widely among the studies and therefore were categorised into three types of measures:

1) Monetary - currency values of out-of-pocket expenses and percentage of out-of-pocket spending to income ratios.

2) Objective - question sets on tangible solutions to ease financial burden such as to increase debt levels, borrow money from family or friends, sell assets, withdraw money from retirement or savings funds, file for bankruptcy.

3) Subjective - question sets on perceptions of cancer-related financial burden and which cover the psychological impacts.

However, even within these three categories, there was heterogeneity relating to the scope of data collected. For example, monetary measures included either direct medical expenses or direct and indirect expenses such as travel, accommodation or parking. It is important to note that most measures used in the studies in our review were not validated or tested for reliability. Therefore, how rigorous they are at measuring what they are supposed to measure is uncertain. Monetary measures are problematic when relying on participant recall, while comparability across studies is difficult when cost components differ and cover different time periods. With 72% of studies using cross-sectional designs, drawing causal inferences between financial toxicity outcomes and determinants was not possible.[12] Financial hardship may have existed prior to the cancer or due to other concurrent health conditions. The cancer experience might have not caused, but exacerbated existing financial problems.[14-16] Directionality and temporality issues are also present in these cross-sectional designs. However, other methodological strengths in the study design exemplified by good response rates >50%, large samples and analysis indicated by adjustment for potential confounders, provide confidence when the interpreting the results.

There are few Australian studies examining the economic burden on patients with cancer.[3,10,17-19] Although they provide snapshots of the burdens Australians face for breast cancer,[17] prostate cancer,[3] colorectal cancer,[10] mixed cancers,[19] and patients with cancer in rural locations,[18] these studies include small and selective samples which preclude generalisations. Two of the studies are over a decade old.[17,18] More recently, one study observed changes in employment after colorectal cancer (n=239) and compared findings with a non-cancer control group in middle-aged working adults.[10] The findings showed 27% had not returned to work 12 months after their diagnosis compared with 8% leaving work in the matched general population group.[9] The median time off after cancer was 91 days and 75% of the sample took up to six months off work. In a sample of men recently diagnosed with prostate cancer (within 16 months of the survey) (n = 65), men reported spending a median $8000 (interquartile range $14,000) for their cancer treatment, while 75% of men spent up to $17,000.[3] Twenty per cent of all men found the cost of treating their prostate cancer caused them 'a great deal' of distress.

How common is financial toxicity?

Considering the measurement variation and issues reported above in 25 of the most recent studies in this field,[12] evidence for the extent of financial toxicity following cancer is imprecise. When monetary measures alone were used, the findings from the recent review indicated the frequency of financial toxicity among cancer survivors ranged from 28 to 48%.[12] When financial toxicity was measured with participants responding to objective or subjective questions, the frequency ranged from 16 to 73%. Some of the factors which were consistently associated with financial toxicity were being female, low income at baseline, younger age, adjuvant and anti-neoplastic therapies, advanced cancer, more recent diagnosis and living further away from treatment centres. In three studies, the financial burdens were examined within cancer populations alongside non-cancer control groups.[6,20,21] All indicated statistically significantly higher burden for individuals with cancer relative to non-cancer control groups. The above-mentioned review had consistent findings with two other reviews.[4,13] One assessed perceived financial burden and found 15 to 78% experienced financial hardship, with low income households identified as the most significant risk factor.[13] A second US-based review, found high prevalence of tangible measures and non-adherence to treatments as coping mechanisms to high financial costs.[4]

There is also evidence from several studies to indicate financial toxicity lives up to its name in impacting the quality of life of patients with cancer. Mental well-being was markedly worse for patients experiencing financial toxicity in three recent studies.[15,22,23] Increased financial burden among 2108 patients with cancer was the strongest independent predictor of poor quality of life in the US study by Fenn et al.[24]

Implications for research

The categories used in reporting outcomes in the recent review may help researchers design studies in future and determine exactly which aspect of hardship they are targeting. The measurement of financial toxicity in cancer should be standardised as this would increase the comparability of research findings across samples, aiding pooling of results and interpretation across different settings.

One such tool,[25] the COST-FACIT, has recently been developed by Souza et al. This 11-item survey covers objective and subjective questions about financial stress and work-related issues during the past seven days and uses a Likert scale rated from 'Not at all' to 'Very much'. A recent study demonstrated the reliability and validity of this tool in patients with metastatic cancer.[26] In addition, as reductions in work income are an important aspect of financial toxicity, the Institute for Medical Technology Assessment Productivity Cost Questionnaire (iPCQ) may also be useful in future research.[27] The iPCQ measures productivity losses of paid work due to absenteeism and presenteeism (present at work but underperforming), and unpaid work. It comprises 18 items and questions are phrased 'over the past four weeks'. Although there are calls for further validation studies of the COST-FACIT and iPCQ,[25,27] these are probably the best tools currently available compared with unvalidated and less comprehensive options. Further research is needed to more accurately estimate the extent of financial toxicity and to understand the extent of the impacts on patient health and access to healthcare. For example, are patients forgoing medications or doctors' appointments? Are patients delaying optimal recovery from cancer? Are patients forced to compromise treatment options? Does the experience of financial toxicity aggravate other toxicities?

Implications for cancer care services

Financial toxicity among families facing cancer exists in the context of the health system, how health services are organised and who pays for them. Financial considerations can be seen as a secondary priority when patients face the stressful experience of cancer and deciding on treatment. Although financial toxicity itself is a complex problem and unique to the patient's circumstances, greater awareness and acknowledgement of financial toxicity is likely to lead to solutions that optimise patient outcomes by cancer care professionals, governments, patients and families, and welfare providers. Healthcare professionals should understand that poorer health outcomes in their patients may arise, not only from the cancer, but also from the financial fallout from cancer.

Financial toxicity can be viewed as a 'household' issue and it can affect any patient regardless of their apparent socioeconomic status. The occurrence of financial toxicity is a function of financial outgoings and expenses alongside the financial incomings, usually from employment, which may be reduced while undergoing cancer care. It is likely that in public health systems where out-of-pocket costs for direct medical services are minimal, wage losses from the time required to receive the cancer treatment and recovery may be more important.[28]

Suggestions to ameliorate the financial burden for patients in tangible ways have included: 1) mandating the full disclosure by doctors of estimated fees and charges related to treatment from all sources; 2) improved communication between health professionals and patients to raise any financial concerns and the ability of patients to return to work should they need/wish to and; 3) creating opportunities for patients to make treatment decisions fully informed of the likely burden.[7,29]

Appropriate discussions about financial concerns should begin from the start of treatment and critical time points, for example upon completion of treatment, preparing patients and their families for the potential financial effects that could have an ongoing impact. Furthermore, screening tools such as the COST-FACIT could be administered for this purpose and may assist health professionals to identify those patients at high risk and refer them to support services.

Conclusion

There is consistent and growing evidence that financial toxicity exists for a significant proportion of patients with cancer. Although the evidence is of moderate quality, it is an important issue to patients and their families. It can have a very negative impact on quality of life and cause distress. Prospective, longitudinal study designs with non-cancer comparison groups would provide more

definitive evidence on the extent of financial toxicity and ultimately inform interventional work. Measuring financial toxicity is possible through the use of new validated tools, but it is important to acknowledge the overall complexity of this topic and the absence of firm definitions or a conceptual model informing this body of evidence.

References

1. de Souza JA, Wong YN. Financial Distress in Cancer Patients. J Med Person. 2013;11(2).doi:10.1007/s12682-013-0152-3.
2. Yabroff KR, Lawrence WF, Clauser S, et al. Burden of illness in cancer survivors: findings from a population-based national sample. J Natl Cancer Inst. 2004;96:1322-30.
3. Gordon LG, Walker SM, Mervin MC, et al. Financial toxicity: a potential side effect of prostate cancer treatment among Australian men. Eur J Cancer Care (Engl). 2017;26(1).doi:10.1111/ecc.12392. Epub 2015.
4. Bestvina CM, Zullig LL, Yousuf Zafar S. The implications of out-of-pocket cost of cancer treatment in the USA: a critical appraisal of the literature. Future Oncol. 2014;10:2189-99.
5. Jan S, Kimman M, Peters SA, et al. Financial catastrophe, treatment discontinuation and death associated with surgically operable cancer in South-East Asia: Results from the ACTION Study. Surgery. 2015;157:971-82.
6. Mahal A, Karan A, Fan VY, et al. The economic burden of cancers on Indian households. PLoS One. 2013;8:e71853.
7. Zafar SY. Financial Toxicity of Cancer Care: It's Time to Intervene. J Natl Cancer Inst. 2015;108(5).pii:djv370.doi:10.1093/jnci/djv370.
8. Laba TL, Essue BM, Jan S. Financing options to sustain Medicare: are we committed to universalism? Med J Aust. 2015;203:244-5.e1.
9. Zafar SY, Peppercorn JM, Schrag D, et al. The financial toxicity of cancer treatment: a pilot study assessing out-of-pocket expenses and the insured cancer patient's experience. Oncologist. 2013;18:381-90.
10. Gordon LG, Beesley VL, Lynch BM, et al. The return to work experiences of middle-aged Australian workers diagnosed with colorectal cancer: a matched cohort study. BMC Public Health. 2014;14:963.
11. Mehnert A. Employment and work-related issues in cancer survivors. Crit Rev Oncol Hematol. 2011;77:109-30.
12. Gordon LG, Merollini KM, Lowe A, et al. A Systematic Review of Financial Toxicity Among Cancer Survivors: We Can't Pay the Co-Pay. Patient. 2016;31:31.
13. Azzani M, Roslani AC, Su TT. The perceived cancer-related financial hardship among patients and their families: a systematic review. Support Care Cancer. 2015;23:889-98.
14. Kimman M, Jan S, Yip CH, et al. Catastrophic health expenditure and 12-month mortality associated with cancer in Southeast Asia: results from a longitudinal study in eight countries. BMC Med. 2015;13:190.
15. Sharp L, Timmons A. Pre-diagnosis employment status and financial circumstances predict cancer-related financial stress and strain among breast and prostate cancer survivors. Support Care Cancer. 2016;24:699-709.
16. Stump TK, Eghan N, Egleston BL, et al. Cost concerns of patients with cancer. J Oncol Pract. 2013;9:251-7.
17. Gordon L, Scuffham P, Hayes S, et al. Exploring the economic impact of breast cancers during the 18 months following diagnosis. Psychooncology. 2007;7:7.
18. Gordon LG, Ferguson M, Chambers SK, et al. Fuel, beds, meals and meds: out-of-pocket expenses for patients with cancer in rural Queensland. Cancer Forum. 2009;33(3):202-208
19. McKay G, Knott V, Delfabbro P. Return to work and cancer: the Australian experience. J Occup Rehabil. 2013;23:93-105.
20. Davidoff AJ, Erten M, Shaffer T, et al. Out-of-pocket health care expenditure burden for Medicare beneficiaries with cancer. Cancer. 2013;119:1257-65.
21. Ramsey S, Blough D, Kirchhoff A, et al. Washington State cancer patients found to be at greater risk for bankruptcy than people without a cancer diagnosis. Health Aff (Millwood). 2013;32:1143-52.
22. Kale HP, Carroll NV. Self-reported financial burden of cancer care and its effect on physical and mental health-related quality of life among US cancer survivors. Cancer. 2016;122:283-9.
23. Khera N, Chang YH, Hashmi S, et al. Financial burden in recipients of allogeneic hematopoietic cell transplantation. Biol Blood Marrow Transplant. 2014;20:1375-81.

24. Fenn KM, Evans SB, McCorkle R, et al. Impact of financial burden of cancer on survivors' quality of life. J Oncol Pract. 2014;10:332-8.
25. de Souza JA, Yap BJ, Hlubocky FJ, et al. The development of a financial toxicity patient-reported outcome in cancer: The COST measure. Cancer. Epub 2014;120:3245-53. doi: 10.1002/cncr.28814.
26. de Souza JA, Yap BJ, Wroblewski K, et al. Measuring financial toxicity as a clinically relevant patient-reported outcome: The validation of the COmprehensive Score for financial Toxicity (COST). Cancer. Epub 2016;123:476-484. doi: 10.1002/cncr.30369.
27. Bouwmans C, Krol M, Severens H, et al. The Institute for Medical Technology Assessment Productivity Cost Questionnaire: A Standardised Instrument for Measuring and Valuing Health-Related Productivity Losses. Value Health. Epub 2015;18:753-8. doi: 10.1016/j.jval.2015.05.009.
28. Lauzier S, Levesque P, Mondor M, et al. Out-of-pocket costs in the year after early breast cancer among Canadian women and spouses. J Natl Cancer Inst. 2013;105:280-92.
29. Tucker-Seeley RD, Yabroff KR. Minimizing the "financial toxicity" associated with cancer care: advancing the research agenda. J Natl Cancer Inst. 2015;108(5).pii:djv410.doi:10.1093/jnci/djv410