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Title: Financial toxicity among patients with cancer – where to from here?

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The author has no funding or conflicts of interest to disclose.

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In oncology, the term ‘financial toxicity’ basically means the financial hardship or financial burden for patients and families that arise from cancer treatment and ongoing expenses. Individuals from any socio-economic group may experience this and it can occur in both low- and high-income countries. There are two key contributors; 1) high medical payments by individuals/households and 2) reduced income while being treated or recovering from cancer. The former is likely to impact more individuals in high-income countries while the latter is more problematic in poor households although clearly, individuals will be worse when faced with both high out-of-pocket medical expenses (outgoings) and concurrent loss of earnings (incomings). In some studies, financial hardship is defined as spending greater than 30% of household income on health care and is called ‘catastrophic spending’¹.

What is the state of science in financial toxicity?

Studies reporting on the personal financial burdens of cancer are not new. There are hundreds of published studies and several reviews on the topic. In our recent systematic review ², we assessed the most recent evidence of financial toxicity and the ways in which researchers measured it. Due to the large number of the measures of financial toxicity possible, we categorised them into three broad areas: 1) *monetary measures*: currency values of out-of-pocket expenses and ratio of out-of-pocket spending to income; 2) *objective measures*: 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; and 3) *subjective measures*: question sets on perceptions of cancer-related financial burden and which cover the psychological impacts ².

These three areas each measure a different aspect of financial toxicity with currency values being absolute but not revealing much about the ways in which people coped

(indicated by the Objective measures) or what was the actual impact on distress levels (indicated by Subjective measures). When monetary measures were used, the findings from our review indicated the frequency of financial toxicity among cancer survivors ranged from 28% to 48%². Using objective or subjective measures, the frequency ranged from 16% to 73%². 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 rural living. In three studies, there were statistically significantly higher burden for individuals with cancer relative to non-cancer control groups².

Methodological concerns and research priorities for consideration

Several improvements could be made for future studies of financial toxicity to strengthen their rigour. If financial toxicity is to be comprehensively researched, collecting complementary measures from each of the three categories is advisable. Most measures used in the studies in our review were not validated or tested for reliability. Standardising the measurement of financial toxicity in cancer is strongly advised as it means research findings can be more comparable across samples. One tool, the COST-FACIT, and was developed and validated by Souza *et al.* (2014) is an 11-item survey covering both objective and subjective questions and work-related issues^{3,4}. When collecting data on monetary costs, participant recall needs to be restricted to prospective, short and frequent data collections, using closed questions and a wide range of cost types. Longitudinal designs are needed with 72% of studies in our review using cross-sectional designs². Financial hardship could have existed for individuals prior to the cancer or from other concurrent diseases and the cancer experience worsening financial hardships. Therefore, collecting data before the cancer diagnosis will improve understanding of baseline financial situations.

Finally, each country and healthcare setting is unique and there is a need to recognise the country-specific protections of health-related costs incurred by patients with cancer. Costs may include: health system expenditures for treatment and care-related resources, other financial costs (supportive care, respite, aids, home modifications, transport, accommodation), productivity costs (work time lost, carer costs), transfer costs (welfare and disability payments, taxation revenue to government forgone), non-financial costs or burden of disease (pain, suffering, quality of life loss). Obviously different cancer types will have different sorts of cost burdens⁵, often dictated by cancer aggressiveness, survival expectations and age at diagnosis. For example, a 35-year-old woman with breast cancer could be faced with AU\$40,300 in lost productivity and out-of-pocket expenses on average whereas a working-age man with lung cancer could incur AU\$203,600 in economic costs⁶. Further research should investigate the role of oncology nurses including nurse navigators and care coordinators in assessing and addressing financial toxicity in patients across the cancer trajectory, from diagnosis to survivorship and ultimately end of life care.

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