



Global Haematology

A survey in Nepalese patients with acute leukaemia: a starting point for defining financial toxicity of cancer care in low-income and middle-income countries

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For the Nepali translation see Online for appendix 1

For more on **financial toxicity and how to assess it** see *EClinicalMedicine* 2020; **20**: 100269 and *Ann Oncol* 2019; **30**: 1061–70

For more on **bone marrow transplantation in Nepal** see *Biol Blood Marrow Transplant* 2018; **24**: S312–13

For more on **the Comprehensive Score for Financial Toxicity studies** see *Cancer* 2017; **123**: 476–84, **Articles** *Lancet Haematol* 2015; **2**: e408–16, and *J Glob Oncol* 2019; **5**: 1–8

For more on **financial toxicity assessment in Italy** see *Ann Oncol* 2016; **27**: 2224–29

For more on the **financial impact of cancer surgery in India** see *J Glob Oncol* 2018; **4**: 1–9

For more on the **cost of cancer treatment in Nepal** see *Front Public Health* 2019; **7**: 160

For more on the **cancer groundshot** see **Comment** *Lancet Oncol* 2018; **19**: 288–90

For more on **public-private partnerships to support universal health coverage** see *Global Health* 2019; **15**: 75

See Online for appendix 2

Financial toxicity in cancer care refers to the detrimental effects of excess financial strain caused by the diagnosis of cancer on the wellbeing of patients, their families, and society. Although financial toxicity is now being recognised as an important policy issue in high-income countries (HICs), it has always been one of the biggest hurdles of cancer care in low-income and middle-income countries (LMICs). Paradoxically, most research aiming to understand the causes and consequences of financial toxicity in patients with cancer comes from HICs, while contributions from LMICs have been scarce despite patients in these countries bearing the most severe consequences.

To understand the burden of financial toxicity among Nepalese patients with cancer, we did a survey in patients with newly diagnosed acute leukaemia who completed consolidation chemotherapy and were admitted to the Civil Service Hospital, the largest haematology centre in Nepal and the only one that offers bone marrow transplantation services in the country. Thus, the respondents can be considered a representative sample of Nepalese patients with acute leukaemia. Inpatient admission is considered a major cause for financial toxicity in Nepal as patients have to travel long distances to Kathmandu and caregivers spend a substantial amount of money on lodging and food.

Since there is no uniform tool to assess financial toxicity and tools specific for LMICs are virtually non-existent, we had to consider how to define financial toxicity in this setting. The Comprehensive Score for Financial Toxicity (COST) tool has been validated as an objective measure to assess financial toxicity in patients with cancer in the USA and has also been tested in patients with haematological malignancies or those with solid tumours in Japan. An Italian study assessed financial toxicity using one question to assess whether patients felt financial toxicity: from “not at all” to “very much” on a Likert scale. However,

the questionnaire items listed in the COST tool or the subjective scale used in the Italian study seemed irrelevant in the context of Nepal. One study in patients with cancer undergoing surgery in India used out-of-pocket expenses of more than 10% the annual household income as a measure of financial toxicity. However, in Nepal, surveying patients' annual household income is unreliable because some government and hospital subsidies rely on annual household income levels. Since September 2011, the government of Nepal provides a one-time support of approximately US\$1000 to each patient with cancer who falls in the low-income category. Therefore, on the basis of our experience interacting with Nepalese cancer patients, we decided that three key parameters represented financial toxicity in this setting: selling of property (house, land, or livestock) to support treatment; taking a monetary, interest-based loan from other people (eg, relatives or friends); and fundraising or asking for charity from the public, which involves obtaining a document provided by the hospital confirming the cancer diagnosis that can then be used for fundraising. Charitable donations need not be returned and do not incur interest unlike monetary loans. We defined financial toxicity as the presence of any one of these three parameters, severe financial toxicity as the presence of at least two, and extreme financial toxicity when all three parameters were reported (table).

We surveyed 112 patients (68 [61%] male) with acute leukaemia admitted to hospital between Jan 23, 2014, and Dec 16, 2016. Patient characteristics are in appendix 2. 27 (24%) patients were aged 11–20 years. 63 (56%) patients had acute myeloid leukaemia, 40 (36%) acute lymphoblastic leukaemia, and nine (8%) had acute promyelocytic leukaemia. Excluding seven children of primary school age (<10 years old) who had not joined school at the time of the analysis, 35 (33%) of 105 patients were uneducated, 48 (46%) completed secondary school or higher education, 3 (3%) were attending primary school, and the rest (19 patients [18%]) did not complete secondary school. Excluding students and children (n=20), 47 (51%) of 92 patients were unemployed, 9 (10%) were housewives, 13 (14%) were self-employed, and 23 (25%) had an salaried job.

All patients suffered financial toxicity as per our definition (table). The most common financial hardship involved asking for charity (105 [94%] patients), followed by borrowing loans from friends or relatives (99 [88%] patients), and

Survey results (n=112)	
Financial toxicity hardship parameters	
Asking for charity from the public	105 (94%)
Borrowing loans subject to interest from friends or relatives	99 (88%)
Selling property (house, land, or livestock)	97 (87%)
Severe financial toxicity (2 of 3 parameters)	108 (96%)
Extreme financial toxicity (all 3 parameters)	82 (73%)

Table: Financial toxicity measures and survey results

selling properties (97 [87%] patients). When borrowing loans from friends or relatives, patients reported paying as much as 36% interest per annum. Severe financial toxicity, defined as having to undergo two of three financial hardship parameters, was reported by 108 (96%) of patients and extreme financial toxicity, defined as having to undergo all three hardship parameters, was reported in 82 (73%) patients.

A high prevalence of financial toxicity among patients with cancer in LMICs is not unusual; however, we were surprised that all patients surveyed suffered financial toxicity and almost all had severe financial toxicity. One probable reason for this finding could be that patients who come to the Civil Service Hospital, a publicly funded hospital, may be selectively poor. Nepal has a health-care system of public and private hospitals, with private hospitals offering services at a higher price than public hospitals. In our survey, most patients were from outside Kathmandu and unemployed (appendix 2), representing a relatively underprivileged group who could not afford treatment in private hospitals or abroad. Additionally, in Nepal the treatment for acute leukaemia might be higher than that for solid tumours. A previous study in Nepal suggested a median treatment cost of US\$3461 for patients with solid tumours, while the Nepal Leukemia support Society has recorded treatment costs ranging from \$5000 to \$25 000 for patients with acute leukaemia, including the cost of bone marrow transplantation when needed.

Data on financial toxicity in LMICs are scarce, presumably because financial toxicity is considered a low-priority issue in global cancer policy in settings where building new infrastructure, training manpower or access to newer diagnostic modalities top the agenda. However, without understanding financial toxicity and its impact, cancer policy could be misled into conflicting prioritisation. We argue that addressing financial toxicity is an example of cancer groundshot type research: while LMICs might not be able to provide the same level of financial protection to cancer patients as HICs, there are several low-hanging fruits that can be implemented easily. Surveys such as ours can help identify and prioritise interventions for

short-term and long-term policies. Our finding that most patients with acute leukaemia were paying very high interest rates to borrow money from others provides a simple opportunity for the government or non-profit organisations to intervene in the short term by offering loans at cheap interest rates to families affected by cancer. Otherwise, patients will continue to be victims of profiteering from people who charge high interest rates at a time of hardship. A long-term priority of the Nepalese government should be to build cancer centres in other parts of the country, given that 93% of our patients were from outside Kathmandu. Interventions to improve employment opportunities and special employment programmes for cancer survivors could also help mitigate the effects of financial toxicity. Such employment opportunities could be provided together with loan subsidies so that a cancer survivor could pay back the loan with their salary in the long term. The government should also provide protection for caregivers who sold their property to pay for cancer treatment for a family member. The absence of a national health insurance system in Nepal had forced patients to pay for all of their expenses out of pocket, thereby contributing to financial toxicity. In 2016, Nepal launched a pilot health-care insurance programme in three districts, which has since expanded to 60 (78%) of 77 districts in the country and might help mitigate this problem to some extent. Nepal could also look at public-private partnerships as a means to achieving universal health coverage, as has been suggested for other LMICs.

We need more research to understand the burden and impact of financial toxicity in cancer patients in LMICs. The definition and categorisation of financial toxicity we used have not been validated; validation of a tool to measure financial toxicity in LMICs should be the focus of future research. We hope that our study will serve as a starting point for defining and understanding the financial toxicity of cancer care in LMICs, and ultimately help with policy making to address this problem.

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