THE FINANCIAL BURDEN OF CUTANEOUS LYMPHOMA: WHAT AN INTERNATIONAL PATIENT SURVEY REVEALED

Gregg Murray, MD, BM BS, BSc, MSc, Tallaght University Hospital, Dublin, Ireland
Kevin Molloy, MB Bch BAO MRCPI PhD, Tallaght University Hospital, Dublin, Ireland
Cutaneous Lymphoma Foundation

Cutaneous lymphoma is a chronic disease with well-recognised and often debilitating symptoms, including persistent itch, discomfort, and visible skin changes, and carries a substantial burden on patients' quality of life. What has been far less well understood is the personal financial cost of living with the disease. Although patients frequently describe significant out-of-pocket expenses related to their care, these costs have rarely been measured systematically or reported in the medical literature. This gap in knowledge limits our ability to fully understand the true burden of disease and to advocate effectively for patient support.

How the study was done

To address this gap, we conducted an international patient-reported survey designed to quantify the real-world financial burden of cutaneous lymphoma and to examine how costs vary according to disease stage and subtype. The study used validated patient-reported outcome measures to capture both financial impact and health-related quality of life in a standardised way. Over 270 adults with cutaneous lymphoma from multiple countries participated, providing detailed information on disease characteristics and personal costs incurred over a one-year period.

Financial burden was assessed using questions that captured direct medical costs, direct non-medical costs, and indirect costs such as lost income or reduced working capacity. Health-related quality of life was assessed using the Patient-Reported Impact of Dermatological Diseases (PRIDD) questionnaire. The PRIDD is a validated tool measuring physical, psychological, social, and day-to-day life impact of skin disease. This approach allowed us to examine not only how much patients spend, but how financial burden relates to overall wellbeing.

Out-of-pocket costs: the headline findings

Out-of-pocket costs were substantial among the respondents of the survey. The approximate average annual out-of-pocket cost per patient was approximately $2,700, with one quarter of patients reporting annual expenses exceeding $8,000. These costs extended well beyond medical treatments alone. Direct medical expenses, such as medications or therapies not fully reimbursed, had an annual cost of around $270. Direct non-medical expenses, including travel, parking, accommodations, and supportive care, contributed approximately $600 per year. Indirect costs, such as lost income, reduced working capacity, or reliance on informal caregiving, represented the largest component of financial burden, exceeding $700 annually. These findings highlight that the financial impact of cutaneous lymphoma is multifaceted and not confined to healthcare charges.

Costs increased sharply with disease stage

Financial burden increased markedly with disease severity. Patients with early-stage disease reported annual out-of-pocket costs of approximately $2,400, whereas those with late-stage disease reported costs of around $7,000 per year, representing nearly a threefold increase. Among patients with more advanced disease, some reported annual out-of-pocket costs exceeding $12,000. This stage-dependent rise in costs reflects the cumulative impact of more intensive treatments, more frequent healthcare visits, and increased need for supportive care as disease progresses

Disease subtype mattered: especially Sézary syndrome

Clear differences were also observed between disease subtypes. Patients with mycosis fungoides reported annual out-of-pocket costs of approximately $2,800. In contrast, patients with Sézary syndrome experienced substantially higher financial burden, with costs exceeding $12,000 per

year. Patients with primary cutaneous B-cell lymphoma reported considerably lower costs, with of approximately $1,000 annually. These differences likely reflect the complexity of care and treatment intensity associated with certain subtypes, particularly Sézary syndrome, which often requires systemic therapies, frequent monitoring, and additional supportive interventions.

Financial toxicity: cost relative to income

To better understand how out-of-pocket costs affect patients in real terms, financial toxicity was assessed by examining how much of a person's annual income was spent on cutaneous lymphoma-related expenses. While some patients reported relatively modest costs, a substantial proportion experienced significant financial strain.

Overall, more than one quarter of patients spent over 10% of their annual income on disease-related costs. Nearly one in ten patients spent more than 30% of their income, a level commonly regarded in cancer care as severe financial toxicity. These findings show that for a meaningful subset of patients, the financial impact of cutaneous lymphoma extends far beyond inconvenience and can represent a major economic burden.

Financial toxicity was notably greater in patients with more advanced disease. Patients with late-stage cutaneous lymphoma spent a much higher proportion of their income on out-of-pocket costs than those with early-stage disease, with nearly four in ten late-stage patients exceeding the 10% income threshold. Severe financial toxicity, defined as spending more than 30% of income, was also more common in late-stage disease.

The greatest financial strain was observed among patients with Sézary syndrome. In this group, over half of patients spent more than 10% of their annual income on disease-related expenses, and nearly one third spent more than 30% of their income. These figures highlight the disproportionate economic burden faced by certain patient groups within the cutaneous lymphoma community.

Why this matters

Importantly, financial burden was closely linked to quality of life. Patients who reported higher out-of-pocket costs also reported greater physical, emotional, and social impact from their disease. This reinforces that financial stress is not a separate issue, but an integral component of the lived experience of cutaneous lymphoma.

By systematically quantifying out-of-pocket costs, this study provides some of the first robust patient-reported evidence that financial toxicity is a core dimension of disease burden in cutaneous lymphoma. These findings can inform future advocacy efforts, encourage clinicians to address financial strain as part of routine care, and support the development of targeted financial and supportive interventions for those most at risk.

Most importantly, this work demonstrates the value of patient participation in research. By sharing their experiences, patients and care partners are helping to shape future care, improve awareness within the medical community, and ensure that the full impact of cutaneous lymphoma is recognised and addressed.