

Financial burden is associated with postponing care and decreasing physical and emotional quality of life among patients with multiple myeloma and chronic lymphocytic leukemia

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Background: Numerous factors contribute to the financial burden experienced by the cancer population, including medical expenses and possible job disruption or loss. The financial burdens that accompany a cancer diagnosis can influence cancer-care decisions, including the delay of essential treatment or appointments, with deleterious effects on physical and mental quality of life (QOL). Further, certain sociodemographic groups face increased risk of financial burden. The aim of this study was to examine the relationships between financial burden, postponing care, and physical and emotional quality of life among patients with multiple myeloma (MM) and chronic lymphocytic leukemia (CLL).

Methods: 435 patients (72% MM; 28% CLL) enrolled in the Cancer Support Community's online survey, the Cancer Experience Registry, answered questions related to financial burden (8 items; yes/no response), postponing care (6 items; 5-point Likert scale), and QOL assessed using Patient-Reported Outcomes Measurement Information System (PROMIS-29v2.0) subscales (Anxiety, Depression, Physical Function, and Fatigue) with transformed T scores. We applied Structural Equation Modeling (SEM) to understand the direct and indirect relationship of financial burden (tally of "yes" responses to the 8 financial cost variables) with latent constructs comprising postponing care, physical QOL, and emotional QOL, and sociodemographic and clinical predictor variables.

Results: Sample characteristics: mean age=62 yrs (9.2); 88% non-Hispanic White; 6% non-Hispanic Black; mean time since diagnosis=5.2 yrs (4.3); 28% ISS Stage 3 for MM or Rai Stage 3-4 for CLL. Regarding financial status, 21% have an annual income <\$40k; 22% spent >\$500 in monthly out-of-pocket (OOP) costs to cover cancer care and an additional 23% spent over \$250. Due to the financial costs of cancer care, 29% of participants depleted their savings, 19% borrowed against or used money from a retirement plan, 13% liquidated assets, 7% collected unemployment insurance, 4% took an extra job, 4% chose a less effective treatment, 4% cashed in a life insurance policy early, and 2% had their house foreclosed. While 41% were moderately to very seriously concerned about health insurance or money, 66% reported that no one from their health care team talked to them about costs. Based on the percent reporting sometimes, often, or always engaging in behaviors related to postponing care: 12% postponed doctor's appointments, 5% postponed follow-up screening or bloodwork, 6% postponed filling prescriptions, 5% skipped dosages of prescribed drugs, 12% delayed complementary treatment including therapy, and 16% postponed psychological counseling or support.

SEM analyses demonstrate that age (standardized path coefficient $\beta=-0.17$), low income ($\beta=0.24$), OOP costs ($\beta=0.18$), time since diagnosis ($\beta=0.11$), and advanced stage ($\beta=0.17$) had a significant ($p<.05$) effect on financial burden and financial burden, in turn, had a significant

effect on postponing care ($\beta=0.40$) Further, financial burden had both a direct ($\beta=-0.17$) and indirect ($\beta=-0.10$) effect through postponing care on physical QOL, and both a direct ($\beta=0.15$) and indirect ($\beta=0.12$) effect through postponing care on emotional QOL. The χ^2 of the final model was 454.2 (df=129, $p<.001$) and was a reasonably good fit to the data (RMSEA=0.076).

Conclusions: Findings highlight the significant effect of financial burden on postponing care and poorer QOL among MM and CLL patients. Financial burden was associated with patients' treatment decisions for both cancer and psychological care, and while many patients reported distress about money and health insurance, the majority did not discuss cost of care with their health care team. Thus, MM and CLL patients may benefit from access to no- or low-cost preventative and supportive psychosocial care, as well as financial counseling and assistance with health care team communication. Patient-focused organizations help address this need through no-cost resources, including distress screening tools, access to a financial counselor on a toll-free helpline, and information about treatment decision-making. Future research that incorporates cost of care into physician-patient communication is warranted.