



# Biology of Blood and Marrow Transplantation

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## Financial Burden in Recipients of Allogeneic Hematopoietic Cell Transplantation



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### A B S T R A C T

Although allogeneic hematopoietic cell transplantation (HCT) is an expensive treatment for hematological disorders, little is known about the financial consequences for the patients who undergo this procedure. We analyzed factors associated with its financial burden and its impact on health behaviors of allogeneic HCT recipients. A questionnaire was retrospectively mailed to 482 patients who underwent allogeneic HCT from January 2006 to June 2012 at the Mayo Clinic, to collect information regarding current financial concerns, household income, employment, insurance, out-of-pocket expenses, and health and functional status. A multivariable logistic regression analysis identified factors associated with financial burden and treatment nonadherence. Of the 268 respondents (56% response rate), 73% reported that their sickness had hurt them financially. All patients for whom the insurance information was available (missing,  $n = 13$ ) were insured. Forty-seven percent of respondents experienced financial burden, such as household income decreased by >50%, selling/mortgaging home, or withdrawing money from retirement accounts. Three percent declared bankruptcy. Younger age and poor current mental and physical functioning increased the likelihood of financial burden. Thirty-five percent of patients reported deleterious health behaviors because of financial constraints. These patients were likely to be younger, have lower education, and with a longer time since HCT. Being employed decreased the likelihood of experiencing financial burden and treatment nonadherence due to concern about costs. A significant proportion of allogeneic HCT survivors experience financial hardship despite insurance coverage. Future research should investigate potential interventions to help at-risk patients and prevent adverse financial outcomes after this life-saving procedure.

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### INTRODUCTION

Financial hardship and concern about medical costs are increasingly reported after medical treatment [1–4]. Extremely severe financial outcomes, such as bankruptcy, have been reported in cancer patients [5–7]. Studies have also reported the adverse impact of financial concerns on quality of life and treatment adherence [1–4,8–10]. Although part of the financial burden may be due to high out-of-pocket (OOP) costs, a decrease in household income due to loss of employment and other nonmedical costs also adds to the

fiscal distress for most households. The problem is further compounded for allogeneic hematopoietic cell transplantation (HCT) survivors because of prior treatments, long hospital stays, prolonged intensive follow-up, living away from home to relocate near to the transplantation center for at least the first 3 months after HCT, extended period of work loss for patient and caregiver, and occurrence of chronic medical problems, such as chronic graft-versus-host disease (GVHD) and late complications. In an online survey of 369 HCT survivors, 42% were concerned about health insurance and 30% reported financial problems [11].

Only a few studies have attempted to describe the OOP costs in this patient population [12–14]. To the best of our knowledge, no studies have described the overall financial experience of allogeneic HCT recipients or examined, in detail, the factors associated with adverse financial consequences of this expensive, resource-intensive procedure. We conducted

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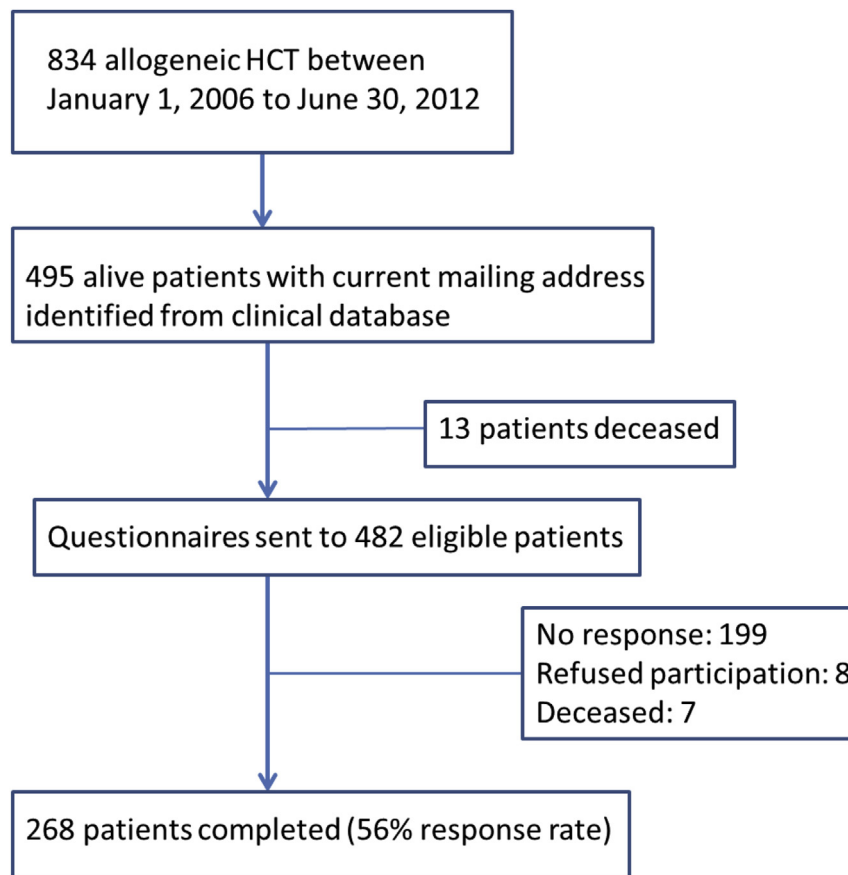


Figure 1. Study Participation Flowchart. HCT, hematopoietic cell transplantation.

an observational study of self-reported information to characterize the subjective and objective financial burden in allogeneic HCT survivors. We also sought to describe the impact of financial burden on health behaviors and evaluate the risk factors for objective financial burden and treatment nonadherence due to concern about medical costs.

#### PATIENTS AND METHODS

All adult patients who had an allogeneic HCT performed between January 1, 2006 to June 30, 2012 at 1 of the 3 Mayo Clinic sites (Rochester, Arizona, and Jacksonville) and who were reported to be alive, with a current mailing address available at the time of the survey, were included. The study was approved by the institutional review board at Mayo Clinic in Arizona.

Because of the lack of a validated instrument, a 25-item questionnaire was designed to gather information about self-reported subjective and objective financial burden along with OOP expenses, medication copayments, and sociodemographic information, such as race and ethnicity, education level, employment status, insurance, and household income (a copy of the questionnaire attached, [Supplementary Data](#)). Information about concerns regarding the cost of medical care leading to potentially deleterious health behaviors was also collected. The survey was designed based on a literature review with the help of experts from the survey research center at Mayo Clinic, Rochester. A formal patient pilot was not performed, but feedback was collected from a small group of transplantation physicians and nurse coordinators regarding clarity of the questions. Information collected on the survey represented the patients' status at time of survey completion.

Self-administered questionnaires were mailed to study patients in December 2012 and were re-sent if a response was not received within 4 weeks of the initial mailing. Age, sex, and information about the disease and HCT were available from the clinical research database. Race and ethnicity data was retrieved from the clinical database for comparison between the respondents and nonrespondents, though in the multivariate

analysis, self-reported race/ethnicity obtained from the questionnaire was used. Median household income was inferred from zip codes, using the 2010 census data, to compare the socioeconomic status between respondents and nonrespondents [15].

#### Study Variables

Race/ethnicity was categorized as Non-Hispanic whites, Hispanics, and non-whites. Income was divided into 2 categories (<\$2000/month and >\$2000/month), as \$2000/month is the closest to the federal poverty guideline figure for a 4-person household [16]. Education level was categorized as "high school or less," "some college/associate degree," or "4-year degree or higher." Employment was divided into 4 main categories: employed, unemployed, retired, and medical disability. Primary health insurance was divided into 4 categories: private, Medicaid, Medicare, and others, including Tricare, Indian Health Services, and Veterans' Affairs. Medicare information was further distinguished as Medicare with or without a supplemental plan, depending on if the patient checked "insurance purchased directly" or specified a supplemental plan in "others" category, in addition to Medicare. Health insurance coverage was considered to be poor if the insurance company had denied coverage for part of treatment "sometimes" or "often," or if the patients answered "disagree or strongly disagree" to the question about being satisfied with insurance coverage for transplantation-related costs. All the above variables were obtained from the survey and reflect the status at the time of questionnaire. Self-reported variables were used in the analysis, as it has been suggested that, relative to medical records and administrative claims data, self-reported data are valid and maybe more accurate. In the area of race and ethnicity data quality, for example, our research has shown self-report data to be superior to the data ascertained from claims data, largely because of high levels of missing or unknown race/ethnicity in the latter [17]. Similarly, self-reported insurance status is commonly used as the source of national health insurance, uninsurance, and underinsurance estimates by researchers and health policy makers [18].

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