



## The 65th ASH Annual Meeting Abstracts

## POSTER ABSTRACTS

## 903.HEALTH SERVICES AND QUALITY IMPROVEMENT -MYELOID MALIGNANCIES

**Caregiver Perspectives on Housing, Finances and Employment Post-Allogeneic Hematopoietic Cell Transplant**

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**Background:**

Allogeneic hematopoietic cell transplantation (alloHCT) is a potentially curative treatment for individuals diagnosed with blood cancers and disorders. Most transplant centers (TCs) require a caregiver for 24 hours per day, seven days per week, for at least 100 days post-alloHCT. However, there is limited knowledge of the evidence behind this requirement. Additionally, these requirements can have implications for caregivers in multiple aspects of their lives. This study aimed to learn more about alloHCT caregiver experiences in the first 100 days post-alloHCT to explore the impact of caregiver requirements.

**Methods:**

Web-based interviews were conducted from May 2022-February 2023 with a convenience sample of adult caregivers of adult alloHCT patients in the United States (US). Caregivers' patients were 100 days to 1-year post-alloHCT, with no relapse. Interviews were recorded and transcribed; thematic analysis was conducted by two independent reviewers. These results focus on the themes of housing, finances and employment, which arose during the interviews.

**Results:**

Sixteen caregivers participated, and included spouses (n=12, 75%), parents (n=3, 19%), and a fiancé (n=1, 6%). They generally cared for patients who received an unrelated alloHCT (n=14, 87.5%), and there was representation from all regions in the US. The median distance from the caregiver's home to the TC was 55 miles (range: 3 to 2000 miles).

Caregivers who needed to relocate described staying with family, in hotels, transplant housing, or renting an apartment. Caregivers also described the stressor of having to figure out where to stay, with a tight timeline and requirements for cleanliness and distance to the TC, as well as the difficulty of relocating to a new city without knowing anyone, the area or traffic patterns, and described the need for affordable options. Those with access to housing with other alloHCT caregivers/patients found support from others going through similar experiences. Of the caregivers who did not need to relocate, one noted the convenience of family living nearby; and another described household emergencies that resulted in financial and logistical challenges.

Financial challenges mentioned by caregivers included medication, transportation, unexpected expenses, the importance of navigating finances, and the experience of not making enough money to meet their needs, while making too much money to qualify for financial assistance. Some also learned about financial assistance when it was too late or when it would have been helpful earlier and were not sure how they were expected to find these opportunities. Those who received financial assistance, regardless of the amount, were very grateful and noted it made a difference in their experience. Though caregivers shared their financial challenges, many noted they felt "lucky" or "privileged," recognizing that if circumstances had been different, they, or others in less fortunate financial circumstances, may have had more difficulties.

Caregivers were variably employed and included those who were retired, employed, self-employed, and not employed. Those who were employed mentioned the importance of the Family Medical Leave Act (FMLA), but also described the need to work to maintain income and health insurance. Employed caregivers also shared they were able to work effectively and provide care, despite some being told by their TC that they could not. The majority of those employed credited their ability to work to their employers' support and flexibility.

**Conclusions:**

This study interviewed adult caregivers of adults receiving alloHCT in the US to understand the caregiver experience and to explore the impact of caregiver requirements. The current caregiver requirement of most TCs can be a barrier not only to

patients, but to caregivers. In this study, caregivers shared their housing, financial, and employment experiences. Knowledge of these experiences can help inform interventions to help support caregivers, and inform strategies to transform the caregiver requirement to allow for individual situations. Further information is needed on barriers faced by individuals unable to access alloHCT and patients who may not have had a caregiver. Results from this study will facilitate the development of programs to help improve patient and caregiver experiences.

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