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Letter to Editor

Bone marrow transplantation for thalassemia: How much is a child's life worth?

Dear Editor,

I read with interest the article by Faulkner describing the experience of the Cure2Children (C2C) program in supporting allogeneic matched sibling donor bone marrow transplant (BMT) for thalassemia patients in India and Pakistan.[1] The thalassemia-free survival (TFS) rate for Lucarelli Class I and II patients was 84% (n = 82), which is a significant achievement and similar to the rate for established institutions such as Christian Medical College in Vellore, India (TFS = 78% n = 104)[2] and Armed Forces Bone Marrow Transplant Centre in Rawalpindi, Pakistan (TFS = 79%, n = 42).[3] Faulkner does not clarify the centers involved or the number of BMT performed at each center, which would have been helpful to the reader, but I assume this omission was at the request of the centers involved.

The strategy pursued by C2C emphasized sustainability as the key, and relied on performing a site visit, ensuring key elements were present or trained at each institution, providing appropriate ongoing expert advice support, and collecting patient data to ensure results were available for continuous quality improvement. In many ways, this was the identical approach successfully used by other organizations such as the Jiv Daya Foundation and others involved in trying to improve childhood cancer care in India and other low-income countries (LIC).[4] Faulkner has correctly emphasized the need to adapt BMT treatment protocols and supportive care standards in LIC to employ the most cost-effective and least toxic means which still ensure adequate results, in the same way that International Society of Paediatric Oncology (SIOP) has adapted modified chemotherapy protocols for Wilm's tumor and other childhood cancers in LIC to minimize toxicity and maximize outcomes.[5]

India's first successful allogeneic BMT was done in 1983 at Tata Memorial Hospital, Mumbai, and its utility in thalassemia major is well-recognized. Since allogeneic BMT costs $10,000-20,000, the same as 3-5 years of blood transfusion and chelation, we can question why getting thalassemia major patients to undergo BMT is still a challenge in India, Pakistan, and other LIC? The primary barriers are two-fold: Achieving optimal outcomes is a concern that Faulkner has shown can be addressed, but "abandonment" or failure to seek therapy is an issue with economic roots.[6] Although BMT costs "only" $10,000; median per capita income in India is $1,597 annually. Since most governments in LIC countries pay for transfusions and chelation, but not for BMT; access to BMT is unlikely to change without advocacy through nongovernmental organizations (NGOs) to change public policy, and help patients to access government support that already exists.

In summary, Faulkner has documented important strategies that can be used to improve outcomes in BMT in LIC, but how to decrease the failure to seek such care due to the cost of the procedure itself is the key problem. The question we must continually ask ourselves is: How much is a child's life worth?

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