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Post haplo-identical stem cell transplant for sickle cell disease: Parents' experiences and challenges in caregiving

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Abstract

Introduction:Haplo Identical Stem Cell Transplant (SCT) procedure in some countries is still considered experimental and performed only as part of research studies because it presents with a number of complications during and after the transplant, ranging from the high risk for infections, Graft-versus-host disease (GVHD), Graft failure, Nutrition problems, Low blood counts, dermatological challenges, Social and emotional concerns and others. The number of haplo identical SCT procedures nonetheless, continues to rise as parents in many African countries seek treatment for the increasing diagnosis of sickle cell disease among children.Parents as caregivers for their Post- Haplo identical SCT children are destined to face greater number of challenges with which there is perhaps little research on such shared experiences.This article intends to further the understanding and knowledge of the care giving aspects through a 2 year care giving experience for a nine year old female child Post Haplo-identical SCT, by a family living in Rwanda.

Methodology and Findings:Using a case report approach, six key points emerge from a care giving perspective of parents' experiences and challenges to include; nutritional adjustments, continuous home monitoring and evaluation of the child's general wellbeing, compliance to routine consultation / medications, father's direct involvement and social interaction difficulties

Conclusion and Recommendation:Despite this procedure being delicate during and after transplant, our experience has shown that pre/ post -haplo identical SCT orientation and experienced doctors in different specialties' related to the complications have so far greatly contributed to our post-transplant adaptation to care giving.

Key Words: Haplo identical Stem Cell Transplant, Parents Experiences, Care-Giving

Biography

Moses Kayongo is an experienced Lecturer with a demonstrated history of working in the field of Public Health. Skilled in Public Speaking, passionate in public health research methodology, Planning implementing and evaluating public health programs, and Data Analysis. Strong education professional with a Doctor of Public Health focused in Community Health and Preventive Health Care from Adventist University of the Philippines.



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