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

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### Statement of the Problem:

Haplo Identical Stem Cell Transplant (SCT) procedure in some countries is still considered experimental and performed only as part of research studies because of the complications during and after the transplant such as high risk for infections, Graft-versus-host disease (GVHD), Graft failure, Nutrition problem, 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 are destined to face a greater number of challenges yet there has not been any documented shared experience of this specific procedure. The purpose of this study report is to describe the 2year caregiving experience and challenges by a family living in Rwanda, since their nine-year-old daughter's Post Haplo-identical SCT, done on (December 28<sup>th</sup>, 2016) at Christian Medical College Hospital, Vellore, India to further the understanding and knowledge of the caregiving aspects of this procedure.

**Methodology/Finding:** Using a case report approach, six key points emerge from a caregiving perspective of parents' experiences and challenges namely: 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

besides the mother's role.

**Conclusion:** Despite this procedure being delicate and complex during and after transplant, our experience as caregivers has shown that Pre/Post-Haploidentical SCT orientation and existing experienced doctors in the different specialties' related to the complications have so far greatly contributed to our post-transplant adaptation to care to give.

### Biography

Moses Kayongo holds a Masters and a Doctorate in Public Health (DrPH) has expertise in Preventive Health Care. He is currently working as Assistant Professor at University of Lay Adventists of Kigali (UNILAK) and Adventist University of Central Africa (AUCA) as an adjunct Lecturer teaching public health courses and research methodology. He has a research interest in self-care management of Noncommunicable diseases however after his Doctoral studies' completion, his second child was diagnosed at 5years with sickle cell disease and suffered several strokes. Given his educational background, he developed a research interest in Sickle Cell self-care management and has since developed and supported several awareness programs for parents of children with sickle cell disease.

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