

Title: Development of a self-care model for children living with sickle cell disease in Ghana

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Abstract

Introduction: Sickle cell disease (SCD) is the most common haemoglobinopathy. The frequency of pain crises and resulting hospitalizations may increase without appropriate self-care in the home setting. Therefore, it is important to understand which factors affect self-care at home. Self-care models are known to help engage children in proper self-care management. It is therefore against this backdrop that this research is being conducted, to help develop a Ghana child friendly self-care model for the performance of self-care at home. **Research questions:** what is the perceived self-efficacy of children/parents in the prevention of sickle cell disease crisis at home and hospital visit? what are the perceived availability of social support for children/parent and sickle cell disease crisis prevention together with hospital visit? what are the perceived self-care ability and self-care action of children and parents for the prevention of crisis and hospital visits? **Methods:** A mixed method approach will be used for this study. **Designs:** An explanatory sequential mixed method design will be used for the research. **Setting:** Setting will be the greater Accra Regional Hospital and the 37 military hospital both in Ghana. **Data collection:** Data will be collected first for the quantitative phase of the research with questionnaires and analysed this will be followed by a qualitative data collection with a semi-structured study guide and analysed. **Data Analysis:** will be done statistically for the quantitative data while coding will be carried out for the qualitative data for the generation of themes and subthemes. Permission for the study will be sought from Noguchi Memorial Institute for Medical Research Institutional Review Board (NMIMR-IRB) with the use of informed consent.

Expected outcome: Results from the study will be used to design a self-care model for children living with sickle cell disease in Ghana.

Keywords: sickle cell, disease, parent and children, children, self-care, model, Ghana