

Title: Evaluation of health-related quality of life of children living with urinary schistosomiasis using PedsQLTM 4.0 SF15™ and effects of the disease on iron levels in infected children in Kwale County, Kenya

Author: Terer, Carolyn Chebet

Abstract: Health-related quality of life (HRQoL) of children is a growing field of research and has emerged as an important health outcome in clinical trials, clinical practice improvement strategies, and health care services and evaluation especially in the developed countries. HRQoL focuses on individual's subjective evaluation of their physical, emotional and Social well being which is linked to World Health Organization's definition of health. Parasitic diseases affect the quality of life in children. Negative effects associated with *Schistosoma haematobium* infections in school age children include damage to physical, cognitive, intellectual growth and nutritional deficiencies. No studies have been carried on quality of life assessment of children living with urogenital schistosomiasis in Kwale County. The objective of this study was to evaluate the utility of survey instrument (pedsQUM4.0 SF15) in measuring quality of life of children living in *S. haematobium* endemic areas, to determine the effect of urogenital schistosomiasis on physical, social, emotional, nutritional and school functioning of children and to determine dietary iron adequacy among children living with schistosomiasis. The study employed a cross sectional case control study design in five *Schistosoma haematobium* endemic villages (KinangoA, Magodzoni, Gwadu, Milalani and Dzitenge) in Kwale County, Coast Province, Kenya. School age children (5- 18 years old) in five selected villages were examined for *Schistosoma haematobium* infection and 802 children were subjected to HRQoL study using PedsQLTM 4.0 SF15 tool. The domains tested included Physical, Emotional, Social and School functioning. The study also involved parallel proxy parents' tests. Non infected children were used as controls. Data was analyzed using SAS 9.1 for Windows. P values of less than 0.05 were considered to be statistically significant. Cronbach's alpha reliability coefficient was used to check for consistency of the results and Cohen's effect size was used to test the validity of the tool. The effect of urogenital Schistosomiasis infection on quality of life was elucidated for the first time. All Pediatrics Quality of life (PedsQLTM 4.0 SF15) scales showed satisfactory reliability of (0.70) according to Cronbach's alpha recommendation. Comparison between urogenital schistosomiasis infected and non infected group did not have significant differences in all the domains, but the tool was only able to show significant differences in villages with moderate risk prevalence of the disease. Prevalence of *Schistosoma* infection in the study villages ranged from 22.9% to 62.2%. When controlled for confounding factors the tool showed differences in stunting and SES. A good agreement was noted between self and proxy reports in all domains except in emotional and social domains. PedsQLTM4.0 SF15 is a reliable and valid tool for measuring HRQoL in children with chronic parasitic infections. *S. haematobium* affects the quality of life of children as was evident in the study. The study presents strong evidence that many children with urogenital Schistosomiasis experience low HRQoL which is attributed to low SES. Inadequate iron diet was significantly associated with anaemia in infected children. Further research is warranted to determine the reproducibility and responsiveness properties of HRQoL testing in relation to urogenital schistosomiasis.

