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

**BY:**

**CAROLYN CHEBET TERER (B.SC. HONS-FOOD NUTRITION AND DIETETICS)**

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# DECLARATION

This thesis is my original work and has not been presented for a degree in any other university.

SIGNATURE: …….. Date: ……..

CAROLYN CHEBET TERER

P57/13137/09

**SUPERVISORS:** This thesis has been submitted for review with our approval as supervisors.

1. SIGNATURE……DATE:……

   DR. NGETHE MUHOHO (PhD)

   School of health Sciences

   Department of Pathology

   Kenyatta University

2. SIGNATURE: ……DATE……

   DR. FRANCIS MUTUKU (PhD)

   Research Officer

   DVBD/CWRU/Emory University

   Polyparasitism project

# DEDICATION

This thesis is dedicated to my father; John Terer, mother; Esther Terer, sisters and brothers and all children living with urogenital schistosomiasis in endemic areas.

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# LIST OF ABBREVIATIONS AND ACRONYMS

**ANOVA** Analysis Of Variance

**CDC** Centers for Disease Control

**CKD** Chronic Kidney Disease

**CWRU** Case Western Reserve University

**DVBND** Division of Vector Borne and Neglected Tropical Diseases

**FFQ** Food Frequency Questionnaire

**HIV** Human Immunodeficiency Virus

**HRQoL** Health Related Quality of Life

**ICC** Intra Class Correlation

**IDA** Iron Deficiency Anaemia

**MOH** Ministry Of Health

**NCST** National Council for Science and Technology

**NIH** National Institute of Health

**NTD**s Neglected Tropical Diseases

**PedsQL™** Pediatrics Quality of Life inventory tool

**PedsQL™ 4.0 SF15**: Pediatric Quality of Life Inventory 4.0 Short Form 15

**QoL** Quality of life

**SAS** Statistical Analysis Software

**SES** Socio-Economic Status

**S.*h*** Schistosoma haematobium

**WHO** World Health Organization

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# DEFINITION OF TERMS

**Adequate iron diet:** in this study was defined as the consumption of iron rich foods and absorption of sufficient iron necessary to maintain health. It was measured according to institute of medicine, food and nutrition board guidelines by age and sex. Children aged 4-8 years 10mg/day, males and females 9-13 years 8mg/day, females 14-18 years 15mg/day and males 14-18 years 11mg/day.

**Anaemia:** was defined as hemoglobin below the recommended levels according to WHO criteria by age and sex for ages <12 yr, Hb < 11.5 g/dL; for ages ≥ 12 yr, Hb < 12 g/dL; but for males ≥ 15 yr, Hb < 13 g/dL.

**Effect size:** in this study was measure of the strength of the relationship between two variables in a statistical population.Calculated as (difference in means between two variables)/pooled standard deviation for total.Measured using cohens effect size as small (0.20 – 0.49), medium (0.50 – 0.79), and large (≥ 0.80) in magnitude.

**Haematuria:** in this study meant presence of red blood cells (erythrocytes) in the urine of infected children.

**Health Related Quality of life**: refers to the physical, psychological, and social domains of health seen in areas influenced by a person's experiences, beliefs, expectations, and perceptions

**Intra Class Correlation:** Was defined as agreement between scores and rated as : ≤0.40, poor to fair agreement; 0.41 to 0.60, moderate agreement; 0.61 to 0.80, good agreement; and 0.81 to 1.00, excellent agreement.

**Iron deficiency**: is a state in which there is insufficient iron to maintain the normal physiological function of tissues such as the blood, brain, and muscles.

**Likeart scale:** in this study was the response scale for each item as ‘‘never’’ (0), ‘‘almost never’’ (1), ‘‘sometimes’’ (2), ‘‘often’’ (3), and ‘‘almost always’’ (4).

**Socio economic status:** in this study was defined as high or low basing on the pricipal component analysis weights on assets ownership, housing type and living conditions.

**Stunting:** was measured as height for age (HAZ) and compared with WHO standard values $\leq -2$ for HAZ.

**Mean iron intake per day:** in this study was calculated by; $\sum$ (food item * frequency of consuming in number of days* amount of iron per standard portion)/365.

***Schistosoma haematobium*:** A chronic disease caused by digenetic parasitic helminths (schistosomes also known as Blood flukes) that destroy blood vessels and body organs. A light *S. haematobium* infection was categorized as detection of 1–99 eggs/10 ml of urine, a moderate infection as 100–399 eggs/10 ml, and a heavy infection as ≥400 eggs/10 ml.

**Quality of life** was defined according to the World Health Organization (WHO), as the individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.

# 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 (PedsQL™ 4.0 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 (Kinango A, 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 PedsQL™ 4.0 SF15tool. 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. Cronbachs alpha reliability coefficient was used to check for consistency of the results and cohens 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 (PedsQL™ 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. PedsQL™ 4.0 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 schistosomiais 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.

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# CHAPTER ONE: INTRODUCTION

## 1.1 Background to

## 1.2 the study

Health-related quality of life (HRQoL) measurement has emerged as an important health outcome in clinical trials, clinical practice improvement strategies, and health care services research and evaluation (Fayers and Machin, 2000, Varni *et al.*, 1999b). It facilitates assessing risk, tracking health status, and measuring treatment outcomes in pediatric populations (Achenbach *et al.*, 1987, Varni *et al.*, 1999). HRQoL measurement 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 (WHO, 1946). Urogenital schistosomiasis is a communicable disease of major public health and socio-economic importance in the world. Its transmission is mainly influenced by exposures to environmental factors (contact with infested water, distance to infected water bodies), individual characteristics (treatment history, sex, and age) and socioeconomic factors (occupation, education) (Kapito-Tembo *et al.*, 2009, Satayathum *et al.*, 2006). An estimated 700 million people worldwide may be at risk of infection as their agricultural, domestic and recreational activities expose them to infested water and more than 207 million people are infected worldwide (WHO, 2008). It is largely a disease of the poor in the developing world with poor access to safe drinking water and adequate sanitation. The infection perpetuates poverty in many low- and middle-income countries (Chitsulo *et al.*, 2000, Engels *et al.*, 2002, King and Dangerfield-Cha, 2008). It is caused by digenetic blood trematodes transmitted through contaminated water that involves snails as intermediate hosts. The three main species infecting humans are *Schistosoma*

*haematobium,* that causes urogenital schistosomiasis, *S. japonicum,* and *S. mansoni* that cause intestinal schistosomiasis (WHO, 2008). Schistosomiasis is endemic in much of sub Saharan Africa where suitable habitats for snails of genus *Bulinus*, the intermediate host for *S. haematobium* are abundant (Brown, 1994, Jordon and Webbe, 1993). Bulinids are aquatic snails found in slow running rivers and streams, stationary water masses including shallow open dams and other water pools (Clennon *et al.*, 2006, Kariuki, 2004). Different species of *Bulinus globosus* and *Bulinus nasutus* africanus species are associated with the transmission of *S. haematobium* along the coastal line (Clennon *et al.*, 2006, O'Keefe, 1985) .

In Kenya, more than six million people are infected with urogenital or intestinal schistosomiasis (Chitsulo *et al.*, 2000, Satayathum *et al.*, 2006). *S. haematobium* is highly endemic along the coast, where human exposure occurs primarily at pond and streams. In some locations, open wells and boreholes are available, but because they typically yield hard water and are not suitable for bathing or laundry, local residents use them only for limited domestic activities, while continuing to rely on surface water sources for virtually all domestic water activities including drawing water, laundry, bathing, swimming crossing the rivers and streams and other agriculture related activities. As a result there is long and extensive exposure to the parasites in the water (e.g., laundry, swimming) (el Kholy *et al.*, 1989). Direct mortality is relatively low, but the disease burden is high in terms of chronic pathology and disability, despite advances in recent years in the diagnosis, treatment, and control of transmission of the parasite (Engels *et al.*, 2002). Hematuria, anemia, and undernutrition are clinical correlates of infection in childhood (Stephenson *et al.*, 1989). Long-term manifestations of infection include scarring and

deformity of the ureters and bladder, chronic bacterial super infection, and kidney failure. While *Schistosoma haematobium* infection is chronic by nature and is unlikely to be directly fatal, its toll of morbidity is high in endemic areas, where health care budgets are often limited (King, 2001). The negative effects on school-age children caused by the infections include damage to physical, cognitive, and intellectual growth, nutritional deficiencies, and the increased likelihood of having malfunctioning kidneys, and cervical or squamous cell bladder carcinoma (WHO, 2002).

This study employed a cross-sectional case control study design, and was carried out in the south coast region of Kenya which is urogenital schistosomiasis endemic area. The primary objectives of this study were to: The objective of this study was to evaluate the utility of survey instrument (PedsQL™ 4.0 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 urogenital schistosomiasis. Quality of life was assessed using Pediatrics Quality of Life survey instrument Short Form with 15 items (PedsQL™ 4.0 SF15). The PedsQL™ 4.0 SF15 is a brief, standardized, generic assessment instrument that systematically assesses patients' and parents' perceptions of HRQoL in pediatric patients with chronic health conditions, with five subscales of physical, emotional, social, school and total functioning (Varni *et al.*, 1999). The tool is used to measure HRQoL in healthy children and adolescents, and in those with acute and chronic health conditions.

## 1.2 Problem statement

Urogenital schistosomiasis constitutes a major public health challenge in Kenya especially among school age children**.** Prior surveys carried out by the Division of Vectorborne and Neglected Tropical Diseases (DVBNTD)/ Case Western Reserve University (CWRU)/ Emory University in the study area in 2009-2010 established that the prevalence of *S. haematobium* in school age children in the study villages ranges from 23-62 % (Bustinduy *et al.*, 2011). Schistosome infections are associated with anemia, impaired growth, and impaired development and cognition of school age children (King *et al.*, 2005).The disease can last for several years and result in chronic inflammation caused by the parasite eggs trapped in host tissues.

Because schistosomiasis is a multi-decadal chronic disease that begins in early childhood, and because it is a disease that may affect nearly everyone in endemic communities, its impact on personal health-related quality of life (HRQoL) has been difficult to gauge accurately. Communities living in S. *haematobium* endemic areas of the south coast have low social economic status and in many cases practice poor hygiene and sanitation especially with regard to disposal of human waste. They have limited access to safe water for domestic use; hence, they depend on water from streams and ponds that harbour the intermediate snail hosts of the schistosome parasites. Despite the provision of effective chemotherapy (Praziquantel) for mass treatment of the disease by the Ministry of Health (MOH), re-infection can occur rapidly, given continued dependence on contaminated water, and the lack of residual protection following treatment.

### 1.3 Purpose of the study

Schistosomiasis is growing as a public health concern due to exploding population growth and increase in suitable aquatic snail habitats due to construction of hydroelectric dams, agricultural irrigation systems and watering sources for domestic livestock (Sturrock, 2001). In Msambweni district 52% of school-aged children were reported to be infected with S. *haematobium* (Clennon *et al.*, 2006). In addition to the direct impact of infections, schistosomiasis results also in fatigue, physical, cognitive impairment and interacts with co-infections with other infectious diseases like human immunodeficiency virus (HIV) and malaria (Gryseels *et al.*, 2006). These parasitic diseases may affect the quality of life in children. Negative effects associated with S. *haematobium* infections in school age children include damage to physical, cognitive, intellectual growth and nutritional deficiencies. No studies had been carried out in south coast region on quality of life assessment of children living with schistosomiasis. Therefore this study evaluated the quality of life of children infected with urogenital schistosomiasis specifically the effects of the disease on; physical, social, emotional and school performance, assessed the utility of the survey instrument in measuring HRQoL of urogenital schistosomiasis infected children, and to find out if anaemia in infected children is attributed to inadequate iron diet.

### 1.4 General objective

To assess the health related quality of life of children living with schistosomiasis.

### 1.5 Specific objective

1. To evaluate the utility of survey instrument (PedsQL™ 4.0 SF15) in measuring quality of life of children living in *S. haematobium* endemic areas.
2. To determine the effect of urogenital schistosomiasis on physical, social, emotional, nutritional and school functioning of children.
3. To determine dietary iron adequacy among children living with urogenital schistosomiasis.

### 1.6 Hypothesis

**Null hypothesis**

- PedsQL™ 4.0 SF15 is not a reliable tool to measure quality of life of children living in S. *haematobium* endemic areas.
- There's no relationship between urogenital schistosomiasis intensity and effects on physical, social, emotional and school functioning of children.
- Anaemia in children is not associated with urogenital schistosomiasis.

## 1.7 Research questions

1. Is PedsQL™ 4.0 SF15 a useful tool to measure the quality of life of children living with urogenital schistosomiasis?
2. Does urogenital schistosomiasis impact on the quality of life of children?
3. Is anaemia in children infected with S. *haematobium* caused by inadequate iron diet?

## 1.8 Significance of the study

The primary beneficiaries of the study will be children living in endemic areas. This will lead to improved HRQoL due to adjustment for age, sex, socioeconomic status, undernutrition, anemia, and hookworm parasites in the study; that demonstrated relative poverty, stunting, wasting, and *S. haematobium* infection as significant correlates of HRQoL scores, with differential effects in high- and moderate-prevalence communities.

Because schistosomiasis is a multi-decadal chronic disease that begins in early childhood, and because it is a disease that may affect nearly everyone in endemic communities, its effects on personal health-related quality of life (HRQoL) will be easy gauge accurately using PedsQL™ 4.0 SF15.

The Ministry of Health will benefit from the research as it can replicate the study to similar regions which will help in effective prioritization and monitoring of schistosomiasis control.

## 1.9 Delimitation and limitation

### Delimitation

- The study was not limited by logistics and time frame hence all eligible children were included in the study.

### Limitations

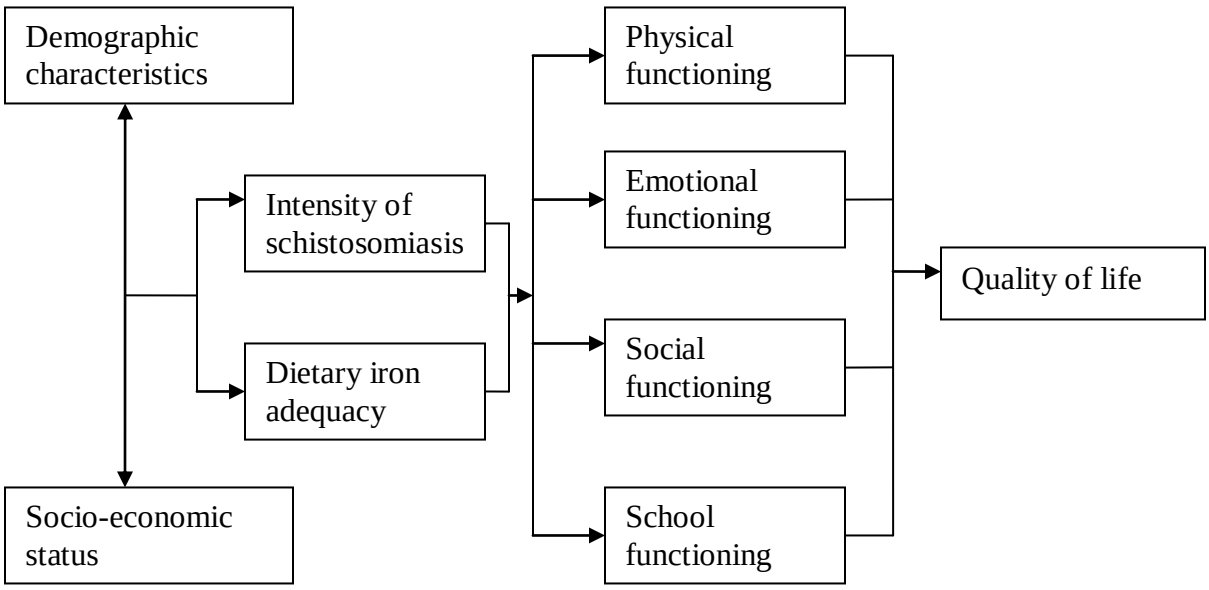
- The study never considered bioavailability of iron in non hemme sources of food (legumes, vegetables and dairy products) and the amount of food consumed by every child. Hence the results may overestimate a child's mean daily iron consumption.
- The study was carried out just before the long rains and this is a time when infection intensity and prevalence is very low as the dams and most streams are dry. Hence the likely reason to no significant difference in the results on effects of urogenital schistosomiasis on HRQoL.

## 1.10 Assumption

The mode of administration of the PedsQL™ 4.0 SF15 questionnaire was interviewer-based; thus, the high response rate. Since all interviews across all villages were conducted by two trained research assistants using one-to-one administration, the study assumed the interviewer effect was not significant in affecting the results of the study.

### 1.11 Conceptual framework

In the conceptual framework below, quality of life of children with and without urogenital schistosomiasis is dependent on demographic characteristics i.e. age and sex, and on socio-economic status of households. The type of food consumed in a family and its health seeking behaviors may vary depending on the socio-economic status of the family. Presence of parasitic disease will interfere with individual's body food requirements, digestion and absorption and general well being in an individual. Schistosome parasites destroy body cells and lining causing bleeding which depletes iron in the body and impact on the health status of children. This may also have impact on the main elements of the domains of health related quality of life, namely, emotional, social, and physical as well as school wellbeing of the child.




Source: Constructed from literature review

**Figure 1.1: Conceptual framework of QoL**

# CHAPTER TWO: LITERATURE REVIEW

## 2.1 Introduction

## 2.2 Discovery of schistosomiasis

Schistosomiasis is an ancient disease of man. Eggs of schistosome parasites were first seen by Theodor Maximilian Bilharz, a German pathologist in Egypt in 1851, who foundthe eggs of *Schistosoma haematobium* during the course of a post mortem (Nunn and Tapp, 2000). Bilharz wrote a paper in 1856 describing the worms more fully and named them *Distoma haematobium*. Based on their unusual morphology Meckel von Helmsback, in 1856 created the genus *Bilharzia* for them. In 1858 Weinland proposed the name *Schistosoma* (Greek: 'split body') after the male worms' morphology. Despite *Bilharzia* having precedence, the genus name *Schistosoma* was officially adopted by the International Commission on Zoological Nomenclature. The term *Bilharziasis* used to describe infection with these parasites is still in use in medical circles (Warren *et al.*, 1993).

## 2.3 Epidemiology of schistosomiasis

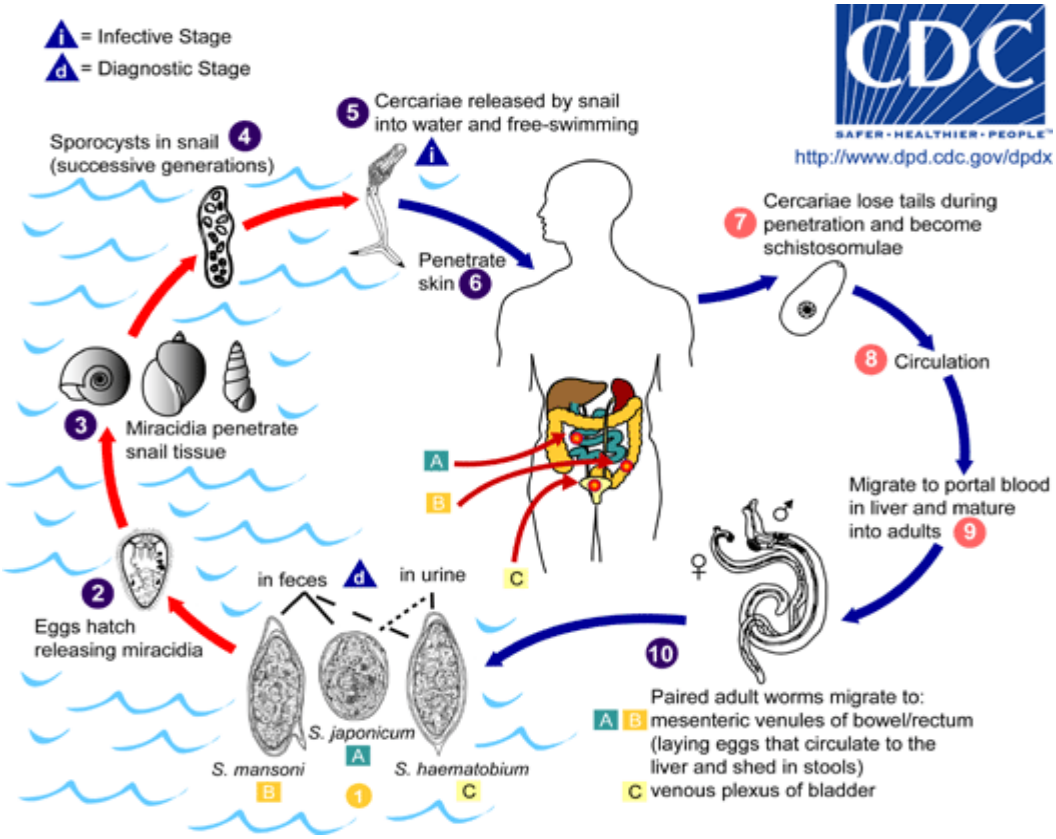
Schistosomiasis is a chronic disease caused by digenetic blood flukes or helminths of Genus schistosoma, These parasitic helminths are endemic in 74 developing countries, causing severe morbidity especially in children under the age of 14 (WHO, 2008). Schistosomiasis remains an important global public health problem with an estimated 200 million cases reported annually (Engels *et al.*, 2002). An estimated 700 million people worldwide may be at risk of infection through their agricultural, domestic and

recreational activities that expose them to infested water. The vast majority (85%) of cases reported annually occur in sub- Saharan Africa, where over 150,000 deaths are attributable to chronic infection with *S. haematobium* in this region (Southgate *et al.*, 2005). Most people at risk live in poor communities without access to safe drinking water and adequate sanitation, hygiene and play habits that make children especially vulnerable to infection, and in many areas a large proportion of school-age children are infected. In Nigeria, Malawi and Kenya studies showed high prevalence among school going children (Ayoya *et al.*, 2009, Kapito-Tembo *et al.*, 2009, Watanabe *et al.*, 2011).

### 2.4 Life cycle of schistosomiasis

Infection with *Schistosoma haematobium* occurs through direct contact with water contaminated by infected fresh water snails belonging to the genus bulinus. Various Bulinus species of snails are associated with the infection in different areas. Important Bulinus species in our region include, *Bulinus nasutas* and *Bulinus africanus* associated with the infection along the coastal line in Kenyan South Coast (O'Keefe, 1985, Sturrock, 2001). *Bulinus globosus* are associated with infection in hinterland Kwale District. Fresh water becomes contaminated by *Schistosoma* eggs when infected people urinate in or near the water. Under optimal conditions the eggs hatch and release miracidia, which swim and penetrate the snail intermediate hosts. The stages in the snail include 2 generations of sporocysts and the production of cercariae. Upon release from the snail, the infective cercariae swim, penetrate the skin of the human host, and shed their forked tail, becoming schistosomulae. The schistosomulae migrate through several tissues and stages to their residence in the veins. Adult worms' pair up and move to the venous

plexus of bladder. The females deposit eggs in the small venules of bladder. The eggs are moved progressively toward the lumen of the bladder and ureters and are eliminated with urine (WHO, 2002).




Source: http://www.dpd.cdc.gov/dpdx/HTML/Urogenital schistosomiasis.htm

**Figure 2.1: Life cycle of schistosomiasis**

### 2.5 Pathology and diagnosis

Symptoms of schistosomiasis are caused primarily by the body's reaction to the parasite eggs, rather than by the adult worms themselves. The parasite eggs which are laid along

the blood capillaries have a terminal spine which pierces the capillary wall and penetrate in to the lumen of the urinary bladder hence causing blood in urine or haematuria. Most of the eggs trapped in the tissue of bladder wall are the ones responsible for granuloma formation as a result of host's immune response. The toll of morbidity host immune response against schistosoma eggs is high in endemic areas. Various studies demonstrated different forms of morbidity due to *schistosoma haematobium*: Stephenson and others observed that urinary iron loss due to *S. haematobium* was associated with anaemia and poor physical fitness of Kenyan children and Malian children (Ayoya *et al.*, 2009, Stephenson *et al.*, 1985). Watanabe and others observed that cystitis associated with *S. haematobium* infection caused irritation and hyper contraction of the bladder resulting in heavy voiding of urine (Watanabe *et al.*, 2011). Prolonged and intensive infections may result in fatal diseases like kidney failure and cancer of the bladder (King and Dangerfield-Cha, 2008, WHO, 2002). Matsuyama and others reported carcinoma cells in the bladder of males with chronic schistosomiasis (Matsuyama. *et al.*, 2000).

### 2.6 Prevention and control

Prevention and control of schistosomiasis is based on treatment, snail control, improved sanitation, provision of safe water and health education (CDC, 2004). The WHO strategy for schistosomiasis control focuses on reducing disease through periodic, targeted treatment with anti helminthic drug. The current drug of choice is Praziquantel administered once as a single dose. This is a highly effective drug with a cure rate above 95% reported in school children in a number of studies (Kihara *et al.*, 2007, WHO, 2002).

Effects of chemotherapy are only short term in the reduction of morbidity in the community but this must be supported by other long term measures for effective reduction of transmission potentials; Such as preventive measures including sanitation improvement, improvement of the existing domestic water system and health education. (King *et al.*, 2006).

### 2.7 Health related quality of life

Quality of Life is used in a wide range of contexts, including the fields of international development, healthcare, and politics. Quality of life should not be confused with the concept of standard of living, which is based primarily on income. Instead, standard indicators of the quality of life include not only wealth and employment, but also the built environment, physical and mental health, education, recreation and leisure time, and social belonging (Dereck, 2009)

Health-related quality of life (HRQoL) is a complex patient reported outcome that provides an assessment of how an illness, its complications, and its treatment affect the patient. It has become increasingly important measure of patient-reported outcomes (Guyatt *et al.*, 2007). Assessment of HRQoL, the portion of Quality Of Life (QoL) determined by one's physical health, has been increasingly undertaken in pediatric chronic illness as healthcare professionals agree that traditional endpoints such as symptom reduction are no longer sufficient when evaluating medical outcomes (Guyatt *et al.*, 2007). A lot of work has been done in North America and Europe to develop disease-specific scales, general health profiles and health indices (Drummond, 1987, Varni *et al.*, 1999). In contrast, very few studies in Africa have attempted to either develop new health

care output measures or apply developed instruments (Kirigia, 1998). Amuyunzu, Fox-rushby, Kirigia and others studied the use of HRQoL instruments in Kenya focusing on culture and resonance of language in *Schistosoma mansoni* infected persons in Mwea irrigation scheme. Health-related quality of life of children is a growing field of research. Quality of life is used to evaluate the general well-being of individuals and societies (Hijmans *et al.,* 2010). A recent systematic review (Eiser and Morse, 2001) concluded that one of the more promising measures for children was the PedsQL™ developed in the United States by James W. Varni. the advantages of PedsQL™ include brevity, availability of age appropriate versions and parallel forms for child and parent (Upton P. *et al.,* 2008, Varni *et al.,* 1999). Several studies have used health related quality of life instrument in pediatrics with chronic diseases. The validity and reliability of the instrument has been confirmed as a population health measurement tool and in different child populations with chronic illnesses in descriptive and evaluative studies (Berkes A. *et al.*, 2010, Felder-Puig *et al.*, 2004, Gerson A.C. *et al.*, 2010, Gerson *et al.*, 2010, Konstantina *et al.*, 2008, Van Dellen *et al.*, 2007, Varni *et al.*, 2001)

### 2.8 Role of parent proxy report

The availability of measures with parallel child and parent versions has raised questions about the level of agreement between children's own views and those of their parents about child functioning. In a review of the relationship between child and parent HRQoL ratings, Eiser and Morse concluded agreement is dependent on the domain being measured, with higher agreement for physical aspects of health compared to emotional or social aspects(Eiser and Morse, 2001).

It is well documented in both the adult and pediatric literature that information provided by proxy-respondents is not equivalent to that reported by the patient (Achenbach *et al.*, 1987, Sprangers and Aaronson, 1992), neither those with chronic health conditions , nor healthy children(Yeh *et al.*, 2005) While pediatric patient self-report should be considered the standard for measuring perceived HRQoL, there may be circumstances when the child is too young, too cognitively impaired, too ill or too fatigued to complete a HRQoL instrument effectively, and in such cases parent proxy-reports may be needed (Hays *et al.*, 2006). Also, in most cases it is the parents' responsibility to seek health care when their children are sick. Thus, HRQoL instruments should be selected that measure the perspectives of both the child and parent since these two perspectives can provide complementary information related to healthcare utilization, risk factors, and quality of care (Varni *et al.*, 2005).Measuring health from the perspective of children and their parents provides a level of accountability.

**2.9 Role of iron**

Iron is a mineral needed by our bodies. Iron is a part of all cells and does many things in our bodies. For example, iron (as part of the protein hemoglobin) carries oxygen from our lungs throughout our bodies. Having too little hemoglobin is called anemia. Iron also helps our muscles store and use oxygen. Iron is a part of many enzymes and is used in many cell functions. Enzymes help our bodies digest foods and also help with many other important reactions that occur within our bodies (Stoltzfus, 2001).

Iron deficiency is a condition resulting from too little iron in the body. Iron deficiency is the most common nutritional deficiency and the leading cause of anemia. Iron deficiency

when sufficiently severe causes anaemia. Although some functional consequences may be observed in individuals who have iron deficiency without anaemia, cognitive impairment, decreased physical capacity, and reduced immunity are commonly associated with iron deficiency anaemia. In severe iron deficiency anaemia, capacity to maintain body temperature may also be reduced. Severe anaemia is also life threatening (WHO/UNICEF., 2009)

Poor nutrition especially iron deficiency in school-aged children is associated with retardation of growth and poor cognitive development (Pollit, 1997). The school age children are at risk of iron deficiency because of an expanding red cell and muscle mass(Onimawo *et al.*, 2010)

### 2.9.1 Signs and symptoms of iron deficiency

Too little iron can impair body functions, but most physical signs and symptoms do not show up unless iron deficiency anemia occurs. Someone with early stages of iron deficiency may have no signs or symptoms. This is why it is important to screen for too little iron among high risk groups. Signs of iron deficiency anemia include; feeling tired and weak, decreased work and school performance slow cognitive and social development during childhood, difficulty maintaining body temperature, decreased immune function, which increases susceptibility to infection, glossitis (an inflamed tongue) (Onimawo *et al.*, 2010).

### 2.9.2 Causes of IDA

Because of their rapid growth, infants and young children need more iron than older children. Sometimes it can be hard for them to get enough iron from their normal diet. When people lose blood, they also lose iron. They need extra iron to replace what they have lost. Increased blood loss can occur with heavy menstrual periods, frequent blood donation, as well as with some stomach and intestinal conditions (food sensitivity, hookworms and schistosomiasis.(WHO/CDC, 2007). Inadequate iron diet intake, bioavailabilty of iron in foods; Iron from meat, poultry, and fish (i.e. heme iron) is absorbed two to three times more efficiently than iron from plants (i.e., non-heme iron). Foods containing vitamin C also enhance non-heme iron absorption when eaten at the same meal. Substances (such as polyphenols, phytates, or calcium) that are part of some foods or drinks such as tea, coffee, whole grains, legumes and milk or dairy products can decrease the amount of non-heme iron absorbed at a meal. Calcium can also decrease the amount heme-iron absorbed at a meal (Tatala *et al.*, 1998).

### 2.9.3 Prevention of iron deficiency

In general, you can eat a healthful diet that includes good sources of iron. A healthful diet includes fruits, vegetables, whole grains, fat free or nonfat milk and milk products, lean meats, fish, dry beans, eggs, nuts, and is low in saturated fat, transfats, cholesterol, salt, and added sugars. In addition to a healthful diet that includes good sources of iron, you can also eat foods that help your body absorb iron better. For example, you can eat a fruit

or vegetable that is a good source of vitamin C with a food or meal that contains non-heme iron. Vitamin C helps your body absorb the non-heme iron foods you eat, especially when the food containing non-heme iron and the vitamin-C rich food are eaten at the same meal (WHO/CDC, 2007).

This study therefore evaluated the cause of anaemia in the infected children if inadequate iron diet or urogenital schistosomiasis was associated.

### 2.10 Association between schistosomiasis and iron deficiency anaemia

The causes of anemia in the developing world are multifactorial and include nutritional deficiencies, extra-corporal blood loss, higher prevalence of hemoglobinopathies, and inflammation. These etiologies often coexist and are difficult to distinguish due to limited diagnostic capabilities in resource-poor settings (Shaw and Friedman, 2011).

Urogenital schistosomiasis has an adverse effect on cognitive development. Poor iron status and iron deficiency anaemia (IDA) are closely linked to diminished educational performance since urogenital schistosomiasis cause blood loss and lead to iron deficiency anaemia (WHO, 2002). The anemia caused by iron deficiency constitutes one of the largest and most common nutritional problems in the world (Stoltzfus, 2001). It is estimated that one half of schoolchildren in developing countries are anemic (WHO/CDC, 2007). Iron deficiency anemia has been associated with negative effects on cognitive development, school performance, infant growth, resistance to infection, infant birth weight, and infant and maternal morbidity and mortality (Brabin *et al.*, 2001). Previous studies provided evidence that relatively heavy infections of *S. haematobium*

can cause urinary iron loss which, if persistent, results in iron deficiency anemia (Ayoya *et al.*, 2009, Prual *et al.*, 1992) and can also reduce physical fitness of children (Bustinduy *et al.*, 2011, Stephenson *et al.*, 1985). Recent review on morbidity due to schistosoma infection suggested a causative link between the infection, anti-parasite inflammation, and risk for anaemia, growth stunting and under-nutrition as well as exacerbation of co-infections, impairment of cognitive development and physiological capacities among infected individuals ((King and Dangerfield-Cha, 2008)). Kimura and others demonstrated significantly low mental test scores in *S. haematobium* infected Kenyan children as compared to non infected group (Kimura *et al.*, 1992). Urogenital schistosomiasis has an adverse effect on cognitive development. Studies by Ayoya and others on Nigerian children, showed significant association in growth retardation, absence from school and decreased school performance in infected children (Ayoya *et al.*, 2009). Infection with *S. haematobium* can also result in lower growth rates (Stoltzfus *et al.*, 1997, Warren *et al.*, 1993) and this may also be a route by which infection leads to impaired performance because under nutrition affects cognitive development and educational achievement. The negative influence of infection on child growth in developing countries has been extensively documented. While under-nutrition has been cited as the common cause for such growth patterns, the influence of infections including schistosomiasis is also considerable. Anaemia is a common problem throughout the world and iron deficiency is the most prevalent nutritional deficiency in the world. It affects mainly the poorest segment of the population, particularly where malnutrition is predominant and the population exposed to a high risk of water-related infection. Due to the numerous nutritional deficiencies and infectious diseases that co-exist with schistosome infections, which are also related to increased risk for anemia, careful

control for confounding variables or use of an experimental design is necessary to quantify this association (Shaw and Friedman, 2011). Recent cross-sectional studies have better adjusted for potential confounders, allowing for an improved estimation of the true relationship between urogenital schistosomiasis and anemia (Friedman *et al.*, 2005, Tatala *et al.*, 1998)

### 2.11 Social economic status

Schistosomiasis is both a disease of poverty and one of the neglected tropical diseases(Hotez *et al.*, 2007, King and Dangerfield-Cha, 2008). The poverty attributable to schistosomiasis results from disfigurement or other long-term illnesses, impaired childhood growth and development, and reduced productive capacity (King 2010, Muhumuza *et al.*, 2009). Asset indices provide an alternative welfare measure for large household surveys that lack data on income or expenditure (e.g. Demographic and Health Surveys), thus enabling the analysis of socio-economic inequalities in health (Chuma and Molyneux, 2009, Filmer and Pritchett, 2001). Whereas previous studies have mainly suggested that the influence of social economic conditions on the prevalence and intensity of schistosomiasis infection is mainly mediated through low social economic class being more likely to result in contact with infectious water at an increasing intensity(King *et al.*, 2005, Van der Werf *et al.*, 2003), and due to limited access to mass treatment (Guyatt *et al.*, 2001, Kabatereine *et al.*, 2007, Tohon *et al.*, 2008) in endemic areas.

# CHAPTER THREE: METHODOLOGY

## 3.1 Introduction

This chapter highlights the methodology used in the study. It identifies the study design, the study area, the study variables, the study population, the sampling technique including sample size determination. It also includes the construction of the research instruments, data collection techniques, pilot study and ethical considerations in the study. This sub study was part of an on-going comprehensive project on eco-epidemiology of four parasitic diseases - malaria, urogenital schistosomiasis, filariasis and hookworms (referred here as the polyparasitism project undertaken by division of vector borne and neglected tropical diseases).

## 3.2 Research design

A cross-sectional case-control study design was adopted in this study; where cases and controls were children who tested positive or negative for schistosomiasis respectively during the parasitological surveys in five selected villages. Children were eligible if: they had participated in the parasitological examinations and anthropometric measurements were aged between 5–18 years old and they had provided child assent and written parental consents.

Quality of life was assessed by the Pediatrics Quality of life survey (PedsQL™ 4.0 SF15) instrument (Varni *et al.*, 2001), that measures the child's and parent's perceptions of the child's comprehensive quality of life. The survey tool is administered separately to children and teens for self-reporting and to parent using proxy forms. It takes

approximately 5 minutes to complete and has been shown to be reliable and valid measure of quality of life (Varni *et al.,* 2001). Each age group was studied using a PedsQL™ questionnaire designed to fit the ages of children, with the parent proxy report complementing the data given by the children. A tabular food frequency questionnaire was designed and used to collect data on 36 iron foods consumed in the area. Data was collected between April-June 2011 at the beginning of long rains when the intensity of infection was low.

### 3.2.1 Health related quality of life measurements

A generic HRQoL Short Form instrument (PedsQL™ 4.0 SF15) usually composed of instructions, items and corresponding response categories or response choices was used to collect data. The original version of the instrument is written in US English (Appendix 4), forward translation to Swahili language was done by two professional native language speakers (Swahili speaking health professionals from the area) and checked by a third person for consistency. The translations apply also to food frequency questionnaire. The questionnaires were administered by four trained research assistants (speakers of native languages of the communities) from each village under my supervision. The PedsQL™ 4.0 SF15 core scales are comprised of parallel child self-report and parent proxy-report formats. Child self-report includes ages 5-7, 8-12, and 13-18 years. Parent proxy-report includes ages 2-4 (toddler), 5-7 (young child), 8-12 (child), and 13-18 (adolescent), and assesses parent's perceptions of their child's HRQoL. The items for each of the forms are essentially identical, differing in developmentally appropriate language, or first or third

person tense. The instructions ask how much of a problem each item has been during the past one month. A 5-point response scale is utilized across child self-report for ages 5-18 and parent proxy-report (0 = never a problem; 1 = almost never a problem; 2 = sometimes a problem; 3 = often a problem; 4 = almost always a problem). To further increase the ease of use for the young child self-report (ages 5-7), the response scale is reworded and simplified to a 3-point scale (0 = not at all a problem; 2 = sometimes a problem; 4 = a lot of a problem), with each response choice anchored to a happy to sad faces scale. Parent proxy-report also includes the toddler age range (ages 2-4), which does not include a self-report form given developmental limitations on self-report for children younger than 5 years of age, and includes only 3 items for the school functioning scale.

Items are reverse-scored and linearly transformed to a 0-100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0), so that higher scores indicate better HRQoL. Scale Scores are computed as the sum of the items divided by the number of items answered (this accounts for missing data). If more than 50% of the items in the scale are missing, the Scale Score is not computed (Berkes *et al.*, Varni *et al.*, 1999). In addition to the single scale scores there is the possibility to calculate summary scores: the Physical Functioning Subscale Score whereas to create the Psychosocial Functioning Score, the mean is computed as the sum of the items divided by the number of items answered in the Emotional, Social, and School Functioning Subscales.

### 3.2.2 Socioeconomic status

Individual SES scores were based on asset questionnaire data that provided information on type of housing, occupation, water sources for domestic use and drinking, faecal disposal facilities, ownership status of land and home, radio, bicycle, television and mobile phone. The scores were used to create an index representing the wealth of the households interviewed. A summary SES score composed of all questionnaire items was calculated by using principal components analysis (PCA) to appropriately weight questionnaire items, as described by Gwatkin and others (Gwatkin *et al.*, 2000). For this study according to the weights an individual was either of high or low SES.

### 3.2.3 Anthropometric measurements

Anthropometric data of eligible children was obtained as follows; Weight was obtained by digital weight-scale (SECA model 803, Hanover, MD) and was rounded to the nearest 0.1 kg. Height was measured with the use of a stadiometer (SECA model 214, Hanover, MD) and measurements were read to the nearest 1.0 cm. Instruments were calibrated daily prior to use to a zero (0) reading. Every measurement was performed twice and the mean values were used for analysis. Reference population Z-scores were calculated for each subject's height-for age (HAZ) using the US Centers for Disease Control and Prevention's Epi Info™, Version 3.5.1 (CDC, Atlanta, GA) from the year 2000 (Ogden *et al.*, 2002).

### 3.2.4 Schistosoma haematobium examination

Egg burden for *S.haematobium* was assessed by Nuclepore filtration method of parasite eggs in 10 ml samples of urine. All the children provided a single sample of a mid-morning urine specimen that was immediately processed as described (Peters *et al.*, 1976). Ten ml of urine in each sample was examined for the presence of schistosoma eggs. A light *S. haematobium* infection was categorized as detection of 1–99 eggs/10 ml of urine, a moderate infection as 100–399 eggs/10 ml, and a heavy infection as ≥400 eggs/10 ml. For consistent comparison between other publications in all reports of Coast Province for *S. haematobium* studies, this classification of intensity was used although it is different from the current World Health Organization (WHO) definition of light infection as < 50 eggs/10 ml of urine and heavy infection as ≥50 eggs/10 ml.

### 3.2.5 Anaemia examination

Blood collection and processing finger prick blood was used to obtain a hemoglobin measurement (Hemocue, Sweden). Anemia was categorized on the basis of age- and sex-specific hemoglobin cutoffs recommended by the WHO: hemoglobin ≥11.5 g/dl for children aged 12 years, ≥12 g/dl for children aged 12–14 years and non pregnant females ≥15 years, and ≥13 g/dl for males aged ≥15 y(WHO/UNICEF., 2009). Mild, moderate, and severe anemia were defined as hemoglobin concentrations below the WHO cutoff but ≤9 g/dl, ≤7 but_9 g/dl, and ≤7 g/dl, respectively (WHO/CDC, 2007).

### 3.2.6 Dietary iron assessment

A semi quantitative food frequency questionnaire (FFQ) consisting of 36 local iron rich foods including fruits was developed and administered to the parents of the children. Frequencies of consuming a particular food were entered as daily, 2-5 times a week, once week, once a month and after a long time or never. Mean iron/per day of every child was calculated by $\sum$ (food item * frequency of consuming in number of days* amount of iron per standard portion)/365. The mean iron calculated was then compared to the recommended daily intake.

## 3.3 Variables

### 3.3.1 Dependent variables

The dependent variable of this study was; Quality of life.

### 3.3.2 Independent variables

The independent variables for this study were demographic characteristics, socio-economic status, physical functioning, emotional functioning, social functioning, school functioning, infection intensity, stunting and dietary iron adequacy.

### 3.4 Location of the study

The site of the study was Kwale County in South Coast of Coast Province, Kenya. Kwale County comprises three districts namely; Msambweni in the South- East, Kwale in the central region and Kinango in the Western hinterland. (Figure 3.1).The districts border Tanzania to the south-west and the Indian Ocean to the east. The area is hot and humid year-round with annual mean temperature of 23 ºC- 34 ºC and average relative humidity of 60% - 80%. Altitude ranges from 0 to 462 meters above sea level, with the majority of the region within 100m of sea level. The two rainy season are, April to June (long rains) and October-November (short rains), but rain falls in most months, especially near the coastline. Total annual precipitation ranges from 900-1500mm along the coastal belt to 500–600mm inland. Drainage system is poor and this consists of slow running streams. Stationary ponds are common and shallow open dams for animal watering are common.

The polyparasitism project is being conducted in 8 villages, four in Msambweni district, three in Kwale district and three in Kinango district. Polyparasitism project data collection procedures are initiated by a demographic survey in each of the study villages, followed immediately by a parasitological survey where all consenting individuals aged five and above are tested for malaria, urogenital schistosomiasis, filariasis and hookworm. As part of the polyparasitism project's objective to examine the long- term morbidity associated with polyparasitism, a subset of study subjects, 5-18 years old, are recruited to participate in extended examinations of nutritional status, physical fitness and quality of life assessment. These are individuals who have already participated in the parasitological survey, and who consent to the nutritional status examination. Due to logistic and time constrains, this study was limited to five of the 8 villages Milalani

(Msambweni district), Magodzoni (Kwale district) and Kinango A, Gwadu and Dzitenge (Kinango district) representing the four ecological settings.

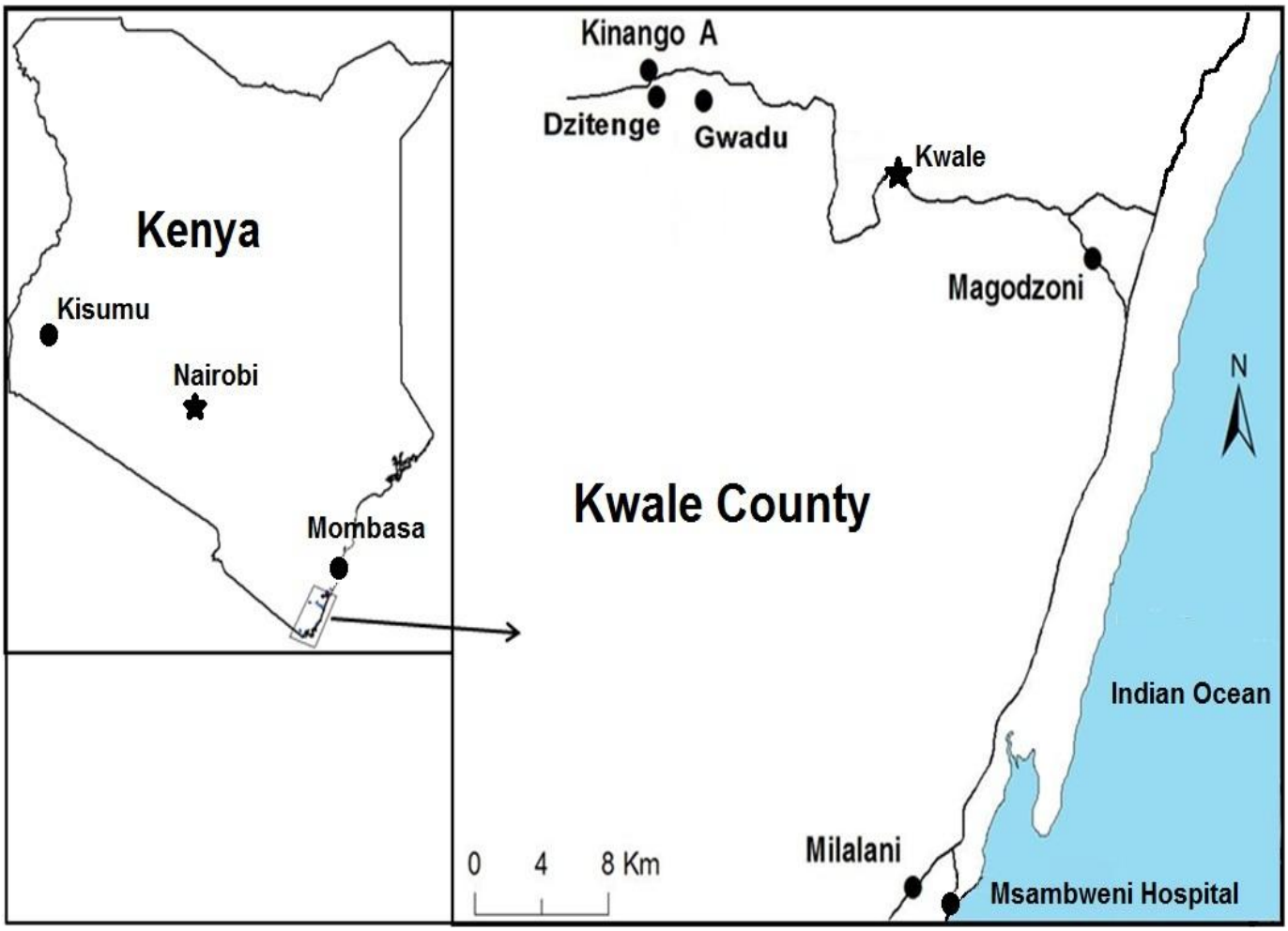



**Figure 3.1: Map of the study area in Kwale County with villages surveyed. Inset map of Kenya**

### 3.5 Target population

The target populations were all children aged 5-18 years in Kwale County.

### 3.6 Sampling techniques and sample size

#### 3.6.1 Sampling techniques

The study employed non-probability sampling techniques. Purposive sampling was used to select villages and specific respondents who fit the criteria of the study population i.e. children who had participated earlier in parasitological surveys and anthropometrics survey.

#### 3.6.2 Sample size determination

All eligible children in the study villages were included in the study.
(Figure 3.3) shows how eligible children were selected in the study area.

### 3.7 Study population

The study population consisted of children aged 5-18 years who had participated in both the parasitological and nutritional status assessment in the five selected villages.

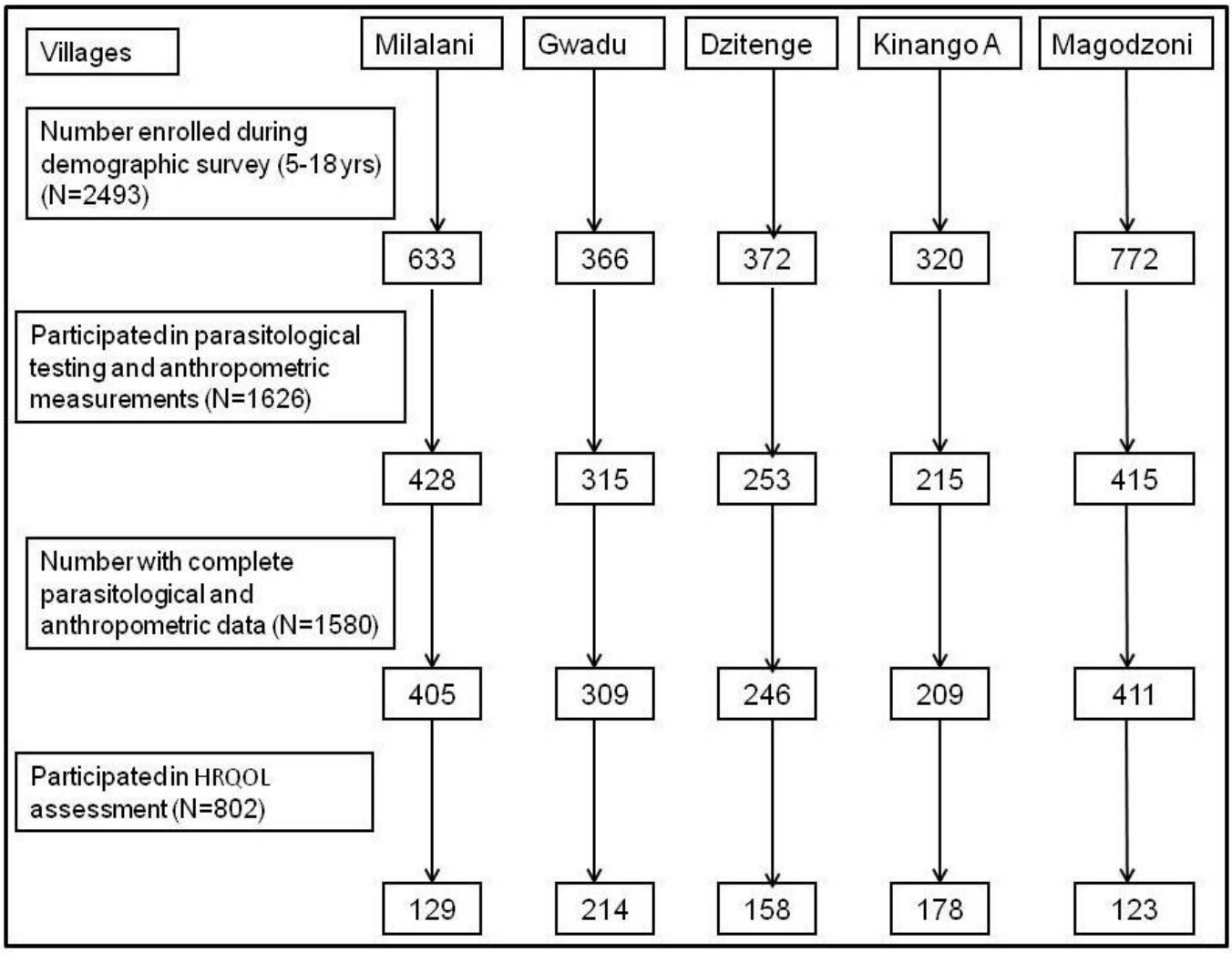



**Figure 3.3 Flow chart of study participation in the five selected villages**

### 3.8 Construction of research instruments

Standardized and validated PedsQL™ 4.0 SF15questionnaire (translated into Swahili) child self report and parent proxy report for the age groups (5-7, 8-12 and 13-18) was used to collect data on quality of life.

Tabular food frequency questionnaire was constructed based on 36 local iron rich foods consumed in the study areas, and was used to assess dietary iron consumption patterns.

A socio demographic questionnaire was formulated to provide data on demographic, social and asset ownership for social economic status standing.

### 3.10 Pre-testing of study tools

Translated questionnaires were pre-tested in a similar village outside the study area (Milalani) to determine whether the translated instructions, items and response choices are acceptable, whether it was understood in the way intended, and whether the language used was simple and appropriate.

#### 3.10.1 Reliability

The PedsQL™ 4.0 SF15 Short Form scale's internal consistency reliability was determined via Cronbach's coefficient alpha. A reliability of $\geq 0.70$ is recommended to compare groups of patients, whereas $> 0.90$ is recommended for comparing individuals(Cronbach, 1951).

#### 3.10.2 Validity

Construct validity was determined by comparing scales scores across those with infected and non infected children.

### 3.11 Data collection techniques

A standard Health Related Quality of Life (HRQoL) questionnaire was used to collect data. The original version of the instrument is written in US English (Appendix 10-15). Forward translation to Swahili language was done by local health professional. The translations apply also to food frequency questionnaire. The questionnaires were administered by four trained research assistants (speakers of native languages of the communities) from each village. Questions were read aloud in local language by interviewers.

### 3.12 Data analysis

#### 3.12.1 Analysis of demographic, parasitological, anthropometric, socioeconomic, health status and dietary iron intake data

Raw data was entered and cleaned using Excel 2007. Statistical analyses were conducted using both SPSS for Windows, version 19.0 (SPSS, Inc., Chicago, IL) and SAS for Windows, version 9 (SAS Institute Inc., Cary, North Carolina).Descriptive statistics was performed to give frequencies and means of independent variables. For estimation of socioeconomic status (SES), housing conditions and household ownership of selected assets to construct an asset index based on principal component analysis (PCA) (Gwatkin *et al.*, 2000). Participating households were divided into two equal sized groups (low and higher socioeconomic standing) according to their scores from the principal components analysis. Chi square tests were used to test for differences in proportions in categorical variables, and the Mann-Whitney U test was used to assess differences in intensities of

infection, age and hemoglobin. Analysis of variance (ANOVA) was used to compare infection intensity among villages. P values of less than 0.05 were considered to be statistically significant.

### 3.12.2 Analysis of HRQoL data

*Feasibility* of the PedsQL™ 4.0 SF15 generic version was determined from the average percentage of missing responses. The percentage of all possible item responses left unanswered was calculated for each subject on each single and summary scale and averaged over subjects. *Utility* of the instruments in terms of distributional coverage overall and by subscale was evaluated by calculating the percentage of subscale-level average responses reaching the minimum (floor) or the maximum (ceiling) of the scoring scale. In QoL studies, floor and ceilings effects are used to evaluate the depth of a health problem being measured. If floor effects exist, it means the QoL tool is showing a lower than actual HRQoL, and if ceiling effects exist, QoL tools may be underestimating QoL or the magnitude of the problem being measured. Studies with small floor or ceiling effects (1–15%) are considered to meet acceptable measurement standards, whereas studies with moderate floor or ceiling effects (>15%) are considered less precise in measuring latent constructs at the extremes of the scale (McHorney and Tarlov, 1995, Terwee *et al.*, 2007).

PedsQL™ 4.0 SF15 questionnaire internal consistency reliability was determined using Cronbach's alpha coefficient scale. Internal consistency is a measure of the extent to which items in a questionnaire (subscale or scale) are correlated (homogeneous), thus measuring the same concept. It is an important measurement property for questionnaires

that intend to measure a single underlying concept (construct) by using multiple items such as (Cronbach, 1951). Scales with reliabilities of 0.70 or greater are recommended for comparing patient groups, while a reliability criterion of 0.90 is recommended for analyzing individual patient scores (Nunnally and Bernstein, 1994). A low Cronbach's alpha indicates a lack of correlation between the items in a scale, which makes summarizing the items unjustified. A very high Cronbach's alpha (>0.95) indicates high correlations among the items in the scale, i.e., redundancy of one or more items (Terwee *et al.*, 2007). Construct validity was determined utilizing the known-groups method, which compares scale scores across groups known to differ in the health construct being investigated. In our study the known groups are the children who tested positive and negative for *S. haematobium* egg output, who will henceforth be referred to as 'egg-positive' and 'egg-negative', respectively. Known groups validity was examined through a comparison of these egg-positive and egg-negative groups, of children from families of lower versus higher SES, of stunted versus non-stunted children, and those from high prevalence (high risk) villages versus moderate prevalence (lower risk) villages, using independent *t*-tests.

To complement statistical testing, effect sizes are presented to assist in the interpretation of the relative degree of between-group score differences by indexing these differences to within-group score variation (Cohen, 1988), with lesser import if the between-group score difference is small relative to the within-group variation in scores. Effect size utilized in these analyses was calculated by taking the difference between the score means for either cases *vs.* controls, stunted *vs.* not stunted children, children from low SES *vs.* high SES, or children from high-risk *vs.* moderate risk villages, divided by the pooled standard deviation of the egg-negative/high SES/not stunted/lower-risk village

categories, as appropriate (Kazis *et al.*, 1989). Effect sizes for differences in means are designated as small (0.20 – 0.49), medium (0.50 – 0.79), and large (≥ 0.80) in magnitude (Fowler, 1995). Agreement between child self-report and parent proxy-report was determined through 2-way mixed-effect model (absolute agreement, single measure) intra class correlations (McGraw and Wong, 1996). Intra class correlation results are generally interpreted as follows: ≤0.40, poor to fair agreement; 0.41 to 0.60, moderate agreement; 0.61 to 0.80, good agreement; and 0.81 to 1.00, excellent agreement (Bartko, 1966).

### 3.12 Logistical and ethical considerations

The study was performed under protocol approved by Graduate School Kenyatta University, Department of community health, Kenyatta University, the Kenya Medical Research institute ethical review committee Nairobi and National Council of Science and Technology (NCST). Prior to carrying out data collection child verbal assent and signed parental/guardian consents were sought. Questions were read aloud in local language by an interviewer for all children and mothers. The participants were explained about the study purpose, objectives, benefits and risks for informed consent. Confidentiality was ensured by avoiding writing names on the research tools, instead they were coded. This study was sponsored by NIH USA through division of vector borne diseases (DVBD).

# CHAPTER FOUR: DATA ANALYSIS, RESULTS AND DISCUSSION

## 4.1 Introduction

This chapter presents the results and discussion of the data collected from the respondents in the study area. The results include the demographic characteristics of respondents, feasibility, construct validity and internal consistency reliability of PedsQL™ 4.0 SF15 tool, parent child concordance, impact of urogenital schistosomiasis on HRQoL domains and correlation between schistosomiasis, anaemia and iron diet. To assess the impact of exposure to schistosomiasis, the study examined differences in observed PedsQL™ 4.0 SF15 outcomes on several levels; high-prevalence vs. moderate-prevalence villages, *S. haematobium* egg-positive vs. egg-negative individuals, and according to cofactors likely to influence HRQoL (presence or absence of lower SES, anemia, or undernutrition).

## 4.3 Results

### 4.3.1 Socio-demographic characteristics of the parent respondents

The PedsQL™ 4.0 SF15 tool was administered to 835 children and 800 of their parents. Overall, incomplete questionnaires were found for 33 children (5.0%) and 35 parents (4.4%), yielding 802 children and 765 parents with complete HRQoL data. Nearly all (95%) parent respondents were females and only (5%) being males. Most (68%) of the respondents were Muslims and the rest being Christians (31%) or other (1%). A high proportion (81%) had either never gone to school, enrolled for madrassa or were primary

school dropouts, and the remaining few had reached secondary (10%) and college (9%) levels. The predominant ethnic groups were Duruma (60%) and Digo (25%) and the rest were Kamba (11%) or other (4%). The parent respondents were generally married (85%) with the rest being unmarried (15%). Toilets/latrines were reported by 61% of the respondents. The most common occupation of the parents was farming (37%), and 32% of their spouses were employed. The major food sources were the individual farms (56%), with the rest either purchased (42%) or from donations (2%).

These socio-demographic characteristics of the respondents are as shown in table 4.1 below.

**Table 4.1: Distribution of socio-demographic characteristics of parent respondents**

| Independent variable | Frequency n=765<br><br>No. | Percentage (%) |
|---|---|---|
| **Sex** | | |
| ▪ Male | 38 | 5 |
| ▪ Female | 727 | 95 |
| **Highest level of education** | | |
| ▪ None | 260 | 34 |
| ▪ Madrassa | 38 | 5 |
| ▪ Primary | 321 | 42 |
| ▪ Secondary | 77 | 10 |
| ▪ College | 69 | 9 |
| ▪ University | 0 | 0 |
| **Marital status** | | |
| • Yes | 650 | 85 |
| • No | 115 | 15 |
| **Religion** | | |
| • Muslim | 520 | 68 |
| • Christian | 237 | 31 |
| • other | 8 | 1 |
| **Occupation** | | |
| ▪ Employed | 168 | 22 |
| ▪ Farming □ | 291 | 38 |
| ▪ Fishing | 145 | 19 |
| ▪ Trade | 61 | 8 |
| ▪ Other | 100 | 13 |
| **Tribe** | | |
| ▪ Digo | 191 | 25 |
| ▪ Duruma | 459 | 60 |
| ▪ Kamba | 84 | 11 |
| ▪ Other | 31 | 4 |
| **Source of food** | | |
| ▪ Farm | 429 | 56 |
| ▪ Bought | 321 | 42 |
| ▪ Donations | 15 | 2 |
| **Toilet/latrine** | | |
| ▪ Yes | 467 | 61 |
| ▪ No | 298 | 39 |

### 4.3.2 Demographic, nutritional, socioeconomic and health status features of children

A total of 802 children participated in the study 51.3% were females, and ages of the children ranged from 5 to 18 years, with a mean of 10.6 (± 3.5) years. The majority of the children in Milalani, Magodzoni, and Gwadu (the more rural villages) came from families of low SES while most children in Kinango A and Dzitenge (the more urban villages) came from families of higher SES.

The overall *S. haematobium* infection prevalence was 42.2% (766/1580), similar for males and females, but significantly different by village (Table 4.2) and by age group (Table 4.3). *S. haematobium* infection intensity was highest in 8-12 yr olds and lowest in 5-7 yr olds ($P < 0.01$, Table 4.3), and varied significantly by village (Table 4.2) with an overall geometric mean intensity of infection of 37.5 eggs/10mL of urine. Males had significantly heavier infection than females ($P < 0.02$). There were also significant inter-village and across-age group differences in the proportion of anemic children and in mean hemoglobin levels (Tables 4.2 and 4.3).

Many study children had either acute undernutrition, as measured by wasting (BAZ score $\leq$ -2), chronic undernutrition, as measured by stunting prevalence (HAZ score $\leq$ -2), or both. The highest malnutrition levels were recorded in villages closer to the coastline (Milalani and Magodzoni) compared to the more inland villages (Gwadu, Dzitenge, and Kinango A) (Table 4.2). Wasting and stunting were lowest in the 5-7 yr age group compared to older age groups (Table 4.3).

**Table 4.2: Demographic, nutritional and health status characteristics of children in study villages**

| | Villages | | | | | | |
|---|---|---|---|---|---|---|---|
| **Independent variable** | **Milalani (N=129)** | **Magodzoni (N=123)** | **Gwadu (N=214)** | **Dzitenge (N=158)** | **Kinango A (N=178)** | **All Villages (N=802)** | ***P* value[a]** |
| **Mean age (SD)** | 10.9 ± (3.5) | 10.9 ± (3.5) | 10.6 ± (3.6) | 10.3 ± (3.3) | 10.2 ± (3.3) | 10.6 ± (3.5) | **<0.05** |
| **% Female** | 50.4 | 49.1 | 53.0 | 51.6 | 54.0 | 51.3 | >0.5 |
| **% Lower SES** | 63.5 | 52.5 | 71.2 | 29.3 | 22.5 | 51.4 | **<0.0001** |
| ***Sh* prevalence** | 62.2 | 22.9 | 53.4 | 37.8 | 29.7 | 42.2 | **<0.0001** |
| ***Sh* geometric mean intensity (eggs per 10ml of urine)** | 40.4 | 16.5 | 49.0 | 40.4 | 42.5 | 37.5 | **<0.01** |
| **% Anemic[b]** | 48.6 | 25.5 | 38.5 | 35.4 | 33.0 | 36.5 | **<0.0001** |
| **Mean hemoglobin, gm/dL (Range)** | 11.7 (4.6-16.4) | 12.4 (4.3-17.2) | 12.1 (5.2-17.5) | 12.2 (6.8-16.5) | 12.3 (6.6-17.4) | 12.1 (4.3-17.5) | **<0.0001** |
| **% Stunted[c]** | 29.1 | 37.2 | 34.1 | 20.3 | 17.6 | 29.3 | **<0.0001** |
| **% Wasted[d]** | 11.8 | 22.6 | 10.7 | 8.5 | 11.0 | 13.8 | **<0.0001** |

**Abbreviations**: SD, Standard deviation; SES, socioeconomic status; Sh+, *Schistosoma haematobium* egg-positivity

[a] P value refers to significance of differences among the villages by Mann-Whitney U test, ANOVA, or chi-square testing.

[b] Anemia based on WHO age-specific hemoglobin (Hb) criteria: for ages <12 yr, Hb<11.5 g/dL; for ages≥12 yr, Hb<12 g/dL; but for males≥15 yr, Hb<13 g/dL. [c] Stunting: in height-for-age Z score (HAZ) $\leq$ - 2 [d] Wasting: BMI-for-age Z score (BAZ) $\leq$ - 2

**Table 4.3: Demographic, nutritional and health status characteristics of children by age group**

| Independet variable | 5-7 years (N=358) | 8-12 years (N=716) | 13-18 years (N=506) | *P* value[a] |
|---|---|---|---|---|
| **Mean age (SD)** | 6.1 ± 0.8 | 10.0 ± 1.4 | 14.6 ± 1.5 | -- |
| **% Female** | 48.3 | 53.2 | 50.6 | >0.2 |
| **% Lower SES** | 55.3 | 50.4 | 50.0 | >0.2 |
| ***Sh+* prevalence** | 33.0 | 42.0 | 48.8 | **<0.0001** |
| ***Sh+* geometric mean intensity (eggs/10mL of urine)** | 28.7 | 48.7 | 31.2 | **<0.05** |
| **% Anemic[b]** | 36.9 | 33.5 | 40.5 | **<0.05** |
| **Mean hemoglobin, g/dL (Range)** | 11.9 (4.3-16.5) | 12.1 (4.6-17.4) | 12.4 (5.2-17.5) | **<0.0001** |
| **% Stunted[c]** | 17.3 | 30.2 | 36.6 | **<0.0001** |
| **% Wasted[d]** | 7.0 | 14.4 | 17.8 | **<0.0001** |

**Abbreviations**: SD, Standard deviation; SES, socioeconomic standing; Sh+, *Schistosoma haematobium* egg-positivity

[a] P value refers to significance of differences among the villages by Mann-Whitney U test, ANOVA, or chi-square testing.

[b] Anemia based on WHO age-specific hemoglobin (Hb) criteria (WHO/CDC, 2007): for ages <12 yr, Hb<11.5 g/dL; for ages≥12 yr, Hb<12 g/dL; but for males≥15 yr, Hb<13 g/dL.

[c] Stunting: in height-for-age Z score (HAZ) ≤ - 2

[d] Wasting: BMI-for-age Z score (BAZ) ≤ - 2

### 4.3.3 Nutritional status of children by gender

The results of combined villages showed more males being stunted (56% *vs.* 44%, $\chi^2$=9.2, $P < 0.01$) or wasted (60% *vs.* 40%%, $\chi^2$= 14.8, $P < 0.0001$) as compared to females (Figure 4.1).

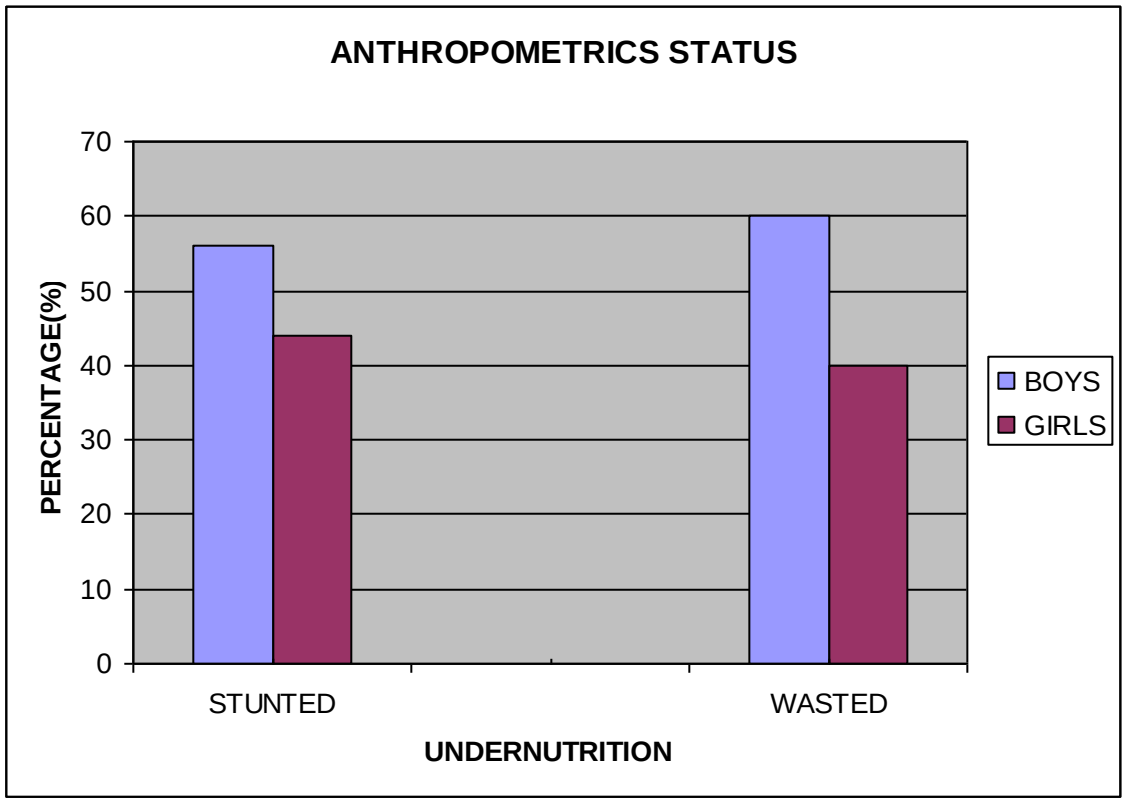



**Figure 4.1: Percentage of wasted and stunted by gender**

### 4.3.4 Prevalence of urogenital schistosomiasis among children 5-18 years

The prevalence of S.*haematobium* in the five selected villages is shown in figure 4.2. Prevalence of urogenital schistosomiasis among children 5-18 years was highest in Milalani (62.2%) and Gwadu (53.4%) villages, (here referred to as high-prevalence villages, according to WHO guidelines (WHO, 2002) as compared to Magodzoni, Dzitenge, and Kinango A villages (here referred to as moderate prevalence villages).

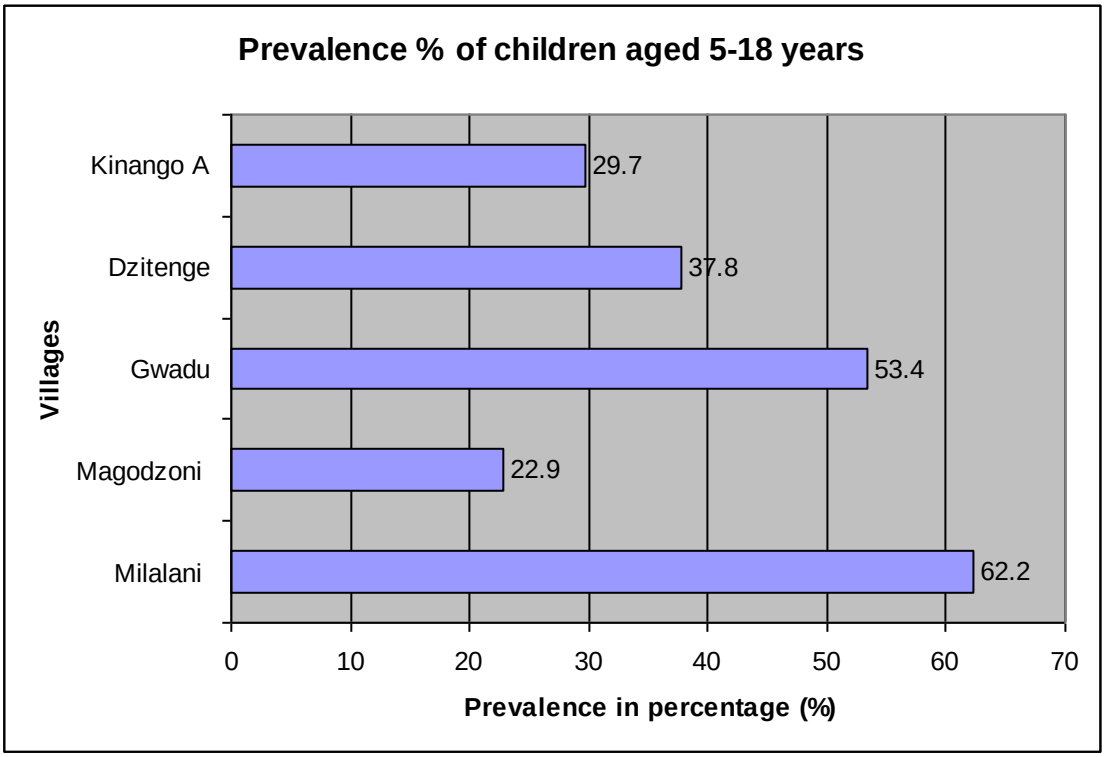



**Figure 4.2: prevalence of urogenital schistosomiasis among children (5-18yrs) in the five selected villages**

### 4.3.5 Intensity of urogenital schistosomiasis in different age groups

Infection intensity was generally low with only a few children heavily infected. The 5-7, 8-12 and 13-18 age group were 13%, 20% and 17% respectively (figure 4.3). Children in the 8-12 age groups had higher geometric mean infection intensity (48.7) and lowest in 5-7 yr olds (28.7) $P < 0.01$ (table 4.3).

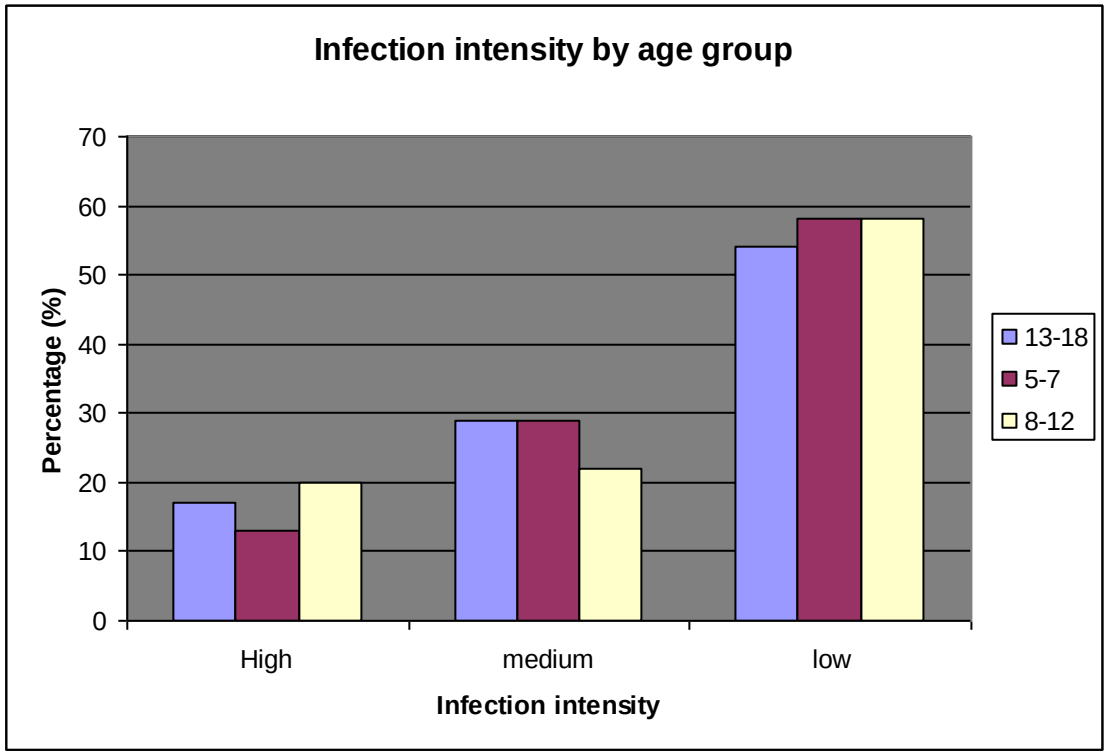



**Figure 4.3: Intensity of infection as per age groups**

### 4.3.6 Feasibility and validity of PedsQL™ 4.0 SF15

Table 4.4 below shows the missing responses and the floor and ceiling effects noted in the PedsQL™ 4.0 SF15 administration in the study area. Missing values were found in both child self-report (range: 0.0-5.4%) and parent proxy-reports (range: 0.2-4.4%). The school function scale had the highest missing values for both self and parent proxy-reports. Floor effects were found in both self and parent-proxy reports (range: 0.0-1.3). Influential ceiling effects (*i.e.,* > 15%) were found in the physical, social, and school function scales in self report, with highest values noted for the school function scale. Relevant ceiling effects were found in all scales in the parent proxy report except for the total scores.

**Table 4.4: Missing responses, floor and ceiling effects of the PedsQL™ 4.0 SF15 of children and proxy report**

| Scale | # items | Infected (N=352) | | | Non infected (N=450) | | | Overall (N=802) | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | % Missing | % Floor | % Ceiling | % Missing | % Floor | % Ceiling | % Missing | % Floor | % Ceiling |
| **Child self-report** | | | | | | | | | | |
| Physical Functioning | 5 | 0.3 | 0.0 | **71.0** | 0.6 | 0.2 | **71.6** | 0.5 | 0.1 | **71.3** |
| Emotional functioning | 4 | 0.0 | 0.0 | 8.5 | 0.9 | 0.0 | 14.7 | 0.5 | 0.0 | 12.0 |
| Social Functioning | 3 | 0.0 | 0.0 | **27.6** | 0.2 | 0.4 | **34.7** | 0.1 | 0.2 | **31.5** |
| School functioning | 3 | 3.3 | 1.1 | **74.4** | 2.8 | 1.3 | **77.8** | 3.0 | 1.2 | **76.3** |
| Psychosocial score | 10 | 3.3 | 0.0 | 5.1 | 3.6 | 0.0 | 9.6 | 3.5 | 0.0 | 7.6 |
| Total scores | 15 | 3.6 | 0.0 | 4.5 | 4.3 | 0.0 | 8.0 | 4.0 | 0.0 | 6.5 |
| **Parent proxy-report** | | **N=333** | | | **N=432** | | | **N=765** | | |
| Physical Functioning | 5 | 0.3 | 0.0 | **78.1** | 0.7 | 0.2 | **74.5** | 0.5 | 0.1 | **76.1** |
| Emotional functioning | 4 | 0.0 | 0.0 | **20.1** | 0.9 | 0.2 | **25.9** | 0.5 | 0.1 | **23.4** |
| Social Functioning | 3 | 0.0 | 0.0 | **35.4** | 0.2 | 0.0 | **45.1** | 0.1 | 0.0 | **40.9** |
| School functioning | 3 | 4.8 | 0.0 | **46.8** | 2.0 | 0.2 | **50.2** | 3.3 | 0.1 | **48.8** |
| Psychosocial score | 10 | 4.8 | 0.0 | 12.6 | 3.1 | 0.0 | **17.6** | 3.9 | 0.0 | **15.4** |
| Total scores | 15 | 5.1 | 0.0 | 12.6 | 3.8 | 0.0 | **15.7** | 4.4 | 0.0 | 14.4 |

% Floor/Ceiling = the percentage of scores at the extremes of the scaling range. Floor or ceiling effects in the range of 1–15% are acceptable while those >15% [**in BOLD]** are considered to provide less precise estimates.

### 4.3.7 Internal consistency reliability of PedsQL™ 4.0 SF15

The internal consistency/reliability of PedsQL™ 4.0 SF15 was analyzed using cronbachs alpha coefficients. A reliability criterion of ≥ 0.70, are recommended for comparing patient groups and ≥ 0.90 are recommended for analyzing individual patient scores. Cronbach's α (alpha) was estimated for each PedsQL™ 4.0 SF15 domain for parents and children separately to assess internal consistency. The scales of majority of the children with and those without urogenital schistosomiasis approached the standard of reliability criterion of .90 recommended for analyzing individual patient scale scores, while the total scale score across the two groups exceeded the minimum reliability.70 required for group comparisons except for cases in (13-18) age group α (0.64) (table 4.5). For proxy report all the individual and total scores exceeded the recommended reliability

**Table 4.5: Internal consistency reliability for PedsQL™ 4.0 SF15 using cronbach alpha statistics[a]**

| Scale | Young children (5-7) | | Children (8-12) | | Adolescent (13-18) | | Overall | |
|---|---|---|---|---|---|---|---|---|
| | Cases | Controls | Cases | Controls | Cases | Controls | Cases | Controls |
| **Child self-report** | **N=84** | **N=109** | **N=147** | **N=200** | **N=121** | **N=141** | **N=352** | **N=450** |
| Physical Functioning | 0.86 | 0.89 | 0.86 | 0.87 | 0.83 | 0.87 | 0.85 | 0.87 |
| Emotional functioning | 0.79 | 0.81 | 0.76 | 0.82 | 0.74 | 0.80 | 0.76 | 0.81 |
| Social Functioning | 0.83 | 0.85 | 0.79 | 0.82 | 0.76 | 0.80 | 0.79 | 0.82 |
| School functioning | 0.84 | 0.86 | 0.84 | 0.85 | 0.83 | 0.83 | 0.83 | 0.85 |
| Psychosocial score | 0.73 | 0.77 | 0.70 | 0.75 | 0.66 | 0.73 | 0.69 | 0.74 |
| Total scores | 0.72 | 0.76 | 0.68 | 0.73 | **0.64** | 0.71 | 0.67 | 0.73 |
| **Parent proxy-report** | **N=80** | **N=105** | **N=139** | **N=192** | **N=114** | **N=135** | **N=333** | **N=432** |
| Physical Functioning | 0.88 | 0.90 | 0.87 | 0.90 | 0.87 | 0.87 | 0.87 | 0.89 |
| Emotional functioning | 0.84 | 0.80 | 0.78 | 0.86 | 0.83 | 0.84 | 0.81 | 0.84 |
| Social Functioning | 0.88 | 0.82 | 0.80 | 0.87 | 0.87 | 0.86 | 0.85 | 0.86 |
| School functioning | 0.86 | 0.87 | 0.85 | 0.87 | 0.86 | 0.86 | 0.86 | 0.87 |
| Psychosocial score | 0.79 | 0.77 | 0.72 | 0.80 | 0.78 | 0.78 | 0.76 | 0.79 |
| Total scores | 0.78 | 0.75 | 0.71 | 0.79 | 0.77 | 0.77 | 0.75 | 0.78 |

[a] Cronbach alpha values ≥ 0.70 are recommended for comparing patient groups, and ≥ 0.90 are recommended for analyzing individual patient scores

### 4.3.8 Comparison of HRQoL *S. haematobium* positive *vs.* negative status

Table 4.6 presents the results of HRQoL scores for infected and healthy children with their proxy reports. For all PedsQL™ 4.0 SF15 scales (except physical functioning in parent proxy-report) children who tested negative for *S. haematobium* egg output and their parents reported better HRQoL than those who tested egg-positive during parasitological examination. However, for the overall combined village data, none of these group wise differences in child self-report was statistically significant, and the majority of the effect sizes were small, with the largest effect size (the only one in the medium range) observed for the social subscale (effect size = 0.21). Parents of controls reported better HRQoL scores for their children compared to parents of cases for all subscales, except in the physical subscales. However, these parental HRQoL scores were only statistically different for the social scale $P < 0.05$, and effect sizes were all of small magnitude.

**Table 4.6: PedsQL™ 4.0 SF15 unadjusted scores for *S. haematobium* infected *vs*. non infected status**

| Scale | # items | Infected | | | Non infected | | | Differ -ence | Effect Size[a] | *t* score | *P* value[b] |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | N | Mean | SD | N | Mean | SD | | | | |
| **Child self-report N=802** | | | | | | | | | | | |
| Physical Functioning | 5 | 352 | 95.3 | 11.1 | 450 | 95.4 | 11.6 | 0.1 | 0.09 | 0.07 | >0.5 |
| Emotional functioning | 4 | 352 | 64.7 | 19.0 | 450 | 66.6 | 20.3 | 1.9 | 0.17 | 1.39 | >0.1 |
| Social Functioning | 3 | 352 | 77.7 | 19.0 | 450 | 80.0 | 19.7 | 2.3 | 0.21 | 1.65 | >0.05 |
| School functioning | 3 | 352 | 88.3 | 22.4 | 450 | 89.0 | 22.6 | 0.7 | 0.06 | 0.45 | >0.5 |
| Psychosocial score | 10 | 352 | 76.1 | 12.7 | 450 | 77.7 | 14.2 | 1.6 | 0.14 | 1.58 | >0.1 |
| Total scores | 15 | 352 | 81.8 | 9.8 | 450 | 82.8 | 11.1 | 1.0 | 0.09 | 1.43 | >0.1 |
| **Parent proxy-report N=765** | | | | | | | | | | | |
| Physical Functioning | 5 | 333 | 95.4 | 12.7 | 432 | 95.1 | 12.5 | -0.3 | -0.03 | -0.41 | >0.5 |
| Emotional functioning | 4 | 333 | 71.1 | 22.5 | 432 | 73.0 | 22.6 | 1.9 | 0.16 | 1.18 | >0.2 |
| Social Functioning | 3 | 333 | 83.2 | 16.2 | 432 | 85.5 | 16.6 | 2.3 | 0.20 | 1.97 | **<0.05** |
| School functioning | 3 | 333 | 85.5 | 19.3 | 432 | 86.4 | 19.4 | 0.9 | 0.08 | 0.63 | >0.5 |
| Psychosocial score | 10 | 333 | 79.9 | 13.8 | 432 | 81.6 | 14.7 | 1.7 | 0.14 | 1.66 | >0.1 |
| Total scores | 15 | 333 | 84.5 | 11.5 | 432 | 85.5 | 11.8 | 1.0 | 0.09 | 1.22 | >0.2 |

[a] Effect size = (difference between cases and controls) / SD of controls. Effect sizes are typically designated as small (0.20 – 0.49), medium (0.50 – 0.79), or large (≥ 0.80).
[b] $P < 0.05$ (independent sample t-test).

### 4.3.9 Parent-child concordance

Table 4.7 below presents the intraclass correlations (ICCs) between child self-reports and parent proxy-reports of the PedsQL™ 4.0 SF15 scales. Fair to good agreement was found in the Generic Core Scales of both the *S. haematobium* egg-positive and egg-negative (control) groups. ICCs were generally higher in the control group. Lower correlation values were obtained in the social function scales across all age groups, and in the physical scale in 5-7 year olds. Children and their parent proxies consistently showed good to excellent agreement for school and psychosocial scales across all age groups.

**Table 4.7: Agreement between self-report and parent proxy-report PedsQL™ 4.0 SF15 score scales**

| | Young children (5-7) | Children (8-12) | Teens (13-18) | All ages |
|---|---|---|---|---|
| ***Sh*[a] egg-positive** | | | | |
| Physical Functioning | 0.09 | **0.51** | **0.55** | **0.47** |
| Emotional functioning | **0.41** | 0.23 | 0.38 | 0.34 |
| Social Functioning | 0.19 | 0.20 | 0.13 | 0.18 |
| School functioning | **0.56** | **0.49** | **0.58** | **0.54** |
| Psychosocial score | **0.93** | **0.90** | **0.92** | **0.92** |
| Total scores | 0.30 | 0.30 | **0.50** | 0.37 |
| ***Sh* egg-negative** | | | | |
| Physical functioning | 0.37 | **0.49** | 0.40 | **0.44** |
| Emotional functioning | 0.40 | 0.40 | 0.34 | **0.41** |
| Social functioning | 0.37 | 0.28 | **0.47** | 0.39 |
| School functioning | **0.64** | **0.60** | **0.63** | **0.65** |
| Psychosocial score | **0.94** | **0.93** | **0.95** | **0.94** |
| Total scores | **0.57** | **0.47** | **0.52** | **0.55** |

Inter-Class Correlation (ICC) values for survey results are considered as poor to fair agreement (≤ 0.40), moderate agreement (0.41 to 0.60), good agreement (0.61 to 0.80) or excellent agreement (0.81 to 1.00) (Bartko, 1966). **Bold face** indicates moderate or better agreement between child and parent-proxy. [a]**Abbreviation**: Sh, *Schistosoma haematobium*;

### 4.3.10 Comparison of HRQoL of infected and non infected children from high risk and moderate risk villages

In comparison of infected and non infected children from high risk and moderate risk villages; within the moderate risk villages, the PedsQL™ 4.0 SF15 scores children who were not infected had significantly higher HRQoL in all scales except physical and school scales (for both child-self and parent-proxy reports), with effect sizes mostly in the medium range. The PedsQL™ 4.0 SF15 infected vs. non infected score differences within the high risk villages were small and not significant, and mostly in the opposite direction for most scales (Table 4.8).

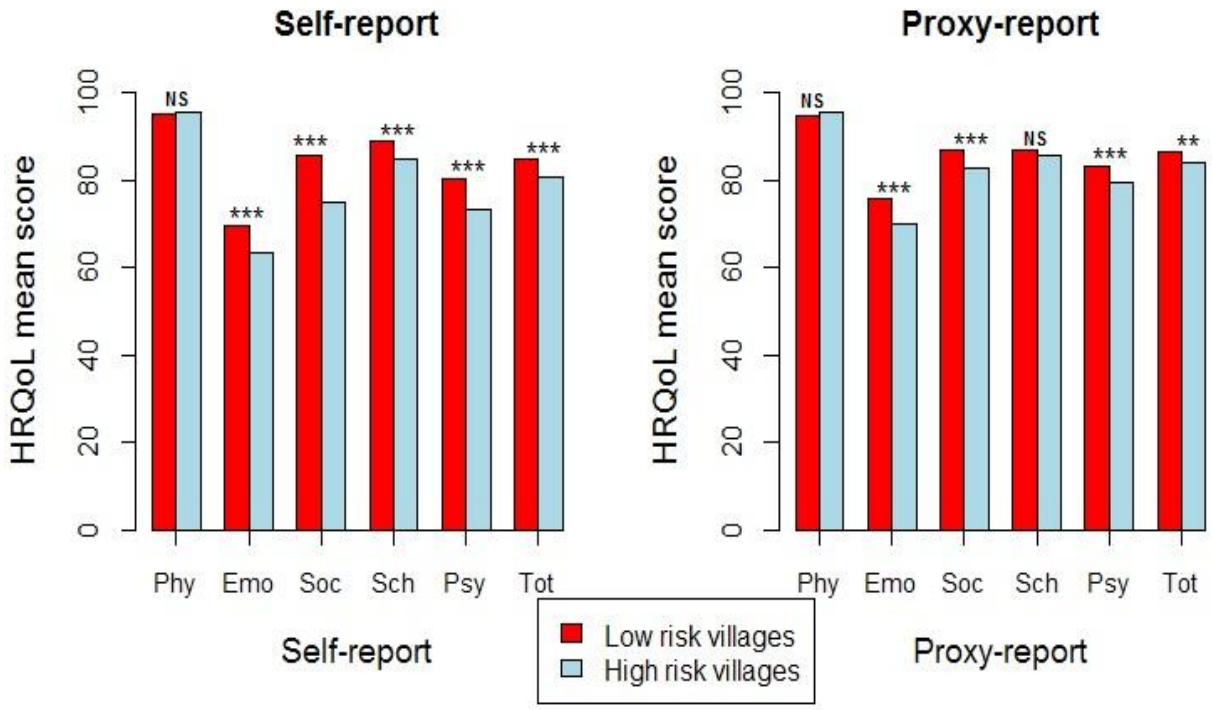
**Table 4.8: PedsQL™ 4.0 SF15 score scales for children and parents within high and moderate prevalence villages**

| | High Prevalence | | | Moderate Prevalence | | |
|---|---|---|---|---|---|---|
| | ***infected*** | ***Non infected*** | **Effect size** | ***infected*** | ***Non infected*** | **Effect size** |
| **Scale** | Mean (SD) | Mean (SD) | | Mean (SD) | Mean (SD) | |
| **Child self-report** | N=241 | N=260 | | N=111 | N=190 | |
| Physical Functioning | 96.0 (9.5) | 95.1 (11.2) | -0.08 | 93.6 (13.8) | 95.7 (12.2) | 0.20 |
| Emotional functioning | 63.7 (19.5) | 63.2 (19.5) | -0.04 | 66.7 (17.8) | 71.3 (20.5)* | 0.44 |
| Social Functioning | 75.2 (20.4) | 75.0 (21.3) | -0.02 | 83.2 (14.1) | 86.9 (14.6)* | 0.35 |
| School functioning | 84.8 (17.3) | 84.5 (19.9) | -0.03 | 88.7 (15.8) | 88.8 (15.5) | 0.09 |
| Psychosocial score | 73.5 (13.5) | 73.1 (14.6) | -0.04 | 78.3 (11.2) | 81.3 (12.8)* | 0.29 |
| Total scores | 81.0 (9.7) | 80.4 (10.9) | -0.05 | 83.4 (9.7) | 86.1 (10.5)* | 0.26 |
| **Parent proxy-report** | N=225 | N=249 | | N=108 | N=183 | |
| Physical functioning | 96.1 (11.7) | 95.2 (12.0) | -0.07 | 94.1 (14.6) | 94.9 (13.2) | 0.07 |
| Emotional functioning | 70.5 (23.8) | 69.6 (25.1) | -0.07 | 72.1 (19.4) | 77.7 (17.9)* | 0.51 |
| Social functioning | 82.3 (17.1) | 83.5 (17.8) | 0.10 | 84.9 (13.9) | 88.3 (14.4)* | 0.31 |
| School functioning | 84.9 (20.1) | 86.2 (19.5) | 0.10 | 86.8 (17.6) | 86.7 (19.3) | -0.09 |
| Psychosocial score | 79.3 (14.7) | 79.7 (15.6) | 0.17 | 81.3 (11.7) | 84.2 (12.9)* | 0.27 |
| Total scores | 84.3 (11.7) | 84.2 (12.4) | -0.06 | 84.9 (10.9) | 87.3 (10.9) | 0.22 |

Effect size = (difference between cases and controls)/SD of controls.
Effect sizes are designated as small (.20), medium (.50), and large (.80).
*$p < 0.05$ (independent samples t-test). Abbreviations: SD, standard deviation.

### 4.3.11 Comparison of self and proxy report in high and moderate risk villages

Significant differences were observed in both self and proxy reports in all domains of HRQoL (P <0.0001) between high and moderate risk villages, irrespective of disease status with exception of physical functioning for both and school functioning for proxy report that was not significant (figure 4.4).




**Abbreviations**: Phy=Physical; Emo=Emotional; Soc=Social; Sch=School; Psy=Psychosocial, Tot=Total. NS=Not significant; **P< 0.001; ***P <0.0001.

**Figure 4.4: PedsQL™ 4.0 SF15 score scales contrasting high and moderate risk villages for self and proxy reports**

### 4.3.12 Comparison of HRQoL between stunted and not stunted children

A total of 236 (29.4%) children were stunted irrespective of infection status. All scales reported lower quality of life in stunted children, with significant differences in psychosocial p=02 and total scales p=02 in self-reports, and in the school functioning scale p=03 in the proxy-report. The effect sizes were small in emotional functioning (0.25) and psychosocial score (0.23) for self report and School functioning (0.29) for proxy report as shown in table 4.9 below.

**Table 4.9: PedsQL™ 4.0 SF15 score scales for children with stunted children and not stunted children**

| Scale | No. of items | Stunted children | | | Not stunted children | | | Diffe-rence | Effect Size | *t* score | *P* value |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | N | Mean | SD | N | Mean | SD | | | | |
| **Child self-report** | | | | | | | | | | | |
| Physical Functioning | 5 | 236 | 94.6 | 10.8 | 566 | 95.6 | 11.6 | 1.0 | 0.09 | 1.11 | 0.27 |
| Emotional functioning | 4 | 236 | 63.9 | 19.7 | 566 | 66.5 | 19.7 | 2.6 | 0.25 | 1.71 | 0.09 |
| Social Functioning | 3 | 236 | 77.8 | 19.6 | 566 | 79.5 | 19.6 | 1.7 | 0.16 | 1.13 | 0.26 |
| School functioning | 3 | 236 | 87.4 | 24.2 | 566 | 89.2 | 21.8 | 1.8 | 0.17 | 1.00 | 0.32 |
| Psychosocial score | 10 | 236 | 74.2 | 14.0 | 566 | 76.6 | 13.7 | 2.4 | 0.23 | 2.23 | 0.02* |
| Total scores | 15 | 236 | 81.0 | 10.3 | 566 | 82.9 | 10.6 | 1.9 | 0.18 | 2.35 | 0.02* |
| **Parent proxy-report** | | | | | | | | | | | |
| Physical functioning | 5 | 217 | 94.7 | 11.6 | 548 | 95.4 | 13.0 | 0.7 | 0.06 | 0.71 | 0.48 |
| Emotional functioning | 4 | 217 | 71.4 | 22.5 | 548 | 72.5 | 22.6 | 1.1 | 0.09 | 0.61 | 0.54 |
| Social functioning | 3 | 217 | 84.1 | 18.0 | 548 | 84.6 | 15.8 | 0.5 | 0.04 | 0.39 | 0.70 |
| School functioning | 3 | 217 | 83.6 | 20.6 | 548 | 87.0 | 18.8 | 3.4 | 0.29 | 2.16 | 0.03* |
| Psychosocial score | 10 | 217 | 78.9 | 15.6 | 548 | 80.5 | 14.4 | 1.6 | 0.14 | 1.35 | 0.18 |
| Total scores | 15 | 217 | 84.2 | 11.9 | 548 | 85.5 | 11.6 | 1.3 | 0.11 | 1.38 | 0.17 |

Effect size = (difference between stunted and not stunted respondents)/SD of not stunted respondents.
Effect sizes are designated as small (.20), medium (.50), and large (.80).
*p < .05, (independent samples t-test).

### 4.3.13 Comparison of HRQoL between children from lower and higher socioeconomic status

In both child self and parent proxy reports, lower SES was significantly associated with lower HRQoL in all scales except the physical functioning p=0.13 for child self report and p=0.30 for proxy report, with effect sizes mostly in medium to high range (table 4.10). Within the low SES group, when comparisons were made between egg-positive and egg-negative children, egg-positives reported lower HRQoL compared to controls. However, when similar comparisons were made within the higher SES group, the differences were very small and inconsistent, with some scales reporting higher HRQoL among egg-positive children (data not shown).

**Table 4.10: PedsQL™ 4.0 SF15 score scales for children from lower and higher socioeconomic status**

| Scale | # items | Children from low SES families | | | Children from higher SES families | | | Diffe-rence | Effect Size | *t* score | *P* value |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | N | Mean | SD | N | Mean | SD | | | | |
| **Child self-report** | | | | | | | | | | | |
| Physical Functioning | 5 | 352 | 94.7 | 11.6 | 450 | 95.9 | 11.1 | 1.2 | 0.12 | -1.51 | 0.13 |
| Emotional functioning | 4 | 352 | 62.3 | 19.4 | 450 | 68.9 | 19.6 | 6.6 | 0.64 | -4.78 | 0.00* |
| Social Functioning | 3 | 352 | 75.6 | 19.9 | 450 | 82.1 | 18.4 | 6.5 | 0.63 | -4.83 | 0.00* |
| School functioning | 3 | 352 | 85.4 | 25.2 | 450 | 91.7 | 19.2 | 6.3 | 0.61 | -3.94 | 0.00* |
| Psychosocial score | 10 | 352 | 74.1 | 13.6 | 450 | 79.6 | 13.0 | 5.5 | 0.53 | -5.84 | 0.00* |
| Total scores | 15 | 352 | 80.2 | 10.3 | 450 | 84.3 | 10.3 | 1.5 | 0.40 | -5.67 | 0.00* |
| **Parent proxy-report** | | | | | | | | | | | |
| Physical functioning | 5 | 357 | 94.7 | 12.9 | 408 | 95.7 | 12.3 | 1.0 | 0.09 | -1.03 | 0.30 |
| Emotional functioning | 4 | 357 | 69.4 | 24.5 | 408 | 74.6 | 20.5 | 5.2 | 0.45 | -3.20 | 0.00* |
| Social functioning | 3 | 357 | 82.8 | 17.0 | 408 | 86.0 | 15.9 | 3.2 | 0.27 | -2.67 | 0.01* |
| School functioning | 3 | 357 | 84.4 | 20.8 | 408 | 87.5 | 17.9 | 3.1 | 0.27 | -2.16 | 0.03* |
| Psychosocial score | 10 | 357 | 78.9 | 15.7 | 408 | 82.7 | 12.8 | 3.8 | 0.33 | -3.70 | 0.00* |
| Total scores | 15 | 357 | 83.5 | 12.5 | 408 | 86. 5 | 10.8 | 3.0 | 0.26 | -3.50 | 0.00* |

Effect size = (difference between stunted and not stunted respondents)/SD of not stunted respondents.
Effect sizes are designated as small (.20), medium (.50), and large (.80).
*p < .05, (independent samples t-test).

### 4.3.14 Comparison of mean iron per day (mg) consumption and disease status

In comparison of infected and non infected children, significant differences were observed in consumption of animal proteins (p<.0001), legumes and nuts (p=0.0091) and fruits (p=0.0001).There is no significant difference in consumption of carbohydrates and vegetables among the two groups (Table 4.11).

**Table 4.11: Comparison of mean iron per day (mg) consumption and disease status**

| **Children with Urogenital schistosomiasis** | | | | **Children without Urogenital schistosomiasis** | | | | |
|---|---|---|---|---|---|---|---|---|
| **Food group** | **N** | **Mean Iron/day (mg)** | **SD** | **N** | **Mean Iron/day (mg)** | **SD** | **T value** | ***Significance (P)*** |
| Carbohydrates | 318 | 1.48 | 1.04 | 399 | 1.46 | 1.00 | 0.17 | *0.8638* |
| Animal proteins | 318 | 4.12 | 4.70 | 399 | 6.15 | 5.87 | -5.02 | *<.0001*** |
| Legumes/Nuts | 318 | 1.54 | 1.27 | 399 | 1.80 | 1.32 | -2.62 | *0.0091** |
| Fruits | 318 | 1.17 | 1.25 | 399 | 1.55 | 1.36 | -3.86 | *0.0001** |
| Vegetables | 318 | 7.68 | 3.37 | 399 | 7.38 | 3.64 | 1.19 | *0.1566* |
| *Total Iron* | *318* | *16.00* | *8.48* | *399* | *18.34* | *10.06* | *-3.31* | *0.0010** |

Abbreviatin:mg milli grams

*P< 0.001; **P <0.0001

### 4.3.15 Comparison between Dietary iron, anaemia and urogenital schistosomiasis

A significant association was noted between anaemia and diet $\chi^2$=3.76 1 df $p$=0.04. 53.3% of those getting inadequate iron diet were anaemic. There was no association between urogenital schistosomiasis and anaemia $\chi^2$=1.38 1 df $p$ =0.24. 49% of children with urogenital schistosomiasis were anaemic.

**Table 4.12: Comparison between dietary iron, anaemia and urogenital schistosomiasis**

| **Anaemic** | | | **Normal** | | **Significance** |
|---|---|---|---|---|---|
| **Variable** | No. | % | No. | % | |
| **Diet** | | | | | $\chi^2$=3.76 |
| Adequate diet | 247 | 44.8 | 305 | 55.2 | df=1 |
| Inadequate diet | 88 | 53.3 | 77 | 46.7 | $p$=0.04 |
| Total | 335 | 46.7 | 382 | 53.3 | |
| **Infection status** | | | | | $\chi^2$=1.38 |
| S.h+ | 173 | 49 | 177 | 51 | df=1 |
| S.h- | 199 | 45 | 241 | 52 | $p$ =0.24 |
| Total | 372 | 47 | 418 | 53 | |

## 4.4 Discussion of findings

### 4.4.1 Utility of PedsQL™ 4.0 SF15

The findings of this study on utility of PedsQL™ 4.0 SF15 is evident in floor and ceiling effects, missing values, internal consistency reliability, validity and agreement between the report provided by child self report and parent proxy report.

The floor effects were largely absent in the study population, except in the school scale where negligible (<1.3%) floor effects were observed, especially among controls. On the other hand, substantial ceiling effects were evident in almost all scales, and were more prominent in physical and school scales particularly among controls (*Sh* egg - negative). This means that the PedsQL™ 4.0 SF15 questionnaire likely underestimated HRQoL, especially for children who tested negative for *S. haematobium* egg output. While ceiling effects are a common phenomenon, they restrict the ability of the HRQoL tool to detect change or describe health above the average in more healthy populations (Chan *et al.*, 2005, Chen *et al.*, 2007, Raat *et al.*, 2007, Ziegelbauer *et al.*, 2010)

Significant difference was noted in agreement between the questionnaires filled by the children vs. the proxy ones filled by their parents in emotional and social domains resulting in significant differences in the summary scores for psychosocial and total domains ($P$<.0001 for all these scores).These findings are consistent with other studies (Eiser and Morse, 2001, Felder-Puig *et al.*, 2004, Upton P. *et al.*, 2008)that showed higher agreement in physical domains and lower ones in psychosocial domains.

### 4.4.2 Effects of schistosomiasis on HRQoL

Mothers' education was associated with higher HRQoL scores. The majority of mothers (81%) had never been to school or had attained at most primary education. These results are in agreement with other published studies that have shown positive association between maternal education and higher HRQoL scores (Gerson A.C. *et al.*, 2010, Hassan *et al.*, 2006, Van Dellen *et al.*, 2007).

In the initial analysis of HRQoL, there was a clear trend towards lower HRQoL in all measurement scales (except physical scale) among children with *S. haematobium*, but the differences were not significant. This trend was confirmed in parent-proxy reports, which indicated the same trend in all performance scales, and for the social scale, parents of infected children did report significantly lower HRQoL scores than parents of non infected children. These results are similar to recent studies of other NTDs that suggest no clear differences in HRQoL between infected and non-infected health states (Fürst *et al.*, 2011, Ziegelbauer *et al.*, 2010). When adjustments were made on likely confounding factors, i.e. SES, prevalence and undernutrition across the village levels significant differences were noted.

SES was the strongest and most consistent correlate in all the domains. This implies that lower SES is in endemic areas affected the risk of *Schistosoma* infection by either limiting water-use options and/or access to health care, or through other poverty-related factors (Bethony *et al.*, 2001, King, 2010, King and Bertino, 2008, Raso *et al.*, 2005). These results are in line with other studies on chronic diseases and the effects of SES on HRQoL (Hassan *et al.*, 2006, Hijmans *et al.*, 2010, Van Dellen *et al.*, 2007). The

association is not surprising since higher SES typically reflects, among others, access to superior educational and health care opportunities, access to safe water and food that may be beneficial to children's HRQoL. Schistosomiasis is a disease that is long known to be most prevalent among the poor who have no access to safe drinking water and adequate sanitation, and, in turn, to perpetuate poverty. In endemic areas, nearly 100% of local residents will become infected at some point during their lives, and will be at risk for schistosomiasis-associated disease manifestations. Thus, schistosomiasis is likely to be both a cause and an effect of continuing rural poverty in these areas (King, 2010).

The finding of this study showed a strong village-type effect (with high-prevalence status having significantly lower HRQoL scores), but with significant interaction between village type and all other covariates tested. The findings indicated that *S. haematobium* egg positivity was significantly associated with reduced HRQoL in moderate prevalence villages, whereas in high-prevalence villages, it was associated with higher HRQoL. I believe that in high-prevalence villages, infection status is already saturated, so that egg-positivity reflects mainly those with heavier infections. In the high-prevalence setting, this sub-group includes older children with greater mobility (Kvalsvig, 1981), who may therefore have better scores on the PedsQL™ 4.0 SF15 scales. In moderate prevalence villages, where egg testing is more likely to reliably distinguish infected and uninfected children, *S. haematobium* egg-positivity was significantly associated with lower HRQoL scores.

Previous investigations described strong associations between growth stunting and low intensity *Schistosoma* infections (Friedman *et al.*, 2005, King, 2010, King and

Dangerfield-Cha, 2008, Zhou *et al.*, 2005); thus the joint association of lower HRQoL with local prevalence and stunting in findings of this study. Significant differences were observed in other group-wise analysis, indicating lower HRQoL for children resident in high-*S. haematobium* prevalence villages as compared to those living in moderate-prevalence villages, and significantly lower HRQoL for children with growth stunting.

The survey tool detected differences in HRQoL in villages with high prevalence of the disease which is a clear indicator of long term chronic manifestation of the disease which is attributable to growth impairment. These findings were similar to other studies that indicated negative impact on HRQoL scores in the social and physical domains (Gerson A.C. *et al.*, 2010). Of the stunted children in this study, 56% were boys, a similar ratio to the one found by (King and Dangerfield-Cha, 2008), suggesting a larger and more permanent impact on boys than on girls.

### 4.4.3 Effects of urogenital schistosomiasis on iron levels

The findings of this study demonstrated no association between urogenital schistosomiasis and anaemia but iron diet was significantly associated with anaemia. Inadequate iron diet was the cause of anaemia in infected children and non infected children in the endemic areas. This may be attributed to the mitigating effects of diet and to the high prevalence of anaemia (45%) in the absence of schistosomiais. The findings of this study were contradicting other studies that attributed anaemia to schistosomias (Ayoya *et al.*, 2009, Shaw and Friedman, 2011, Sturrock, 2001) and inline with a study in Tanzania that related inadequate iron diet to be the cause of anaemia in S.*haematobium* infected populations (Tatala *et al.*, 1998).

# CHAPTER FIVE: SUMMARY, CONCLUSION AND RECOMMENDATIONS

## 5.1 Introduction

This chapter covers the summary of the entire study, implications of the study findings, conclusions made, recommendations made from the study and gaps requiring further research which were not addressed in this study. To my knowledge, this is the first study to measure self-rated multidimensional HRQoL related to schistosomiasis using PedsQL™ SF 15.

## 5.2 Summary

Because schistosomiasis is a multi-decadal chronic disease that begins in early childhood, and because it is a disease that may affect nearly everyone in endemic communities, its impact on personal health-related quality of life (HRQoL) has been difficult to gauge accurately. In order to provide a more precise estimate of urogenital schistosomiasis' impact on overall health status, the study used a standardized questionnaire, the PedsQL™ 4.0 SF15 inventory to interview children, aged 5-18 yr, and their parents, to quantify their reported physical, social, emotional, and scholastic performance status. Scores were significantly lower in villages having high *Schistosoma* prevalence, as compared those having moderate prevalence. In adjusting for age, sex, socioeconomic status, undernutrition, anemia, and hookworm parasites, the study found that relative poverty, stunting, wasting, and *S. haematobium* infection were significant correlates of HRQoL scores, with differential effects in high- and moderate-prevalence communities. The greatest differences were noted in the psychosocial domains of performance. I

conclude that exposure to schistosomiasis has an overall detrimental effect on HRQoL at a level of 2-4% impairment. New implementation of better diagnostics for children is expected to refine the estimates of this association, as will follow-up studies of HRQoL following effective individual and community deworming.

### 5.3 Implications of the findings

Findings from this study provide important information on the confounding factors and the effects of schistosomiasis on HRQoL of children. When the study adjusted for potential confounders; i.e. for age, sex, socioeconomic status, undernutrition and anemia, the study found that poverty, stunting, and *S. haematobium* infection were significant correlates of HRQoL scores, with differential effects in high- and moderate-prevalence communities. Hence these findings will be of help to the ministry of health, non governmental organizations, policy makers and any other concerned stakeholders in putting the right interventions and policies for schistosomiasis control.

The capability of PedsQL™ 4.0 SF15 to portray differences in HRQoL scores makes it a valuable tool for measuring health related outcomes parasitic infections and other non communicable diseases of public health concerns in children populations as this study was the first one to use the measurement tool for the first time in Kenya.

Despite other studies in Kwale County associating urogenital schistosomias to cause anaemia in infected population due to urinary iron loss, this study finding associated inadequate iron diet to also be the cause anaemia in infected children. Hence the need for more nutrition intervention measures in the area.

## 5.4 Conclusions

Based on the results of this study the following conclusions were drawn:

- PedsQL™ 4.0 SF15 is a suitable tool for assessing quality of life in children with urogenital schistosomiasis. The findings on its reliabilities were high (alphas generally ≥0.70), floor effects were acceptable and identification of children from both low socioeconomic status and 'high risk' villages was valid. PedsQL™ 4.0 SF15 was an effective tool for measuring quality of life in children living with urogenital schistosomiasis. Thus rejecting the null hypothesis of this study that; PedsQL™ is not a reliable tool to measure quality of life of children living in schistosomiasis endemic areas.
- Schistosomiasis lowers the health related quality of life of children. Its intensities and effects on physical, emotional, social, school and nutritional functioning was evident in the findings on high risk and moderate risk villages as well as in the moderate prevalence villages. Thus rejecting the null hypothesis that; there's no relationship between schistosomiasis intensity and its effects on physical, social, emotional, nutritional and school functioning of children.
- Anaemia in infected children was caused by inadequate iron diet intake in the endemic areas. Thus accepting the null hypothesis that; anaemia in children is not associated with urogenital schistosomiasis as was evident in the findings of this study.

## 5.5 Recommendation

Based on these findings the following recommendations were made:

- PedsQL™ 4.0 SF15 use in Kenya and in less-developed countries makes it a valuable tool for evaluating health related quality of life children and as a measure for burden of chronic disease conditions as it was reliable and valid tool.
- The findings presented provide evidence-based results on the effects of urogenital schistosomiasis on HRQoL of children, for decision making by policy makers in the ministry of medical services and public health and sanitation Kenya for effective control of schistosomiasis.
- PedsQL™ 4.0 SF15 is a suitable tool to use in large scale schistosomiasis control programmes, because of its practicability (administered within 5 minutes). It can appropriately be used to rapidly tease out high transmission localities for further adjustment.
- The clear capability of PedsQL™ 4.0 SF15 tool to identify geographical areas with different transmission intensities and socioeconomic status groups is particularly important in schistosomiasis control programmes.

- The findings on dietary iron show that nutritional anemia is health problem in this community. With respect to the other causes of anemia, intervention measures should be directed appropriately to the contributing factors and health and

nutrition education should also be given to help the community adapt to new behavior and food habits that may result from these interventions.

### 5.6Further research

- Further research is needed, especially on its reproducibility and responsiveness of PedsQL™ 4.0 SF15 (ability to detect clinically important changes over time) in relation to urogenital schistosomiasis and include supplemental serologies (circulating antigen testing, anti-schistosoma IgG4), in order to minimize the misidentification of the true infection status of 'cases' and 'controls'.

- The difficulties in measuring physical and school health illustrated here also point to the need for further research and the development of schistosomiasis specific PedsQL™ 4.0 SF15 tool to enhance assessment of *Schistosoma* infection-related health impact.
- A study on all food items should be carried out using 24 hour recall so as to give the true measure of mean iron consumed per day as this study was limited to assuming that the amounts of iron consumed were standard portions and bioavailable.

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**APPENDIX 1: Socio-demographic questionnaire English version**

## SECTION 1 Socio-demographic Characteristics

### KWALE,MSAMBWENI and KINANGO DISTRICT STUDY: DEMOGRAPHIC QUESTIONNAIRE

**Village No** ☐ **Household No** ☐☐☐ **Person ID:** ☐☐☐☐☐☐
**Study ID:**

**Interviewer Name:** _____ **Interview Date (DD/MM/YYYY):** ☐☐ / ☐☐ / ☐☐☐☐

### SECTION A: IDENTIFICATION OF INFORMANT

| | | | |
|---|---|---|---|
| A1 | **What is your sex?** | □ Male | □ Female |
| A2 | **What was your first language?** | □ Duruma<br>□ Digo | □ Kamba<br>□ Other: _____<br>□ Refused |
| A3 | **What is your tribe?** | □ Digo<br>□ Duruma<br>□ Kamba | □ Other: _____<br>□ Refused |
| A4 | **What is your religion?** | □ Islam/Muslim<br>□ Christianity/Christian | □ Other: _____<br>□ Refused |

| | | | | |
|---|---|---|---|---|
| A5 | **Are you ( informant) married ?** | □ Yes | □ No | □ Refused |
| A6 | **What is your parity status?** | □ 1<br>□ 2<br>□ 3 | □ 4<br>□ 5<br>□ 6 | □ Others specify<br>_____ |
| A7 | **Do you have any children?** | □ Yes | □ No | □ Refused |
| | **What is your occupation?** | □Housewife<br>□Employed | □ Farming<br>□ fishing<br>□Trade | □Other_____ |
| | **What is the source of household food items?** | □Farm<br>□Bought | □ Donations | □Other_____ |
| A39 | **What was the highest level of schooling that you completed?** | □ Primary<br>□Secondary | □ College<br>□ University | □ None<br>□ Madrassa | □ Refused |
| A8 | **Do you own or rent the house where you live?** | □ Own<br>□ Other: _____ | □ Rent | □ Refused |
| A9 | **What is the type of flooring in your dwelling? ( Interviewer should confirm by inspection)** | □ Dirt/earth<br>□ Wood/plank<br>□ Tile | □ Other _____<br><br>□ Cement | |

| | | |
|---|---|---|
| A10 | **What is the roof made out of? ( Interviewer confirm by inspection)** | □ Natural material □ Other _____<br>□ Corrugated iron<br>□ RoofingTiles |

**SECTION B: HABITS**

| | | | | |
|---|---|---|---|---|
| A11 | **What is your main source of cooking fuel?** | □ Electricity<br>□ Paraffin<br>□ Gas | □ Firewood<br>□ Charcoal<br>□ Other: _____ | □ Solar<br>□ Refused |
| A12 | **What is the principal household source of drinking water?** | □ Piped water in house<br>□ Piped water in public tap<br>□ Public Well | □ Rain<br>□ River/canal<br>□ Dam or pond<br>□ Borehole well with pump | □ Other_____<br><br><br>□ Borehole well |
| A13 | **What is your main source of lighting at night?** | □ Electricity line<br>□ Pressure Lamp<br>□ Lantern<br>□ Tin Lamp | □ Fuel Wood<br>□ Solar electrical battery<br>□ Candles<br>□ Other: _____ | □ Kerosene<br>□ Refused |
| A14 | **Do members in your household work their own land or the family's land for agriculture?** | □ Own<br><br>□ None | □ Family<br><br>□ Both | □ Rent<br>□ Refused<br>□ Other _____ |
| A15 | **Do you own a telephone?** | □ Yes | □ No | □ Refused |
| A16 | **Do you own a radio?** | □ Yes | □ No | □ Refused |
| A17 | **Do you own a television?** | □ Yes | □ No | □ Refused |
| A18 | **Do you own a bicycle?** | □ Yes | □ No | □ Refused |
| A19 | **Do you own a motorized vehicle** (e.g. automobile, scooter)**?** | □ Yes | □ No | □ Refused |
| A20 | **Do you have a flush toilet?** | ☐ Yes | ☐ No | ☐ Refused |
| A21 | **Do you use a latrine?** | ☐ Yes | ☐ No | ☐ Refused |

**APPENDIX 2: Socio-demographic questionnaire swahili version**

## KWALE, MSAMBWENI and KINANGO DISTRICT STUDY: DEMOGRAPHIC QUESTIONNAIRE

**Nambari ya kijiji :** ☐ **Nambari ya nyumba:** ☐☐☐ **Nambari ya mshiriki:** ☐☐☐☐☐☐

**Jina la mtafiti:** _____ **Tarehe (DD/MM/YYYY):** ☐☐ / ☐☐ / ☐☐☐☐

### KITENGO A: TAKWIMU ZA KIJAMII

| | | | |
|---|---|---|---|
| A1 | **Jinsia?** | □ Mume | □ Mke |
| A2 | **Je kabila lako ni ipi?** | □ Duruma<br>□ Digo | □ Kamba<br>□ nyingine: _____<br>□ Amekataa |
| A3 | **Dini?** | □ Muislamu<br>□ Mkristo | □ Nyingine: _____<br>□ Amekataa |

| | | | | |
|---|---|---|---|---|
| A4 | **Je umeolewa?** | □ Ndio | □ La | □ Amekataa |
| A5 | **Je una watoto?** | □ Ndio | □ La | □ Amekataa |
| A6 | **Kama ndio wangapi?** | □ 1<br>□ 2<br>□ 3 | □ 4<br>□ 5<br>□ 6 | □ Nyingine bainisha _____ |
| | **Je unafafanya kazi gani?** | □Sina kazi<br>□Nimeajiriwa | □ Ukulima<br>□ Kuvua samaki<br>□Biashara | □Nyingine_____ |
| | **Je vyakula mnavovitumia nyumbani mnatoa wapi?** | □Shamba<br>□Kununua | □ Kupewa na mashirika | □ Nyingine _____ |
| A7 | **Kiwango cha juu cha elimu?** | □ Primari<br>□Shule ya upili | □ College<br>□ chuo kikuu | □ Hakuna<br>□ Madrassa<br>□ Amekataa |
| A8 | **Je jumba unaloishi ni yako binafsi ama ni ya kukodisha?** | □ Yangu binafsi<br>□ Nyingine: _____ | □ kukodisha | □ Amekataa |
| A9 | **Sakafu ya nyumba imejengwa na nini? ( Mtafiti lazima hahakikishe kwa kutizama)** | □ mchanga<br>□ mbao<br>□ Taili | □ Nyingine _____<br>□ saruji | |

| | | | |
|---|---|---|---|
| A10 | **Je paa la nyumba limetengenezwa na nini? (Mtafiti lazima hahakikishe kwa kutizama)** | □ nyasi/makuti<br>□ mabati<br>□ taili | □ Nyingine _____ |

**KITENGO B: MAZOEA**

| | | | | |
|---|---|---|---|---|
| A11 | **Ni aina gani ya moto kinachotumiwa kupika?** | □ stima<br>□ mafuta<br>□ Gesi | □ kuni<br>□ makaa<br>□ Nyingine : _____ | □ miale ya jua<br>□ Amekataa |
| A12 | **Je maji ya kukunywa yatoka wapi?** | □ Mfereji kwa nyumba<br>□ Mfereji ya jamii<br>□ Kisima cha jamii | □ mvua<br>□ Mtoni<br>□ bwawa<br>□ kisima kubwa | □ Nyingine _____<br><br><br>□ kisima ndogo |
| A13 | **Ni mwangaza upi mnaoutumia wakati wa usiku?** | □ Stima<br>□ Taa ya pumzi<br>□ Taa<br>□ koroboi | □ Kuni<br>□ miale ya jua<br>□ Candili<br>□ Other: _____ | □ Mafuta ya taa<br>□ Amekataa |
| A14 | **Je jamii wanaoishi katika boma hili wanalima shamba lao ama ni ya familia?** | □ Yangu<br><br>□ Hakuna | □ Familia<br><br>□ Yote mbili | □ Kukodisha<br>□ Amekataa<br>□ Nyingine _____ |
| A15 | **Je una simu?** | □ Ndio | □ La | □ Amekataa |
| A16 | **Je una radio?** | □ Ndio | □ La | □ Amekataa |
| A17 | **Je una runinga/televisheni?** | □ Ndio | □ La | □ Amekataa |
| A18 | **Je una baiskeli?** | □ Ndio | □ La | □ Amekataa |
| A19 | **Je una gari au pikipiki** ? | □ Ndio | □ La | □ Amekataa |
| A20 | **Je una choo?** | ☐ Ndio | ☐ La | ☐ Amekataa |
| A21 | **Je watumia choo chako?** | ☐ Ndio | ☐ La | ☐ Amekataa |

**APPENDIX 3: Ripoti ya mtoto wa miaka (5-7)**

ID# _____

Date:_____

# PedsQL™ 4.0 SF15

## Pediatric Quality of Life Inventory

**Version 4.0 Short Form (SF15)**

**Ripoti ya mtoto wa miaka (5-7)**

Maagizo kwa mwenye kuhoji:

*Nitakuhuliza maswali kuhusu mambo ambayo yanaweza kuwa shida kwa baadhi ya watoto. Ninataka kujua ni kiasi gani cha shida hii kwa mtoto wako.*
Onyesha mtoto Nambari hizi huku hukimwelezea jinsi ya kukupa majibu.
Kama sio shida kabisa kwako, elekeza mkono wako kwenye nambari 1
*Kama ni shida wakati mwingine, elekeza nambari 2*
*Na ikiwa ni shida sana kwako, elekeza mkono kwenye nambari 4*
Nitasoma kila swali. Nawe utaelekeza kidole chako katika nambari hizi huku ukilinganisha ni kiasi gani cha shida kwako. *Tutajaribu moja kama zoezi.*

Uliza mtoto afanye kidoko cha vidole ili kubainisha kama swali limejibiwa sahihi. Rudia swali kama mtoto amekufanyia tofauti matendo yake.
Fikiria jinsi umekuwa ukiendelea katika wiki chache zilizopita. Tafathali sikiza kwa makini kila sentensi na unieleze ni kiwango kipi shida hii imekuwa kwako.
Baada ya kusoma kifaa hiki na ishara iliyo kwenye Nambari Kama mtoto anaonekana kuwa na tashwishwi ama kutoelewa jinsi ya kujibu, soma kila jibu huku ukielekeza kidole chako katika kila nambari

| KUHUSU HALI YA MWILI *(SHIDA NA…)* | Hakuna | Shida Kidogo | Wakati mwingine | Mara kwa mara | Kila Mara |
|---|---|---|---|---|---|
| 1. Je ni vigumu kwako kutembea | 0 | 1 | 2 | 3 | 4 |
| 2. Je ni vigumu kwako kukimbia | 0 | 1 | 2 | 3 | 4 |
| 3. Je ni vigumu kwako kufanya sporti na mazoezi | 0 | 1 | 2 | 3 | 4 |
| 4. Je ni vigumu kwako kuinua kitu kizito | 0 | 1 | 2 | 3 | 4 |
| 5. Je ni vigumu kwako kufanya kazi za nyumbani (Kama kuinua vifaa vya kuchezea) | 0 | 1 | 2 | 3 | 4 |

| KUHUSU HALI YA HISIA *(SHIDA NA…)* | Hakuna | Shida Kidogo | Wakati mwingine | Mara kwa mara | Kila Mara |
|---|---|---|---|---|---|
| 1. je unahisi hofu/uoga | 0 | 1 | 2 | 3 | 4 |
| 2. je unahisi mnyonge/mwenye huzuni | 0 | 1 | 2 | 3 | 4 |
| 3. je unahisi hasira | 0 | 1 | 2 | 3 | 4 |
| 4. Je unawasiwasi kuhusu kile kitakachotendeka kwako | 0 | 1 | 2 | 3 | 4 |

| KUHUSU NINAVYO WASILIANA NA WENGINE *SHIDA NA….)* | Hakuna | Shida Kidogo | Wakati mwingine | Mara kwa mara | Kila Mara |
|---|---|---|---|---|---|
| 1. Nina shida kuwasiliana na watoto wengine | 0 | 1 | 2 | 3 | 4 |
| 2. Watoto wengine hawataki kuwa marafiki wako | 0 | 1 | 2 | 3 | 4 |
| 3. Je, watoto wengine wanakuchokoza | 0 | 1 | 2 | 3 | 4 |

.

| KUHUSU SHULE *(SHIDA NA…)* | Hakuna | Shida Kidogo | Wakati mwingine | Mara kwa mara | Kila Mara |
|---|---|---|---|---|---|
| 1. je ni vigumu kwako kuwa makini shuleni | 0 | 1 | 2 | 3 | 4 |
| 2. Je wasahau mambo | 0 | 1 | 2 | 3 | 4 |
| 3. Je ni viguumu kwako kufanya kazi za shule kwa wakati unaofaa ? | 0 | 1 | 2 | 3 | 4 |

**APPENDIX 4: Ripoti ya wazazi wa watoto wa miaka (5-7)**

ID# _____

Date:_____

# PedsQL™ 4.0 SF15

**Version 4.0 Short Form (SF15)**

## **Repoti ya wazazi ya watoto** (Miaka **5-7**)

MAAGIZO

. Katika kurasa hili, kuna mambo ambayo yanaweza kuwa shida kwa mtoto wako

.

Tafadhali tueleze kiwango cha kila shida kwa mtoto wako katika mwezi moja uliopita kwa kuchora mviringo

:

**0** Kama hakujawai kuwa na shida
**1** Kama shida Kidogo
**2** Kama wakati mwingine kuna shida
**3** kama mara kwa mara ni shida
**4** kama kila mara ni shida

Hakuna jibu lililo ni sahihi au lisilo sahihi.
Kama huelewi swali tafathali tafuta usaidizi

*Katika mwezi moja uliopita, shida hili limekuwa cha kiwango gani kwa mtoto wako*

| **KUHUSU HALI YA MWILI** ***(shida na…)*** | Hakuna shida | Shida kidogo | Wakati mwingine | Mara kwa mara | Kila mara |
|---|---|---|---|---|---|
| 1. Ni vigumu kwake kutembea zaidi ya urefu wa kiwanja cha kandanda | 0 | 1 | 2 | 3 | 4 |
| 2. Ni vigumu kwake kukimbia | 0 | 1 | 2 | 3 | 4 |
| 3. Ni vigumu kwake kufanya sporti na mazoezi | 0 | 1 | 2 | 3 | 4 |
| 4. Ni vigumu kwake kuinua kitu kizito | 0 | 1 | 2 | 3 | 4 |
| 5. Ni vigumu kwake kufanya kazi za nyumbani (Kama kuinua vifaa vyake vya kuchezea) | 0 | 1 | 2 | 3 | 4 |

| **KUHUSU HISIA** ***(shida na…)*** | Hakuna shida | Shida kidogo | Wakati mwingine | Mara kwa mara | Kila mara |
|---|---|---|---|---|---|
| 1. kuhisi hofu/uoga | 0 | 1 | 2 | 3 | 4 |
| 2. kuhisi huzuni/ Mnyonge | 0 | 1 | 2 | 3 | 4 |
| 3. kuhisi hasira | 0 | 1 | 2 | 3 | 4 |
| 4. wasiwasi kuhusu kitakachotendeka kwake | 0 | 1 | 2 | 3 | 4 |

| **KUHUSU MAWASILIANO** ***(shida na…)*** | Hakuna shida | Shida kidogo | Wakati mwingine | Mara kwa mara | Kila Mara |
|---|---|---|---|---|---|
| 1. kuwasiliana na watoto wengine | 0 | 1 | 2 | 3 | 4 |
| 2. Watoto wengine hawataki kuwa marafiki wake | 0 | 1 | 2 | 3 | 4 |
| 3. watoto wengine wanamchokoza | 0 | 1 | 2 | 3 | 4 |

| **KUHUSU SHULE** ***(shida na…)*** | Hakuna shida | Shida kidogo | Wakati mwingine | Mara kwa mara | Kila Mara |
|---|---|---|---|---|---|
| 1. Ana shida ya kuwa makini darasani | 0 | 1 | 2 | 3 | 4 |
| 2. Huwa anasahau mambo | 0 | 1 | 2 | 3 | 4 |
| 3. Ni vigumu kwake kufanya kazi za shule kwa wakati unaofaa | 0 | 1 | 2 | 3 | 4 |

**APPENDIX 5: Ripoti ya mtoto wa miaka (8-12)**

ID#
_____
__

Date:_____
_____

# PedsQL™ 4.0 SF15

**Version 4.0 Short Form (SF15)**

**REPOTI YA MTOTO** (ages **8-12**)

MAAGIZO

Katika kurasa hili, kuna mambo ambayo yanaweza kuwa shida kwako tafathali tueleze kiwango cha shida kila kimekuwa kwako katika mwezi uliopita kwa kuchora mviringo :

**0** kama hakujawahi kuwa na shida
**1** kama shida kidogo
**2** kama wakati mwingine kuna shida
**3** kama kila mara kuna shida
**4** kama kila mara ni shida

hakuna jibu lililo ni sahihi ama lisilo sahihi.

Kama huelewi swali tafathali tafuta usaidizi

| Kuhusu Afya yangu na Kazi Zangu (*SHIDA NA …)* | Hakuna | shida kidogo | Wakati mwingine | Mara kwa mara | kila mara |
|---|---|---|---|---|---|
| 1. ni vigumu kwangu kutembea urefu wa kiwanja cha kananda | 0 | 1 | 2 | 3 | 4 |
| 2. Ni vigumu kwangu kukimbia | 0 | 1 | 2 | 3 | 4 |
| 3 Ni vigumu kwangu kufanya sporti na mazoezi | 0 | 1 | 2 | 3 | 4 |
| 4. Ni vigumu kwangu kuinua kitu kizito | 0 | 1 | 2 | 3 | 4 |
| 5. Ni vigumu kwangu kufanya kazi za nyumbani | 0 | 1 | 2 | 3 | 4 |

| Kuhusu hali ya hisia (*SHIDA NA …)* | hakuna | Shida kidogo | Wakati mwingine | Mara kwa mara | kila mara |
|---|---|---|---|---|---|
| 1. Nahisi uoga au hofu | 0 | 1 | 2 | 3 | 4 |
| 2. Nahisi Mnyonge/huzuni | 0 | 1 | 2 | 3 | 4 |
| 3. Nahisi kukasirika | 0 | 1 | 2 | 3 | 4 |
| 4. nina wasiwasi kuhusu kitakachotendeka kwangu | 0 | 1 | 2 | 3 | 4 |

| Kuhusu ninavyo wasiliana na wengine *(SHIDA NA….)* | Hakuna | Shida Kidogo | Wakati mwingine | Mara kwa mara | Kila Mara |
|---|---|---|---|---|---|
| 1. Nina shida kuwasiliana na watoto wengine | 0 | 1 | 2 | 3 | 4 |
| 2. Watoto wengine hawataki kuwa marafiki wangu | 0 | 1 | 2 | 3 | 4 |
| 3. Watoto wengine wananichokoza | 0 | 1 | 2 | 3 | 4 |

| Kuhusu Shule *(SHIDA NA…)* | Hakuna | Shida Kidogo | Wakati mwingine | Mara kwa mara | Kila Mara |
|---|---|---|---|---|---|
| 1. Ni vigumu kuwa makini darasani | 0 | 1 | 2 | 3 | 4 |
| 2. Ninasahau mambo | 0 | 1 | 2 | 3 | 4 |
| 3. Nina shida kufanya kazi za shule kwa wakati unaofaa | 0 | 1 | 2 | 3 | 4 |

**APPENDIX 6: Ripoti ya wazazi wa watoto wa miaka (8-12)**

ID# _____

Date:_____

# PedsQL™ 4.0 SF15

**Version 4.0 Short Form (SF15)**

## **Repoti ya wazazi** ya **watoto** (Miaka **8-12**)

MAAGIZO

Katika kurasa hili, kuna mambo ambayo yanaweza kuwa shida kwa mtoto wako .

Tafadhali tueleze kiwango cha kila shida katika mwezi moja uliopita kwa kuchora mviringo :

**0** Kama hakujawai kuwa na shida
**1** Kama shida Kidogo
**2** Kama wakati mwingine kuna shida
**3** kama mara kwa mara ni shida
**4** kama kila mara ni shida

Hakuna jibu lililo ni sahihi au lisilo sahihi.

Kama huelewi swali tafathali tafuta usaidizi

Katika mwezi moja uliopita**,** Ni kiwango kipi cha shida mtoto wako amekuwa nayo …

| **KUHUSU HALI YA MWILI (shida na…)** | **Hakuna shida** | **Shida kidogo** | **Wakati mwingine** | **Mara kwa mara** | **Kila mara** |
|---|---|---|---|---|---|
| 1. Ni vigumu kwake kutembea zaidi ya urefu wa kiwanja cha kandanda | 0 | 1 | 2 | 3 | 4 |
| 2. Ni vigumu kwake kukimbia | 0 | 1 | 2 | 3 | 4 |
| 3. Ni vigumu kwake kufanya sporti na mazoezi | 0 | 1 | 2 | 3 | 4 |
| 4. Ni vigumu kwake kuinua kitu kizito | 0 | 1 | 2 | 3 | 4 |
| 5. Ni vigumu kwake kufanya kazi za nyumbani (Kama kuinua vifaa vyake vya kuchezea) | 0 | 1 | 2 | 3 | 4 |

| **KUHUSU HISIA (shida na…)** | **Hakuna shida** | **Shida kidogo** | **Wakati mwingine** | **Mara kwa mara** | **Kila mara** |
|---|---|---|---|---|---|
| 1. kuhisi hofu/uoga | 0 | 1 | 2 | 3 | 4 |
| 2. kuhisi huzuni/ Mnyonge | 0 | 1 | 2 | 3 | 4 |
| 3. kuhisi hasira | 0 | 1 | 2 | 3 | 4 |
| 4. wasiwasi kuhusu kitakachotendeka kwake | 0 | 1 | 2 | 3 | 4 |

| **KUHUSU MAWASILIANO (shida na…)** | **Hakuna shida** | **Shida kidogo** | **Wakati mwingine** | **Mara kwa mara** | **Kila Mara** |
|---|---|---|---|---|---|
| 1. kuwasiliana na watoto wengine | 0 | 1 | 2 | 3 | 4 |
| 2. Watoto wengine hawataki kuwa marafiki wake | 0 | 1 | 2 | 3 | 4 |
| 3. watoto wengine wanamchokoza | 0 | 1 | 2 | 3 | 4 |

| **KUHUSU SHULE (shida na…)** | **Hakuna shida** | **shida kidogo** | **Wakati mwingine** | **Mara kwa mara** | **Kila Mara** |
|---|---|---|---|---|---|
| 1. Ana shida ya kuwa makini darasani | 0 | 1 | 2 | 3 | 4 |
| 2. Huwa anasahau mambo | 0 | 1 | 2 | 3 | 4 |
| 3. Ni vigumu kwake kufanya kazi za shule kwa wakati unaofaa | 0 | 1 | 2 | 3 | 4 |

**APPENDIX 7: Ripoti ya vijana barobaro (13-18)**

ID# _____

Date:_____

# PedsQL™ 4.0 SF15

**Version 4.0 Short Form (SF15)**

## Ripoti ya vijana barobaro (Miaka **13-18**)

**MAAGIZO**

Katika kurasa hili, kuna mambo ambayo yanaweza kuwa shida kwako tafathali tueleze kiwango cha shida kila kimekuwa kwako katika mwezi uliopita kwa kuchora mviringo

**0** Kama hakujawai kuwa na shida
**1** Kama shida Kidogo
**2** Kama wakati mwingine kuna shida
**3** kama mara kwa mara ni shida
**4** kama kila mara ni shida

Hakuna jibu lililo ni sahihi au lisilo sahihi.

Kama huelewi swali tafathali tafuta usaidizi

Katika mwezi moja uliopita, ni kiwango kipi cha shida kimekuwa kwako …

| **Kuhusu Viungo ya mwili na kazi nyinginezo (SHIDA NA…)** | Hakuna | **shida kidogo** | Wakati mwingine | **Mara kwa mara** | kila mara |
|---|---|---|---|---|---|
| 1. Ni vigumu kwangu kutembea zaidi ya urefu wa uwanja | 0 | 1 | 2 | 3 | 4 |
| 2. Ni vigumu kwangu kukimbia | 0 | 1 | 2 | 3 | 4 |
| 3. Ni vigumu kwangu kufanya sporti na mazoezi | 0 | 1 | 2 | 3 | 4 |
| 4. Ni vigumu kwangu kuinua kitu kizito | 0 | 1 | 2 | 3 | 4 |
| 5. Ni vigumu kwangu kufanya kazi za nyumbani | 0 | 1 | 2 | 3 | 4 |

| **Kuhusu hisia (SHIDA NA…)** | Hakuna | **shida kidogo** | Wakati mwingine | **Mara kwa mara** | kila mara |
|---|---|---|---|---|---|
| 1. Nahisi uoga/hofu | 0 | 1 | 2 | 3 | 4 |
| 2. Nahisi mnyonge /huzuni | 0 | 1 | 2 | 3 | 4 |
| 3. Nahisi kukasirika | 0 | 1 | 2 | 3 | 4 |
| 4.Nina wasiwasi kuhusu kitakachotendeka kwangu | 0 | 1 | 2 | 3 | 4 |

| **Kuhusu ninavyo wasiliana na vijana wengine (SHIDA NA…)** | Hakuna | **shida kidogo** | Wakati mwingine | **Mara kwa mara** | kila mara |
|---|---|---|---|---|---|
| 1. Nina shida kuwasiliana na vijana wenzangu | 0 | 1 | 2 | 3 | 4 |
| 2. Vijana wengine hawataki kuwa marafiki wangu | 0 | 1 | 2 | 3 | 4 |
| 3. Vijana wengine wananichokoza | 0 | 1 | 2 | 3 | 4 |

| **Kuhusu shule (SHIDA NA…)** | Hakuna | **shida kidogo** | Wakati mwingine | **Mara kwa mara** | kila mara |
|---|---|---|---|---|---|
| 1.Nina shida kuwa makini darasani | 0 | 1 | 2 | 3 | 4 |
| 2. Huwa nasahau mambo | 0 | 1 | 2 | 3 | 4 |
| 3 Nina shida kufanya kazi za shule kwa wakati unaofaa | 0 | 1 | 2 | 3 | 4 |

**APPENDIX 8: Repoti ya wazazi ya vijana barobaro (Miaka 13-18)**

ID#_____
_____

Date:_____
____

# PedsQL™ 4.0 SF15

**Version 4.0 Short Form (SF15)**

## **Repoti ya wazazi ya vijana barobaro** (Miaka **13-18**)

MAAGIZO

Katika kurasa hili, kuna mambo ambayo yanaweza kuwa shida kwa mtoto wako tafathali tueleze kiwango cha shida kila kimekuwa katika mwezi uliopita kwa kuchora mviringo :

**0** kama hakujawahi kuwa na shida
**1** kama shida kidogo
**2** kama wakati mwingine ni shida
**3** kama mara kwa mara ni shida
**4** kama kila mara ni shida

Hakuna jibu lililo sahihi au lisilo sahihi.

Kama huelewi swali tafathali tafuta usaidizi

Katika mwezi moja uliopita, ni kiwango kipi cha shida kijana wako amekuwa nayo …

| KUHUSU HALI YA MWILI Shida na…) | Hakuna shida | Shida kidogo | Wakati mwingine | Mara kwa mara | Kila mara |
|---|---|---|---|---|---|
| 1. Ni vigumu kwake kutembea urefu wa uwanja wa kandanda | 0 | 1 | 2 | 3 | 4 |
| 2. Ni vigumu kwake kukimbia | 0 | 1 | 2 | 3 | 4 |
| 3. Ni vigumu kwake kufanya sporti na mazoezi | 0 | 1 | 2 | 3 | 4 |
| 4. Ni vigumu kwake kuinua Kitu Kizito | 0 | 1 | 2 | 3 | 4 |
| 5. Ni vigumu kwake kufanya kazi za nyumbani | 0 | 1 | 2 | 3 | 4 |

| KUHUSU HISIA (Shida na…) | Hakuna shida | Shida kidogo | Wakati mwingine | Mara kwa mara | Kila mara |
|---|---|---|---|---|---|
| 1.. Kuhisi hofu/uoga | 0 | 1 | 2 | 3 | 4 |
| 2. Kuhisi huzuni/ Mnyonge | 0 | 1 | 2 | 3 | 4 |
| 3. Kuhisi hasira | 0 | 1 | 2 | 3 | 4 |
| 4. Ana wasiwasi kuhusu kitakachotendeka kwake | 0 | 1 | 2 | 3 | 4 |

| KUHUSU MAWASILIANO (shida na…) | Hakuna shida | Shida kidogo | Wakati mwingine | Mara kwa mara | Kila mara |
|---|---|---|---|---|---|
| 1. Ana shida kuwasiliana na vijana wengine | 0 | 1 | 2 | 3 | 4 |
| 2. Vijana wengine hawataki kuwa marafiki wake | 0 | 1 | 2 | 3 | 4 |
| 3 Vijana wengine wanamchokoza | 0 | 1 | 2 | 3 | 4 |

| KUHUSU SHULE (shida na…) | Hakuna shida | Shida kidogo | Wakati mwingine | Mara kwa mara | Kila mara |
|---|---|---|---|---|---|
| 1. Ana shida kuwa makini darasani | 0 | 1 | 2 | 3 | 4 |
| 2. Huwa anasahau mambo | 0 | 1 | 2 | 3 | 4 |
| 3. Ni vigumu kwake kufanya kazi za shule kwa wakati unaofaa | 0 | 1 | 2 | 3 | 4 |

**APPENDIX 9: Food frequency questionnare (swahili version)**

| **Kikundi ya chakula** | **Aina ya chakula** | **Kinatumiwa mara ngapi** | | | | |
|---|---|---|---|---|---|---|
| | | **KILA SIKU** | **MARA 2 HADI 5 KWA WIKI** | **MARA MOJA KWA WIKI** | **MARA MOJA KWA MWEZI** | **BAADA YA MUDA MREFU AU HAUJAWAHI KULA** |
| Nafaka | Unga wa sima | | | | | |
| | Mchele | | | | | |
| | Mtama | | | | | |
| | Unga wa ngano | | | | | |
| | Mihogo | | | | | |
| Maharagwe | Maharagwe | | | | | |
| | Kunde | | | | | |
| | Pojo | | | | | |
| | Njugu | | | | | |
| | Mbaazi | | | | | |
| Mboga | Mchunga | | | | | |
| | Mrenda | | | | | |
| | Kisamvu | | | | | |
| | Futswe | | | | | |
| | Mkunde | | | | | |
| | Malenge(kumbu) | | | | | |
| | Sukuma wiki | | | | | |
| | Mchicha | | | | | |
| | Matawi ya malenge | | | | | |
| Matunda | Machungwa | | | | | |
| | Papai | | | | | |
| | Maembe | | | | | |
| | Limau | | | | | |
| | Ndizi | | | | | |
| | Mapera | | | | | |
| | Passion(tree top) | | | | | |
| | Nanasi | | | | | |
| Mayai | Mayai ya kuku | | | | | |
| | Mayai ya bata | | | | | |
| Nyama na Samaki | Nyama ya ng'ombe | | | | | |
| | Nyama ya mbuzi | | | | | |
| | Maini | | | | | |
| | Samaki wakubwa | | | | | |
| | Dagaa (omena) | | | | | |
| Maziwa | Maziwa ya ng'ombe | | | | | |
| | Maziwa ya mbuzi | | | | | |

**APPENDIX 10: Young child report (ages 5-7)**

ID# _____

Date:_____

# PedsQL™ 4.0 SF15™

## Pediatric Quality of Life Inventory

**Version 4.0 Short Form (SF15)**

YOUNG CHILD REPORT (ages 5-7)

Instructions for interviewer:

***I am going to ask you some questions about things that might be a problem for r you. I want to know how much of a problem any of these things might be for you.***

Show the child the template and point to the responses as you read.

***If it is <u>not at all</u> a problem for you, point on number one (1)***

***If it is <u>sometimes</u> a problem for you, point on number two (2)***

***If it is a problem for you <u>a lot</u>, point to the number four (4)***

***I will read each question. Point to the numbers to show me how much of a problem it is for you. Let's try a practice one first.***
Ask the child to demonstrate snapping his or her fingers to determine whether or not the

question was answered correctly. Repeat the question if the child demonstrates a response that is different from his or her action.

Think about how you have been doing for the last few weeks. Please listen carefully to each sentence and tell me how much of a problem this is for you.

After reading the numbers, if the child hesitates or does not seem to understand how to answer, read the response options while pointing at the numbers.

| **Physical Functioning *(PROBLEMS WITH…)*** | **Not at all** | **Some-times** | **A lot** |
|---|---|---|---|
| 1. Is it hard for you to walk | 0 | 2 | 4 |
| 2. Is it hard for you to run | 0 | 2 | 4 |
| 3. Is it hard for you to play sports or exercise | 0 | 2 | 4 |
| 4. Is it hard for you to pick up big things | 0 | 2 | 4 |
| 5. Is it hard for you to do chores (like pick up your toys) | 0 | 2 | 4 |

Remember, tell me how much of a problem this has been for you for the last few weeks.

| **Emotional Functioning *(PROBLEMS WITH…)*** | **Not at all** | **Some-times** | **A lot** |
|---|---|---|---|
| 1. Do you feel scared | 0 | 2 | 4 |
| 2. Do you feel sad | 0 | 2 | 4 |
| 3. Do you feel mad | 0 | 2 | 4 |
| 4. Do you worry about what will happen to you | 0 | 2 | 4 |

| **Social Functioning *(PROBLEMS WITH…)*** | **Not at all** | **Some-times** | **A lot** |
|---|---|---|---|
| 1. Is it hard for you to get along with other kids | 0 | 2 | 4 |
| 2. Do other kids say they do not want to play with you | 0 | 2 | 4 |
| 3. Do other kids tease you | 0 | 2 | 4 |

| **School Functioning *(PROBLEMS WITH…)*** | **Not at all** | **Some-times** | **A lot** |
|---|---|---|---|
| 1. Is it hard for you to pay attention in school | 0 | 2 | 4 |
| 2. Do you forget things | 0 | 2 | 4 |
| 3. Is it hard to keep up with schoolwork | 0 | 2 | 4 |

**APPENDIX 11: Parent report for young children (ages 5-7)**

ID# _____

Date:_____

# PedsQL™ 4.0 SF15

**Version 4.0 Short Form (SF15)**

PARENT REPORT for YOUNG CHILDREN (ages 5-7)

**DIRECTIONS**

On the following page is a list of things that might be a problem for **your child**. Please tell us **how much of a problem** each one has been for **your child** during the **past ONE month** by circling:

**0** if it is **never** a problem
**1** if it is **almost never** a problem
**2** if it is **sometimes** a problem
**3** if it is **often** a problem
**4** if it is **almost always** a problem

There are no right or wrong answers.

If you do not understand a question, please ask for help.

*In the past **ONE month,** how much of a **problem** has your child had with …*

| **Physical Functioning** ***(PROBLEMS WITH…)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Walking more than one block | 0 | 1 | 2 | 3 | 4 |
| 2. Running | 0 | 1 | 2 | 3 | 4 |
| 3. Participating in sports activity or exercise | 0 | 1 | 2 | 3 | 4 |
| 4. Lifting something heavy | 0 | 1 | 2 | 3 | 4 |
| 5. Doing chores, like picking up his or her toys | 0 | 1 | 2 | 3 | 4 |

| **Emotional Functioning** ***(PROBLEMS WITH…)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Feeling afraid or scared | 0 | 1 | 2 | 3 | 4 |
| 2. Feeling sad or blue | 0 | 1 | 2 | 3 | 4 |
| 3. Feeling angry | 0 | 1 | 2 | 3 | 4 |
| 4. Worrying about what will happen to him or her | 0 | 1 | 2 | 3 | 4 |

| **Social Functioning** ***(PROBLEMS WITH…)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Getting along with other children | 0 | 1 | 2 | 3 | 4 |
| 2. Other kids not wanting to be his or her friend | 0 | 1 | 2 | 3 | 4 |
| 3. Getting teased by other children | 0 | 1 | 2 | 3 | 4 |

| **School Functioning** ***(PROBLEMS WITH…)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Paying attention in class | 0 | 1 | 2 | 3 | 4 |
| 2. Forgetting things | 0 | 1 | 2 | 3 | 4 |
| 3. Keeping up with school activities | 0 | 1 | 2 | 3 | 4 |

**APPENDIX 12: Child report (ages 8-12)**

ID# _____

Date:_____

# PedsQL™ 4.0 SF15™

## Pediatric Quality of Life Inventory

**Version 4.0 Short Form (SF15)**

CHILD REPORT (ages 8-12)

**DIRECTIONS**

On the following page is a list of things that might be a problem for you. Please tell us **how much of a problem** each one has been for you during the **past ONE month** by circling:

**0** if it is **never** a problem
**1** if it is **almost never** a problem
**2** if it is **sometimes** a problem
**3** if it is **often** a problem
**4** if it is **almost always** a problem

There are no right or wrong answers.

If you do not understand a question, please ask for help.

In the past **ONE month**, how much of a **problem** has this been for you

| **About My Health and Activities (PROBLEMS WITH…)** | Never | **Almost Never** | Some-times | **Often** | Almost Always |
|---|---|---|---|---|---|
| 1. It is hard for me to walk more than one block | 0 | 1 | 2 | 3 | 4 |
| 2. It is hard for me to run | 0 | 1 | 2 | 3 | 4 |
| 3. It is hard for me to do sports activity or exercise | 0 | 1 | 2 | 3 | 4 |
| 4. It is hard for me to lift something heavy | 0 | 1 | 2 | 3 | 4 |
| 5. It is hard for me to do chores around the house | 0 | 1 | 2 | 3 | 4 |

| **About My Feelings (PROBLEMS WITH…)** | Never | **Almost Never** | Some-times | **Often** | Almost Always |
|---|---|---|---|---|---|
| 1. I feel afraid or scared | 0 | 1 | 2 | 3 | 4 |
| 2. I feel sad or blue | 0 | 1 | 2 | 3 | 4 |
| 3. I feel angry | 0 | 1 | 2 | 3 | 4 |
| 4. I worry about what will happen to me | 0 | 1 | 2 | 3 | 4 |

| **How I Get Along with Others (PROBLEMS WITH…)** | Never | **Almost Never** | Some-times | **Often** | Almost Always |
|---|---|---|---|---|---|
| 1. I have trouble getting along with other kids | 0 | 1 | 2 | 3 | 4 |
| 2. Other kids do not want to be my friend | 0 | 1 | 2 | 3 | 4 |
| 3. Other kids tease me | 0 | 1 | 2 | 3 | 4 |

| **About School (PROBLEMS WITH…)** | Never | **Almost Never** | Some-times | **Often** | Almost Always |
|---|---|---|---|---|---|
| 1. It is hard to pay attention in class | 0 | 1 | 2 | 3 | 4 |
| 2. I forget things | 0 | 1 | 2 | 3 | 4 |
| 3. I have trouble keeping up with my schoolwork | 0 | 1 | 2 | 3 | 4 |

**APPENDIX 13: Parent report for children (ages 8-12)**

ID# _____

Date:_____

# PedsQL™ 4.0 SF15™

## Pediatric Quality of Life Inventory

**Version 4.0 Short Form (SF15)**

PARENT REPORT for CHILDREN (ages 8-12)

**DIRECTIONS**

On the following page is a list of things that might be a problem for **your child**. Please tell us **how much of a problem** each one has been for **your child** during the **past ONE month** by circling:

**0** if it is **never** a problem
**1** if it is **almost never** a problem
**2** if it is **sometimes** a problem
**3** if it is **often** a problem
**4** if it is **almost always** a problem

There are no right or wrong answers.

If you do not understand a question, please ask for help.

*In the past **ONE month,** how much of a **problem** has your child had with …*

| **Physical Functioning** ***(PROBLEMS WITH…)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Walking more than one block | 0 | 1 | 2 | 3 | 4 |
| 2. Running | 0 | 1 | 2 | 3 | 4 |
| 3. Participating in sports activity or exercise | 0 | 1 | 2 | 3 | 4 |
| 4. Lifting something heavy | 0 | 1 | 2 | 3 | 4 |
| 5. Doing chores around the house | 0 | 1 | 2 | 3 | 4 |

| **Emotional Functioning** ***(PROBLEMS WITH…)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Feeling afraid or scared | 0 | 1 | 2 | 3 | 4 |
| 2. Feeling sad or blue | 0 | 1 | 2 | 3 | 4 |
| 3. Feeling angry | 0 | 1 | 2 | 3 | 4 |
| 4. Worrying about what will happen to him or her | 0 | 1 | 2 | 3 | 4 |

| **Social Functioning** ***(PROBLEMS WITH…)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Getting along with other children | 0 | 1 | 2 | 3 | 4 |
| 2. Other kids not wanting to be his or her friend | 0 | 1 | 2 | 3 | 4 |
| 3. Getting teased by other children | 0 | 1 | 2 | 3 | 4 |

| **School Functioning** ***(PROBLEMS WITH…)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Paying attention in class | 0 | 1 | 2 | 3 | 4 |
| 2. Forgetting things | 0 | 1 | 2 | 3 | 4 |
| 3. Keeping up with schoolwork | 0 | 1 | 2 | 3 | 4 |

**APPENDIX 14: Teen report (ages 13-18)**

ID#
_____
_

Date:_____
____

# PedsQL™ 4.0 SF15
# Pediatric Quality of Life Inventory

**Version 4.0 Short Form (SF15)**

TEEN REPORT (ages 13-18)

**DIRECTIONS**

On the following page is a list of things that might be a problem for you. Please tell us **how much of a problem** each one has been for you during the **past ONE month** by circling:

**0** if it is **never** a problem
**1** if it is **almost never** a problem
**2** if it is **sometimes** a problem
**3** if it is **often** a problem
**4** if it is **almost always** a problem

There are no right or wrong answers.

If you do not understand a question, please ask for help.

*In the past **ONE month**, how much of a **problem** has this been for you …*

| **About My Health and Activities** ***(PROBLEMS WITH…)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. It is hard for me to walk more than one block | 0 | 1 | 2 | 3 | 4 |
| 2. It is hard for me to run | 0 | 1 | 2 | 3 | 4 |
| 3. It is hard for me to do sports activity or exercise | 0 | 1 | 2 | 3 | 4 |
| 4. It is hard for me to lift something heavy | 0 | 1 | 2 | 3 | 4 |
| 5. It is hard for me to do chores around the house | 0 | 1 | 2 | 3 | 4 |

| **About My Feelings** ***(PROBLEMS WITH…)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. I feel afraid or scared | 0 | 1 | 2 | 3 | 4 |
| 2. I feel sad or blue | 0 | 1 | 2 | 3 | 4 |
| 3. I feel angry | 0 | 1 | 2 | 3 | 4 |
| 4. I worry about what will happen to me | 0 | 1 | 2 | 3 | 4 |

| **How I Get Along with Others** ***(PROBLEMS WITH…)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. I have trouble getting along with other teens | 0 | 1 | 2 | 3 | 4 |
| 2. Other teens do not want to be my friend | 0 | 1 | 2 | 3 | 4 |
| 3. Other teens tease me | 0 | 1 | 2 | 3 | 4 |

| **About School (problems with…)** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. It is hard to pay attention in class | 0 | 1 | 2 | 3 | 4 |
| 2 I forget things | 0 | 1 | 2 | 3 | 4 |
| 3. I have trouble keeping up with my schoolwork | 0 | 1 | 2 | 3 | 4 |

**APPENDIX 15: Parent report for teens (ages 13-18)**

ID#_____
_____

Date:_____
____

# PedsQL™ 4.0 SF15

**Version 4.0 Short Form (SF15)**

PARENT REPORT for TEENS (ages 13-18)

**DIRECTIONS**

On the following page is a list of things that might be a problem for **your teen**. Please tell us **how much of a problem** each one has been for **your teen** during the **past ONE month** by circling:

**0** if it is **never** a problem
**1** if it is **almost never** a problem
**2** if it is **sometimes** a problem
**3** if it is **often** a problem
**4** if it is **almost always** a problem

There are no right or wrong answers.

If you do not understand a question, please ask for help.

*In the past **ONE month,** how much of a **problem** has your teen had with;*

| **Physical Functioning *(PROBLEMS WITH…)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Walking more than one block | 0 | 1 | 2 | 3 | 4 |
| 2. Running | 0 | 1 | 2 | 3 | 4 |
| 3. Participating in sports activity or exercise | 0 | 1 | 2 | 3 | 4 |
| 4. Lifting something heavy | 0 | 1 | 2 | 3 | 4 |
| 5. Doing chores around the house | 0 | 1 | 2 | 3 | 4 |

| **Emotional Functioning *(PROBLEMS WITH…)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Feeling afraid or scared | 0 | 1 | 2 | 3 | 4 |
| 2. Feeling sad or blue | 0 | 1 | 2 | 3 | 4 |
| 3. Feeling angry | 0 | 1 | 2 | 3 | 4 |
| 4. Worrying about what will happen to him or her | 0 | 1 | 2 | 3 | 4 |

| **Social Functioning (PROBLEMS WITH…)** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Getting along with other teens | 0 | 1 | 2 | 3 | 4 |
| 2. Other teens not wanting to be his or her friend | 0 | 1 | 2 | 3 | 4 |
| 3. Getting teased by other teens | 0 | 1 | 2 | 3 | 4 |

| **School Functioning *(PROBLEMS WITH…)*** | Never | Almost Never | Some-times | Often | Almost Always |
|---|---|---|---|---|---|
| 1. Paying attention in class | 0 | 1 | 2 | 3 | 4 |
| 2. Forgetting things | 0 | 1 | 2 | 3 | 4 |
| 3. Keeping up with schoolwork | 0 | 1 | 2 | 3 | 4 |

**APPENDIX 16: Food frequency questionnaire English version**

Frequency of iron food intake (consumption patterns). From the foods that we use, I will ask you the frequency of consuming the following foods

| **FOOD GROUP** | **SPECIFIED FOOD** | **FREQUENCIES** | | | | |
|---|---|---|---|---|---|---|
| | | **Everyday** | **2-5 times a week** | **Once a week** | **Once a month** | **After a long time or never** |
| Starchy cereals (Nafaka) | Maize | | | | | |
| | Rice | | | | | |
| | Millet | | | | | |
| | Wheat flour | | | | | |
| | Cassava | | | | | |
| Legumes and Nuts | Beans | | | | | |
| | Cowpeas | | | | | |
| | Greengrams | | | | | |
| | Groundnuts | | | | | |
| | Mbaazi | | | | | |
| Vegetables | Mchunga | | | | | |
| | Mrenda | | | | | |
| | Kisamvu | | | | | |
| | Futswe | | | | | |
| | Cowpeas leaves | | | | | |
| | Pumkin | | | | | |
| | kales | | | | | |
| | Amaranth | | | | | |
| | Pumkin leaves | | | | | |
| Fruits | Orange | | | | | |
| | Pawpaw | | | | | |
| | Mango | | | | | |
| | Lemon | | | | | |
| | Bannana | | | | | |
| | Quava | | | | | |
| | Passion fruit | | | | | |
| | Pineapple | | | | | |
| Eggs | Chicken eggs' | | | | | |
| | Duck eggs' | | | | | |
| Meat and Fish | Beef | | | | | |
| | Goat's meat | | | | | |
| | Liver | | | | | |
| | Big fish | | | | | |
| | Dagaa | | | | | |
| Milk | Cow's milk | | | | | |
| | Goat's milk | | | | | |
| | | | | | | |

**APPENDIX 17: Permission from Kenyatta University graduate school**


KENYATTA UNIVERSITY
OFFICE OF THE DEAN, GRADUATE SCHOOL

E-mail: kubps@yahoo.com
dean-graduate@ku.ac.ke
Website: www.ku.ac.ke

P.O. Box 43844, 00100
NAIROBI, KENYA
Tel. 810901 Ext. 57530


**Our Ref:** P57/13137/09 **Date:** 4th July, 2011

The Permanent Secretary,
Ministry of Higher Education,
Science & Technology
P.O. Box 30040,
NAIROBI.

Dear Sir/Madam,

**RE: RESEARCH AUTHORIZATION**

I write to introduce **Ms. Carolyn Chebet Terer** is a Postgraduate Student of this University. She is registered for a M.P.H. degree programme in the Department of Public Health.

Ms. Chebet intends to conduct research for a thesis project entitled, "**Evaluation of Health-Related Quality of Life of Children Living with Urinary Schistosomiasis Using PedsQL™ and Assessment of Dietary Iron Intake in South Coast Kenya.**"

Any assistance given to her will be highly appreciated.

Yours faithfully,

JOHN M. ODONGI
FOR: DEAN, GRADUATE SCHOOL

*JMO/bkk*

**APPENDIX 18: Permission from district commissioner**

# OFFICE OF THE PRESIDENT
## PROVINCIAL ADMINISTRATION AND INTERNAL SECURITY

Telegrams: "DISTRICTER" MSAMBWENI
Telephone: 020 8013589
When replying please quote
E-mail address: dcmsambweni@yahoo.com

THE DISTRICT COMMISSIONER
MSAMBWENI DISTRICT
P.O. BOX 93
**MSAMBWENI**

Ref. No. **ADM. 15/15 VOL. I/49**

**29th September, 2011**

Carolyn Chebet Terer
Kenyatta University
P.O. Box 43844
**NAIROBI**

**RE: RESEARCH AUTHORIZATION**

This is to inform you that your request to carry out research in **"Evaluation of health related quality life of children living with urinary schistosomiasis using PedsQL and assessment of dietary iron intake in South Coast Kenya"** has been granted for the period ending 30th June, 2012.

**J. T. WASONGA**
**FOR: DISTRICT COMMISSIONER**
**MSAMBWENI DISTRICT**

C.C.

District Officer
- ✓ Diani }
- ✓ Msambweni } Please accord her the necessary assistance.
- ✓ Lunga Lunga }

**APPENDIX 18: Permission from NCST**

REPUBLIC OF KENYA

# NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

Telegrams:"SCIENCETECH", Nairobi
Telephone: 254-020-241349, 2213102
254-020-310571, 2213123.
Fax: 254-020-2213215, 318245, 318249
When replying please quote

P.O. Box 30623-00100
NAIROBI-KENYA
Website: www.ncst.go.ke

Our Ref: **NCST/RRI/12/1/MED-011/117**

Date: **30th August 2011**

Carolyn Chebet Terer
Kenyatta University
P. O. Box 43844
NAIROBI

**RE: RESEARCH AUTHORIZATION**

Following your application for authority to carry out research on **"Evaluation of health related quality life of children living with urinary schistosomiasis using PedsQL and assessment of dietary iron intake in south Coast Kenya"** I am pleased to inform you that you have been authorized to undertake research **in Msambweni,Kinango& Kwale Districts** for a period ending ***30th June, 2012.***

You are advised to report to **The District Commissioners, The District Education Officers, and The District Medical Officers of Health Msambweni,Kinango& Kwale Districts** before embarking on the research project.

On completion of the research, you are expected to submit **one hard copy and one soft copy** of the research report/thesis to our office.

**P.N. NYAKUNDI**
**FOR: SECRETARY/CEO**

Copy to:

**APPENDIX 19: Consent form (Swahili version)**

**UNIVERSITY HOSPITALS CASE MEDICAL CENTER**
**KENYA MEDICAL RESEARCH INSTITUTE (KEMRI)**
**CONSENT FOR INVESTIGATIONAL STUDIES**
**Project Title:** Eco-epidemiology of Urogenital schistosomiasis, Malaria and Polyparasitism in Coastal Kenya
**Principal Investigator: Carolyn Chebet Terer**
**Nutrition and Quality of Life assessment Substudy**

Huu ni mradi wa utafiti. Mradi wa utafiti unahusu wale tu wanachagua kushiriki. Tafadhali chukua muda kabla ya kuamua kushiriki. Zungumza na marafiki na jamii.

Dkr. Charles King kutoka Case Western Reserve University (CWRU) USA na wenzake walioko na Division of Vector Borne and Neglected Tropical Diseases (DVBND), katika Wizara ya Afya Kenya wanakualika kujiandikisha kwenye mradi ambao umedhaminiwa na vituo vya National Institutes of Health katika USA. **Wewe/mtoto wako,** unaulizwa kujiunga na mradi huu kwa sababu unaishi kwa eneo ambalo liko na hatari ya kuambukizwa ugonjwa wa kichocho, na magonjwa mengine. Unaulizwa kujiunga na huu utafiti-mdogo kwa sababu ulishiriki katika uchunguzi wa hapo awali ya anthropometrics.

KWA NINI UTAFITI-MDOGO UFANYWE?

Tunataka kujua mengi juu ya ugonjwa huu wa kichocho, na jinsi inavyo dhuru maisha ya watoto na lishe bora katika kijiji ambacho unaishi. Tunatarajia kuelewa mengi juu ya kuenea kwa ugonjwa huu ndiyo tuwe na uwezo wa kuzuia kuenea kwa ugonjwa huu kwa siku za usoni. Huu utafiti-mdogo utasaidia kuelewa zaidi vile ugonjwa huu unachangia kudhuru afya ya mtoto wako na ukuaji.

NI WATU WANGAPI WATAJIUNGA NA HUU UTAFITI-MDOGO?

Katika mradi wa utafiti-mkuu takriban watu 14,000 - 18,000 waume, wake na watoto wa miaka 5 na zaidi wanashiriki kwenye mradi huu katika mtaa unapoishi. Kwa huu utafiti-mdogo tungetaka kuandikisha watu 790 kati yao kina mama na watoto wao kati ya miaka mitano (5) na kumi na tisa (18).

NI NINI INAHUSIKA KWENYE HUU UTAFITI-MDOGO?
Wewe na mtoto wako mtaelezewa juu ya huu utafiti-mdogo kikamilifu.tutawauliza mtupatie idhini ya mtoto kujiunga na huu utafiti-mdogo. Tutauliza mtoto wako kama yeye mwenyewe atakubali kushiriki kwenye huu utafiti. Mtoto akikataa kujiunga kwa sababu yoyote, basi sisi hatutamwandika kwenye orodha ya washiriki. Mtoto wako akikubali kuingia kwenye utafiti, basi atapewa karatasi ambayo ina maelezo kamili ya utafiti mdogo.

Tutakuhuliza wewe na mtoto wako maswali kuhusu ugonjwa huu wa kichocho na jinsi inavyodhuru hali ya maisha yake.Tutakuhuliza pia maswali kuhusu vyakula mnavyoviila na mara ngapi kwa siku,wiki, mwezi au kama hamjawahi kuviila.

Mtoto wako ataulizwa maswali fupi kuhusu maisha yake ya kila siku kama akihisi njaa anajisikia vipi au pengine kama anachoka kutembea shuleni. Majibu yao yatatusaidia kujua madhara ya ugonjwa huu katika kufanya kazi zao za kila siku.

NITAKUWA KWA HUU UTAFITI MDGO KWA MUDA GANI?

Utakuwa kwa huu utafiti mdogo wakati wa uchunguzi wa hali ya lishe bora na hali ya maisha. zitatuchukua muda wa kama dakika kumi kutimiza. Uchunguzi huu utarudiwa baada ya mwaka mmoja.

MADHARA YA UTAFITI MDOGO NI GANI?

Hakuna madhara inatarajiwa kutokea katika huu utafiti-mdogo.

JE KUNA FAIDA YEYOTE KUJIUZISHA NA UTAFITI HUU?

Hakuna faida yoyote ya kibinafsi kwa wale wanaoshiriki kwa huu utafiti mdogo. Kushiriki kwako kunaweza kuchangia juu ya kuangamiza ugonjwa wa kichocho. ugonjwa huu unapatikana kwa jamii yenu. Utafiti huu unaweza kuzuia kuenea kwa huu ugonjwa katika familia na jamii zenu. Mwisho, kujiunga kwako au mtoto wako kwa utafiti huu mdogo utasaidia kugundua mengi kuhusu ugonjwa huu kote duniani

NI NJIA ZIPI ZINGINE ZILIZOPO?

Si lazima kujiunga na huu mradi wa utafiti mdogo. Na ukijiunga, una haki ya kuisimamisha wakati wowote upendavyo.

NA KUHUSU SIRI?

Juhudi zitafanywa kuhakikisha kwamba habari zako zitawekwa kuwa siri. Lakini hatuwezi tukahakikishia wewe siri kabisa. Habari zako zinaweza zikapatiwa watu wengine kulingana na kisheria. Mashirika ambayo yanaweza kuangalia habari zako kulingana na sheria ni kama; Wizara ya Afya Kenya (Ministries of medical services and Public Health and Sanitation), Division of Vector Borne and Neglected Tropical Diseases (DVBNTD), na National Institutes of Health (NIH) katika United States.

GHARAMA NI NINI?

Hakuna gharama kwa kujiunga kwa utafiti huu mdogo. Uchunguzi wowote ambayo utafanya na umetajwa kwenye utafiti huu utalipiwa na mradi. Ugonjwa au majeraha yoyote kutokana na utafiti huu mdogo, utachukuliwa kama hatari na utapewa matibabu iliyostahili katika hospitali ama kituo cha afya kilicho karibu nawe. Hakuna malipo yoyote kwa wale watashiriki kwa huu utafiti mdogo.

HAKI ZA WENYE KUSHIRIKI NI GANI?

Kushiriki kwa huu utafiti mdogo ni kwa hiari yako. Mtoto wako anaweza kuchagua kujiunga au kujiondoa kwa utafiti huu wakati wowote. Hautapoteza chochote kwa kujiondoa kwa utafiti huu mdogo.
Tutakueleza matokeo yoyote inayohusu afya yako, uzima au uamuzi wa kuendelea kuwa kwa mradi.

## Ufupi wa haki zako wakati unashiriki katika utafiti

Kushiriki kwako katika utafiti huu ni kwa hiari yako. Kwa kukataa kujiunga na utafiti hautanyimwa haki zako za kawaida za afya au udhulumiwe au kupoteza faida zako unazostahili kupata. Ukiamua kujiunga, unaweza pia kuamua kujiondoa wakati wowote bila kudhulumiwa au kupoteza faida yoyote. Ikiwa habari inatokana na huu utafiti itaandikwa kwa vitabu, majina yako itawekwa kuwa siri. Kama habari inatokana na utafiti huu itaonyesha kuwa kutakuwa na madhara au faida, utaelezewa kikamilifu hili uamue kama utaendelea ama utajiondoa kwenye utafiti..

## Jinsi la kupata maelezo

Dkr. Eric Muchiri au mmoja wa wahusika wake _____ amekueleza vile itakavyokua kuhusu madhara, hatari, na faida zilizoko na unaweza kuwasiliana naye kutumia nambari ya simu 20-725833 or 20-725601. Kwa maelezo zaidi kuhusu kuugua ama madhara yatakayotokana na taratibu za utafiti, na pia haki za muhusika zinaweza kupatikana kutoka kwa; KEMRI/National Ethical Review Committee (ERC), PO Box 54840, Nairobi 00200 katika (020) 272-2541 au Director KEMRI, PO Box 54840, Nairobi katika (020)272-2541, au Chief Medical Officer katika United States (216) 844-3695 ama umuandikie; The Chief Medical Officer, The Center for Clinical Research, University Hospitals Case Medical Center, 11100 Euclid Avenue, Lakeside 1400, Cleveland, Ohio, 44106-7061 U.S.A.

## Sahihi

Ninaelewa kwamba kuweka sahihi kwa karatasi hii ya idhini, nimeelezwa kuhusu utafiti huu na nina kakubali kwa hiari yangu; nimeuliza maswali yangu na nimejibiwa kwa kiwango cha kutosheka; ninakubali kushiriki katika utafiti huu; ninaelewa kwamba kwa kuweka sahihi kwa karatasi hii ya idhini, sitaepukana na haki zangu za kisheria au madaraka ya mchunguzi au mdhamini wa mradi; nimepata nakala ya karatasi hii ya idhini.

_____
Sahihi ya mshiriki

_____
Jina la mshiriki lililochapishwa

_____
Sahihi ya msimamizi jina la msimamizi
Kama mshiriki ni mtoto, mzazi/msimaizi wake aweke sahihi hapo chini;

_____
tarehe_____
mzazi au mlezi halali sahihi

uhusiano na mshiriki _____

_____ tarehe_____
_____
Sahihi ya mtu anapeana idhini jina la mtu anapeana idhini lililochapishwa
(Must be study investigator or individual who has been designated in the Checklist to obtain consent.)

_____ tarehe_____
Sahihi ya mchunguzi mkuu

**APPENDIX 20: Recommended Dietary Allowance (RDA) for iron by age and sex**

| Recommended Dietary Allowance (RDA) for iron by age and sex. | | |
|---|---|---|
| **Age/Group** | **Life Stage** | **Iron (mg/day)** |
| **Infants** | 0–6 months | 0.27* |
| | 7–12 months | 11 |
| **Children** | 1–3 years | 7 |
| | 4–8 years | 10 |
| **Males** | 9–13 years | 8 |
| | 14–18 years | 11 |
| | 19–30 years | 8 |
| | 31–50 years | 8 |
| | 51–70 years | 8 |
| | >70 years | 8 |
| **Females** | 9–13 years | 8 |
| | 14–18 years | 15 |
| | 19–30 years | 18 |
| | 31–50 years | 18 |
| | 51–70 years | 8 |
| | >70 years | 8 |
| **Pregnant Women** | 14–18 years | 27 |
| | 19–30 years | 27 |
| | 31–50 years | 27 |
| **Lactating Women** | 14–18 years | 10 |
| | 19–30 years | 9 |
| | 31–50 years | 9 |

Source: Dietary Reference Intakes, Institute of Medicine, Food and Nutrition Board