

# Adopting a Pediatric HIVQUAL-H Framework in Measuring the Quality of Pediatric HIV Care in Haiti

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## Abstract

**Objective:** Haiti has the largest pediatric HIV population in the Americas. The U.S. President's Emergency Plan for AIDS Relief has been instrumental to increase access to care for Haiti's pediatric HIV population. Though electronic medical records (EMRs) have facilitated this care, there are limited published data on the quality of care. This study aimed to use an adapted quality of pediatric HIV care framework in Haiti.

**Methods:** This is a retrospective study of active pediatric HIV patients less than 15 years of age seen at the Saint Damien Hospital HIV clinic in Tabarre, Haiti from January 2012 to December 2016. Clinical and laboratory data were abstracted from the EMR based on a Pediatric HIVQUAL-H framework generated by incorporating Haitian pediatric HIV guidelines into the Thai HIVQUAL model focusing on eight core and four expanded indicators.

**Results:** There were 393 different patients analyzed separately by calendar year, accounting for 1473 patient-years analyzed. Overall, 96.8% received clinical monitoring (1426), 99.4% PJP prophylaxis (1465), 98.5% TB screening (1452), and 98.7% growth (1454) and 98.8% oral health (1455) assessments; 89.8% received yearly CD4 monitoring (1323), 94.6% antiretroviral treatment (1394), and 92.5% adherence monitoring (1362); viral load monitoring was only done 50% of the time (730). The overall hospitalization rate was 4% (66/1473). Only 31% (181/589) of patients over 10 years old were disclosed to their diagnosis. Immunizations were not reliably documented.

**Conclusion:** The HIVQUAL-H framework identified rates of important clinical indicators, highlighting those needing improvement in an easy to track format. Viral load monitoring, oral health care, HIV disclosure, and immunizations are areas that could use focused interventions at this facility to improve standard of care for this population. This tool could be easily adapted for other pediatric HIV programs in developing countries with similar resource constraints.

**Keywords:** Global health; Haiti; Healthcare quality indicators; HIV; Pediatrics

## Introduction

### Pediatric HIV burden in Haiti

Haiti is home to the largest pediatric human immunodeficiency virus (HIV) population in the Americas. As of 2017, there are roughly 150,000 people living with HIV in Haiti 7000 of which are children under the age of 15 [1]. In 2004, the United States President's Emergency Plan for AIDS Relief (PEPFAR) began providing free antiretroviral therapy (ART). Early infant diagnosis (EID) for HIV has also been expanded since the introduction of PEPFAR; the country has gone from 9 sites where EID testing was performed in 2009 to 106 sites in 2014 [2]. Based on the latest pediatric HIV guidelines for Haiti, all inpatient and outpatient clinics should provide HIV testing as well as testing for all malnourished children and children receiving immunizations [2,3]. In 2017, of all infants <12 months who were screened for HIV, the total transmission rate was 5.7%, which was a slight increase from the prior year [1]. According to PEPFAR's 2018 country report, about 3530 pediatric patients aged less than 15 years were receiving ART, however, this number only represented about 50% of the infected children [4]. There is a need for continued expansion of ART coverage to all infected children; this process, however, should be accompanied by comprehensive quality of care measures, to ensure optimal care in the context of limited resources.

### The proposed model

An available quality of care tool that has been used in developed countries includes the HIVQUAL model [5-7]. This model was created by

the New York State Department of Health Acquired Immune Deficiency Syndrome (AIDS) Institute as the first set of framework for assessing adult HIV quality of care measures [8]. In 2003, Thailand adapted and implemented HIVQUAL to fit the Thai national HIV guidelines, resources, and health care system [6,7]. A Pediatric HIVQUAL-T was subsequently adapted for use in pediatric HIV patients in Thailand. Their model was first used in five pilot-site hospitals in 2005 and expanded to 10 other hospitals in 2010 and has been a very useful tool for ongoing quality improvement (QI) using hospital data on pediatric HIV care. Through their analyses, several areas needing development (ex. increasing assessment of immunization and dental history) were identified and have been successfully enhanced to provide a positive impact on the quality of patient care [5]. The HIVQUAL software was introduced in Haiti along with an electronic medical record (EMR) system to a few hospitals in 2007 [9,10]. All comprehensive data from HIVQUAL reported so far have been mostly focused on adults or overall adult/pediatric combined data with limited pediatric details

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(see Appendix 1 for sample report) [9]. There is a need to analyze more pediatric specific data such as adherence to treatment, growth and nutrition assessments, hospitalizations and mortality in order to improve care and outcomes. A dedicated comprehensive pediatric assessment adapted for pediatric HIV care in Haiti, HIVQUAL-H, would be an essential quality improvement measurement tool.

### The setting

Saint Damien Hospital, the largest pediatric hospital in Haiti, is located in the town of Tabarre, just outside of the capital of Port-au-Prince. The facility has a total of 150 inpatient beds and on-site outpatient clinics, including a clinic dedicated to HIV-infected children. About 800 HIV infected children aged 0 to 15 years are seen yearly in the outpatient HIV clinic [11]. This HIV clinic has had an EMR system (Isanté - Seattle, Washington) since 2009 which incorporates portions of the HIVQUAL-based software (termed HEALTHQUAL since 2013). The latest version includes additional indicators more specific to the adult population such as family planning and uterine cancer screening [10]. Using this EMR and HEALTHQUAL, several abstract presentations of QI projects at St. Damien were presented in 2011 and 2013 and were based on limited HIV care indicators (CD4 count, immunization status, and ART) [12-14]. A few other QI projects were also done at this facility leading up to 2016, but not focused on specific quality of care indicators of pediatric patients (ex. level of adherence among all HIV patients, clinical retention of HIV patients, mental health evaluation in HIV patients, re-evaluation of patients in the emergency room prior to admission, community dispensing of ART). There are no published comprehensive analyses of the specific pediatric HIV care at Saint Damien nor in the country.

The aim of our study was to adapt the HIVQUAL model that was successfully used in Thailand for pediatrics to include country-relevant pediatric guidelines and indicators to provide a comprehensive overview of the adequacy of Haiti's pediatric HIV care while providing quality measures that can be used to optimize that care.

### Materials and Methods

This is a retrospective chart review of electronic medical records of active and infected pediatric HIV patients less than 15 years of age from 2012 to 2016 from the pediatric HIV outpatient clinic at Saint Damien Hospital in Tabarre, Haiti. HIV-exposed infants and HIV-infected persons age 15 and above were excluded (patients who turned 15 during any year had their data used through that calendar year only). The EMRs of all eligible patients were reviewed for basic demographic information (age and sex), where the rounded age in years was determined by using age on the final day of the year. Using a combination of previous HIVQUAL models [5-8] and Haiti's national pediatric HIV care guidelines [3] a pediatric HIVQUAL-H model was generated (Table 1) to collect relevant clinical and laboratory indicators. Core indicators include clinical status monitoring (World Health Organization [WHO] HIV staging), CD4 count, viral load monitoring, growth assessment, *Pneumocystis jirovecii* pneumonia (PJP) prophylaxis, clinical tuberculosis (TB) screening, ART, and ART adherence monitoring. Data were also collected on expanded indicators including immunization history, oral health assessment, HIV disclosure to child, and number of hospitalizations.

### Pediatric HIVQUAL-H

#### Core indicators

Clinical staging was based on the 2007 World Health Organization

classification with stage 1-4 [15]. Only the latest staging classification was recorded for each calendar year. Laboratory monitoring indicators recorded were CD4 counts and viral loads obtained per calendar year; both the number of checks and the worst values were recorded from each year. CD4 values were recorded as percentage for patients <6 years and as absolute values for those  $\geq 6$  years [16-18]. Viral loads were recorded in copies per mL. Growth assessment included the height in centimeters and/or weight in kilograms when measured in a calendar year with only the most recent values recorded. Clinical TB screening was documented based on completion of required yearly screening questions, regardless of screening outcome. Both ART and *Pneumocystis jirovecii* pneumonia (PJP) prophylaxis were assessed based on relevant medications listed in EMR or not during a given calendar year. In the EMR, adherence is tracked in a special adherence visit note; a standard of 4 completed adherence visit notes per year met the adherence criteria (Table 1).

#### Expanded indicators

According to the Haitian HIV guidelines, HIV-exposed and asymptomatic HIV positive children should receive the following vaccines by the age of 2 years: Bacille Calmette-Guerin (BCG), oral polio vaccine (OPV) x3, Pentavalent (Diphtheria-Tetanus-acellular Pertussis [DTaP], Haemophilus influenza type B [Hib], Hepatitis B [Hep B]) x3, Rotavirus x2, Measles-Rubella (MR) or Measles-Mumps-Rubella (MMR) x1 [3]. Only patients with documentation for meeting all the parameters above according to their age were counted as up to date on their vaccines. Other documented but not required vaccines were also tallied, especially pneumococcal vaccines, including pneumococcal conjugate vaccine-7 (PCV7) and pneumococcal polysaccharide vaccine-23 (PPSV23).

Oral health assessment was counted as completed for a calendar year if reported in the exam portion of a visit note and any mention of dental discoloration, caries, or abnormal finding was counted as evidence of dental disease. Referral to a dentist was recorded when documented in the plan portion of a visit note for a given calendar year. HIV disclosure status was recorded according to the documentation in visit notes. The target age for disclosure was age 10 based on the policy of the local institution which is consistent with an average age for disclosure as found in reviews of multiple studies across the world (age 8-12 years) [19,20]. Hospitalizations and associated diagnoses were recorded based on documentation within the assessment and plan of the HIV clinic visit notes from the year. Each hospitalization was tallied separately, even if the same child was admitted several times in the same year.

Collected data were aggregated by calendar year per patient for longitudinal comparison. Each patient was assessed for meeting each indicator separately for each eligible calendar year data were available. This study protocol was reviewed and approved by both the University of Nebraska Medical Center (UNMC) Institutional Review Board as well as the Haitian Ministry of Health National Bioethics Committee. Study data were collected and managed using the REDCap electronic data capture tools hosted at UNMC. Service and support was provided by the Research Information Technology Office, which is funded by the UNMC Vice Chancellor for Research.

#### Statistical Analysis

Descriptive statistics (counts and percentages, means, standard deviations, medians, minimums and maximums) were used to summarize the data. For each Pediatric HIVQUAL-H indicator, the

	Indicator Name	Indicator Definition			
Core Indicators	Clinical status monitoring	Number of HIV-infected children who receive documented clinical staging (WHO staging) <b>at least once a year.</b>			
	CD4 monitoring	Number of HIV-infected children who receive a CD4 test (% for children aged <6 years or count for children aged ≥6 years) <b>at least once a year.</b>			
	Viral load monitoring	Number of HIV-infected children on ART who have a viral load test <b>at least once a year.</b>			
	Growth Assessment	Number of HIV-infected children who receive a <b>weight and height assessment at least once a year.</b>			
	<i>Pneumocystis jirovecii</i> pneumonia (PJP) Prophylaxis	Number of HIV-infected children given prophylaxis <b>every year (for any part of the year)</b> based on age category and CD-4 count. Trimethoprim-sulfamethoxazole for PJP prophylaxis is recommended for the following: <ul style="list-style-type: none"> <li>• All HIV-infected children aged &lt;1 year</li> <li>• HIV-infected children aged ≥ 1 year and CD4 &lt;15%</li> <li>• HIV-infected children aged ≥ 6 year and CD4 &lt;200 cell/mm<sup>3</sup></li> </ul>			
	Clinical Tuberculosis (TB) Screening	Number of HIV infected children who are screened for history of TB contact, TB signs and symptoms (chronic cough, prolonged fever, weight loss, night sweats) <b>at least once a year.</b>			
	Antiretroviral Treatment	Number of HIV-infected children a year on ART for <b>any part of the year.</b> All infected children should be on therapy.			
	Antiretroviral adherence monitoring	Number of HIV-infected children on ART who receive <b>at least four</b> adherence assessments every year.			
	Expanded indicators	Immunization History	Number of HIV-infected children who are documented as <b>up to date on standard immunizations</b> by year.		
<table border="0"> <tr> <td style="text-align: center;">Standard:</td> <td style="text-align: center;">When available:</td> </tr> <tr> <td> <ul style="list-style-type: none"> <li>• Bacille Calmette-Guerin (BCG)</li> <li>• Pentavalent x3 (DTaP, Hib, Hepatitis B)</li> <li>• Oral Polio x3</li> <li>• Rotavirus x2</li> <li>• Measles-Mumps or MMR x1</li> </ul> </td> <td> <ul style="list-style-type: none"> <li>• Pneumococcal (PCV-7) x3</li> <li>• Varicella x1</li> <li>• Cholera x2</li> <li>• Meningococcal AC x1</li> <li>• Typhoid x1</li> <li>• Influenza x1 yearly</li> </ul> </td> </tr> </table>			Standard:	When available:	<ul style="list-style-type: none"> <li>• Bacille Calmette-Guerin (BCG)</li> <li>• Pentavalent x3 (DTaP, Hib, Hepatitis B)</li> <li>• Oral Polio x3</li> <li>• Rotavirus x2</li> <li>• Measles-Mumps or MMR x1</li> </ul>
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Oral Health Assessment		Oral health should be assessed by medical doctor or dentist or nurse <b>at least once a year.</b> Children with abnormal oral health should be referred to a dental clinic.			
HIV disclosure to child	Number of HIV-infected children aged <b>&gt;10 years</b> who are disclosed to their status for any length of time in the year.				
Hospitalization	Number of HIV-infected children hospitalized at least once in the year.				

Table 1: Pediatric HIVQUAL-H: Indicators and Definitions in Haiti, 2012-2016.

proportion of patients meeting the indicator definition was determined separately for each calendar year. Fisher's exact test was used to see if there were associations between performance and time period. The Cochran-Armitage trend test was used to test if there was a linear trend in performance during the five-year period. The level of significance is set at P-value <0.05. Statistical analyses were carried out using SAS Version 9.4 (Cary, North Carolina, USA).

## Results

Over the five-year period, there were 393 unique patients, with 283 patients in 2012, 291 in 2013, 290 in 2014, 298 in 2015 and 311 in 2016 accounting for 1473 patient-years (PY) analyzed (Table 2). Less than 50% were males (699/1473 PY) with a median age of 8 years and range of 0-15 years (Table 3).

Indicator Name	Overall patients meeting criteria by year, N (%)						P value for trend
	2012 N=283 (%)	2013 N=291 (%)	2014 N=290 (%)	2015 N=298 (%)	2016 N=311 (%)	Total <sup>a</sup> N=1473 (%)	
<b>Core Indicators</b>							
Clinical status monitoring	272 (96.1)	278 (95.5)	277 (95.5)	295 (98.9)	304 (97.7)	1426 (96.8)	0.0196
CD4 monitoring	283 (100)	291 (100)	288 (99.3)	294 (98.6)	167 (53.6)	1323 (89.8)	<0.0001
Viral load monitoring	54 (19.0)	133 (45.7)	293 (79.3)	37 (12.4)	276 (88.7)	730 (49.5)	<0.0001
Growth assessment	283 (100)	284 (97.5)	280 (96.5)	296 (99.3)	311 (100)	1454 (98.7)	NS <sup>b</sup>
PJP prophylaxis	282 (99.6)	290 (99.6)	288 (99.3)	297 (99.6)	308 (99.0)	1465 (99.4)	NS
Clinical TB screening	282 (99.6)	284 (97.5)	279 (96.2)	297 (99.6)	310 (99.6)	1452 (98.5)	NS
Antiretroviral treatment	256 (90.4)	274 (94.1)	274 (94.4)	285 (95.6)	305 (98.0)	1394 (94.6)	<0.0001
Adherence monitoring	270 (95.4)	270 (92.8)	266 (91.7)	273 (91.6)	283 (91.0)	1362 (92.5)	0.0417
<b>Expanded Indicators</b>							
Immunizations up to date	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	-
Oral Health assessment	282 (99.7)	285 (97.9)	281 (96.9)	297 (99.7)	310 (99.7)	1455 (98.8)	NS
HIV disclosure to child <sup>c</sup>	14 (15.6)	44 (43.6)	36 (32.4)	39 (30.0)	48 (30.6)	181 (30.7)	NS
Hospitalization <sup>d</sup>	14 (4.9)	12 (4.1)	12 (4.1)	12 (4.0)	16 (5.1)	66 (4.4)	NS

CD4, cluster of differentiation 4; PJP, *Pneumocystis jiroveci* pneumonia; TB, tuberculosis; HIV, Human Immunodeficiency Virus.

<sup>a</sup>Each eligible patient was assessed separately for meeting criteria each calendar year; based on the 393 unique patients reviewed during the 5-year period, there were 1473 separate patient-years analyzed.

<sup>b</sup>NS: not significant,  $p \geq 0.05$

<sup>c</sup>Based on those age 10+years, 2012: N=90, 2013: N=101, 2014: N=111, 2015: N=130, 2016: N=157, Total: N=589.

<sup>d</sup>Number of different patients hospitalized that year

**Table 2:** Pediatric HIVQUAL-H Performance Measurement Results, St. Damien Hospital - Haiti, 2012-2016.

	2012 N=283 (%)	2013 N=291 (%)	2014 N=290 (%)	2015 N=298 (%)	2016 N=311 (%)
Sex, M	138 (48.7)	141 (48.4)	133 (45.8)	138 (46.3)	149 (47.9)
Age (mean, SD)	7.28, 3.93	8.03, 3.89	8.44, 3.71	8.72, 3.69	9.11, 3.80
Body Mass Index<16 <sup>a</sup>	94 (33.2)	96 (33.0)	84 (29.0)	94 (31.5)	121 (40.3)
Low CD4 count <sup>b</sup>	26 (9.2)	15 (5.2)	20 (6.9)	19 (6.4)	5 (1.6)
Detectable Viral Load <sup>c</sup>	25 (8.8)	50 (17.2)	111 (38.3)	16 (5.4)	53 (17.0)
<b>WHO HIV Stage</b>					
1	38 (13.4)	73 (35.0)	93 (32.0)	32 (10.7)	16 (5.1)
2	199 (70.3)	154 (52.9)	71 (24.4)	96 (32.2)	119 (38.2)
3	26 (9.1)	33 (11.3)	86 (29.6)	125 (41.9)	116 (37.2)
4	8 (2.8)	17 (5.08)	27 (9.3)	42 (14)	53 (17.0)

<sup>a</sup>BMI percentile of less than 5 is usually used as the criterion to determine cut-offs for malnutrition in pediatrics, however we had insufficient data to make those specific calculations for our patients

<sup>b</sup>Number of patients with CD4 count<15% in those <6 years and <200 cell/mL in those  $\geq 6$  years

<sup>c</sup>Number of patients with HIV viral load greater than 300 copies/mL

**Table 3:** Characteristics of 393 unique pediatric HIV patients at St. Damien Pediatric Hospital in Haiti, 2012-2016.

## Core indicators

Overall, 96.8% received clinical status monitoring (1426 PY). In 2012 and 2013 most patients (70.3% and 52.9%, respectively) were classified as stage 2 while in 2015 and 2016 (41.9% and 37.2%, respectively) were classified as stage 3 per WHO guidelines (Table 3). Nutritional assessment was only able to be based on body mass index (BMI). Of those with recorded growth parameters, low BMI (<16) ranged from 29-40% by year. There were insufficient data to calculate BMI percentiles. About 6.5% (85/1310 with measured values) had a clinically low CD4 count (<15% in those 1-6 years and <200 in those age 6 and above) during the study period. Overall, 89.8% received yearly CD4 monitoring (1323 PY). Viral load monitoring was only done 50% of the time (730 PY) with frequency increasing in recent years (Table 2). Of those with measured viral loads, 34.9% (255/730) were detectable at least once in any given year (>300 copies/mL being the local cutoff). Viral load was detected in 5.4-17.2% patients yearly except in 2014

when it was detected in 38.3% of patients (Table 3). 94.6% received antiretroviral treatment (1394 PY). Linear trends were noted for viral load, CD4 count, antiviral therapy (all  $p<0.0001$ ), and clinical staging ( $p=0.02$ ) (Table 2).

Overall, there was 99.4% PJP prophylaxis (1465 PY), 98.5% TB screening (1452 PY), and 98.7% growth assessments (1454 PY). There was an overall medication adherence monitoring rate of 92.5% (1362 PY). The frequency trend over time showed an overall decreasing percentage of meeting the adherence criterion over the five-year period of the study ( $p=0.0417$ , Table 2). There were also some patients not on ART with documented adherence assessments for prophylaxis (76 PY) and not ART, but this was incorporated in the final totals together as it did assess their compliance to the prescribed regimen. We initially aimed to count adherence by the number of adherence notes present; however, on review, several of these templates were completely blank without any actual adherence data recorded (overall around 10%),

Immunization	2012 N=283 (%)	2013 N=291 (%)	2014 N=290 (%)	2015 N=298 (%)	2016 N=311 (%)	Total N=1473 (%)
BCG	123 (43.5)	132 (45.4)	129 (44.5)	129 (43.3)	131 (42.1)	644 (43.7)
Diphtheria-Tetanus-Pertussis	206 (72.8)	218 (74.9)	218 (75.2)	226 (75.8)	228 (73.3)	1096 (74.4)
Haemophilus influenza type b	65 (23.0)	75 (25.8)	83 (28.6)	92 (30.9)	96 (30.9)	411 (27.9)
Hepatitis B	95 (33.6)	106 (36.4)	107 (36.9)	114 (38.3)	119 (38.3)	541 (36.7)
Measles (MMR/MR/Measles)	181 (64.0)	193 (66.3)	191 (65.9)	198 (66.4)	208 (66.9)	971 (65.9)
Oral Polio Vaccine	208 (73.5)	219 (75.3)	220 (75.9)	228 (76.5)	229 (73.6)	1104 (74.9)
Pneumococcal (PCV7 and/or PPSV23)	79 (27.9)	80 (27.5)	86 (29.7)	89 (29.9)	92 (29.6)	426 (28.9)
Rotavirus	-	-	-	-	3 (1.0)	3 (0.2)

BCG, Bacille Calmette-Guerin; PCV7, Pneumococcal Conjugate Vaccine-7; PPSV23, Pneumococcal polysaccharide vaccine-23; MMR, Measles-Mumps- Rubella; MR, Measles-Rubella.

<sup>a</sup>Given low documented immunization rates, these data represent any patient with at least one documented vaccine in that category in or prior to that year, not necessarily full series.

**Table 4:** Documented Immunizations of Pediatric HIV patients in Haiti, 2012-2016<sup>a</sup>.

so we assured at least 4 completed assessments when counting those meeting this criterion.

### Expanded indicators

Overall, immunizations were not reliably documented in the EMR and no patient met the status of being “up to date” per the Haiti HIV guidelines (Tables 2 and 4). The most documented vaccines were DTaP and OPV (both >70% each year) and any form of measles vaccine (around 65% each year). BCG was documented in 40-45% of patients. Hep B, Hib, and Pneumococcal vaccines were all documented roughly at or below 33% each year (Table 4).

Though oral health screening rates were high (99% overall) with 44.9% having documented dental disease (661 PY), only 6.1% of those (40/661) had a documented dental referral (Figure 1). Overall, only 30.7% (181/589) of patients aged 10 years and older were disclosed to their diagnosis, with widely-variable yearly rates from 16-45% across the time period (Table 2). The overall hospitalization rate was 4.5% (66 PY, Table 2) accounting for a total of 79 hospitalizations during that time with malnutrition, TB, and HIV complications accounting for the majority of the reasons (67/111, 60.4%) for admission (Figure 2).

### Discussion

The proposed HIVQUAL-H model provided a good overview of the quality of pediatric HIV care provided at the St. Damien HIV clinic and highlighted some successes and areas that could use improvement.

#### Core indicators

The documentation of the WHO clinical staging was well-done likely due to the fact that it is built into the EMR template as a checkbox, which makes it much easier to complete at each visit. CD4 monitoring used to be the mainstay of the monitoring at this clinic, but has trended down in recent years (from 100% in 2012 to 54.6% in 2016) in favor of increased viral load testing, which became more available in 2014-2016. This also explains why very few had viral loads done in 2012-2013 (under 50%) and that viral load checks became more frequent by 2016 (88.7%) (Table 2). Prohibitive cost may impede more frequent testing which in some settings allows for closer monitoring of response to therapy. There was excellent documentation of all children receiving PJP prophylaxis, regardless of whether they were on ART or not, which is crucial given this high-risk population.

TB screening rates were high, likely related to the pre-written questions within the EMR note templates. However, those with positive screening questions did not have good documentation of subsequent work-up and treatment, likely because this was done in the inpatient

setting and not recorded in the outpatient EMR. We also discovered that during the study period, some patients were placed on empiric daily isoniazid (INH) prophylaxis as per the guidelines of the WHO that came out near the beginning of the study period. The recommendations stated to give at least 36 months of daily INH to HIV patients in TB-endemic regions to help prevent the risk of TB infection in these populations [21]. We recorded the number of patients on any length of isoniazid therapy in each given year (Figure 3).

The rate of the active HIV patients on documented ART therapy was very high, above 90% in all years analyzed with significant trend that increased steadily each year ( $p < 0.0001$ ) indicating excellent work on this indicator by staff in recent years. Some patients not on ART were either very recently diagnosed or waiting for a more stable social situation before being started. Though the overall rate of adherence was high (91.0-95.4% by year over 5-year period), this was only looking for four adherence assessments per year. The standard should really be medication adherence assessment at every clinic visit, though this was difficult to discern as not every patient is seen at the same interval, depending on clinical status and history of compliance. Also, given the adherence assessment is listed separately from the visit notes, the documentation was poor, many templates were not filled out and in our analysis only 4 completed forms from total available in a year counted as adherence. In addition, the percentage of patients meeting this criterion decreased each year, suggesting poorer documentation over time. A more thorough evaluation of the adherence documentation processes could lead to improvement in completion rates and increased amount of true assessments at each visit.

#### Expanded indicators

Immunizations were not reliably recorded and no active patient met the definition of being up to date on vaccines according to the local guidelines. The immunization records were better documented for younger patients, with more adolescent patients often having blank records. Though accurate documentation may be an important issue to address, reliable supplies of routine vaccines may be more of a problem and newer vaccine formulations are only slowly rolling out with Pentavalent (DTaP-Hib-Hep B) vaccine coming in 2012 and Rotavirus not until 2014 [22]. Additional important vaccines in HIV infected population include the pneumococcal vaccines, which are yet to be available routinely and are not yet part of the national guidelines.

Though there was good documentation of oral health assessment, there was a large amount of dental disease described, but not much documentation of dental referrals. No specific dental records were available as the on-site dental clinic where most referrals were sent does not use the

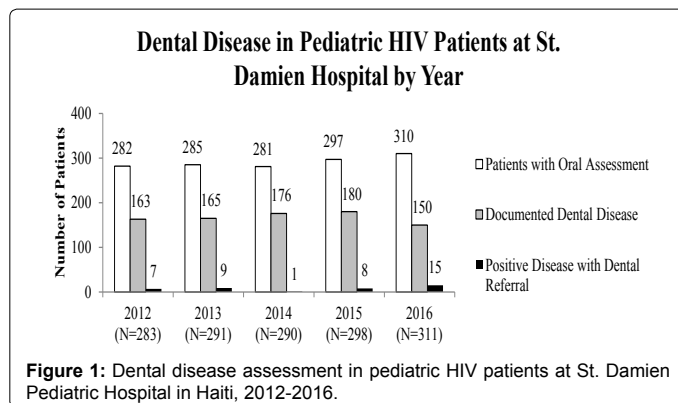
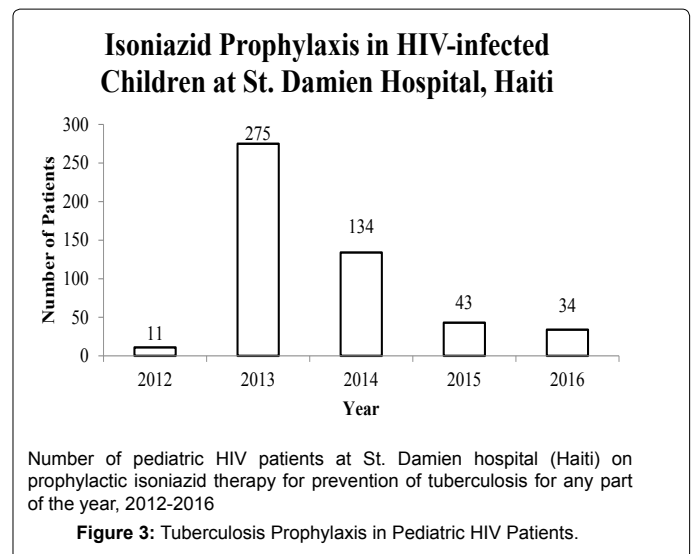
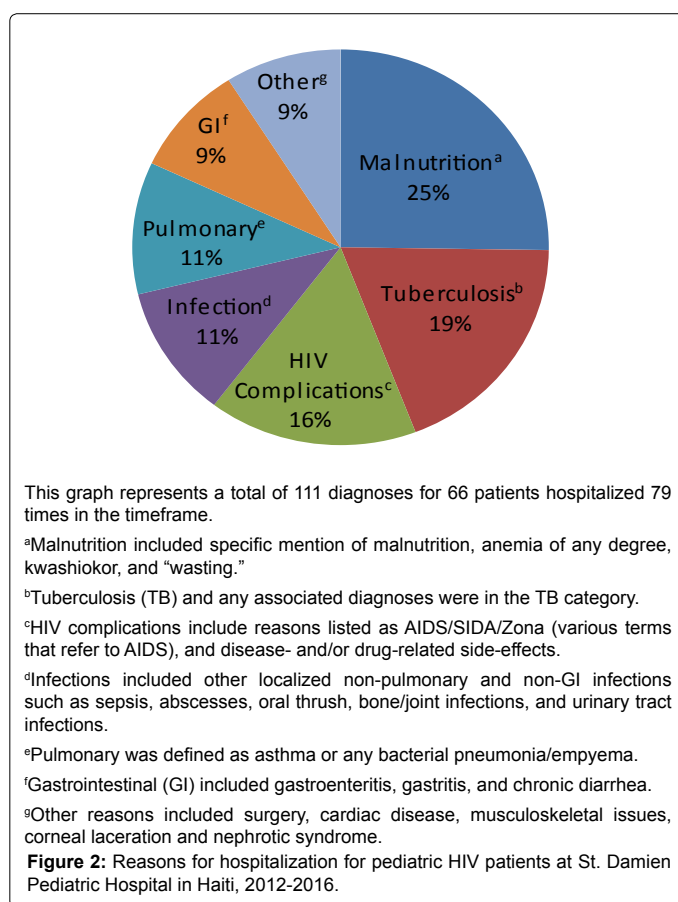


Figure 1: Dental disease assessment in pediatric HIV patients at St. Damien Pediatric Hospital in Haiti, 2012-2016.



Number of pediatric HIV patients at St. Damien hospital (Haiti) on prophylactic isoniazid therapy for prevention of tuberculosis for any part of the year, 2012-2016

Figure 3: Tuberculosis Prophylaxis in Pediatric HIV Patients.



This graph represents a total of 111 diagnoses for 66 patients hospitalized 79 times in the timeframe.

<sup>a</sup>Malnutrition included specific mention of malnutrition, anemia of any degree, kwashiorkor, and "wasting."

<sup>b</sup>Tuberculosis (TB) and any associated diagnoses were in the TB category.

<sup>c</sup>HIV complications include reasons listed as AIDS/SIDA/Zona (various terms that refer to AIDS), and disease- and/or drug-related side-effects.

<sup>d</sup>Infections included other localized non-pulmonary and non-GI infections such as sepsis, abscesses, oral thrush, bone/joint infections, and urinary tract infections.

<sup>e</sup>Pulmonary was defined as asthma or any bacterial pneumonia/empyema.

<sup>f</sup>Gastrointestinal (GI) included gastroenteritis, gastritis, and chronic diarrhea.

<sup>g</sup>Other reasons included surgery, cardiac disease, musculoskeletal issues, corneal laceration and nephrotic syndrome.

Figure 2: Reasons for hospitalization for pediatric HIV patients at St. Damien Pediatric Hospital in Haiti, 2012-2016.

EMR, but separate paper charts. Incorporating referrals and completion of these visits would help improve quality of care.

The disclosure rate is very low compared to the hospital goal (100% disclosed by age 10 years) In discussion with local faculty and families, there is still significant stigma surrounding HIV diagnoses in the community. Parents are afraid to tell their children why they take medications as they worry they may inadvertently share this knowledge with friends and neighbors, which could negatively impact their day-to-day lives. There have been improved efforts over the past couple of years at St. Damien for a more step-wise approach to disclosure with families, including the creation of group activities for children and parents as well as dedicated staff including a clinical psychologist to assist in helping and educating families.

The method of recording the number and reasons for hospitalizations was not reliable and the hospital inpatient records are not within the EMR. An integrated hospital/clinic EMR may address this issue and improve tracking of patient outcome. Though we were able to estimate BMI data based on some recorded heights and weights, a more accurate BMI percentile per age was not feasible due to lack of all necessary data (height, weight and age in months) being recorded reliably within the same visit for most of the patients; therefore a BMI <16 was used to loosely indicate malnutrition. A more detailed evaluation and documentation process regarding nutritional status is needed, preferentially to incorporate calculations of WHO Z-scores to allow for the most accurate identification and categorization of at-risk children. This is particularly important as malnutrition was found to be the leading cause of documented hospital admissions in this population during the study period (Figure 2).

## Strengths

This study had several strengths, foremost being that it provides the first published data regarding a comprehensive assessment of the quality of pediatric HIV care in Haiti. As it was implemented in the largest pediatric center in the country and five years of data were analyzed, the sample size is robust. As well, the data gathered have clearly identified specific areas within important pediatric HIV care categories to develop in this particular facility. There is now a baseline to design targeted interventions to improve areas of deficiency and allow for repeat assessment.

## Limitations

As in any retrospective study, our data were limited to what had been previously recorded in the EMR and therefore, there were several areas that were incomplete or missing. Overall though, given the large pediatric HIV population sampled, the amount of missing elements was more minimal (except in immunizations as discussed above), so we feel the data for the quality of care indicators was still highly accurate.

We only examined the patients currently listed as "active" in their system, which did not allow full assessment across the entire patient population (those who were in the system as inactive due to extended time since last clinic visit, those still with HIV but not on therapy, or those who had been treated during the study period but had since

passed away). Therefore, their system's classification did not allow us to accurately assess mortality rates, as patients that may have been treated in earlier years of the study and died before the time of data collection were not analyzed.

Only the most recent or worst clinical data were recorded from each year where one patient had multiple data values in certain categories. Furthermore, as each patient was assessed separately by calendar year for meeting criteria and these data were later pooled by year, this did not allow for analysis of progress/worsening of individual patients over time.

The current HEALTHQUAL software (Isanté) being used at St Damien is not set to generate reports specific to and in enough detail for pediatrics (see Appendix 1 for sample HEALTHQUAL report and definitions). It would help in the future if the EMR could be adapted to allow for formal reports according to the proposed HIVQUAL-H parameters outlined here allowing for easier and more accurate ongoing surveillance of pediatric data for further improvements.

## Future Direction

Immediate next steps should include in-depth analyses of current documentation processes to identify points in the current system that could be quickly improved to address identified deficiencies, such as recording weight and height and age for proper nutritional assessments at each visit. An important next step would be implementing programs with psychosocial support to help in approaching disclosure of HIV status by the age of 10. We should work towards integrating the HIVQUAL-H model into the EMR at St. Damien.

## Conclusion

This study attempts to address the gaps in knowledge regarding the quality of care monitoring of pediatric HIV patients in Haiti by applying a tool with core and expanded HIV indicators for assessment customized to local guidelines. This assessment shows performance rates of many pediatric HIV indicators in Haiti are good, whereas some need improvement. Viral load monitoring, oral health care, HIV disclosure, and immunizations are areas that could use focused interventions at this facility to improve standard of care for this population.

We think this tool can be easily adapted for other pediatric HIV programs in developing countries with similar resource constraints. The ability to identify these trends will allow for identification of areas needing improvement and future quality improvement projects, ultimately leading to better care for these patient populations.

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