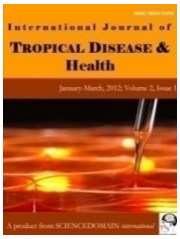

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Mapping an HIV Treatment Program to Identify Barriers to Linkage in HIV Care in Resource Limited Settings

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Authors' contributions

Author KMB preformed data collection, analysis, and manuscript preparation. Author LA defined study design and facilitated in arranging in country ethical review and data analysis. Authors EO, HM, and CM participated in data collection. Author JM facilitated communication between sites. Author PK developed study design, and participated in data analysis and manuscript preparation. All authors read and approved the final manuscript.

Method Article

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ABSTRACT

Aims: To develop a practical method to evaluate and address failures to linkage to care for HIV treatment so as to achieve better access to antiretroviral therapy in resource limited settings.
Study Design: A mixed methods analysis to identify and quantify failure to linkage to care involving intensive program mapping, retrospective quantification of retention data, and statistical analysis.
Place and Duration of Study: AIC Kijabe Hospital, Kijabe Kenya. Data were collected from January 1 to December 31, 2011. Data collection and analysis was conducted in February 2012.
Methodology: First a series of successive interviews of all levels of care providers was used to create a program map and identify linkage points. Following this, data registries

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were identified and cases at each linkage point were quantified. Simple statistical analysis of retention data were then completed and trends analyzed by Kaplan-Meier survival analysis.
Results: Less than 20% of eligible cases testing positive for HIV were enrolled in the treatment program. Most cases enrolled received CD4 testing (78.9%). Most eligible enrolled patients were initiated on ART (82.2%). Patients referred from VCT (voluntary testing) were more likely to be enrolled, receive CD4 testing, and be initiated on therapy. Cases enrolled in the program within 7 days of HIV diagnosis had improved time to initiation of therapy (43 days vs 79 days, p<.001). Cases who received a CD4 test within seven days of diagnosis also had improved time to initiation of therapy (47 vs 77 days, p=.01).
Conclusion: This method proved effective to identify, prioritize, and problem solve to improve linkages to care in our setting. Further evaluation should include prospective studies to identify facilitators to linkage and test interventions.

Keywords: HIV; retention; linkage to care; operational research; resource limited settings.

1. INTRODUCTION

High levels of patient lost to follow-up contribute significantly to patient mortality in resource limited settings [1,2]. Those who are lost to follow up often present later with severe immunosuppression and are more likely to die in the first few months of treatment [3]. Early effective treatment of HIV in resource limited settings has shown not only to improve patient morbidity and mortality [4], but also to prevent transmission of the virus among discordant couples [5]. The growing body of evidence on the process of HIV care and treatment outcomes has led to the recent guidelines update on HIV treatment by the World Health Organization to initiate antiretroviral therapy (ART) when immune cells are higher. The WHO now recommends initiation of ART at a CD_4 count of 500 cells/mm^3 rather than the previous threshold of 350 cells/mm^3 [6]. This means that more people should have access to therapy sooner in the course of HIV infection, which could lead to an estimated 36% decrease in new HIV infections and approximately 3 million lives saved by 2025 [7]. These exciting predictions will only be realized if HIV treatment programs are effective at linkage to care.

However, in 2010 only 49% of those eligible for antiretroviral therapy in sub-Saharan Africa were started on treatment [8]. In sub-Saharan Africa, as many as 55% of patients fail to receive diagnostic testing for disease staging [9], and even fewer are initiated on antiretroviral therapy. Now, with expanded criteria for eligibility, an estimated 16.2 million people are eligible but not yet receiving ART [7]. Emerging insights in the literature suggest that the majority of these patients are lost to health care systems early after HIV diagnosis and many never enroll into treatment programs [9]. This critical linkage to care is referred to as the pre-ART period. The pre-ART period is a stepwise progression from diagnosis to treatment that usually includes an evaluation for program enrollment, CD_4 testing to determine disease staging, and initiation of therapy.

Programs treating people with HIV in resource limited settings report a variety of processes by which patients are enrolled, evaluated, and initiated on therapy, including: multiple clinical and psychological assessments prior to ART initiation, treatment buddies or other disclosure, group sessions, various training on HIV treatment and medications, and pill counts of multivitamins and cotrimoxazole for adherence prior to ART initiation [2,10,11]. These steps may improve adherence to therapy for those who do enroll into treatment programs [12],

however it appears that most cases are lost prior to enrollment. Little is known about factors that may facilitate retention and progression through pre-ART steps. Complicated systems of care compounded by a lack of human resources and information resources may all contribute to poor linkage to care in resource limited settings. Recently, the World Health Organization has called for increased operational research to evaluate the HIV care process and further improve linkage to care, retention and adherence to meet the incredible new demand for treatment.

We developed and implemented an evaluation process to determine pre-ART barriers to care and quantify patient retention across critical linkage points. This information may be used in order to inform a quality improvement plan to facilitate patient linkage. We applied this tool to an HIV treatment program in Kijabe, Kenya. This method is a simple concept that may serve to improve our knowledge of the operational aspects of HIV care in resource limited settings.

2. METHODS

2.1 Study Setting

AIC Kijabe Hospital is a well-known provider of HIV treatment and prevention services in Kenya. The program is community based and patient centered with over 6,000 patients on ART in 2011. Kijabe Hospital has prospectively evaluated adherence strategies to improve retention on therapy and uncovered positive effects of facilitators to adherence on therapy such as pill counts and clinic visits [13].

This study was completed in two simple phases, intensive mapping and quantification of retention, followed by statistical analysis of data.

2.2 Process in Detail

2.2.1 Phase I: Intensive mapping

We first met with host site leadership and were introduced to program staff and care providers. A primary interview was initiated with a provider identified as having extensive knowledge of the program flow and referral methods. During the primary interview, an initial schematic was drawn to map patient flow using boxes to represent essential programmatic steps and arrows to represent decision making and transition through steps. This map was then used as an interview prompt in successive interviews to further clarify patient flow, determine areas of patient drop out, and discuss potential reasons for patient fall out. After introduction, each interview was initiated by first describing the map in detail. Participants were encouraged to interrupt with suggestions to improve or correct the map, and further asked to identify critical linkage points where patients were at risk of falling out of the program. The map was subsequently redrawn to represent the new information and reported back to participants for review and correction. Free form responses concerning drop out points and reasons for drop out were recorded on the series of maps used in the process and later consolidated into themes. The interview process was considered complete when members of each staffing or care provider category in the program were interviewed and when themes were repeating themselves without new insight.

2.2.2 Phase II: Retention by critical linkage point

A total of 5 HIV testing registries were reviewed for cases that tested positive in 2011. Positive cases were linked to the electronic database (IQ Care) to confirm enrollment into the treatment program. For enrolled cases, the database was queried for data including: number receiving a CD_4 result, number of ineligible patients receiving a repeat CD_4 result, number of patients initiating ART, and patient status at time of follow up. A single spreadsheet was compiled for all identified positive cases from the various registries. The final spreadsheet included post-enrollment data for linked cases. Retention rates were calculated as the number of cases documented to have completed a required step divided by total cases eligible for the step, expressed as a percentage.

To determine if a positive case resided within the catchment area, a sample of cases were selected to trace geographical and residential data available through the hospital electronic registration system. The geographical data were reviewed by experienced HIV clinic workers and program data officers to identify cases residing within the catchment area. The sample provided a basis for an estimate of how many cases presented from within the catchment area.

2.2.3 Statistical analysis

Data were analyzed using SPSS v.19 software. Total follow up time was calculated as of February 1, 2012. Factors such as gender, age, method of referral, and baseline CD_4 were evaluated for association with desired outcomes such as enrollment and time to enrollment, ART initiation and time to ART initiation, and time to CD_4 testing, using chi-square or one-way ANOVA tests where appropriate. Time to enrollment and time to baseline CD_4 were dichotomized to early (within 1 week) and late (more than one week) from testing for Kaplan-Meyer survival analysis on survival to ART initiation, using log-rank test for significance.

3. RESULTS

3.1 Program Mapping

A total of 19 staff interviews were conducted, including interviews with medical officers, clinical officers, nurses, community health workers, training staff, program managers, and data officers. The resulting information was compiled in the form of a map which was repeatedly verified over successive interviews. Program flow is represented by boxes in Fig. 1. Testing could occur in multiple locations including inpatient wards, clinics, casualty, and in the community. After testing patients were required to meet with a community health worker in their home and possibly to join a community support group before reporting to the central Kijabe HIV clinic for enrollment in the program. In the enrollment visit, the patient would meet with a care provider and would often complete initial CD_4 testing. The patient would then be scheduled to return to either the central clinic or a peripheral community clinic depending on the patient's preference and location for CD_4 results and staging in about two weeks. For those immediately eligible for ART, the initiation process included repeat home visits if necessary and attending the training seminar with a designated treatment buddy. Seminars were held at Kijabe Hospital only. The patient and the treatment buddy were required to demonstrate understanding of antiretroviral therapy and importance of compliance prior to receiving the first dose of medication. Repeat clinic visits or educational seminars may be recommended on a case by case basis. For those not immediately eligible for therapy, repeat CD_4 testing was scheduled for six months. These patients were required to prove compliance with daily use of co-trimoxazole and multivitamins.

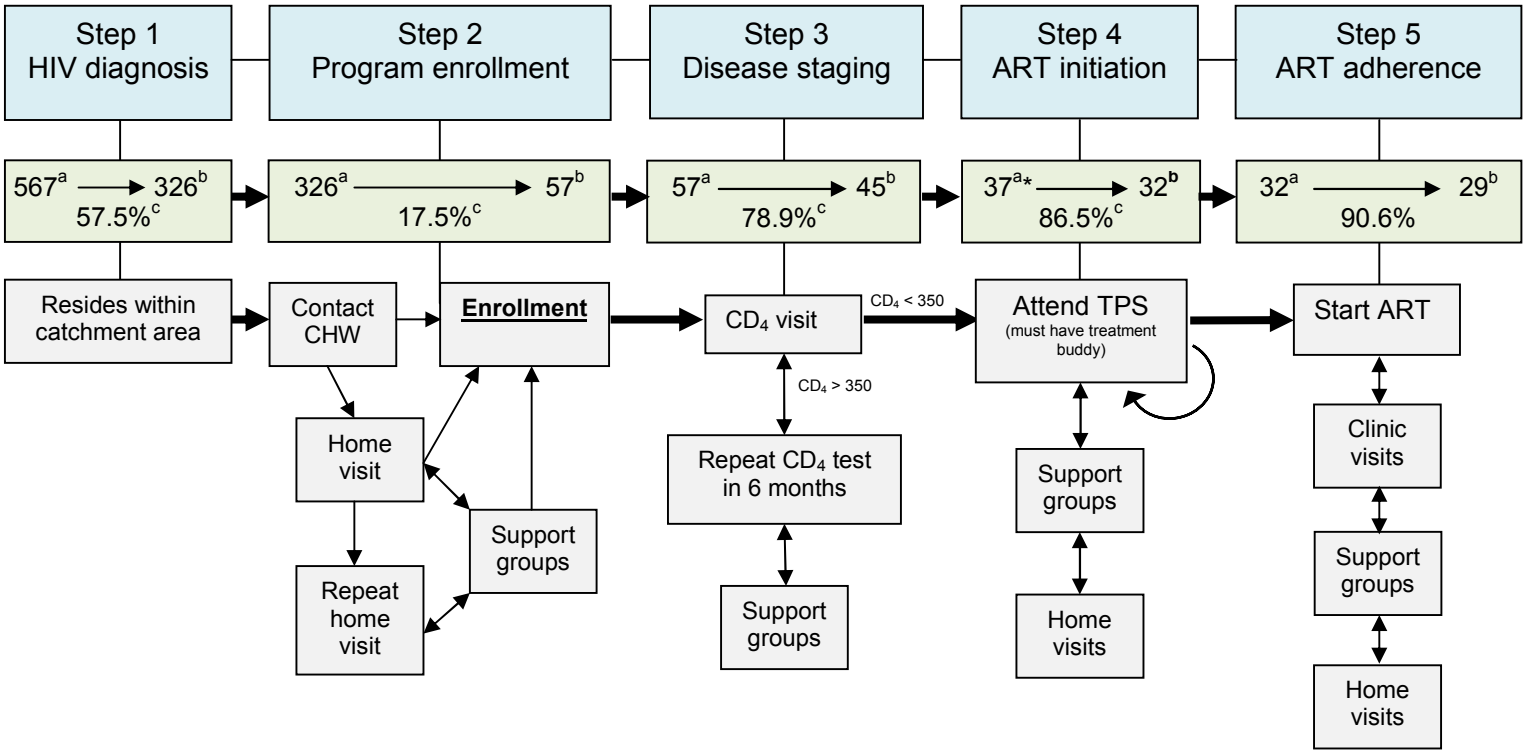


Fig. 1. Map of patient flow and retention rates for the AIC Kijabe Hospital HIV treatment program from testing to treatment for 2011

*a. Number of cases eligible for the step. b. Number of cases that completed the step. c. Retention rate for the step, (retention rate (c)=b/a*100). *There were 8 cases out of the 45 who completed CD_4 testing that were not eligible for ART (17.8%). Half of those (4) received repeat testing and all four were still ineligible for ART after repeat testing*

3.2 Retention by Critical Linkage Point

Data were available to calculate retention at most critical linkage points, shown in Table 1. There were 4801 tests completed in 2011. Of the tests completed there were 567 positive cases. Of positive cases, 204 had identifiable hospital numbers that could be used to trace hospital charts. Of those, only 195 charts were found and reviewed for demographic data. There were 106 cases of the 195 that were traced who resided within the catchment area (57.5%). This percentage was used to extrapolate an estimate of the approximate number of positive cases in 2011 presenting from within the catchment area, or 326 (57.5% of 567 positive cases).

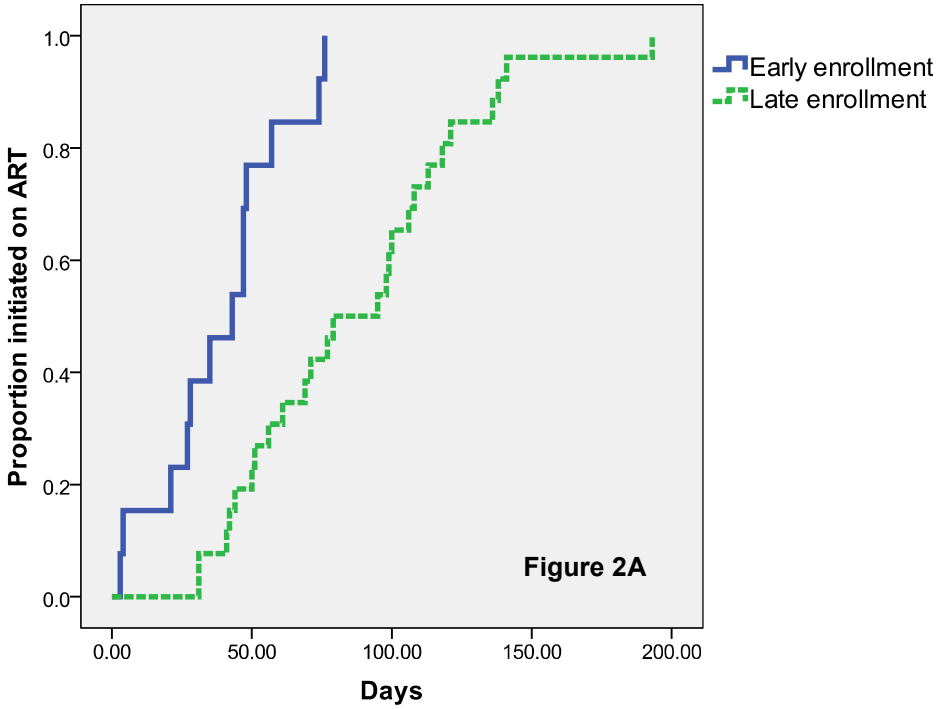
Table 1. Number of cases and retention rates by critical linkage point

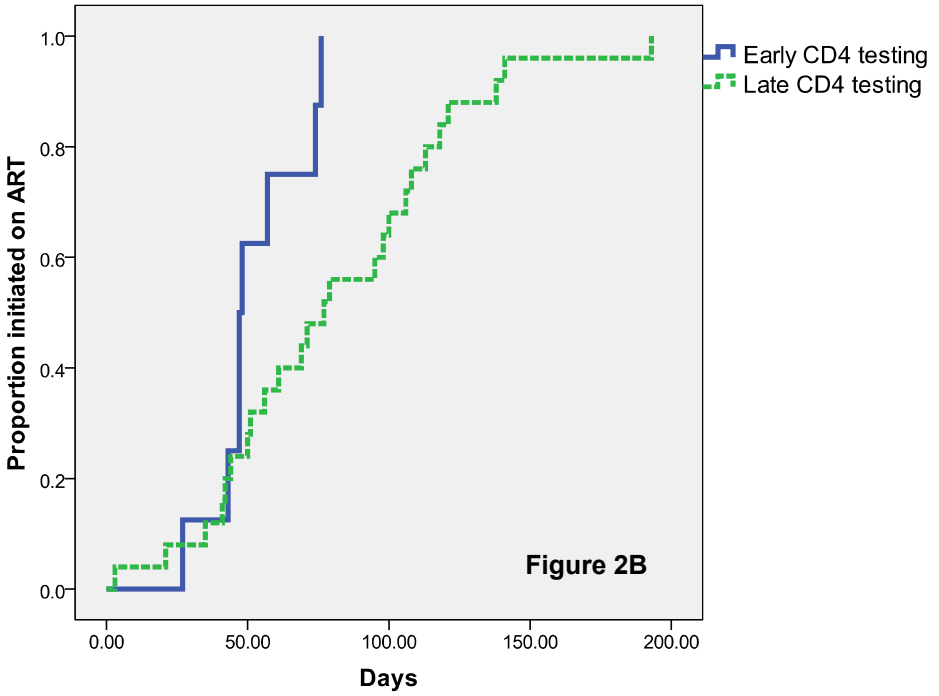
Critical linkage point	Number of cases	Percent of total	Retention rate
Positive cases	567	100.0%	100.0%
Cases within catchment area	326	57.5%	57.5%
Cases enrolled in program	57	10.1%	17.5%
Cases received a CD4 result	45	7.9%	78.9%
Cases eligible for ART at baseline CD4	37	6.5%	82.2%
Eligible cases initiated on ART	32	5.6%	86.5%
Cases in care on ART at follow up	29	5.1%	90.6%

For all other data, the true value (n) determined from the testing registries and the enrollment data are presented in Fig. 1 for each major step where data were available. Of those positive cases estimated to live within the geographical restriction, 57 (17.5%) were linked to care (i.e. enrolled) at Kijabe Hospital. Of those enrolled, 45 cases (78.9%) received initial CD_4 results. Half of the ART-ineligible patients received repeat CD_4 results (4/8) (not shown in Fig. 1. Of those eligible by baseline CD_4 ($CD_4 \leq 350$cells/mm^3, n=37), 32 were initiated on ART (86.5%). Of those eligible for therapy by all criteria (including opportunistic infection criteria such as TB infection), 37 (82.2%) were initiated on ART. There were 29 (90.6%) in care on ART at follow up. A small number (6) were initiated on ART without a recorded CD_4 result.

3.3 Statistical Analysis

We tested for associations of gender, age, CD_4 results, and source of enrollment with desired outcomes including: enrollment, time to enrollment, received a CD_4 test, time to first CD_4 test, ART initiation, and time to ART initiation. There were no significant differences for gender among any of these outcomes. Cases initiating ART in less than 30 days from diagnosis were younger than those initiating later than 30 days (27 years vs 38 years of age, p=.02). The mean baseline CD_4 was lower for those initiating ART than for those who did not (162.4 vs 472.7 respectively, p=.001). Interestingly, cases referred from voluntary counseling and testing program (VCT) were more likely to be enrolled (43.9% VCT vs other, p=.03), enrolled early (45% VCT vs other, p<.001), have a CD_4 test ever completed (44.4% vs other, p=.05), and to have an CD_4 test completed within one week of enrollment (81.8% VCT vs other, p=.001). Other sources of referral included outpatient, casualty, prevention of mother to child transmission, and inpatient referrals.





Figs. 2A and 2B. Time to ART initiation by early and late enrollment and CD_4 testing, respectively

Time to initiation of ART was evaluated by Kaplan-Meier survival analysis for cases who: a) received a CD_4 result within or after 7 days from diagnosis, and b) were enrolled within or after 7 days from diagnosis above Figs. 2A and 2B. The median time to ART initiation for those who were enrolled early (within 7 days) and late (more than 7 days) was 43 days [95% CI: 26.2-59.7] and 79 days [95% CI: 45.3-112.7] , respectively (p<.001).The median time to ART initiation for those who had a CD_4 count within 7 days of diagnosis was 47 days [95% CI: 42.4-51.6] and 77 days [95% CI: 60.7–93.3] for those who received a CD_4 in greater than 7 days (p=.01).

4. DISCUSSION

We developed a methodology that can be used in any setting to evaluate a system of care and retention within that system. We used quantitative data to determine retention rates at each critical linkage point in order to prioritize and problem solve. We found that the points of most significant lost to follow-up were prior to program enrollment; followed by CD_4 testing for disease staging and repeat testing for those not immediately eligible for ART. Early enrollment and early CD_4 testing seemed to improve time to ART initiation.

This data are consistent with known trends in resource limited settings [9]. We have identified three other studies that have followed cases from the point to testing through to initiation of ART [14-16]. Our data are compelling in that we show less than 20% of positive patients were enrolled into care, compared to more the 40% in the articles mentioned. This drop off may be due to multiple factors, including a proportion of cases choosing to follow up elsewhere or treatment refusal [17]. Variable results at other sites likely relate to the major differences across treatment programs in resource limited settings. In contrast, we show retention after enrollment as quite high (78-90%), raising the question that the stringent program requirements for enrollment may be self-selecting for success after enrollment. We also show a positive relationship with referral from VCT to both enrollment and CD_4 testing. Other programs report positive [16] and negative [14] associations between VCT and program enrollment. At Kijabe Hospital, it is possible that the location of VCT, being directly connected to the HIV clinic, may contribute to this association; or that the patient population presenting to VCT is fundamentally different in some way than those come for ambulatory care, inpatient care, or pregnancy.

The method described here through mapping patient flow and quantifying retention at each step is useful for shedding light on previously unknown barriers to linkage in HIV treatment programs and may improve program compliance with monitoring and support of linkage and early retention in care as noted in the International Association of Physicians in AIDS Care guidelines [18]. This study is limited mainly by the logistics of documentation at the site. At Kijabe, there were five separate registers that had to be reviewed for duplicate cases. A separate database was used to identify hospital numbers for each case and attempt to locate individual charts for demographic data. The result was a cumbersome search for charts which may be difficult for on-site workers to accomplish on top of managing busy HIV treatment clinics. Also, some cases were untraceable and could not be included in the data. However, useful information was obtained.

Further work is needed to validate this approach. We suggest a prospective analysis following patients from the point of testing to evaluate linkage to care, reasons for drop-out, and evaluating outcomes such as treatment initiation, mortality, and immuno-suppression. We further suggest that interventions should target early after diagnosis and facilitate early linkages such as program enrollment and early CD_4 testing; interventions such as point of

care CD_4 testing [19], data linking between institutions, and patient navigators [20] may improve linkages in resource limited settings. In fact, point of care CD_4 testing dose appear to improve linkage to care after diagnosis in multiple setting in sub-Saharan Africa, as noted by a recent systemic review of literature [21]. Providing CD_4 testing at the time of HIV diagnosis offers exciting opportunities to improve referrals and linkage, such as with mobile testing sites in South Africa [22]. Early CD4 testing may also be beneficial in communities such as Kijabe where a high number of patients present late in the disease process (about 65% of enrolled patients had CD4<350). The method described here can easily be adapted in resource limited settings in order to identify blockages to retention in care, prioritize problems as part of a quality improvement plan, and continually monitor retention rates in order to readdress solutions as needed.

5. CONCLUSION

In conclusion, the authors have reported here a method for collecting data on the retention of patients throughout the HIV care continuum in a rural clinic system in Kijabe, Kenya. Our data supports other reports that most patients are lost to follow up early in the care process. This method may be used to inform a quality improvement cycle to aid in projects to improve retention in HIV care at any stage.

6. FUNDING

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CONSENT

The authors report that due to the retrospective nature of this study patient consent was not obtained. The authors followed strict guidelines to protect confidentiality and ensured that all data were carefully de-identified and kept secure.

ETHICAL REVIEW

Ethical review for this study was provided by the AIC Kijabe Hospital Ethics Review Board and the University of Texas Medical Branch Internal Review Board.

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COMPETING INTERESTS

Authors have declared that no competing interests exist.

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