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TECHNICAL REPORT

Improving Quality of Care for People with Chronic Diseases in Uganda: *Findings of a Baseline Cross-sectional Study in Buikwe District*

JULY 2012

This report was prepared by University Research Co., LLC (URC) for review by the United States Agency for International Development (USAID). It was authored by Martin Muhire, Humphrey Megere, Esther Karamagi Nkolo, and Nigel Livesley of URC. The chronic care baseline study was funded by the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) and carried out under the USAID Health Care Improvement Project, which is made possible by the generous support of the American people through USAID.

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DISCLAIMER

The views expressed in this publication do not necessarily reflect the views of the United States Agency for International Development or the United States Government.

Acknowledgements: The authors thank the Uganda Ministry of Health, Buikwe district health office, and the staff at the participating health units for their generous support and contribution to this study. We also wish to thank in particular Dr. Godfrey Kayita, Dr. Eric Ikoona of the AIDS control program and Dr. Anthony Musisi Kyayise (SUSTAIN Project) for their contribution to the development of the baseline assessment tool and the entire study.

This study was supported by the American people through the United States Agency for International Development (USAID) and its Health Care Improvement Project (HCI), with funding from the U.S. President's Emergency Plan for AIDS Relief (PEPFAR). HCI is managed by University Research Co., LLC (URC) under the terms of Contract Number GHN-I-03-07-00003-00. URC's subcontractors for HCI include En Compass LLC, Family Health International, Health Research, Inc., Initiatives Inc., Institute for Healthcare Improvement, and Johns Hopkins University Center for Communication Programs. For more information on HCI's work, please visit www.hciproject.org or write hci-info@urc-chs.com.

Recommended citation: Muhire M, Megere H, Karamagi E, Livesley N. 2012. Improving the quality of care for people with chronic diseases in Uganda. Findings of a baseline cross-sectional study in Buikwe District. *Technical Report*. Published by the USAID Health Care Improvement Project. Bethesda, MD: University Research Co., LLC (URC).

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Abbreviations

ART	Antiretroviral therapy
CBO	Community-based organization
CCM	Chronic Care Model
DM	Diabetes mellitus
HCI	USAID Health Care Improvement Project
HIV	Human Immunodeficiency Virus
HSSIP	Health Sector Strategic and Investment Plan
HTN	Hypertension
OPD	Outpatient department
PEPFAR	U.S. President's Emergency Plan for AIDS Relief
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
URC	University Research Co., LLC
USAID	United States Agency for International Development
VHT	Village Health Team
WHO	World Health Organization

EXECUTIVE SUMMARY

Global efforts to treat people with human immunodeficiency virus (HIV) represent the first wide-scale attempt to provide care for people with chronic conditions. These efforts to ameliorate the effects of the HIV pandemic have been extremely successful: for example, PEPFAR funding has provided treatment to 3.9 million people. Despite these successes, a lot of work remains to ensure that HIV treatment continues to be scaled up effectively. In particular the World Health Organization's Treatment 2.0 initiative lists two priorities which require action at the service delivery level: 1) Adapt HIV care and treatment programs so that they are decentralized and appropriately integrated with other health services, with increased community engagement and strategies to improve improved retention in care; and 2) Mobilize communities so that they are fully involved in the planning, delivery, and evaluation of HIV care programs.

The USAID Health Care Improvement Project (HCI) is currently working in Buikwe District in central Uganda to address the last two priorities so that care in the clinic and community is better suited to the needs of patients with HIV. We are using the chronic care model (CCM), developed by the MacColl Institute, and adapted by the World Health Organization to provide guidance on what changes can improve care. As part of this work, we conducted a baseline assessment of care in December 2010 in the district to understand what components of the CCM were in place for patients with HIV. We also investigated whether any components of the CCM are in place for other chronic conditions to see if there were any lessons that could be shared between the various care programs.

Study Objectives

- Estimate the burden of HIV, tuberculosis (TB), hypertension (HTN), and diabetes (DM) on outpatient visits
- Determine the availability of services for these conditions
- Describe systems of care for these conditions by investigating the components of the CCM and finding out which ones were in place,

Data were collected through interviews with patients and providers as well as through the review of the medical records at five hospitals and 10 health centers (level III).

Key Findings

Burden of HIV, TB, HTN and DM on outpatient visits:

- HIV, TB, HTN and DM accounted for 16.4% of all visits (range of 12.5% to 34% at hospitals and 0.8% to 100% at health centers). HIV alone accounted for 13.4% of all visits.

Availability of services for these conditions:

- All hospitals offer diagnosis and care for all the conditions. Of the 10 health centers, all diagnose HIV, one provides treatment; all diagnose and treat TB; all diagnose HTN but only one provides treatment; and two diagnose DM but only one provides treatment.
- Availability of drugs for these conditions was good at the facilities providing care on the day of the visit.
- The percentage of health workers who felt they had sufficient skills to diagnose and treat patients with HIV, TB, HTN, and DM were 89%, 100%, 52%, and 52%, respectively.

Findings about the presence of the components of the CCM:

- Patient knowledge of their treatment was generally poor: 2/9 patients with HIV knew they had to take treatment for life; 0/8 patients with HTN and 1/7 patients with DM knew treatment was for life.

- Clinics were not set up to make visits convenient for patients or to support self-management:
 - Two of six HIV clinics had systems to expedite visits for stable patients so that they did not need to see a clinician; no clinics had such systems for the other conditions.
 - Six of six HIV clinics had staff to educate patients; 15/15 TB clinics; no clinic providing HTN care and 1/6 clinics providing DM care had such staff.
 - Peer counselors were available to provide ongoing support in 1/6 HIV clinics and in no other clinics.
- Medical records and registers were available for HIV and TB patients but not for other conditions.
- Decision support was present in paper form to help providers adhere to standards for HIV and TB patients.
- Links to community-based support was poor for patients with all conditions:
 - Two of six HIV clinics had links with community groups (one with the government village health teams and one with a community-based organization); these clinics also linked TB patients with the community support; no clinics provided community links for patients with HTN or DM.
 - Six of six HIV clinics and 6/15 TB clinics encouraged patients to identify treatment supporters.

In conclusion, there is a pressing need to improve care for patients with chronic conditions in Buikwe. Patients with HIV and TB are more likely to receive care and to visit clinics which are set up to meet the needs of patients with chronic conditions, but there is still considerable room for improvement for caring for patients with these conditions. In particular, patients with HIV and the other conditions require more support to learn about their disease (including knowing that treatment is for life) and how to better manage it. They also require support in the community.

Based on the limited prevalence data for these conditions, only 12.1% of patients with HIV, TB, HTN, and DM are currently receiving care in the district. Addressing this unmet need will require extensive efforts at all levels of the health system. While HIV services still need to be improved, some of the lessons and practices learned in rolling out HIV care can be spread to the other services as well. Some of these changes can be put in place at the facility and district levels. Other changes will require support from the national government and also the international community. For example, it is likely that the health system will need to focus more on building patient knowledge and self-management skills; support for community-based health programs will be required; and data systems will need to be adapted to provide usable longitudinal patient records.

Because evidence from high-income countries shows that people with chronic conditions are more likely to have more than one such condition, it will be important that efforts to improve chronic conditions care focus on the patients' needs rather than on specific conditions.

I. INTRODUCTION

Global efforts to treat people with human immunodeficiency virus (HIV) represent the first wide-scale attempt to provide care for people with chronic conditions (Rabkin and Nishtar 2011). These efforts to ameliorate the effects of the HIV pandemic have been extremely successful. In 2001, approximately \$1.6 billion dollars was spent on HIV prevention and treatment and 300,000 people were receiving antiretroviral therapy (ART). In 2009, spending had increased to \$15.9 billion and 6.6 million people were receiving ART. An estimated 3.7 million lives have been saved by ART in sub-Saharan Africa (UNAIDS 2011a). PEPFAR funding has been particularly important having contributed \$7 billion in 2011 and provided treatment to 3.9 million people (PEPFAR 2011).

Despite these successes, a lot of work remains to ensure that HIV treatment continues to be scaled up effectively. The World Health Organization's Treatment 2.0 initiative suggests five priorities to build on previous successes. Three priorities require action at the national and international level: 1) Optimize drug regimens; 2) Provide point-of-care and other simplified diagnostic and monitoring tools; 3) Reduce costs. The other two priorities require action at the service delivery level; 4) Adapt HIV care and treatment programmes so that they are decentralized and appropriately integrated with other health services, with increased community engagement and strategies to improve improved retention in care; and 5) Mobilize communities so that they are fully involved in the planning, delivery and evaluation of HIV care programs.

The USAID Health Care Improvement Project (HCI) is currently working in Buikwe District in central Uganda to address the last two priorities so that care in the clinic and community is better suited to the needs of patients with HIV. We are using the chronic care model (CCM), developed by the MacColl Institute, and adapted by the World Health Organization to provide guidance on what changes can improve care (Coleman et al. 2009; WHO 2002). The model has six components: 1) provide self-management support to improve patients' abilities to care for themselves, 2) help health team members to carry out their roles reliably and efficiently by re-organizing processes of care, 3) improve the management of individual patients and of the clinic population by strengthening longitudinal records and record keeping and setting up data panels to allow review of the population; 4) help remind providers to do the right thing and to help them find solutions to difficult problems by providing decision support mechanisms, 5) improving access to support for patients in the community and 6) ensuring organizational support so to make these changes.

As part of this work we conducted a baseline assessment of care in December 2010 in the district to understand what components of the CCM were in place for patients with HIV. We also investigated whether any components of the CCM are in place for other chronic conditions to see if there were any lessons that could be shared between the various care programs. The objectives of the baseline assessment were to:

- Estimate the burden of visits by people with HIV, tuberculosis (TB), hypertension (HTN) and diabetes (DM) on the outpatient department.
- Determine the availability of services for these conditions.
- Compare systems of care for HIV and other chronic conditions.

II. METHODOLOGY

Setting

Buikwe District, located in the central part of Uganda, has a population of 407,100 with an HIV prevalence of 6.8%. The prevalence of HTN and DM is not known. Buikwe has 32 health facilities: five hospitals (one public, four private), no health center level IV (HCIV), 11 health center level III (HCIII), and 16 health centers level II (HCII). Hospitals are led by a senior medical officer supported by another doctor and have wards for men, women, and children, as well as a theatre for carrying out emergency

operations. Health centers level III are led by a senior clinical officer who runs a general outpatient clinic and a maternity ward. Health centers level II are led by enrolled nurse, working with a midwife, and two nursing assistants to run an out-patient clinic. The assessment was carried out in all hospitals and 10 health centers level III. One health center III was excluded as it was new and did not yet have any staff. Level II health centers were excluded because they do not provide treatment for HIV, TB, HTN or DM.

Provider interviews

Structured interviews were used to collect quantitative and qualitative data. The data collection tool was pre-tested in two districts and facilities with similar geographical and population characteristics as Buikwe District. All providers who were found at the facilities on the day of the study and were involved in HIV, TB, HTN or DM management were interviewed. Prior to interviewing any of the respondents, consent was sought by the interviewer. Data were collected and checked for completeness daily.

Interviews were designed to collect data on availability of care and training of staff and to learn how care was provided using the components of the CCM as a guide. Evidence gathered about the components of the CCM included: 1) **Self-management support** – reviewing what services are available to help patients care for themselves, 2) **Delivery design** – reviewing how services have been adapted to the needs of patients with chronic conditions, 3) **Information systems** – review of documented patient information available to health workers, 4) **Decision support** – reviewing what support is available to help health workers provide good care, and 5) **Community linkages** – reviewing what services are available for patients at home.

Patient interviews

Structured interviews were used to collect data from at least one patient per facility who was present on the day of the visit and was receiving treatment for HIV, TB, HTN or DM. Patient interviews were conducted individually for confidentiality.

Review of medical records

All medical records related to HIV, TB, HTN, and DM were reviewed for the 12-month period between July 2009 and June 2010. Findings were tallied on pre-designed sheets and summarized in one Microsoft Excel sheet per facility. Data from these records were used to estimate the number of outpatient visits provided to patients with these conditions. HTN and DM visits were recorded in the registers.

III. RESULTS

Characteristics of interviewees

Providers: Eighty-three providers were interviewed, including medical officers, clinical officers, nurses, counselors, drug dispensers, laboratory technicians, and records assistants (see Table 1).

Table 1: Providers interviewed

Cadre	Total Number	Number female
Medical Officer	7	0
Clinical Officer	16	4
Nurse	42	42
Counselors	5	5
Dispenser	2	1
Laboratory technician	7	0
Records Assistant	4	0

Patients: Twenty-eight patients were interviewed (11 male and 17 female). Table 2 shows the distribution of conditions for which these patients sought care. Their ages ranged from 15 years to 70 years (mean 46.5 years). Patient respondents had been on medication for a range of three months to 18 years (mean 3.7 years) (see Table 2).

Table 2: Patients interviewed

	Number	Number female	Age (median and range) in years	Duration on therapy (median and range) in month
HIV	9	6	38 (22-47)	12 (3-48)
TB	4	3	29.5 (15-42)	5 (4-7)
HTN	8	4	62.5 (36-70)	36 (3-156)
DM	7	4	57 (46-70)	84 (21-216)

Estimates on the burden of HIV, TB, HTN and DM seen in outpatient care in Buikwe

There were a total of 268,879 OPD visits between July 2009 and June 2010 at the 15 facilities. Data for visits was recorded in different ways in different facilities. Four facilities recorded the number of HIV patients but not the number of visits, nine recorded the number of visits but not number of patients, and two had no data on number of patients or number of visits. All facilities recorded the number of patients with TB but not the number of visits. All facilities recorded the number of visits by patients with HTN or DM but not the number of patients. To estimate the total number of visits we estimated that all patients would have six visits a year. Using this approach we estimate that care for HIV, TB, HTN and DM accounted for 44,475 visits (16.5%) of all outpatients' visits (see Table 3).

Table 3: Estimated number of visits

	Recorded number of patients in care	Recorded number of patient visits	Estimated number of visits (recorded number in care x 6 visits + recorded number of visits)
HIV	3,290*	16,328°	36,068
TB	974		5,844
HTN		1,970	1,970
DM		593	593
Total			44,475

* 4 facilities have data on total number of patients with HIV

° 9 facilities have data on total number of visits by patients with HIV

A total of 145,656 (54%) of all outpatient visits occurred at the hospitals and hospital visits accounted for 24,166 (67%), 3,506 (60%), 1,478 (75%) and 486 (82%) of all visits for HIV, TB, HTN, and DM, respectively. The fact that most visits for chronic care occur at hospitals also meant that chronic care made up a larger proportion of visits in hospitals: visits for the four conditions accounted for 20% of all hospital visits (range: 12.5-34%) compared to 12% of all health center visits (range: 0.8-100%). One health center III was set up solely to attend to HIV patients, and therefore 100% of all visits were for chronic conditions. If this facility were excluded, care for chronic conditions accounted for 2.4% of all health center visits (range: 0.8-7.5%).

Availability of services, medicine and equipment for patients with HIV, TB, HTN and DM

Of the 15 facilities, all five hospitals were able to diagnose and treat HIV, TB HTN and DM (see Table 4). All 10 health centers were able to diagnose HIV, but only one provided treatment. All were able to

Table 4: Availability of services for patients

	Hospitals		Health center III	
	# facilities providing the service		# of facilities providing the service	
	Diagnose	Treat	Diagnose	Treat
HIV	5	5	10	1
TB	5	5	10	10
HTN	5	5	10	1
DM	5	5	2	1

diagnose and treat TB. All were able to diagnose HTN, and one provided treatment. Two were able to diagnose DM, and one provided treatment. On the day of the assessment visit, all five hospitals had some of the drugs for treating HIV, TB, HTN and DM that are listed in the Uganda essential drug list although not all the required drugs for HTN or DM were available (see Figure 1). One health centre III had drugs for HIV, 10 had TB drugs, and one center had drugs for HTN and DM (Figure 2). All facilities had equipment for diagnosing HIV, TB and HTN, but only two of the 10 health centers had glucometers for diagnosing DM (Table 5).

Figure 1: Availability of essential drugs on the day of evaluation at 5 hospitals

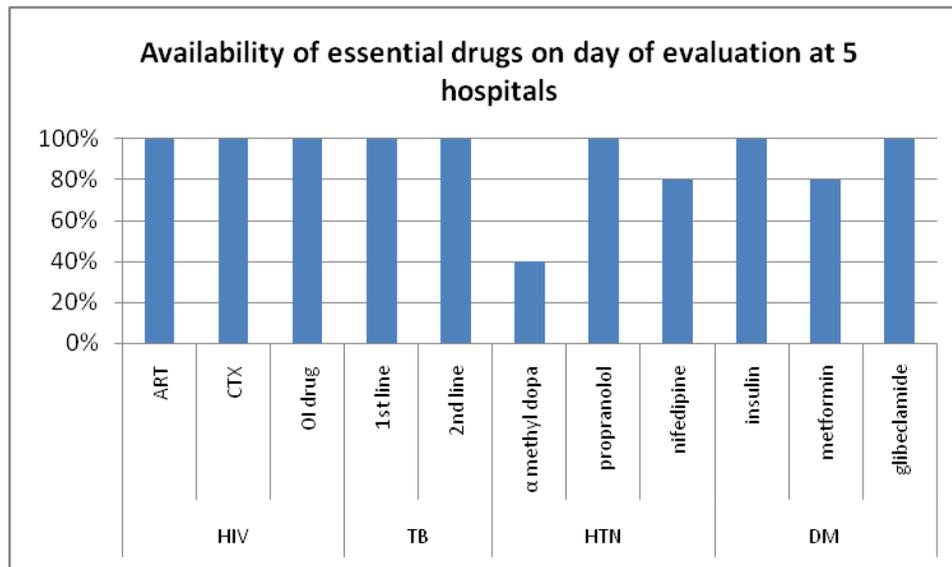
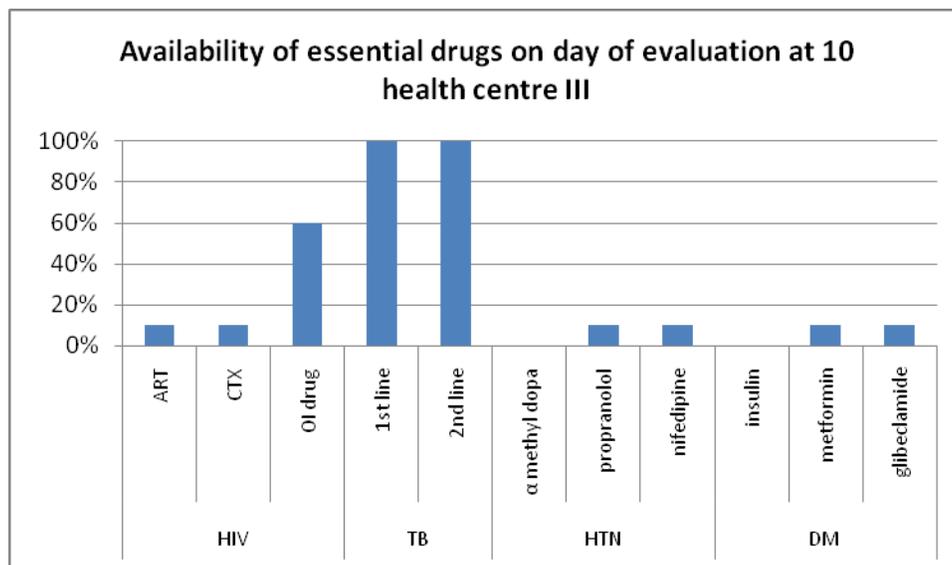


Figure 2: Availability of essential drugs on the day of evaluation at 10 health centers (level III)



Self-reported clinical skills among interviewed providers

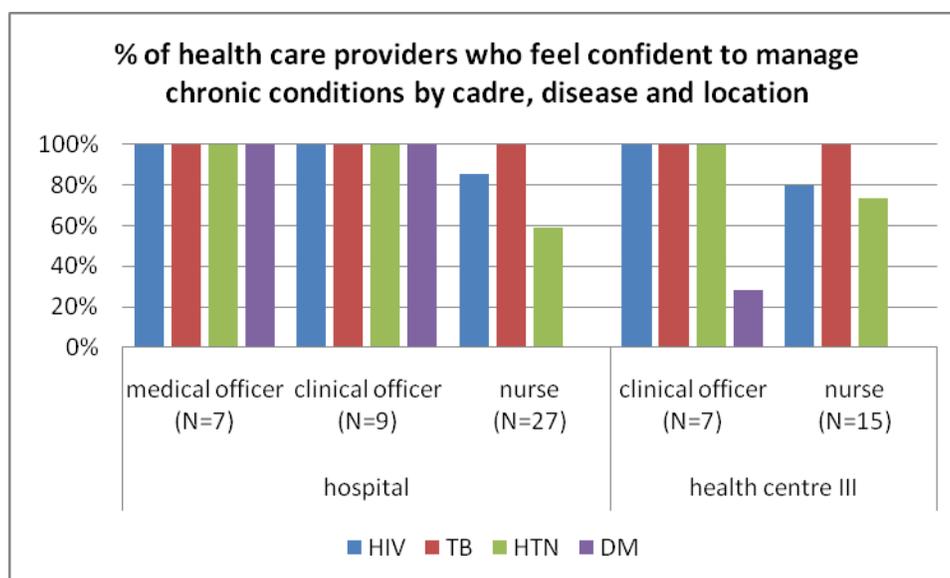
There were 303 trained health workers (13 medical officers, 40 clinical officers, and 250 nurses) working in the district; 65 (21.4%) of them were interviewed, including seven (54%) of the medical officers, 16 (40%) clinical officers, and 42 (17%) nurses. Of these cadres, the number and percentage who felt they had sufficient skills to diagnose and treat patients with HIV, TB, HTN and DM were 58

(89%), 65 (100%), 34 (52%), and 34 (52%), respectively. All medical officers felt comfortable with all four conditions. The nine clinical officers based at the hospitals all were comfortable managing all conditions but only two of the seven at the health centers felt able to manage diabetes. Nurses based at health centers were more likely to feel comfortable managing hypertension than their hospital colleagues; both groups were more likely to be comfortable managing TB than HIV or HTN; and no nurse felt comfortable managing patients with diabetes. Figure 3 shows the breakdown in confidence to diagnose and treat patients with chronic conditions based on cadre and location (hospital vs. health center).

Table 5: Availability of equipment at five hospitals and 10 health centers (level III)

Equipment	Number of hospitals	Number of health centers
HIV testing Kits	5	10
Microscope	5	10
Tb reagents	5	10
X ray machines	4	0
Sphygmomanometer	5	10
Glucometer	5	2
Urine sticks	5	5

Figure 3: Percent of health care providers who feel confident to manage chronic conditions by cadre, disease, and location



Functionality of CCM components in service delivery

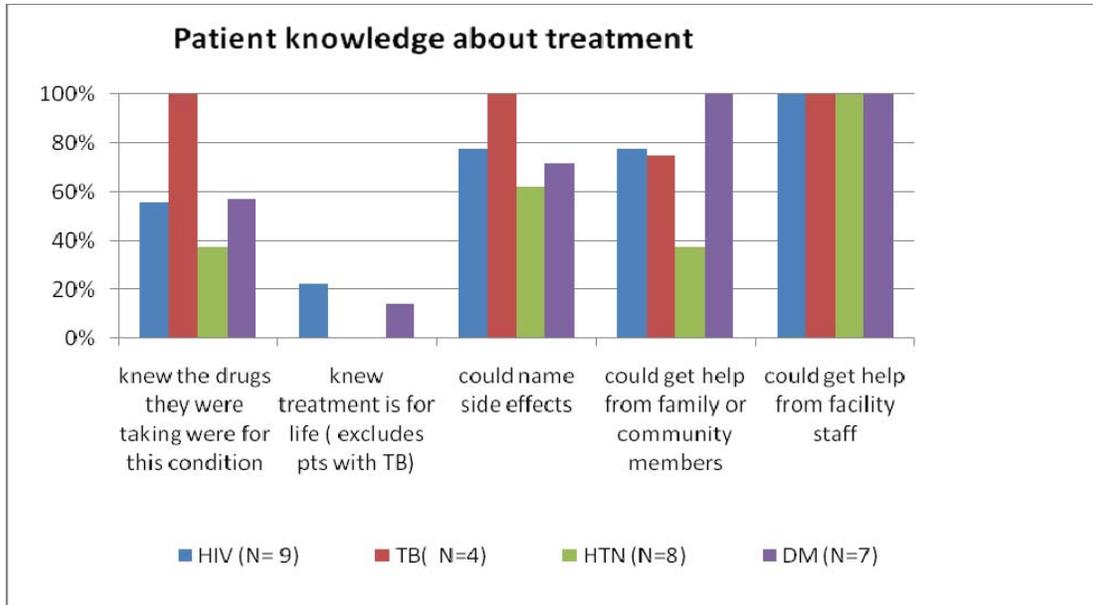
Provider and patient interviews, observation, and record review were used to determine whether components of the CCM were being implemented.

Self-management support for patients with HIV, TB, HTN, and DM: Four of the five hospitals provided health education for patients with HIV and TB. None of the health centers had any patient education for any disease. There was no patient education for patients with HTN and DM at any of the facilities. None of the facilities had mechanisms to help patients manage their condition on a regular basis after they had received the health education.

Of the 28 patients interviewed, 16 knew they were on drugs for HIV, TB, HTN, or DM but none of the 28 patients knew the actual name of the drugs they were taking. Although all patients knew how long

they had been taking medication, only three of the 28 patients with life-long conditions knew they were required to take their medications for the rest of their lives. Twenty-one could name some side effects related to their drugs, 20 could get help with their condition from someone in their family or community, and all could get help from someone at the facility (see Figure 4).

Figure 4: Patient knowledge about treatment



Elements of clinic design to make clinic visits convenient and supportive of patient self-management:

The majority of care for patients with chronic conditions was provided by health care workers also caring for the acutely ill. Clinics specifically for patients with HIV, TB, or DM existed in four (66%), five (33%) and one (17%) of the facilities, respectively, offering these services. Two of these clinics (for HIV) had a triage system to expedite the visit of stable patients so they could get their medication refills without having to see a clinician. At triage, patients were asked whether they needed refills or had complaints. Those who were stable and needed refills were directed to see a nurse for refills, while those with complaints saw clinicians. In all other cases, all patients had an individual visit with a clinician whether they had any medical complaints or not. Dedicated staff to provide health information were available in fewer than half the facilities, and expert patients to provide peer support for patients with chronic conditions were present in only one HIV clinic. Group education was used for both HIV and TB at all five hospitals and in one health center (see Figure 5).

Information systems for caring for patients with HIV, TB, HTN, and DM: Specific registers and individual patient records were present for HIV in six facilities (five hospitals and one health center) and in all 15 facilities for TB. One facility had a register for DM but no individual records. No facilities had registers or individual records for HTN. In the absence of these disease-specific records, clinical information is not available to providers as only diagnosis, patient address, age, and next of kin are recorded in registers.

Decision support to help improve care for patients with HIV, TB, HTN, and DM: A number of decision support mechanisms were in place. All 15 facilities had TB guidelines and reminders posted in the clinic. HIV guidelines were available in 5/6 facilities and reminders available in 6/6 facilities. The reminders included guides to World Health Organization clinical stages of a patient with HIV, lists of the available ARV combinations, and steps for examining a patient’s sputum for TB.

Three of the six facilities that treated HIV had access to HIV specialists to help them with difficult cases via a toll-free telephone line to an information center at the national referral hospital. No decision support mechanisms were available for TB or DM (see Figure 6).

Figure 5: Care delivery system in 15 facilities

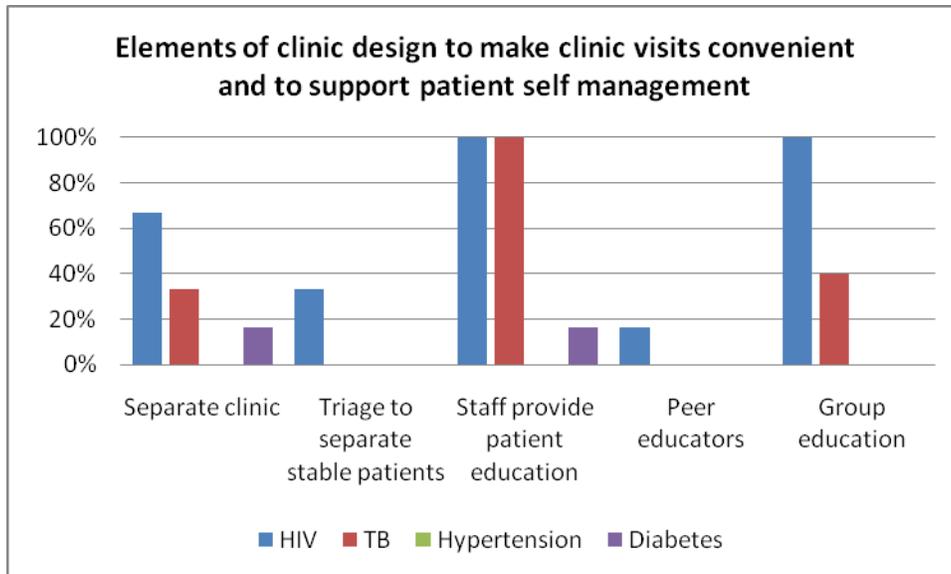
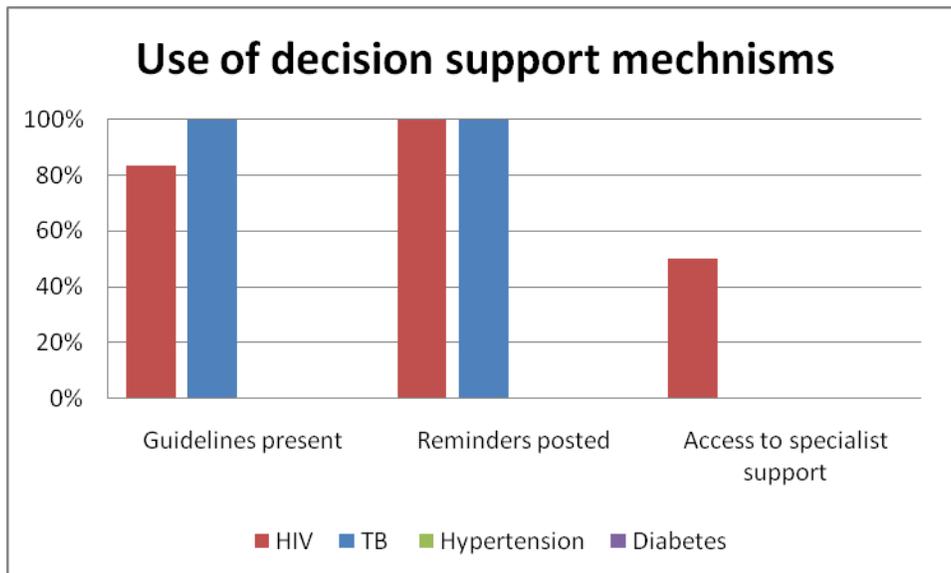
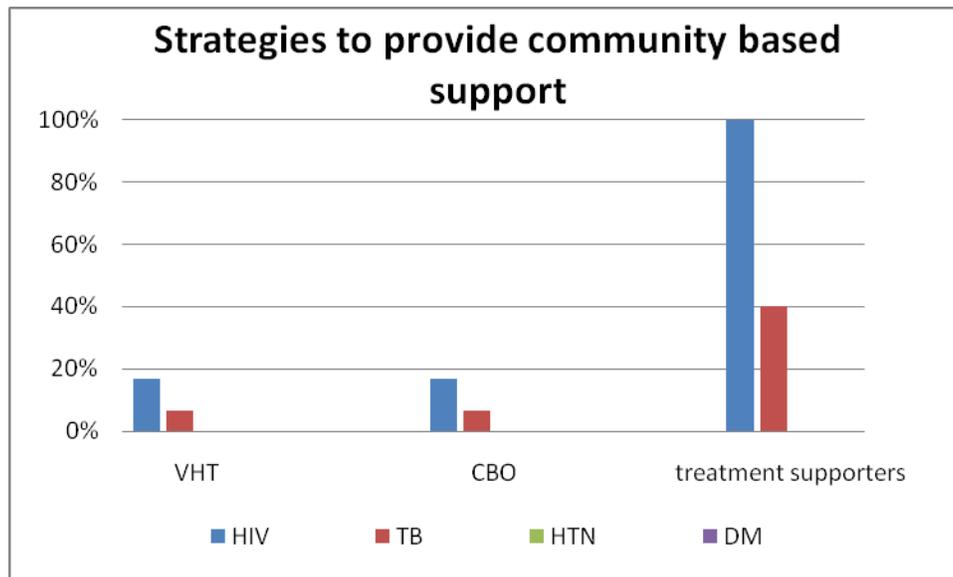


Figure 6: Decision support in 15 facilities



Links to community resources for patients with HIV, TB, HTN, and DM: One facility worked with village health team members (these volunteers form the Ministry of Health’s cadre for providing care and support in the community) to organize HIV and TB education in the community. One facility had a community-based organization (CBO) working closely with health providers to carry out HIV counseling and testing in the communities. Five hospitals and one health center encouraged patients with HIV and TB to identify treatment supporters. These volunteers provide help to patients by picking up drugs if the patient is unable to visit the clinic, providing adherence support, and helping the patient come to the clinic if he or she is very sick. No clinic had a mechanism to provide community-based support for patients with HTN or DM (see Figure 7).

Figure 7: Community linkages at 15 facilities



IV. DISCUSSION

This baseline assessment identified that some facilities delivering HIV care have components of the Chronic Care Model in place. Examples include: all clinics had staff available to educate patients about their disease; four of the six facilities providing HIV care have separate clinics and two have triage systems to make clinic visits more convenient; standard medical records and registers are available in all facilities delivering HIV care; and guidelines are present in five of the six facilities. Despite this, there is considerable room for adding additional components of the CCM to make care more responsive to patient needs. Examples of CCM interventions that could be strengthened include better patient education (only 3/28 patients in this study knew that they were on treatment for life) providing ongoing support to help patients manage their health at home, changes in scheduling and clinic set up to make even more convenient for patients, integrating support for clinical decisions into the work environment and strengthening community support and links with community resources.

The assessment showed HIV and TB programs did not differ on their use of chronic care principles other than that clinics were more likely to have clinical guidelines for TB. Systems for HTN and DM were substantially worse than the other two diseases, and it is clear that programs for non-communicable diseases can learn a lot from the progress made by HIV and TB programs.

The baseline assessment also revealed that there is a pressing need to strengthen the ability of the health system to deliver care to people with chronic conditions. Sixteen percent of all visits are currently focused on the four chronic conditions we assessed. It is likely, however, that there remains a significant unmet need among patients with these conditions.

The population of Uganda is 33.8 million, and Buikwe is home to 1.2% of that population. UNAIDS reports that 1.2 million people are living with HIV in Uganda, so approximately 14,450 of them live in Buikwe (UNAIDS 2011b). Estimated incidence for TB is 330 cases per 100,000 people per year, so we would expect 1,343 cases in Buikwe (WHO 2009). National estimates for HTN and DM do not exist. Two recent population-based studies found 30.4% of the population over 20 years was hypertensive, and 22% of the population over 13 years was hypertensive (Wamala et al. 2009; Maher et al. 2011b). Diabetes was detected in 0.4% of the same sample as the second HTN study (Maher et al. 2011a). Assuming 50% of the population in Buikwe is over 15 years of age and taking estimates of HTN and DM prevalence of 22% and 0.4%, respectively, there are approximately 44,800 people with HTN and 800

people with DM living in Buikwe (Uganda Bureau of Statistics 2002). If each of these people were identified and entered into care and had a mean number of six visits per year, there would be 368,358 total visits for people with these conditions (assuming each person had separate visits for each condition). In comparison, there were 44,475 visits for these conditions in 2010, and 268,879 total outpatient visits in the district. Based on these figures, 12.1% of the estimated numbers who need treatment are receiving treatment (range 0.7% for HTN to 72.5% for TB) (see Table 6).

Table 6: Visits coverage

	Estimated number of required visits per year	Actual number of patient visits July 2009 - 2010	% coverage
HIV	86,700	36,068	41.6%
TB	8,058	5,844	72.5%
HTN	268,800	1,970	0.7%
DM	4,800	593	12.4%
Total	368,358	44,475	12.1%

Meeting the unmet need would lead to a 137% increase in total outpatient visits over current levels. This assessment identified a number of barriers to providing care to this many people. First, care is only available at few facilities in the district. This is particularly true of HIV, HTN, and DM care. Second, some health workers do not feel comfortable treating patients with chronic conditions other than TB. This is particularly true in the lower level facilities. It was not directly assessed but it is unclear if the system has enough human and infrastructure resources to provide this many additional outpatient visits. Care delivery systems that better use the resources of patients and their families, that use these resources to deliver more care at home and in the communities rather than at facilities, and that use resources more efficiently are needed to respond to the increasing prevalence of chronic conditions.

The CCM provides guidance to facilities on how to redesign clinics to meet these needs and emphasizes the need to provide support for patients in their home and community. As such, it provides an evidence-based model for improving care. The progress that has been made in HIV programs can serve as a base from which lessons can be shared with providers caring for patients with hypertension, diabetes, and other chronic conditions.

Building on existing systems such as those developed for HIV care will be important for avoiding some of the problems that disease-focused health systems in high-income countries are facing (Tinetti et al. 2004). Most patients with chronic conditions have more than one such condition, so disease-specific approaches often cause conflict among providers and confusion for patients who have to juggle multiple appointments and contradictory advice (Fortin et al. 2005; Mercer and Watt 2007; Hitchcock et al. 2007). Building a system that focuses on the patient and all of his or her health concerns using the lessons from HIV care may be a way to integrate HIV into the general system, leverage the funds going to HIV care for health systems strengthening, and develop a health system which is more suited to patients needs and the increasing prevalence of chronic conditions.

V. NEXT STEPS

To address the weaknesses in the care system identified in this assessment, the USAID Health Care Improvement Project is working with the Uganda Ministry of Health, patients, and health workers to implement the Chronic Care Model for patients with HIV in Buikwe District. We are supporting teams of health workers, patients, and managers to use quality improvement methods to change their system of care to: 1) help facilities place greater emphasis on building patients' ability to manage their care; 2) make clinic visits more efficient so patients have shorter visits and visits are tailored to the specific needs of the patients; 3) add information on patient self-management goals to the data systems, so that health workers know about patient priorities and can help with planning; 4) increase the role of peer

counselors in supporting other patients; and 5) improve links with community-based support. We are also encouraging teams to apply these lessons to improve services for people living with other chronic conditions.

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