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Healthcare delivery for paediatric and adolescent diabetes in low resource settings: Type 1 diabetes clinics in Uganda

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ABSTRACT

The management of type 1 diabetes (T1DM) includes setting up organised follow-up clinics. A programme for establishing such clinics in Uganda commenced in 2009. The clinics were established along the chronic care model and were integrated into the health structure of other chronic diseases. Web-based electronic medical records were utilised to establish a centralised registry. All children with diabetes below 18 years of age were encouraged to enrol into the programme by attending the nearest established T1DM clinic. At the commencement of the programme, there were 178 patients with T1DM receiving care in various health facilities but without organised follow-up T1DM clinics. These patients were subsequently enrolled into the programme and as of June 30, 2018, the programme had a total of 32 clinics with 1187 children; 3 with neonatal diabetes. Challenges encountered included difficulties in timely diagnosis, failure to provide adequate care in the remote rural areas and failure to achieve pre-defined glycated haemoglobin (HbA1c) goals. Despite these challenges, this observational study demonstrates that healthcare delivery for T1DM organised along the chronic care model and supported by web-based electronic medical records is achievable and provides care that is sustainable. Addressing the encountered challenges should result in improved outcomes for T1DM.

Abbreviations: CCM, Chronic Care Model; CDiC[®], Changing Diabetes in Children; CFI, Custom Factory Integration; CME, Continuing Medical Education; DRC, Democratic Republic of Congo; DSME, Diabetes Self-Management Education; EMR, Electronic Medical Records; ICT, Information and Communication Technology; NCD, Non Communicable Disease; SMBG, self-Monitoring of Blood Glucose; SNF, Sonia Nabeta Foundation; SSA, Sub-Saharan Africa; SSL, Secure Socket Layer; SUGAR CUBES, Sugar-Care-Understanding-Betterment-Education-Support; T1DM, Type 1 Diabetes Mellitus; WDF09-457, World Diabetes Foundation, Project Number 09-457

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Introduction

Type 1 diabetes mellitus (T1DM) is characterised by reduced insulin secretion or absolute deficiency as a result of autoimmune beta-cell dysfunction. It is a chronic disease requiring long-term administration of insulin and interaction with health care professionals; with the primary management goal of preventing acute and long term complications of the disease (American Diabetes Association, 2018). Standard of care for T1DM management is intensive insulin therapy, with auxiliary technological and social support to achieve optimal glycaemic control. Providing effective support for patients in using insulin effectively is essential for good diabetes care. For that support to be effective it must reflect and attend to the needs of patients. However, despite the recent advances in insulin and its administration, patients with T1DM continue to have difficulty in achieving optimal glucose control, especially in low resource countries (Beran & Yudkin, 2010; Beran, Yudkin, & Courten, 2005; Beran, Yudkin, & de Courten, 2006). Furthermore, the organisation of specialised T1DM care in sub-Saharan Africa (SSA) has received little attention (Adisa & Fakeye, 2016; Brown et al., 2014; Coleman, Gill, & Wilkinson, 1998; Steyn, McHiza, & Kengne, 2014), probably because of few numbers of T1DM patients encountered, or the associated high costs of care (Elrayah et al., 2005). In SSA, with increasing numbers of T1DM surviving because of increased availability of insulin (Novo Nordisk, 2017), there is a serious danger of poor metabolic control among the patients with T1DM, that will be followed by short- and long-term diabetes complications, unless appropriate health care delivery for T1DM management is established. Indeed, there has been a need for innovative care structures to optimally manage T1DM, amidst scarce resources in most of SSA region.

Responsibility of long-term care for T1DM lies at the primary care level, which in low resource countries is often provided by nurses working in isolated clinics with limited drugs and equipment. Models of type 1 management in SSA, therefore, need to be sensitive to training levels of the clinic staff, while optimising available resources to meet critical standards of care. Such models of T1DM care should include: (1) enhancement of access to care and continuity; (2) identification and management of patient populations; (3) planning and managing care; (4) provision of self-care and community support; (5) tracking and coordinating care and (6) measure and improve performance (Aselton & Affenito, 2014). In this observational study, we describe the organisational set up to manage T1DM in Uganda 2009–2018 so as to provide insight into the challenges of the provision of care in T1DM and thus develop hypotheses on the future appropriate management of T1DM in low-resource settings. The authors were involved in the organisational set up of the clinics and in the management of the patients.

Methods

Geographical setting

Located on the edge of the Equator, Uganda is located in East Africa and bordered by the Democratic Republic of the Congo (DRC), Kenya, Rwanda, Sudan and Tanzania. The country has an estimated population of 39 million with the youth (under 30 years) accounting for 77% (Uganda Bureau of Statistics, 2017). Uganda is divided into four regions: Northern, Eastern, Central and Western. These regions are further subdivided into 127 districts and one city (the capital city of Kampala). While these groupings do not produce any complete homogeneity, the languages are spoken and cultural practices in each region are closely related and are therefore an important factor when setting up health services. The setting up of T1DM clinics regionally followed this structure.

The Ugandan economy

The economy of Uganda has great potential; and indeed, the country has made a remarkable reduction in monetary poverty in the recent years but is still faced with widespread deprivation in

several non-monetary dimensions of poverty, mainly improved sanitation, access to electricity, education and health care. Thus, in setting up the T1DM specialised clinics, the widespread deprivation in non-monetary dimensions underscored the need to also address and improve access to these very basic services and moreover ensure minimum acceptable quality.

Health services in Uganda

The delivery of health services in Uganda is done by both the public and private sectors, with the Government of Uganda being the owner of most facilities. Access to health services is still limited by geographic inaccessibility to health units especially in rural areas and financial limitations for the poor. In recent years, a variety of health reforms have been implemented to enhance healthcare funding and delivery in the country. The Government of Uganda put forward a National Minimum Health Care Package (UNMHCP) that focuses on four clusters of interest namely: health promotion, disease prevention and community health initiative; maternal and child health; control of communicable diseases; and control of non-communicable diseases (NCD). T1DM is not singularly mentioned in the NCD cluster but implied in the management of diabetes as a whole. The gap between the required and available funds to fulfil this package is wide and affects the availability of drugs and physicians in many health units (Mukasa, 2012). Indeed, despite these rigorous planning and policy changes in the country, out-of-pocket spending is still a barrier to household access to quality care.

Type 1 diabetes (T1DM) clinics

In 2009, the Uganda Government in partnership with the World Diabetes Foundation (WDF09-457 Project) commenced on a programme to improve the care of patients with type 1 diabetes (T1DM), age range 0–18 years. While patients with diabetes onset after the age of 18 years may have been included in the programme, they had not been included in the primary target population. The programme was designed to address the health needs of paediatric and adolescent population affected by diabetes, rather than focusing primarily on individual patients; and the clinics were thus modelled on Uganda being a resource-restricted country. As most of the targeted population would have T1DM these clinics were referred to as specialised T1DM clinics. Prior to 2009, there were no specialised diabetes clinics for T1DM in Uganda, and the few patients with T1DM seen by a physician were followed up in adult diabetes clinics. Specialised T1DM clinics started in four health facilities: Mulago National Referral Hospital, Kampala; St. Francis Hospital, Kampala; Wakiso Health Centre IV, Wakiso; and Arua Regional Referral Hospital, Arua. Masaka Regional Referral Hospital, was added as *a hub*. Wakiso Health Centre IV is situated 10 kilometres from Kampala and is a typical primary care level facility and thus was expected to refer to chronic diseases, when encountered, to the district hospital for follow up. It was to be the model for the management of T1DM at the primary health care level. Mulago National Referral Hospital, Kampala and St. Francis Hospital, Kampala are teaching institutions; and already had type 2 diabetes clinics and specialists in diabetes care and were to be *the hub* in the care of T1DM. Arua Regional Referral Hospital, Arua became the first *spoke* on whose experience further units would be added in the expansion of the programme for care of T1DM. In 2010, Novo Nordisk and Roche Health Care joined with the Uganda Government-WDF09-457 project partnership to form a consortium of Changing Diabetes in Children (CDiC[®]) for Uganda. Under this consortium, T1DM patients enrolled before their eighteenth birthday receive regular and dependable supplies of human insulin, syringes, glucose meters, lancing devices and strips for self-monitoring of blood glucose (SMBG). Furthermore, the programme provides funding for training of health care professionals, patient education and family and community awareness support. With the increased funding and availability of supplies, a further re-organisation of the T1DM healthcare delivery was undertaken with the aim of covering the whole country and to be based on the Chronic Care Model (CCM) for the management of T1DM (Bodenheimer, Lorig, Holman, & Grumbach, 2002; Bodenheimer, Wagner, & Grumbach, 2002). The T1DM clinics

were integrated into the existing Uganda's health structure by: (i) designating space and time for the management of T1DM within a health facility, (ii) training different cadres of health care professionals ranging from nurses and clinical officers to doctors, (iii) utilising available resources to give auxiliary support (family and community) for T1DM patients to optimise insulin therapy, and (iv) establishing a central registry of patients with T1DM, starting with 0–18 years from year 2009. The upper age limit was later increased to beyond 18 years of age at diagnosis to cover all who were not yet married or were still in school.

A stakeholders meeting was convened in 2011 to further harmonise the organisation of the T1DM clinic management. The team included an ICT expert, a social scientist, teachers, a psychologist previously involved in education curriculum development, community members, parents and caregivers of patients with T1DM, children, adolescents and adults with T1DM and health care workers. Recommendations from this meeting were used to draw up a diabetes education-training programme for children and adolescents with T1DM; and management approaches of T1DM at school. The evolved model was extended to specifically address psychosocial and lifestyle issues as well as physical problems, by involving the community and support organisations (the sugar-Care-Understanding-Betterment-Education-Support [sugarCUBES] Association; and the Sonia Nabeta Foundation [SNF]). [Table 1](#) shows the structure of T1DM clinics in Uganda, while [Figure 1](#) shows the elements of the Chronic Care Model (CCM) as adapted for the T1DM health care delivery.

Electronic medical records

Electronic medical records (EMR) are defined as a type of clinical information system, which is dedicated to collecting, storing, manipulating and making available clinical information important to the delivery of patient care (Vishwanath, Singh, & Winkelstein, 2010). An Ideal EMR usually encompasses (i) a longitudinal collection of electronic health information about a person; and (ii) electronic access to person-and population-level information by authorised users. Such a system may be limited in its scope to a single area of clinical information, or it may be comprehensive and cover virtually every facet of clinical information pertinent to patient care. The EMR in Uganda were conceptually grounded to achieve the following eight core functions: (1) Health information and data; (2) result management; (3) order management; (4) decision support; (5) electronic communication and connectivity; (6) patient support; (7) administrative processes and (8) reporting and population health (Singh, Ash, & Sittig, 2013). To begin with, however, we limited the information in the EMR to the capture of clinical data that was pertinent to the improvement of clinical care – growth and development; and prevention of complications. [Figure 2](#) shows the data captured in the EMR.

The literature on EMR in the Africa Region was scanty; specifically, there was no literature on a comprehensive, conceptual model that empirically captured the multidimensional effects of EMR on clinical workflows and it was therefore important that the introduction and implementation of EMR were rolled out in phases, with revisions for change as required. Furthermore, we tracked the attitudes and beliefs of healthcare workers towards the EMR to help further refine the EMR. Indeed, as health facilities with T1DM clinics increased, it became necessary to reduce the information captured in the EMR as the system slowed down and health workers were not able to cope with the load. Comprehensive hard copy files at the individual health facilities were maintained. This was necessary to retain the confidence of both the Ministry of Health and the individual health facilities, as going 'paperless' was new to all the parties; despite it had been clearly demonstrated there was a secure back up and encryption of the records for confidentiality.

Web-based structured electronic medical records

The traditional approach to electronic data management in a clinic setting is to place servers in the clinic sites, and in some systems, data would be periodically transmitted to a central server. In

Table 1. Key elements of the Chronic Care Model (CCM) used in setting up clinics for type 1 diabetes (T1DM) in Uganda.

Element of Care	Implementation of Care Element
The health system: organisation support – culture of the practice & system leadership. This includes patients safety	In 2009, two health facilities were set up as ‘Hubs’ to provide leadership in care: Mulago Teaching Hospital and St. Francis Hospital, Nsambya. Arua Regional Referral Hospital was set up as the first main outreach (‘spoke’), and Wakiso Health Centre IV as a model for the lowest health facility level at which care for T1DM would be provided as shown in Figure 1. Primary health care facilities are directly accessed by community although regional referral hospitals and the teaching hospitals also function as primary care facilities for T1DM. Referral to higher facility is direct to the type 1 diabetes clinic. The final goal was to integrate and streamline the healthcare delivery process for T1DM, thereby increase efficiency with the minimum resources available. Patients safety was a priority in accrediting a facility as T1DM clinic.
Self-Management Support	Education programmes include tele-support from diabetes nurses and other health care using mobile phone technology. Diabetes Self-Management Education (DSME) starts on the very day of diagnosis, and a five-day training structured programme in self-care (Table 2) is given at the age of 10 years onwards, targeting adolescence. In this training, the programme takes advantage of the known self-management skills to improve outcomes: problem-solving; decision making; resource utilisation (for example how to use internet and social media), patient – provider relationship, and taking action. Health workers are specifically instructed to clearly identify support structures for self-care for the patient during sessions on DSME. Family support is considered the most important single factor of improving care in the programme.
Delivery System Design: Patient / Health care Professional Interface and cultural competency / case management	Multidisciplinary input (diabetologist, diabetes nurse specialist, and dieticians). As these were not easily available, we opted for mentorship from the ‘Hubs’ using <i>interception</i> and <i>perception</i> visits. A standard curriculum of training of health care professionals was developed and is followed. Peer mentors and patient support groups (SUGAR – CUBES) help in counselling those with newly detected diseases and those with difficulty in achieving goals. Evidence Based Practice Guidelines are used for care of patients.
Clinical Information Systems including care co-ordination	Web-based Electronic Medical Records (EMR) are used (24 centres before 2017; 31 centres in 2018). Where not established (8 facilities before 2017), comprehensive clinical records were kept at facility, and for every visit a patient was given a clear summary of the proceedings of the visit and a resulting management plan. Coordinating Centre (St. Francis Hospital, Nsambya) maintains the type 1 diabetes registry in an EMR format. The current practice is that patients are given care objectives by the clinical team and this is documented in a summary form in the management plan that is retained by patient and reflected in his/her clinical case records. More in depth management details where appropriate – like pumps (2 patients) / complications are addressed as special sessions. In setting up the EMR, a communication-based intervention aiming at explaining the value, fit, and usefulness of EMR to all the health workers involved in the management of T1DM was employed; and used the pre-and immediate post EMR implementation stages.
Clinical Decision Support Systems	Glucose meters are used for self-monitoring of blood glucose (SMBG) and patients keep a log book. The recommended minimum number of blood glucose tests in a stable patient is 4 for 3 consecutive days and more tests per day in unstable patients. HbA1c is done at least every 4 months and records are entered in patient’s log book and in the clinic files. Multidisciplinary review: doctor and nurse and family. SMS are utilised for reminder messages and answering simple queries.

(Continued)

Table 1. Continued.

Element of Care	Implementation of Care Element
Community Resources and Community Policies	Patients with T1DM, their families, experts in curriculum development, teachers and social scientists were involved in the development of the type of care that would be best for the patient with T1DM in Uganda. Linkages with the community for peer-support, care coordination, and community-based interventions, like exercise centres (gym), swimming including subsidised medications. Recognition of hypoglycaemia by the community and its appropriate management was a priority. Positive community policies, for example encouraging sick children and adolescents to attend health facilities rather than seek traditional medicines are encouraged.

Notes: The CCM identifies the essential elements of a health care system that encourage high-quality chronic disease care. These elements are the health system, self-management support, delivery system design, clinical information systems, decision support and the community.

Uganda, this was expected to be problematic because of unstable electricity power, humidity, dust, security concerns, and difficulty in providing technical support. We aimed to overcome this by a satellite-based Information and Communication Technology (ICT) formulation, with a server hosted in a reliable place (UK), where technical support could be obtained, and electricity power more reliable.

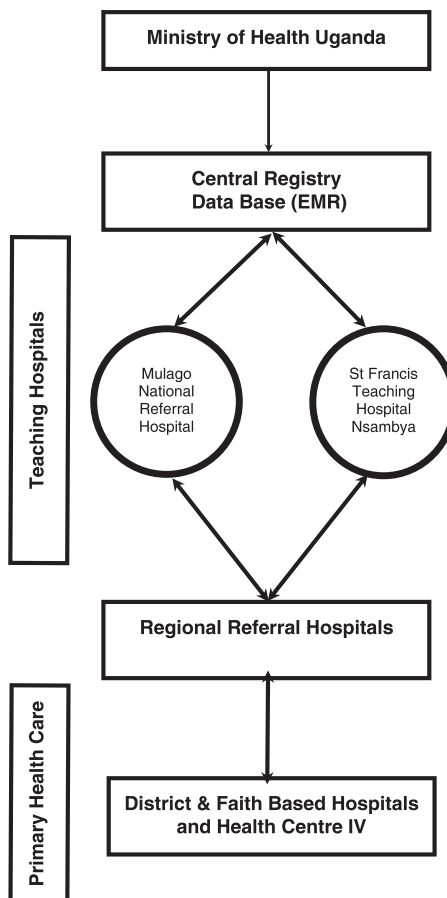


Figure 1. The structure of the health care delivery for type 1 diabetes (T1DM) in Uganda. T1DM, Type 1 Diabetes Mellitus; EMR, Electronic Medical Record.

Data captured into Electronic Health Care Records. The clinics use TECNO® Smart Phone (Tablets) with 4G compatibility																
ID	Clinic	Patient Name	Ethnicity	Sex	Date of Birth	Date of Diagnosis	Date of Registration	Education	Home Housing	Residence Distance	Weight	Height	BP Systolic	BP Diastolic	Clinic Attendance Status	HbA1c

Figure 2. Data captured in the Electronic Medical Records (EMR).

Table 2. Table showing the characteristics of type 1 diabetes (T1DM) patients at the different health level facilities in Uganda.

	Number	Teaching hospital (%)	Regional referral hospital (%)	Faith based hospital (%)	District hospital (%)	Health Centre IV (%)
Health facility type	28	7.1	21.4	46.4	17.9	7.1
Number of patients	1187	30.7	36.1	24.6	4.7	3.9
Gender: female	1187	56.7	47.9	45.5	53.6	52.0
Age at diagnosis (years)	0–5.9	95	44.2	25.3	26.3	2.1
	6.0–9.9	233	32.6	35.2	24.9	4.3
	10.0–18.9	712	28.9	40.0	22.2	4.6
	19+	142	28.2	24.6	35.2	7.8
Active patients	1100	31.7	35.3	24.3	5.0	3.7
Number who died	45	11.1	51.1	26.7	2.2	8.9
Lost to follow up ^a	25	24.0	64.0	8.0	0.0	4.0
Inactive ^b	17	29.4	5.9	64.7	0.0	0.0
Duration diabetes mean ± SD years	1187	6.5 ± 4.4	4.7 ± 3.2	5.3 ± 3.8	4.4 ± 3.8	7.9 ± 5.4

^aRefers to not being traceable after six months of missing an appointment, but patient not confirmed dead.

^bRefers to patient not returning for two consecutive appointments and is alive and contactable.

In case of interruption of transmission, data would be temporarily held in our local Custom Factory Integration (CFI) server until the transmission is restored. This also works for the extra-back up. The cost of hosting servers from the UK is about USD 100 per year.

Security and confidentiality of the electronic medical records

To ensure security and confidentiality of the EMR, a secure socket layer (SSL) – the standard security technology for establishing an encrypted link between a web server and a browser – was established. This ensured that all data passed between the web server and browsers remain private and integral. Furthermore, secure passwords logins for administrators and clinic managers were developed and are kept confidential and changed from time to time. High-level security for the database containing patient data is ensured by data being only accessed through our servers. Requests from non-authorised servers are automatically denied. Export of data is limited to the administrator only. Clinic managers can only enter new data but not edit them. Authorisation to edit data is required from administrators. Data is constantly backed up on a secure cloud server in the UK. Additionally, we maintain a secure backup on our Ugandan servers.

Data entry into electronic medical records

Smart phones, provided by the programme, are used to access the internet for data entry of the EMR and central registry. Where electricity is un reliable, the phones are provided with solar charged battery backups. Health workers’ access of clinic files is limited to their specific site. Passwords are site-specific except that of the administrator. In case a patient from one site presents to a site that is not the parent site, the health worker can contact the administrator for assistance. In this case, the health worker is given temporary access to the file and this is recorded. Currently, the health worker is able to have the following limited administrative support from the EMR:

- Automatically scheduling follow-up visits
- Automatically generating reminders for follow up visits
- Basic Statistical Report
- Upload reading and training material for the health care workers (the administrator)

Training of health care professionals

The training of health care professionals followed a curriculum developed to harmonise the management of type 1 and 2 at the primary care level. The first training is basic diabetes care and looks at how to set up the diabetes clinic and how to follow protocols in the management of diabetes. During the first training session, the administrators of the health units are invited to the training so that they approve of the changes to be effected. Furthermore, during the first training, it is stressed that doctors should appreciate and approve the roles played by the nursing staff in the care of patients with diabetes. The training of the health care workers is conducted at regular intervals for individual sites; and at least once a year collectively for two or three health care workers from each health facility with a T1DM clinic so as to harmonise the management of T1DM in the whole country focusing at different aspects of care. Opportunities are taken for health care workers to attend international and regional conferences. At the health facilities, weekly continuing medical education (CME) is carried out.

Diabetes care protocol

The T1DM clinics have followed management protocols provided by CDiC® programme both for outpatient and inpatient care (Novo Nordisk, 2017).

Study design

This is an observational study and we report on data from January 2009 to June 2018. The study was approved by St. Francis Hospital, Nsambya Review and Ethics Committee (Document No. UG-REC-020) and the Uganda National Council of Science and Technology (Document No. HS209ES).

Statistical analysis

Statistical analysis was done in STATA version 15, StataCorp LLC, 4905 Lakeway Drive, College Station, Texas 77845 USA. A p value of $<.05$ was considered significant.

Results

At the beginning of the programme *Improving Diabetes Care in Children in Uganda*, 178 patients, diabetes duration (mean \pm Standard Deviation [SD]) of 12.4 ± 2.9 years (range 10–26 years), were already receiving care. Of these patients, 17 (9 male; 8 female) were enrolled by Masaka Regional Referral Hospital hub and 161 (80 male; 81 female) enrolled by the St. Francis Hospital, Nsambya hub. This group of patients had no records kept at the health facilities and had no data on HbA1c. The HbA1c done at enrolment among patients already receiving care was (mean \pm SD) $10.0 \pm 0.1\%$; and not significantly different ($p = .12$) from the mean HbA1c at baseline of patients directly enrolled into the programme (mean \pm SD) $9.9 \pm 0.1\%$.

Thirty-two health facilities (932 patients) were progressively established over the period 2009–2018 (Figure 3). All clinics used both EMR and hard copy clinic files except 6 health facilities (265 patients; Masaka Regional Referral Hospital hub) which utilised only hard copy clinic files until June 2018 when their data was also captured into the EMR. Glycated haemoglobin (HbA1c) was done at enrolment (baseline HbA1c) or at the earliest opportunity after the patient was enrolled into care; and subsequently every four months. The mean baseline HbA1c (10.1%) of clinics utilising EMR plus hard copy clinic files did not significantly differ ($p = .17$) from those utilising hard copy

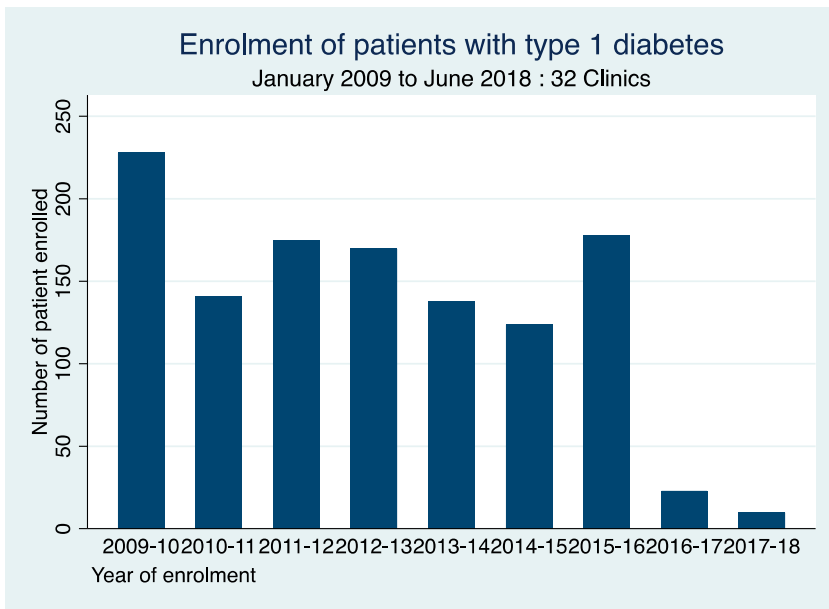


Figure 3. Enrolment of patients with type 1 diabetes.

clinic files only (baseline HbA1c 9.7%). The box plots of serial HbA1c of all the patients are displayed in [Figure 4](#). Box plots in [Figure 5](#) show serial HbA1c segregated by use of EMR plus hard copy clinic files or hard copy clinic files only. Overall, with all the patients grouped together, the mean \pm standard deviation (SD) of HbA1c at baseline (565 evaluable patients) was $10.0 \pm 0.1\%$ (95 Confidence Interval [CI]: 9.7–10.2%), and not significantly different ($p = .07$) from follow up HbA1c: first (565

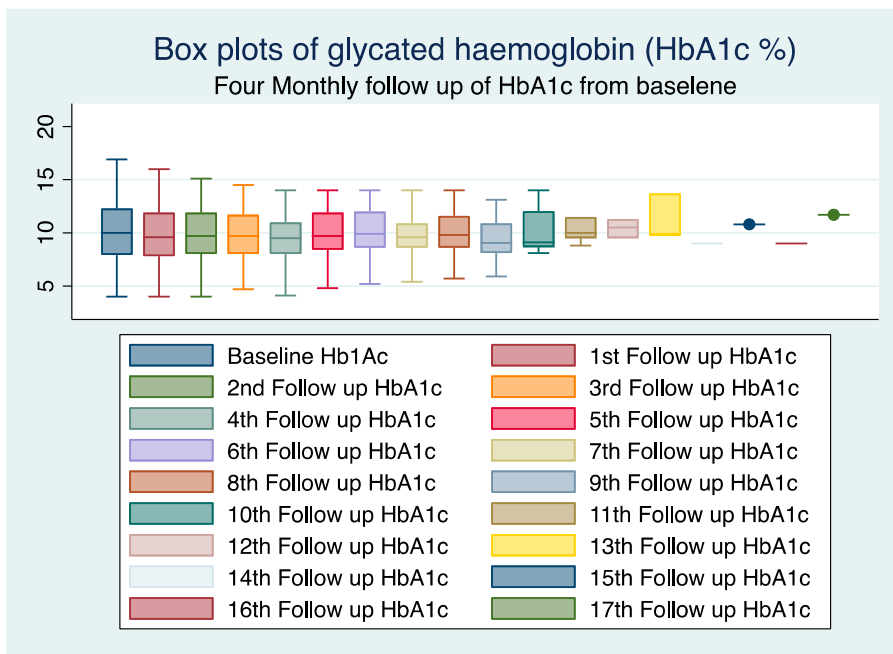


Figure 4. Box plots showing serial glycated haemoglobin (HbA1c%) done at four monthly intervals from baseline (time of enrolment).

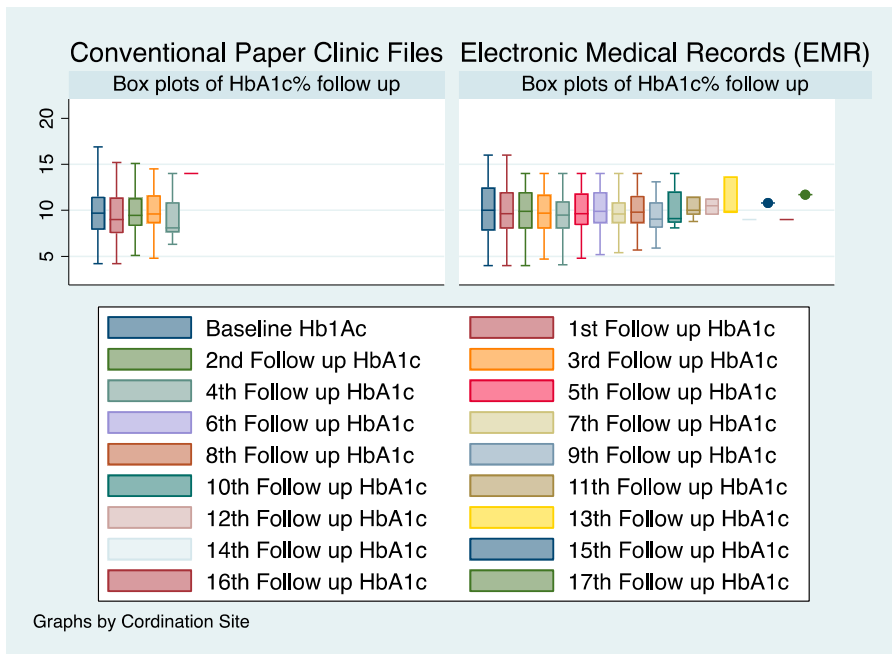


Figure 5. Box plots showing serial glycosylated haemoglobin (HbA1c) of patients whose data was captured into hard copy clinic files only (Conventional paper clinic files only) and those patients whose data was entered directly into the electronic medical records (EMR) at enrolment.

patients) $9.7 \pm 0.1\%$ (95% CI: 9.5–9.9%); second (427 patients) $9.9 \pm 0.1\%$ (95% CI: 9.6–10.1%) ($p = .38$); third (302 patients) $9.9 \pm 0.1\%$ (95% CI: 9.6–10.2%) ($p = .34$); and the fourth (217 patients) $9.6 \pm 0.2\%$ (95% CI: 9.3–9.9%) ($p = .07$). **Table 2** displays the demographic and clinic characteristics of T1DM followed up 2009–2018. Four health facilities – Moroto Hospital, in Karamoja; Jinja Hospital, in Eastern Uganda; Mubende and Mityana Hospitals were recently established, and are not included in this study. In three patients, the diagnosis of diabetes was made before three months of age and was therefore classified as neonatal diabetes. In the first patient, the diagnosis was made at 6 weeks of age, and genetic typing revealed a heterozygous missense mutation, p.R201C on KCNJ11 gene on the Kir6.2 subunit encoding for beta cell ATP-sensitive potassium channel (Nyangabyaki-Twesigye, Muhame, & Bahendeka, 2016). This patient is well controlled on Glibenclamide oral tablets. In the second patient, the diagnosis was made at 2 weeks of age, and genetic typing revealed the INS missense mutation, p.A1a24Aasp. The patient requires insulin therapy. In the third patient, the diagnosis was made at 6 weeks of age and is awaiting a report of genetic testing for neonatal diabetes and is on insulin therapy.

Discussion

This study demonstrates that the management of T1DM poses challenging and bracing efforts to the health worker striving to achieve the desired metabolic control in the patients. While the 178 patients identified with T1DM prior to the commencement of the programme may not be a true indicator of the prevalence of T1DM in Uganda at the time, it still sends a signal that the prevalence of T1DM was not high. The reasons for a low prevalence are multifactorial but may include a high mortality before and immediately after diagnosis.

With the establishment of T1DM clinics in 2009, the cumulative number of patients with T1DM progressively increased (**Figure 3**). The reduction in numbers in 2017 and 2018 may be a result of

having covered most of the Uganda by 2016. The loss to follow up and mortality was considerably low. Disappointingly, however, was the failure to reduce the HbA1c to the desired goal (Figure 4), despite the availability of insulin, glucose monitoring equipment, and trained health care professionals. Further studies are being carried out to identify the reasons for failing to lower the HbA1c to the desired goal of HbA1c < 7.0%. The emerging picture of the likely causes of failure to lower HbA1c includes poor understanding of HbA1c as a target of glycaemic control; less rigorous monitoring of blood glucose – patients and their relatives prefer to check once a day; and fear of hypoglycaemia. Patients with T1DM in Dar-es-Salaam, Tanzania, under a similar programme, had an equally poor glycaemic control with a mean HbA1c of 11.1% (Noorani, Ramaiya, & Manji, 2016). Younger age, having a mother as the primary caregiver, better caregiver knowledge of diabetes, better adherence to blood glucose monitoring regimen and duration of diabetes of less than 1 year were associated with better glycaemic control. Intervention with diabetes education did not seem to improve the poor glycaemic control in another group of T1DM in Tanzania (Mukama, Moran, Nyindo, Philemon, & Msuya, 2013). The establishment of regular care, increased education and monitoring in T1DM in Rwanda improved the HbA1c (Marshall et al., 2013, 2015).

Healthcare delivery for patients with type 1 diabetes (T1DM) in Uganda, still presents challenges that are compounded by the lack of both human and financial resources; and despite the rigorous planning and policy changes in the country, out-of-pocket spending is still a barrier to household access to quality care. While the programme provides insulin and other associated technologies, it does not provide medicines for the co-morbidities, or transport to the health facility, which significantly contributes to out-of-pocket expenditure.

In an extensive review of the barriers for paediatric diabetes care in Africa, Steyn and colleagues (Steyn et al., 2014) pointed out the need for innovative structures and government sustainable policies to deal with increasing numbers of children and adolescents with diabetes. The model of health care delivery for T1DM developed with funding from World Diabetes Foundation (WDF09-457) and Changing Diabetes in Children (CDiC*) in partnership with the Uganda Government was an attempt to have a sustainable programme in a resource-poor country with inbuilt structures to improve quality of care. While the programme has not achieved the targeted glycaemic goals, it has created a structure to investigate ways of improving care by expediting enrolment, minimising loss of follow up and reducing mortality.

There were no T1DM specialised clinics in Uganda prior to this programme, and caution had to be exercised in developing a model of care. Health care delivery is a dynamic process that utilises congruous interactions among different health care providers, each of whom is dependent on the other in terms of skills, knowledge, expertise and physical assistance. The complex interactions between multiple specialised workers are specific to the healthcare organisation and the health care delivery system. The dynamics of the process, however, remain inadequately understood because there is no overarching model that examines and represents its multidimensional complexity in its entirety, more so in a resource-restricted setting. Hence our first task in organising the health-care delivery for the T1DM patients using a chronic care model (CCM), was to adequately consult with stakeholders and to be mindful of sustainability. In Uganda, T1DM care is primarily delivered by nurses who have been trained in the management of T1DM, but who are also required to perform other tasks in their health facility, translating to less time spent with T1DM patients. This is the unfortunate situation imposed by a lack of adequate human and financial resources. Therefore, it was important to ensure that all clinics had adequate supervision by diabetes experts in the management of T1DM; and that the nurses received regular continuous medical education and further training in the management of T1DM. The programme structures have been set to maximally utilise the support of the community, including school support, by having community participation when giving diabetes education to the patients and their care givers.

We opted to use web-based electronic medical records (EMR) so as to improve efficiency and care (Vishwanath & Scamurra, 2016). The process took a format of empirically developing a conceptual model of EMR workflow and noting the impact of the EMR on outpatient clinical workflow and how

the multidimensional effects were empirically conceptualised and represented by the healthcare workers. This was necessary as the EMR concept was new to the health workers and policy makers. Thus, while keeping both hard copies at the health facilities and using EMR was an additional load of work to the health workers, it deemed necessary in a situation where there was a lot of misconceptions on information communication technology (ICT) adoption and implementation. After training adequate numbers of health workers and gaining confidence in the use of EMR, it was then possible to have a model implemented countrywide, and have a central registry for T1DM. Implementing a secure, web-based electronic medical records has allowed data collection and review to occur from many remote sites. The administrator is able to log into all the clinic sites and study what is being done even as the clinic is going on and advise as may be necessary. Using a shared server in a secure environment with stable power and good data backup (including a duplicate machine off-site) has the additional advantage that the most recent data are available to all users. Other positive aspects of the EMR are embedded in the possibility of ensuring large numbers of cases with identifying the information being stripped of identifiers for purposes of medical research on large aggregates for example complications and judge quality of care.

While elsewhere in sub-Saharan Africa (SSA) significant improvements have been achieved in the last decade mainly in the form of dependable insulin supply, there are still few organised health care clinics structured to optimise glycaemic control (Piloya-Were, Sunni, Ogle, & Moran, 2016); and T1DM patients continue to be followed up in adult type 2 clinics. There is a paucity of data on health care delivery for T1DM and we are not able to compare with any other model in SSA, even among the Changing Diabetes in Children (CDiC®) sites in other countries. What will follow is to find ways of improving glycaemic control and to assess the long-term quality of care provided by this model. In the short-term, we have demonstrated that survival and quality of life may be improved (Table 2), albeit not achieving the desired glycaemic control. The high mortality noted in the Regional Referral Hospitals was encountered at the start of the project and due to diabetes ketoacidosis prior to adequate training of the health care workers.

While the healthcare delivery for T1DM has been structured along with the elements of the chronic care model, there are still many challenges. The high HbA1c is a big challenge which requires urgent attention. Negative cultural beliefs, for example, that children do not get diabetes, and instead it is 'the charms' or evil spirits, etc. still exist and have led patients seeking alternative therapy. This leads to stigma and stoppage of insulin therapy, in the search of a cure against the charms and evil spirits.

The internet band width available in the country is narrow, and the system slows down when the files are heavy. This has limited the data we are able to capture. The transfer of health workers after training them has remained a challenge, as training new ones are costly and time-consuming.

There is need to reduce and minimise out-of-pocket cost for medical care, probably by the introduction of health insurance, so that patients can access care for co-morbidities of diabetes, when a need arises, without paying out-of-pocket. Management of co-morbidities is not catered for under CDiC® programme.

Limitations of the study

A major limitation of this study is that it has not been possible to include private-for-profit facilities because Uganda does not yet have national health insurance to cover costs of care at private institutions. Furthermore, transport to designated health facilities managing T1DM is an out-of-pocket cost and this may be a barrier to regular clinic attendance.

The chronic care model is dependent on a responsive government policy to work; and indeed, performs poorly where policy change is slow, as for example in moving to comprehensive EMR or allowing health workers to specialise in diabetes care and not be requested to perform other clinic duties as well. There is yet no government policy for the management of T1DM in Uganda.

The chronic care model was structured to have an audit, but with no inbuilt mechanisms to prompt the health worker for such an audit, hence the danger of unrecognised poor care for long periods.

It was not possible to check for the discrepancies between what was in the hard copy clinical records and the EMR.

Conclusion

We present a model of care for type 1 diabetes (T1DM) based on the Chronic Care Model (CCM) that employs task sharing of diabetes care for T1DM with nurses and clinical officers and supervised by specialists. We implemented a web-based electronic medical record (EMR) system, using a stepwise approach. The model expedites the establishment of clinics and identifies areas to be addressed, but does not provide comprehensive solutions for poor metabolic control. More studies which identify the effect of health system arrangements on various outcomes, particularly metabolic control, are needed.

Declarations

Ethics approval and consent to participate: Approval for this study was obtained from St. Francis Hospital, Nsambya, Review and Ethics Committee; REC No. UG-REC -020 and the Uganda National Council of Science and Technology: document HS209ES.

Consent for publication: Consent for publication was received from the Ministry of Health, Uganda Government (Director General Health services), Ref ADM.45/526/01

Availability of data and material: Datasets used and /or analysed during the current study are available from the corresponding author on reasonable request.

Authors' contributions: Concept and design: SB & RW. Acquisition, analysis, or interpretation of data: All authors. Drafting of the manuscript: SB. Critical revision of the manuscript for important intellectual content: TPW. Statistical analysis: SB & RW. Decision to submit the manuscript for publication: All authors.

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Disclosure statement

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