

Issues and potential solutions when capturing health data in rural clinics in South Africa

Problemas y soluciones potenciales en la captura de datos de salud en clínicas rurales de Sudáfrica

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ABSTRACT

This paper highlights the data and information required by various International bodies, including WHO, PEPFAR, World Bank and the South African Government regarding HIV and its associated programmes and comorbidities. It explores the current collection of data in South African rural clinics and reports on the results from in-depth interviews with nurses regarding the burden of data collection and the perceptions and attitudes to electronic solutions including smart phones and tablet computers.

Key words: clinic registers, data quality, attitudes and knowledge, nurse acceptance.

RESUMEN

Este artículo destaca los datos y la información requeridos por diversos organismos internacionales, como la OMS, el PEPFAR, el Banco Mundial y el Gobierno de Sudáfrica en relación con el VIH y sus programas asociados y comorbilidades. Explora la colección actual de los datos en las clínicas rurales de Sudáfrica y los informes sobre los resultados de las entrevistas en profundidad con las enfermeras con respecto a la carga de la recopilación de datos y las percepciones y actitudes hacia soluciones electrónicas, incluyendo teléfonos inteligentes y tablet PC.

Palabras clave: registro clínico, calidad de datos, actitudes y conocimiento, aceptación por enfermería.

INTRODUCTION

Walter Sisulu University (WSU) is one of three South African historically black universities established in the so-called 'independent homelands' during apartheid. Its Medical Faculty was established in 1985 and is the only medical school in the Province of the Eastern Cape (EC). The EC is home to 6.5 million people that are 13.5 % of South Africa's (SA) population.¹ It is the poorest of SA's nine provinces and primary health care expenditure per capita is well below the national average.

Most of the 6.5 million residents of Eastern Cape Province live in rural areas or small towns. The teaching staff relies heavily on Cuban physicians and 60 % of the staff are not South African.² South Africa is the epicenter of the global HIV and TB epidemics. South Africa has an HIV prevalence of 10.9 % for people aged two years and older, with 5.2 million people estimated to be living with HIV in 2008, the most of any country in the world.³ The total incidence rate of TB in 2008 was 948 cases per 100,000, the highest among the 22 WHO high burden countries.⁴

Alma-Ata Declaration

WHO and United Nations Children's Fund (UNICEF) held an historical international conference on primary health care in Alma-Ata, then the capital of Kazakhstan in September 1978. The conference adopted the Alma-Ata Declaration, which defined primary health care as the key to achieving the goal of "health for all by the year 2000". 134 health ministries signed the Alma Ata Declaration.

This conference focused for the first time ever on the importance of primary health care in national health services.⁵ It called for eight main areas of focus:

1. an adequate supply of safe water and basic sanitation;
2. the promotion of food supply and proper nutrition;
3. maternal and child health care, including family planning;
4. immunization against the major infectious diseases;
5. the prevention and control of locally endemic diseases;
6. appropriate treatment of common diseases and injuries;
7. health education; and
8. the provision of essential drugs.

Thus the WHO "Targets for Health for All" started to change the way health was perceived. At the 51st World Health Assembly the "Health for All in the 21st Century" policy was adopted and has since played a major role defining global priorities for the first 20 years of the 21st century. Ten objectives were formulated to define conditions through which people worldwide could attain the highest possible level of health.

Target 9: Implement global and national health information and surveillance systems

The development of key health status indicators for South Africa within a broad "Health for All" framework was discussed a decade ago and the issues of poor data quality recognised.⁶

The data collected in clinics is used for National Indicators as well as data for funding bodies and specific programs.

"Harmonization for Health in Africa" was created by WHO, UNICEF, UNAIDS, UNFPA, the World Bank and the African Development Bank to help countries get value for money from different sources of funding and of course added to the number of data items that people were required to collect as part of the funding.

Primary health care services to most of the population of South Africa are provided at community health centres (CHCs) and their satellite clinics. These services are provided predominantly by nurses and include preventative and curative services e.g. mother and child health, immunizations, preventative screening and family planning, and treatment of acute and chronic conditions, including nurse initiation and management of patients on antiretroviral therapy (NIM-ART). There are data reporting requirements for evaluation of these services mandated by the Department of Health (DOH).

The National Strategic Plan on HIV, STIs and TB, 2012-2016 (NSP) was recently introduced in South Africa in the form of indicators for the plans targets.

The indicators are (numbers rounded to avoid false accuracy):

- HIV prevalence in 15-to-24-year-olds, estimated at baseline to be 9 % (HSRC Household Survey). The NSP targets a reduction to 4 % in 2016.
- HIV prevalence in key populations. The NSP contains no baseline data for this, even though it proposes a 50 % reduction.
- HIV incidence, estimated to be 1 % in 2012 (ASSA). The goal is to reduce this by half by 2016.
- HIV mortality, estimated at over 40 % of deaths at baseline (Stats SA). The aim is to reduce this percentage by half by 2016.
- TB incidence, estimated to be almost 1 % in 2010 (WHO). South Africa aims to reduce it by half by 2016.
- TB mortality in HIV-negative people, estimated to be 50 per 100,000 in 2010 (WHO). The NSP targets a reduction to 25 per 100,000 in 2016.

- Rate of transmission to infants, estimated to be just under 4% at six weeks after birth in a study published last year by the MRC. South Africa aims to reduce this to less than 2 % at six weeks and less than 5 % at 18 months in 2016.

- Patients alive and on ART. No data is currently available for this indicator, but by 2016 the target is to have 94 % retention in care by one year after commencing ART, 88 % by two years, 82 % by three years, 76 % by four years and 70 % by five years.

This national system recognizes that there are three tiers of data collection that need to work together:

- Paper-based systems at small clinics.
- Standalone electronic data capturing systems at medium-sized clinics.
- Networked Electronic Medical Record systems at large facilities.

CONTENT

Nursing Records

There are reporting requirements mandated by the Department of Health (DOH) for certain conditions and programmes including TB, HIV testing and ART initiation and mother and child health. Currently, data at Community Health Centres (CHC) and clinics are handwritten in registers by nurses, community healthcare workers and clerks and aggregated into data sheets. There are multiple registers due to vertical disease programmes. Data capturers at the Local Service Area (LSA) offices enter data onto the Department of Health Information System (DHIS). However, there are problems with the paper-based system. An evaluation of the DHIS in 10 clinics in rural KwaZulu-Natal revealed a high perceived work burden associated with data collection and collation by the nurses, and data quality was poor.⁷

In an evaluation of 15 clinics in the Nyandeni Health Sub-District in the Eastern Cape Province in 2009, nurses used multiple ledgers for data collection and many inaccuracies were noted in data reporting. The study identified seventeen patient collection tools. Thirteen of these source tools originate from the Department of Health, while three were ordinary notebooks used by all health facilities surveyed to supplement the clinic registers. The maternity register was only found in three health facilities surveyed. This register is used to record delivery information and since most deliveries are conducted in hospitals these registers are mostly found in hospitals. In instances where mothers deliver at home, then clinics serving those communities keep records of the register.

The number of source tools is consistent with an earlier verbal communication with an information manager from another district who claimed that a survey had determined up to 25 clinical registers elsewhere. The design of these data source tools does not make it any easier for clinicians to fill these registers. Apart from the primary health care card the registers are highly structured. The VCT register for example has 30 columns, it accommodates 20 patients per page, the Pre-ART register has 32 columns in them and can accommodate 30 patients while the ART and HAST registers have an excess of 40 columns. The number of columns corresponds to a patient's data attributes, for example the attributes name, gender

and age represent 3 columns in the clinical registers. Some patients recorded in the Pre-ART register require all forty columns to be completed. In cases where more columns are required, for instance when the number of consultations exceeds the number catered for in the register, a new register will have to be opened. These huge numbers of columns and rows mean each register has a number of fields that need to be filled.

The majority of the registers are massive about A3 in size. The registers are designed in such a way that demographic details like patient name and patient address are found on the left hand side of the page while signs, symptoms, progress results extend from the centre towards the end of the page. This design aims to record longitudinal data. Unfortunately the registers only cater for a certain amount of time and once this is exhausted the same patient details have to be re-written in a new register. To fill in a patient's results for instance one needs to pinpoint his or her name on the left hand side of the page and carefully navigate across the page to enter the result. This makes the registers cumbersome to complete. The smaller sized registers are not any better as fields are smaller and just as crammed with data. All data collection tools available at the sites were designed from outside the clinics.

This is in contrast to three notebooks converted by clinicians into record tools. The maximum number of columns in these notebooks was found to be six in the specimen register. An observation during the study was the lack of patient files at the clinic. The closest resemblances to a patient file were primary health care cards carried around by patients

The study concluded that data lacked validity and reliability.⁸ There was no evidence that data analysis informed any policy or programme management in individual clinics.

The Health Informatics Research team found that there are different types of record documents used in Community Health Clinics (CHC). These include the patient's personally retained record. Due to a lack of official stationary, patients usually have to buy and use school exercise books. CHCs have some National Department of Health issued cards e.g. Antenatal Care and child health. There are also up to 17 registers per CHC for recording the attendance of single events related to patient care, specific conditions or procedures e.g. births, tuberculosis, HIV and immunizations. Members of the WSU Health Informatics team conducted in-depth Interviews with nurses in four clinics in the rural areas of Mthatha to elucidate more details about the completion of these multiple records.

Filing

When analyzing the interviews it was found that there were 34 comments associated with the current paper-based filing system. Duplication was identified as a concern related to continuity of care, due to a lack of a complete chronological record. Duplication was also perceived as a waste of time. Missing files was another area of concern, either due to loss by patients or from misfiling in the clinic. In addition, time was spent looking for old registers.

Handwriting

There were 15 comments on the difficulty of reading handwritten notes, both by doctors and nurses. One respondent expressed concern that a wrong medication could be administered:

"It is big problem because if my writing is eligible and I am not here they can give the wrong medication to the patient, I am sorry it needs to be legible".

Time spent on paper records

Comments also expressed concern over the excessive amount of time needed to complete the records often leading to incomplete recording:

"The bad side it takes time and sometimes you are exhausted and you omit some information".

Two respondents made a plea for assistance with recording:

"But it's time consuming because it needs more people, you cannot do it alone, it needs a data capturer".

This highlights that the high workload results in the recording of data occurring sometime after the event i.e. the next day. This may lead to inaccuracies:

"You will have to finish tomorrow and that is not nice because it is today's work, like today I started with yesterday's work".

The following quotes reflect a concern among a number of nurses that they are neglecting patient care in favour of collecting of collecting data:

"Yes and much time is spent on recording than taking care of the patients".

"I think what our superiors need is what is written down, I think they think we must spend time more on registers, not on patients".

Heunis et al⁹ assessed the consistency of TB-HIV data at 20 health facilities (mobile and fixed clinics, health centres and district hospitals) in the Free State Province with the same data recorded at Provincial level. There was a 21 % inconsistency between the data. Interviews with nurses identified staff shortages as the most important challenge in the TB-HIV information system, as well as lack of training and "too many forms to complete". They suggested that a single integrated information system should be implemented.

Thus the National Standards of Care targets are reflected in Health Programs, which in turn are defined as performance indicators.

In addition to collecting clinical data on all services provided by a facility, clinicians are required to report on issues such as infrastructure status and human resources issues such as staff availability etc. Discussions with the provincial information office revealed that in addition to clinical disease management, information collected from the care process is used for secondary purposes such as: administration, financial management, resource allocation, research and so on. All this information originates from data health workers are required to collect on a routine basis. Such an arrangement brings into mind a question posed by Berg and Goorman¹⁰ when they asked whose responsibility is it to do this additional work of data collection, collation, reporting for secondary use and where do the benefits end up? Berg and Goorman emphasize that the task of producing data for secondary use by others, other than the primary givers, is unfairly delegated to the primary care giver. When the goal is to support secondary utilization of data

outside the context of the care process itself, this additional burden is highly problematic.¹¹

It might even be considered unacceptable given the clinicians' time constraints and the fact that this additional task will take them from their primary responsibility, in other words caring for the patient. This does not mean that collection of health data for secondary use is unacceptable; it only means that the collection and use of information should not impose a burden on the individuals collecting it.¹² Moreover, the data being collected should add value to the individuals collecting it. Since clinicians are not using the data they collect it could be assumed that the data they are collecting is of no value to them.

IT in Health Care

There is belief that it is possible for South Africa to "leap frog" directly from poorly functioning paper-based health information systems to highly sophisticated and fully integrated country-wide network solutions based on e.g. telemedicine, smart cards and electronic health records. The use of electronic data sources common to all healthcare settings (e.g. billing or administrative information) has the potential to streamline data gathering and improve public health reporting.

The eHealth Strategy for South Africa 2012 states that all indicator data derived from patient data should be captured electronically at the point of care. Historically data has been collected by nurses in the clinics and recorded in paper registers. The government has been trying to improve the quality of data using dedicated data capture devices to transcribe the nurses' data into an electronic version.

Given the complexities of the development of health IT projects many health IT projects fail. In most instances these failures occur because of insufficient understanding of the needs of health care workers. These electronic solutions certainly have their advantages over paper based information systems. However, as pointed out by Braa and Hedberg¹³ health workers are disempowered when they collect data for others without having any say in what they collect. When they don't receive feedback and do not use the resultant information for improving the management of their facilities, then their efforts in data entry are an exercise in futility. There is evidence that the introduction of an electronic system designed to capture data would only be providing a computerized solution to a non-computerized problem and the result of poor data quality may still exist.

There is evidence that Electronic Medical Records (EMR) can increase the delivery of care that would adhere to guidelines and protocols, enhance the capacity of providers to perform surveillance and monitoring for disease conditions and care delivery, reduce rates of medication errors and decrease utilization of care.¹⁴

Adherents of the socio-technical approach state that in the majority of IT implementations, the technology works fine.¹⁵ The introduction of Health ICT in an organization does not mean it will be used as intended. If the ICT does not align with the clinical work system, intended end-users may reject it, misuse it, sabotage it or work around it. There are many examples in the literature of evidence for this claim.^{16,17} It is estimated that the majority of IT projects in various sectors, including health care, have failed. Failure is commonly defined as any one or all of "significant budget and timelines overruns, under-delivery of value and the outright termination of a project before completion".¹⁸ Problems are now considered to be more managerial than technical, and sociological, cultural and financial issues are paramount.¹⁹

Nurses' knowledge

One of the significant factors in the planned introduction of IT is the attitude of the staff that will be required to use it.¹⁵ Individual users' acceptance of ICT is a crucial factor in determining the success or failure of an ICT system.^{17,20} The nurses in our recent study had very positive attitudes to IT as a way forward. Despite having little or no access to computers, many nurses have the ability to clearly articulate potential benefits of an EMR. Their view referred to point-of-care data entry and the use by nurses of patient related data for care. This is in contrast to the complaints made by them about the waste of time filling in registers.

There were a few comments questioning IT adoption by older staff. None of these gave an opinion as to why they thought this would be true. One respondent thought that older staff would at least try to use a computer. Interestingly, a respondent thought that using the computer for other purposes shouldn't be allowed. The experience of the authors is that during the introduction of information systems, it is much easier to develop adoption by staff by allowing them to play games and surf the Internet, as this will encourage them to use the computer.

Department of Health Information System (DHIS) Data

The nurses spoke positively about the time saving on register completion that the introduction of IT would bring, while still sending the statistics to government as required:

"I think it can help is statistics because now we do the counting and we submit at the end of the month, now we will don't have to".

"I think on our side that works with adults, they can use the computers because they will reduce the work load, like the register because they will reduce the workload, like the register because they have these chronic registers and it's the tick register that they use, they use tick register for chronics and I think it can be useful because it can make things faster more especially in the reception where they register when thy come, it can also limit the time clients wait for their cards".

Positive attitudes to IT

Many nurses expressed an opinion than computerization would release them to see more patients.

"Yes because we see so many patients if we have some computers to put some patient information that would be better".

Access to knowledge

Nurses expected to get quicker access to continuing professional development through the Internet.

"Even things that are related to the nursing profession things like new policies we get them through computers".

A number of respondents commented on the use of IT for research and education. "As I've said for research purposes for education, to improve quality care of the patients and for time management as well and to be updated for new things because if we have the computers we are not going to wait for the circular to come,

we will just check, in the morning we were talking with the young guy that we are going to have an increment he saw it in the Internet".

"Yes because sometimes when you assess the client you come across an unusual condition you can just Google and get help on the management and treatment".

"Maybe when you deal with poison you'll just click and get all the information about management and treatment".

Confidentiality

"When they come everyone can tell that those ones are sufferers, you see the stigma because they are the only ones who have those files, everyone can see so there is no privacy there because other patients can easily identify those".

Contact tracing

One respondent identified that sharing information on a computer would assist in contact tracing for Sexually Transmitted Infections (STIs). "As I highlighted that the patients change cards and others are here today for an STI and you treat her and say bring your partner, so when she is coming tomorrow she didn't bring the partner, and on the queues they know us so she is not going to come to me because I still remembers her face, you find that she is coming for the same problem so now even if she avoids me and consulted by other nurse in another consulting room the nurse will be able to see that she was treated on that".

Cost saving on stationary

"It can save the budget because lot of budget goes to the stationary, less time we spend with the client".

Reduced storage needs: "Jah there can be change, we not gonna have all these files, these files have got the old books, we have files of 1999".

CONCLUSIONS

The notion that Government bodies can decide that health professionals should perform functions like data collection because they happen to be with the patient is commonly accepted as reasonable by such bodies. But one should ask why should health professionals collect data, which is for government use, and takes them away from their real job of patient care. There is ample evidence to show that workers, who collect data that has no meaning or purpose for their work produce poor and unreliable data. Many countries have include into their Information strategies the notion that such data should be collected as a by-product of operational data. Thus giving meaning to the data and increasing the reliability and validity. Why so many countries what to collect all patient data in every health setting for epidemiological purposes leads us to question why they don't undertake stratified sampling and reduce the burden on the vast majority of health care professionals. The use of registers in rural clinics could then focus on collecting patient based data for care and management.

Various data capture methods are being tried by researchers in the Eastern Cape, including:

- a digital pen that memorizes strokes on a preprinted form,
- the use of digital voice recording with automatic transcription to text,
- input of data by nurses using tablets and smart phones.

Our recent survey shows a high ownership and acceptance of smartphones by rural staff. The data collection is by means of x-forms using the ODK data capture open source software kit. Further studies will be undertaken to evaluate the reliability and validity of the use of smart phones to capture contemporaneous data in rural health clinics and the impact this has on care delivery.

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