MANAGING HIV AS A CHRONIC DISEASE: USING INTERACTIVE DATA COLLECTION TO IMPROVE CLINICAL CARE

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As South Africa and the rest of the developing world respond to the AIDS crisis, a critical task will be to develop scalable systems for sustainable and effective delivery of antiretroviral (ARV) drugs in a variety of resource-restricted settings. With the emergence, from national governments, the World Health Organization (WHO) and major international donors, of the political will and funding to support treatment programmes, it has become urgent that we consider how ARVs will be delivered. In this review, we consider how ARVs allow us to manage HIV/AIDS as a chronic disease, and the data systems that are required to support this approach to therapy.

MANAGING HIV/AIDS AS A CHRONIC DISEASE

With modern ARV treatment regimens, sustained high survival rates can be expected.[1,2] However, effective management of patients who qualify for ARVs entails a lifetime commitment by both patient and providers to complex treatment with significant side-effects. A system of efficient chronic care may require comprehensive clinic redesign and a division of labour that allows non-physicians to take greater responsibility for routine care. This model has been used successfully in the developed world for a number of chronic diseases (diabetes, asthma and hypertension).[3] While the AIDS pandemic in the developing world presents a unique set of challenges, the expected prolonged and healthy survival of patients treated with ARVs in resource poor-settings necessitates the development of a comprehensive management strategy for this disease.[4] A number of highly successful ARV pilot programmes have been reported from the developing world, including from South Africa.[5,6] The challenge now is to develop effective programmes that are replicable and scalable within the resource-poor public health sector. Scalable disease management programmes have been implemented successfully in the developing world for perinatal diseases, tuberculosis (TB)[7] and HIV[8,9] in co-operative projects with health improvement organisations supporting national and provincial health programmes.

The outcome of chronic diseases has been most successful in situations where a structured programme of care delivery results in an informed, activated patient population and knowledgeable, proactive, protocol-driven care providers who work collaboratively with their peers.[10] In the Chronic Care Model described by Ed Wagner,[11] this interaction can be supported best by harnessing and integrating the contributions to care from both the community and the clinic (Fig. 1). The design of care in the clinic should take into account the varied needs of the patients, utilise fully the spectrum of skills of the clinic

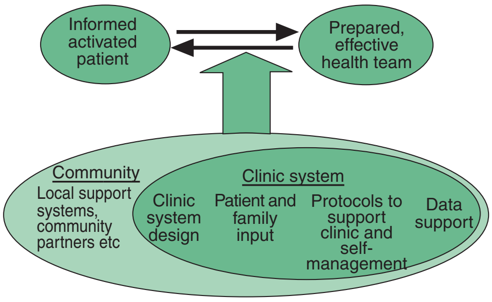


Fig. 1. The chronic care model, adapted from Wagner.[11]

personnel, and strive to accomplish the six attributes of care identified by The Institute of Medicine, i.e. care that is patient-centred, effective, safe, efficient, timely, and equitable.[12] To achieve this, several components of the health care delivery system need to be considered.

HEALTH CARE ORGANISATION (HCO)

While the introduction of new services may stress an already overstretched health system, the introduction of sound disease management practices for ARV delivery provides an opportunity to strengthen the system. To assist in this process HCO leadership should make excellent HIV/AIDS care a goal of the health system, and provide the resources to initiate ARV care (e.g. data systems, data entry personnel, counsellors), remove barriers to clinic redesign, and actively support implementation and ongoing improvement of ARV treatment programmes.

CLINIC SYSTEM DESIGN

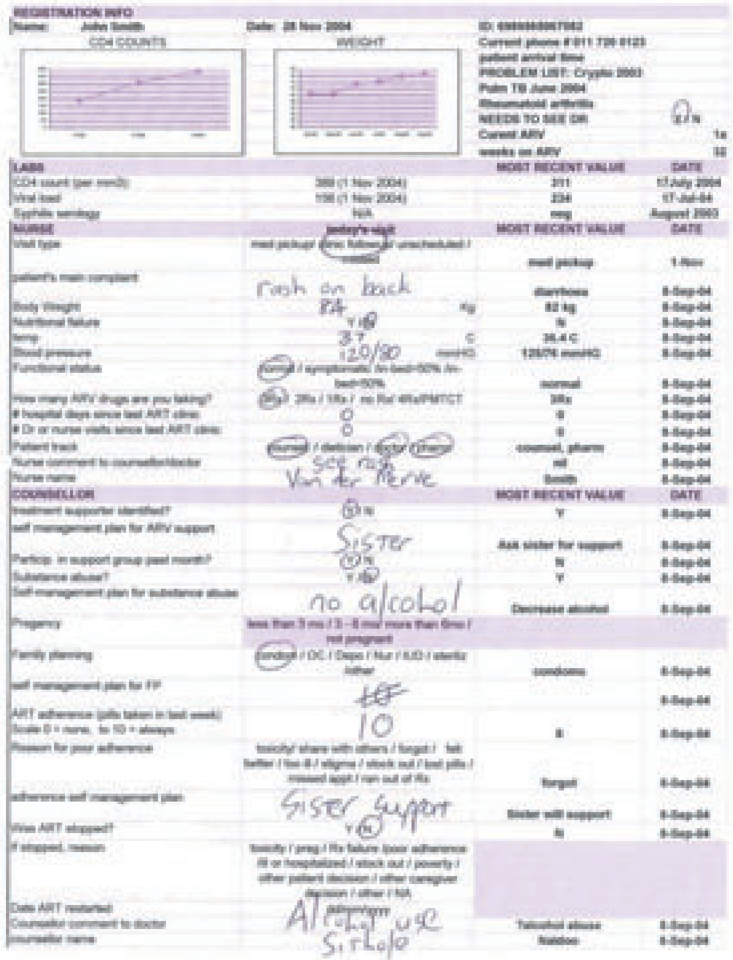
As clinics make the transition from palliative care of AIDS to comprehensive management of HIV/AIDS, the structure of care delivery needs to be redesigned. While many of the reported pilot programmes and initial phases of the South African ARV roll-out are mostly doctor-based, a more nurse-based focus will need to emerge as the service devolves into more of a primary care setting, As suggested by South African Government guidelines,[13,14] new and existing patients who are being prepared for ARVs will have different needs from patients who are being seen repeatedly for ARV maintenance therapy, or patients with HIV who do not qualify for treatment. Patients on chronic therapy can be triaged in streams that stratify patients who need routine care and surveillance ('fast-track') from those who require more complex care or a change in management (e.g. consideration for up- and down-referral). Reassessment of the role of different caregivers often reveals additional human resources that can be harnessed to increase clinic capacity. For instance, as clinics become overburdened and progressively more dysfunctional, caregivers are consumed with inappropriate tasks (e.g. nurses are diverted from patient care to traffic control, directing and placating patients), and time and effort is wasted on data entry that is duplicated throughout the clinic (e.g. pharmacists re-enter demographic data in order to dispense drugs). Clinic efficiency is significantly enhanced when the roles of every member of the care unit are clarified.

CLINIC PROTOCOLS

Management can be organised to support the best available guidelines of ARV therapy and HIV care. The South African guidelines have clear algorithms, which can be incorporated into disease management.[13,14] Patient encounter forms can support these algorithms by promoting information collection and prompt care that relates to the specific needs of the particular stage of a patient's management. Protocols should be adapted periodically through a systematic process that is informed by data collected in the clinic.

SELF-MANAGEMENT SUPPORT

Patients can be given an active role in the management of their disease. The process whereby patients become informed and involved is incorporated into routine clinic management in many HIV clinics with the use of counsellors and teaching sessions. Self-management strategies should be documented and can be reinforced



REGISTRATION INFO

Name: John Smith
Date: 28 Nov 2004
ID: [illegible]
Current phone # 011 720 0123
patient arrival time
PROBLEM LIST: Crypto 2003
Pulm TB June 2004
Rheumatoid arthritis
NEEDS TO SEE DR [✓ Y] / N
Current ARV 1a
weeks on ARV 12

LABS		MOST RECENT VALUE	DATE
CD4 count (per mm3)	388 (1 Nov 2004)	211	17July 2004
Viral load	150 (1 Nov 2004)	234	17-Jul-04
Syphilis serology	N/A	neg	August 2003
NURSE	**today's visit**	**MOST RECENT VALUE**	**DATE**
Visit type	med pickup/ [✓ clinic followup] / unscheduled / missed	med pickup	1-Nov
patient's main complaint	rash on back	diarrhoea	8-Sep-04
Body Weight	84 kg	82 kg	8-Sep-04
Nutritional failure	Y [✓ N]	N	8-Sep-04
temp	37 C	36.4 C	8-Sep-04
Blood pressure	120/90 mmHG	120/76 mmHG	8-Sep-04
Functional status	[✓ normal] / symptomatic / in bed<50% / in bed>50%	normal	8-Sep-04
How many ARV drugs are you taking?	[✓ 3Rx] / 2Rx / 1Rx / no Rx/ 4Rx/PMTCT	3Rx	8-Sep-04
# hospital days since last ART clinic	0	0	8-Sep-04
# Dr or nurse visits since last ART clinic	0	0	8-Sep-04
Patient track	[✓ counsel] / dietician / [✓ doctor] / [✓ pharm]	counsel, pharm	8-Sep-04
Nurse comment to counsellor/doctor	see rash	nil	8-Sep-04
Nurse name	Van der Merwe	Smith	8-Sep-04
COUNSELLOR		**MOST RECENT VALUE**	**DATE**
treatment supporter identified?	[✓ Y] N	Y	8-Sep-04
self management plan for ARV support	Sister	Ask sister for support	8-Sep-04
Particip. in support group past month?	[✓ Y] N	N	8-Sep-04
Substance abuse?	Y [✓ N]	Y	8-Sep-04
Self-management plan for substance abuse	no alcohol	Decrease alcohol	8-Sep-04
Pregnancy	less than 3 mo / 3 - 6 mo / more than 6mo / not pregnant		
Family planning	[✓ condom] / OC / Depo / Nur / IUD / sterilis / other	condoms	8-Sep-04
self management plan for FP			8-Sep-04
ART adherence (pills taken in last week) Scale 0 = none, to 10 = always	10	8	8-Sep-04
Reason for poor adherence	toxicity/ share with others / forgot / felt better / too ill / stigma / stock out / lost pills / missed appt / ran out of Rx	forgot	8-Sep-04
adherence self management plan	Sister support	Sister will support	8-Sep-04
Was ART stopped?	Y [✓ N]	N	8-Sep-04
If stopped, reason	toxicity / preg / Rx failure /poor adherence / ill or hospitalized / stock out / poverty / other patient decision / other caregiver decision / other / NA		
Date ART restarted			
Counsellor comment to doctor	Alcohol use	?alcohol abuse	8-Sep-04
counsellor name	Sithole	Naidoo	8-Sep-04

Fig. 2a. Data collection sheet.

at subsequent visits. Standardised assessments of patient knowledge and barriers to care can be used to design better care. Patients can be motivated, and their adherence can be promoted by seeing their disease indices, including 'improvements' in weight, CD4 counts, and other parameters (Fig. 2a and b). These act as important adherence support tools.

COMMUNITY RESOURCES

The South African programme strongly emphasises the role of community organisations, ranging from support for disclosure and stigma reduction to assistance with palliative care and adherence support. Effective chronic disease management should include linkage of clinic care to community resources (e.g. home visits and partnerships with community activist groups).

ROLE OF DATA SYSTEMS FOR CHRONIC MANAGEMENT OF HIV/AIDS

A key component of chronic disease management is a data collection system that both supports and drives optimal care of the individual patient *and* the treated population. A number of data information capturing systems of varying degrees of sophistication and complexity have been demonstrated to support ARV management in a variety of resource-rich and poor settings. Many of these use a combination of paper- and computer-based record keeping[15] and some have demonstrated the ability to network remote rural clinics with satellite and web-based technology.[9] As South Africa and other sub-Saharan countries grapple with the need to standardise and record data in a variety of settings, there has been an explosion of proposed technology-rich solutions to accomplish this task. Unfortunately, there is often a tension between the needs of data collection systems that allow national and regional health planners to analyse and improve programmes, and the needs of clinicians on the front lines who require a targeted set of measures to help manage their large workloads. While it is possible to integrate these needs, the needs of patient care can become subservient to those of central planners, and caregivers often end up with time-consuming data collection forms that seem to have little relevance to disease management. Setting up a chronic disease registry and a set of measures that support good care is a simple task compared with the complexities of establishing a comprehensive medical record. We propose an interactive data support model that has immediate relevance to the clinician *and* provides data to central planners. In addition, collected data can be used to drive improvement in chronic management of HIV.

Fig. 2b. Data collection sheet.

Data collection that is tied to disease management needs to be integrated into clinical practice, and should be perceived as providing obvious benefit to patient care. The system will fail if the perception is that the system generates additional 'work'. Feedback of patient progress and provider performance is a critical requirement for acceptance of the system. As medical record systems become more sophisticated, laboratory and pharmacy data systems can be fed electronically into the chronic disease registry. The HIV/AIDS disease registry can ultimately be integrated electronically into other chronic disease registries and the comprehensive medical record.

CORE FEATURES OF A CHRONIC DISEASE REGISTRY (TABLE I)

The data collection system should support a streamlined, high-throughput chronic disease management system that promotes excellent treatment of patients with HIV/AIDS, and continuous improvement of care delivery. In addition to improvement in patient outcome, the disease management programme can improve efficiencies (e.g. triage into fast-track and intensive care track care pathways) to allow much greater flexibility of care and higher throughput of patients in clinics with limited human resources. Core data collection should be standardised to allow for expected migration of patients from one site to another and mechanisms established for easy transmission of core data from one ARV site to another, both through user-held information (e.g. card) and connectivity between ARV sites. Standardisation of data collection is a laudable focus of the provincial and national programmes, but this goal should not delay implementation of sound disease management practices at a local level.

An example of a collection form for chronic AIDS management in the era of ARV therapy is shown in Fig. 2. This is a form that has been designed for use in a specific urban Johannesburg ARV clinic and has been extensively modified and improved through continuous in-clinic testing. Although the core data requirements for ARV clinics are universal, each clinic presents a unique set of resources, staffing and structural elements, so no single form is likely to be suitable for all clinics. In addition, this form is likely to undergo significant further transformation as it is repeatedly evaluated by the clinic staff. Data are transferred from the sheet to the computer database at the end of this clinic, and, apart from prompting excellent care, has been found to promote rather than hinder clinic flow. Although the primary focus of this set of measures is disease management, all of the provincial and government required indicators can be reported on through monthly queries of the database. Since the task of filling in the fields can be shared by the various caregivers and administrative personnel the patient encounters during the visit, no single person is saddled with the responsibility of collecting data. If computer-generated forms are used, fields that are not relevant to the current visit (e.g. detailed demographic data) can be suppressed. Duplication of fields can be eliminated by programming the data system to derive information from pre-existing fields (Fig. 2).

The lack of easily accessible historical patient information systems in consultation rooms represents a major obstacle to improving care. A simplified historical graphic of core measures, e.g. weight, CD4 counts, can be displayed on the form as a 'snap-shot' of disease status for the provider and patient (Fig. 2). The disease management form can be pre-filled (by the computer database) with some historical data displayed in adjacent columns, allowing current patient condition to be evaluated in its historical context and avoiding time-consuming searches for previous data.

TABLE I. CORE FEATURES OF A DATA REGISTRY THAT SUPPORTS CHRONIC DISEASE MANAGEMENT FOR HIV/AIDS

- Collection of a core set of measures that promote the best available HIV/AIDS/ARV treatment guidelines, track HIV/AIDS management of the individual patient and the clinic population, and comply with standardised measures for ART reporting as laid out by national Department of Health guidelines
- Collection of data that track the processes of clinic care delivery and historical patient data (including self-management strategies)
- Promotion of streamlined clinic function that allows triaging of care and prompts specific tasks to be completed in sequence as the patient moves through the clinic
- Integration of clinical and pharmacy information that promotes streamlined (non-duplicative) drug-dispensing practices
- Provision of data reports that assist caregivers in the management of individual patients
- Provision to the patient of a portable document that summarises core elements of patient management to date (this document will allow for self-referral or transfer of patient care away from the clinic)
- Provision of data reports that allow evaluation of clinic population outcomes *and* the processes of care delivery in the clinic and community
- Provision of data reports that flag patients who are attending clinic, have missed clinic visits, and/or require specific tasks to be completed at a clinic visit

Restriction of data fields to a minimum set of measures that are perceived to be useful for patient management can promote acceptance and utilisation of this tool.

REPORTING DATA AS A PEER-REVIEW MECHANISM TO IMPROVE CARE

Data represent a powerful tool that can be used to rapidly improve care. Care providers are used to evaluate data, and simple, accessible reports of patient and population data can accelerate change. Allowing staff to see clearly how well they are providing care, against national benchmarks or even against nearby clinics, allows for interrogation of reasons for poor or good performance. Once the patient data are entered into the registry, this information needs to be fed back to providers, not only to prompt excellent individual patient care as described above, but also as a powerful tool to improve clinic performance. The collected data should be easily accessed and filterable so that lists of patients and aggregates of data can be sorted by patient sub-type, patient provider, clinic day, etc. These data can then be used to inform, activate and prepare both the patient and the providers in a way that closes the gap between current clinic practice and ideal care delivery for HIV/AIDS. In addition to the requirement to feed specific fields of data back to the provincial and national health departments, aggregate data should be reported to senior leaders of the health care system to sustain support and enthusiasm for the programme.

CONCLUSION

In the era of ARVs, HIV and AIDS should be managed as a chronic disease. Management of this condition requires thoughtful use of data systems that promote and improve excellent care and improve clinic efficiency. Data collection for AIDS management should supplement, rather than replace, the medical record. The system should facilitate patient flow, promote patient self-management, promote excellent care pathways, provide caregivers ready access to critical historical information, and allow improvement through feedback of patient and clinic populations to clinic providers. It should also fulfil data reporting requirements of national programmes. Introduction of improved disease management practices for HIV provides an opportunity to strengthen the overall health system and the data systems that support care delivery for other diseases.

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