Linking the HDSS and the health care system through patient-held records for the treatment of epilepsy

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From a simple research tool for record linkage to unintentional interventions...

Background: SEEDS

Studies of the Epidemiology of Epilepsy in the Demographic Surveillance Sites

- 5 INDEPTH sites across sub-Saharan Africa
- Aim to study the prevalence, risk factors and outcome of epilepsy

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SEEDS’ Studies

Ongoing demographic surveillance of uniquely identified individuals in demarcated areas (DSS)

- Survey done in 5 INDEPTH DSS sites to identify cases of ACE
- Controls matched to cases
- Follow-up cases for 3-4 years and identify cases accessing and using treatment
- Study A: Prevalence of ACE
- Study B: Identification of risk factors for ACE
- Study C: Magnitude and risk factors of treatment gap
- Study D: Calculate risk ratio for death
- Study E: Identify risk factors for death

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SEEDS-Agincourt

"Patients with ACE will be followed up in the local clinic...for a period of 3-4 years..."

- Agincourt DSS has 6 public health clinics, 1 larger public health centre and 1 private health centre specializing in TB/HIV care
- It would prove difficult to follow-up patients diagnosed as having epilepsy in the DSS solely in the clinics as not all patients attend the clinic
- Furthermore, all patients do not attend single clinic, rather multiple clinics are utilized

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SEEDS-Cohort Study
Statement of Problem

How do you effectively link the DSS with the health system to examine health care utilization (clinic visits)?

Population-based SEEDS cohort (ADSS)  Frequency of health care utilization (Health system)

PICCs: The Research Tool

*Personal Identification Clinic Card*

- Serves as a patient-held link between the demographic surveillance site and the health care system
- Card completed by health care provider during visit
  - Information collected includes date and location of visit to health facilities, whether drugs were prescribed and asks for a signature of the health care provider

The Linkage Methodology

- Information collected during the health care visit is then collected during routine household visits by the fieldworker
- This information is entered into the database and a list of clinic visits is generated
- Fieldworkers than visit each clinic and compare the information collected on the PICCs card to the clinic registry

Results from one clinic

- Took place in one clinic over 12-month period
- 100 PICCs entries, from 19 people with epilepsy who regularly attend the clinic were compared with clinic records
  - 51 records (51%) were matched in both records
  - 7 entries (7%) differed by dates within the same month
  - 42 records (42%) were not found in the clinic registry, though PICCs entry had health care workers' signature
Findings of the PICCs

- Apparent lack of complete data within primary health care clinic registers
- Patient-held records may more accurately reflect health care visits than clinic patient logs.
- Furthermore, patient-held records have shown to be a successful, and accurate link between the HDSS and the health care system

Unintentional Interventions in Clinics

- Nurses now use PICCs cards as way to identify people with epilepsy and ‘fast-track’ them for chronic epilepsy medication
- Nurses suggest that PICCs cards have increased adherence (analysis still pending)
- Nurses using PICCs cards as a way to confirm clinic visits

Limitations of PICCS

- High frequency of misplaced cards (roughly 30% of individuals required a second card)
  - Possible consequences for misplaced card
- Refusal by health care workers to complete cards (“not our work”)
  - Requirement of health care workers’ ‘buy-in’

Future Directions of Research

- Currently comparing and analyzing results from other 5 clinics in Agincourt DSS to allow for more robust findings
- Comparison of patient files, clinic log books and PICCs cards
- Expansion of PICCs card to include other chronic diseases
- Possible use of PICCs at other SEEDS sites

From research tool…

- Successfully allowed for the linkage of SEEDS population-based cohort and health care system
- Indicated health care system’s current record keeping may not be complete
- …to unintentional intervention.
  - Has led to nurses ‘fast-tracking’ people with epilepsy due to quick identification with PICCs
  - Has possibility increase adherence through social pressure (fieldworker visits)

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