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Why are pregnant women dying? An equity analysis of maternal mortality in Malawi

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Abstract

Background: Malawi has one of the highest maternal mortality ratios (MMR) in the world at 1,120 per 100,000 live births. Maternal mortality is therefore a priority issue for the Ministry of Health. The Health Sector Wide Approach (SWAp) Equity and Access Subgroup commissioned a synthesis study to explore issues of access and equity relating to maternal mortality in Malawi and provide practical recommendations for SWAp implementation.

Methods: The study undertook an equity analysis of existing national health databases and synthesised the available operational and academic research findings.

Results: A number of strategies have been developed throughout the past decade to address maternal mortality in Malawi; however there has been a lack of effective implementation. Safe Motherhood interventions account for 46% of the total costs of the essential health package, with 47% of these spent on abortion complications. The expenditure, however, is not equitably distributed: Malawi has only 2% of the basic emergency obstetric care facilities that it requires, but nearly twice as many comprehensive obstetric care facilities, however only 20% of the population lives within 25km of the latter. Additionally, women face high direct and indirect costs in seeking services, even at government facilities which are free at the point of delivery. The total cost of seeking services is approximately 26 days worth of income for a rural woman; for the poorest quintile it can be as much as 50 days worth of income.

Maternal mortality, when examined by wealth quintile, does not initially appear to be inequitable in Malawi. However reasons behind the deaths are different, with those in the upper quintiles being more related to complications of HIV and those in the lower quintiles related to lack of access to services. Levels of education and to a lesser degree, wealth have a strong correlation with skilled attendance during delivery.

Conclusion: This study provides recommendations on how the current maternal mortality strategy may be implemented more equitably than past strategies therefore resulting in a lower MMR for all women, regardless of their location, poverty or educational status.

Background

In 1987, the Safe Motherhood Initiative was launched in Nairobi at an international consultation of UN agencies, governments (including Malawi), donors and NGOs to draw attention to the very high levels of maternal mortality and morbidity in developing countries. Further commitments to reduce maternal mortality were made at various landmark conferences culminating in New York with the Millennium Summit in 2000, which yielded the eight Millennium Development Goals (MDGs). The fifth MDG is to improve maternal health, with the target of reducing the maternal mortality ratio (MMR) by 75% by 2015.

Malawi has one of the highest MMRs in the world at 1,120 per 100,000 live births[1]. The Ministry of Health, through the Health Sector Wide Approach (SWAp) Equity and Access Subgroup, commissioned a synthesis study to look at issues of access and equity relating to maternal mortality in Malawi. This study would be used to inform the baseline for SWAp monitoring in health and access to services. The study also aims to provide practical recommendations for SWAp implementation for increasing poor people's access to health services, in line with the SWAp Programme of Work.

Methods

The study undertook an equity analysis of existing national health databases, including the Demographic and Health Surveys (DHS) of 1992 and 2000 and the 2004 Integrated Household Survey (IHS), and synthesised the available operational and academic research findings through a review of published and grey literature from both international and national sources.

Results

Ministry of Health response to maternal mortality

The problem of high maternal mortality has long been recognised in Malawi. Between 1993 and 2005 a number of strategies were developed, assessments undertaken and task forces established. There appears, however, to have been a lack of effective action on those strategies due to constraints affecting service provision; assessments undertaken in both 1994 and 2005 revealed the same problems[2,3]:

- Inadequate infrastructure, transport and communication systems for referral
- Inadequate essential obstetric drugs, equipment and supplies
- A shortage of trained/skilled personnel with adequate knowledge
- Inadequate monitoring/supervision of midwifery and TBA services
- Inadequate maternal IEC materials and treatment guidelines
- Poor attitudes of health personnel
- A lack of decision making power among women with complications

A new strategy has been developed: *the 'Road Map for Accelerating the Reduction of Maternal and Newborn Mortality and Morbidity in Malawi' (The Road Map),* in response both to the current maternal mortality crisis in Malawi and the African Union call for each country to develop a country-specific Road Map.

The objectives of the Malawian Road Map are:

1. To increase the availability, accessibility, utilisation and quality of skilled obstetric care during pregnancy, childbirth and the postnatal period at all levels of the health care delivery system
2. To strengthen the capacity of individuals, families, communities and civil society organisations and government to improve maternal and neo-natal health

A key element of this is the provision of Basic and Comprehensive Emergency Obstetric Care (BEmOC and CEmOC respectively). Currently Malawi has only 2% of the recommended number of BEmOC facilities, while per head of population, it has nearly twice the recommended number of CEmOC facilities[3], most of which are in district centres and inaccessible due to distance and cost to the majority of the population. Even these do not consistently provide skilled attendance as evidenced by high case fatality rates of 3.4% in EmOC facilities (ibid.).

Costs of Safe Motherhood

Nearly all services are provided by government and CHAM facilities, and are funded under the Health SWAp; the aim of which is to provide the Essential Health Package (EHP) free at point of delivery. The total cost of Safe Motherhood activities according to the EHP is $87.3 million per year; of this, 47% (or a fifth of the total EHP) is spent on complications of abortion[4].
Costs are not only borne by government - women also face high expenses in accessing services. The main types of direct costs are transport to the health facility, food when there, and user fees[5] if they are closer to a CHAM than a government facility. Indirect financial costs identified through qualitative studies[6,7] include the cost of a new chitenje (sarong) necessary for childbirth, the cost of a clean razor and/or the payment of the traditional birth attendant (TBA) prior to referral to health centre. No quantitative studies have been undertaken to date to accurately assess the costs that women face in trying to achieve a safe delivery, however based on other studies,[1,8] rural women are likely to spend around $4.00 American on food (in cash or in kind), possibly more if they are waiting in a maternal waiting shelter, and $1.45 on transport. Where women must visit a CHAM facility the costs are higher still. The average cost of a normal delivery in a CHAM facility is MK243 ($2.15) while the cost of a caesarean section is MK 1,203 ($10.65), although this varies considerably by facility.
Even without user fees, the total cost is approximately 26 days worth of income for a rural woman; for the poorest quintile it can be as much as 50 days worth of income. These costs are not affordable for many rural or poor women, hence the high numbers who 'choose' to deliver in the community - in fact they have no choice.

Who is dying?

Unlike many countries, socio-economic status does not appear to be related to maternal mortality. Table 1 indicates that approximately 2-3% of women are likely to die a maternal death across all quintiles[1]. Further analysis suggests that the reasons behind the deaths are different, with those in the upper quintiles being more related to complications of HIV and those in the lower quintiles related to lack of access to and use of services.

Table 1: Maternal deaths by quintile

Sisters 15-49 years of age DHS 2000 who died since 1995		Quintiles of wealth index				
		Lowest quintile	2nd Quintile	3rd Quintile	4th Quintile	Highest Quintile
Maternal Death	(% within quintiles of wealth)	2.7	2.3	2.4	2.1	2.3

Impact of HIV/AIDS

International data gives some indication that HIV may have a moderating effect on the relationship between poverty and maternal mortality. An analysis of DHS data sets from ten developing but diverse countries revealed significant associations between women's poverty status and survival[9]; in Indonesia the risk of maternal death was around three to four times greater in the poorest than the richest group. However, the association became weaker (no association at 95% confidence limits) for those countries where more than 2% of 15-49 year olds are HIV positive see Table 2.

Table 2: Association between poverty quintile, survival status of women and HIV prevalence

Country (year of DHS survey)	Significance of association between poverty quintile & survival status of women (p value)[9]	% of population aged 15-49 with HIV/AIDS (2001 data)[10]
Nepal (1996)	<0·0001	0.4
Philippines (1998)	<0·0001	<0.05
Mali (1996)	0·0042	1.9
Indonesia (1997)	0·0062	0.1
Burkina Faso (1999)	0·0447	1.8
Kenya (1998)	0·0798	8.0
Tanzania (1996)	0·0877	7.0
Chad (1996)	0·4260	4.9
Ethiopia (2000)	NA	4.1
Peru (2000)	NA	0.4

It is important to note that quintile analysis based on the sisterhood method used in the DHS tends not to be significant at 95% confidence limits, thus the figures should be treated with caution. The authors have not been able to conduct significance tests on this data.

In Malawi, HIV/AIDS has been shown to be a factor in maternal death. The Confidential Enquiries into Institutional Maternal Deaths reported: "The proportion of deaths due to AIDS in indirect maternal deaths is now estimated to be 25%, with a 95% confidence interval of (17.0%, 33.4%)"[11]. In 2003 the urban adult HIV prevalence in Malawi was estimated as 23.0% compared with 12.4% in rural areas[12]. The urban population tends to be wealthier than their rural counterparts: 71% of the urban population is in the highest quintile compared with only 11% of the rural population [3]. We would therefore expect to see more maternal deaths due to HIV in urban areas and thus in the higher quintiles.

The data presented in Table 1 does not reflect this. Given the importance of medical services in preventing maternal death, inequities in access to services among lower quintiles counteract the impact of HIV on maternal death among the higher quintiles.

Poverty and access to skilled attendance

The DHS 2000 reported that only 55% of deliveries occur in institutions[1] while the remainder take place in the community. No change in levels of institutional delivery had occurred since the 1992 DHS. Institutional coverage is clearly low; it is also inequitable. An analysis of the preliminary results from the 2004-2005 IHS[13,4], show that the poorest 10% of women are nearly twice as likely as the wealthiest 10% to be delivered at home or with a TBA. Also, rural women are nearly 4 times as likely to be delivered at home as their urban counterparts; this is highlighted in Table 3 and Figures 1 and 2. Consequently, poorer and rural women are less likely to be delivered by skilled attendants such as nurse-midwives, clinical officers or doctors (the latter two are the only cadres allowed to perform Caesarean sections). The deaths of poorer and rural women are also less likely to be reported as there are no mechanisms in place for consistently registering deaths in the community.

Education and access to skilled attendance

Level of education has a strong correlation with assistance during delivery. Women with education, particularly to secondary level, are less likely to engage in harmful practices or believe in supernatural causes of illness or death. They are more likely to use accessible and functional health facilities resulting in safer pregnancy and childbirth[14]. Figure 3 shows that in Malawi in both 1992 and 2000, women's access to a nurse or midwife increased with her level of education; those with secondary education were 86% more likely than those with no education to be seen by a nurse or midwife. Preliminary data for 2004 also shows the same pattern. While higher literacy and a higher level of education may predispose women to deliver in a health facility, this also partially reflects the fact that more educated women are located in urban areas with greater access to EmOC.

[3] *Based on data from DHS 2000*
[4] *Data compiled by Lindsay Mangham, DFID*

Table 1: Access to care by population groups from IHS 2005

	% of women (12-49 years) that had given birth in the past 2 years	% of pregnant women that regularly attended health clinic	% Delivered at Hospital or Clinic	% Delivered at home or with TBA	% Delivered by a Doctor/ clinical officer (CO)	% Delivered by a Nurse/ Midwife	% Delivered by a TBA
Lowest Quintile	35%	94%	55%	43%	6%	49%	21%
Highest Quintile	26%	94%	72%	28%	15%	56%	14%
Lowest Decile	35%	93%	53%	46%	3%	49%	23%
Highest Decile	22%	95%	75%	25%	16%	58%	12%
Urban	24%	97%	88%	11%	21%	67%	8%
Rural	33%	92%	57%	42%	7%	49%	21%
Northern Region	32%	96%	70%	30%	11%	58%	12%
Central Region	32%	88%	51%	48%	10%	41%	28%
Southern Region	32%	96%	64%	35%	6%	56%	16%

Figure 1: Proportion of Births Delivered by Type of Facility

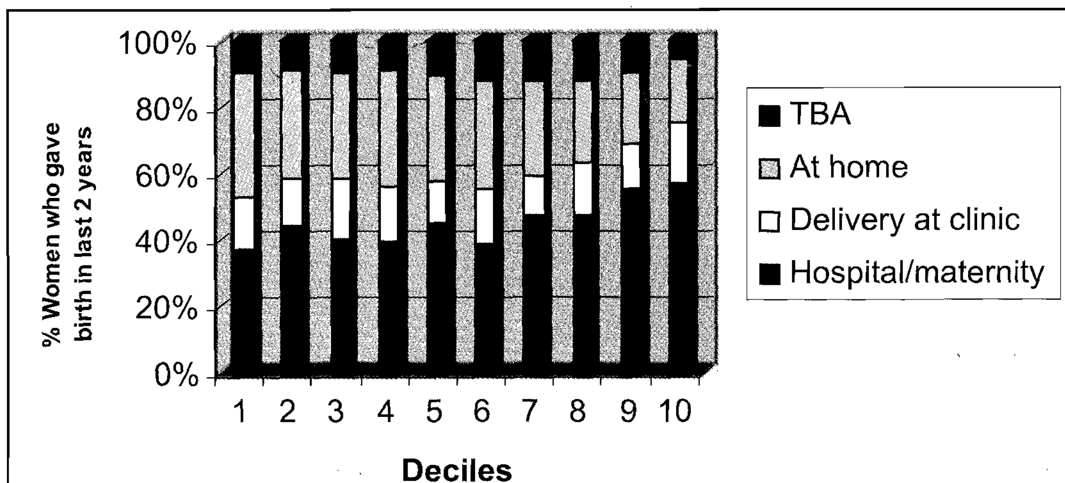
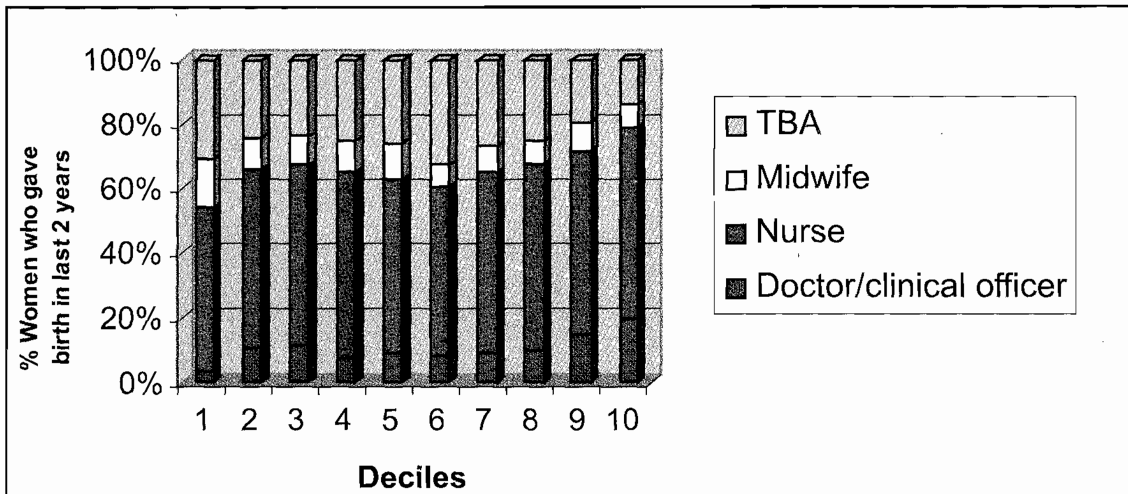
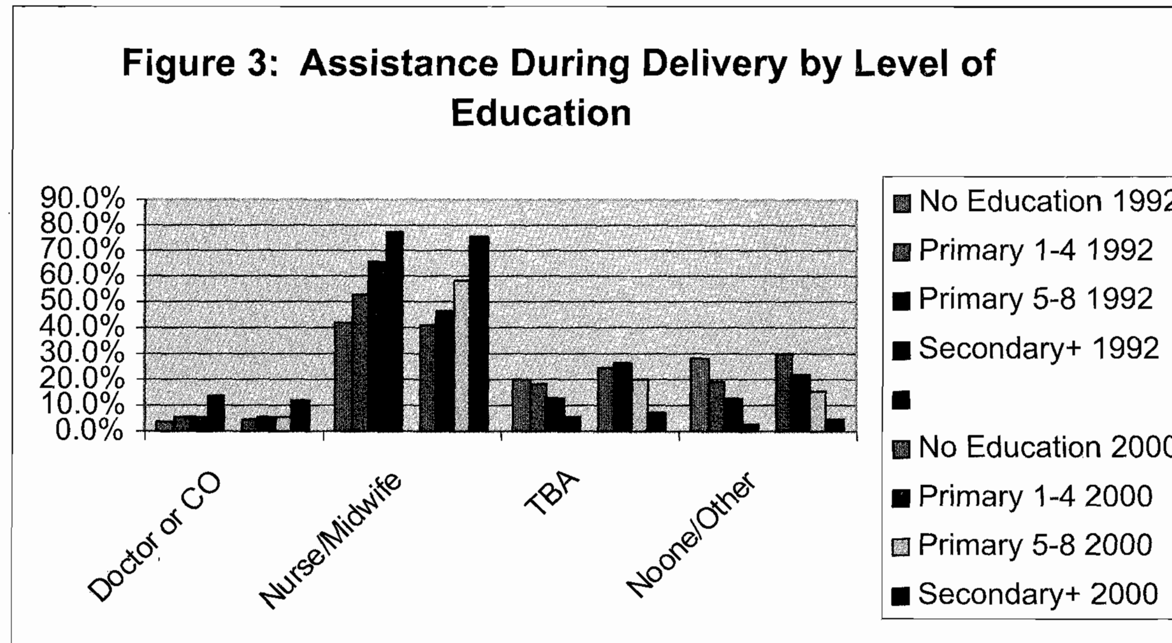


Figure 2: Proportion of Births Delivered by Type of Person

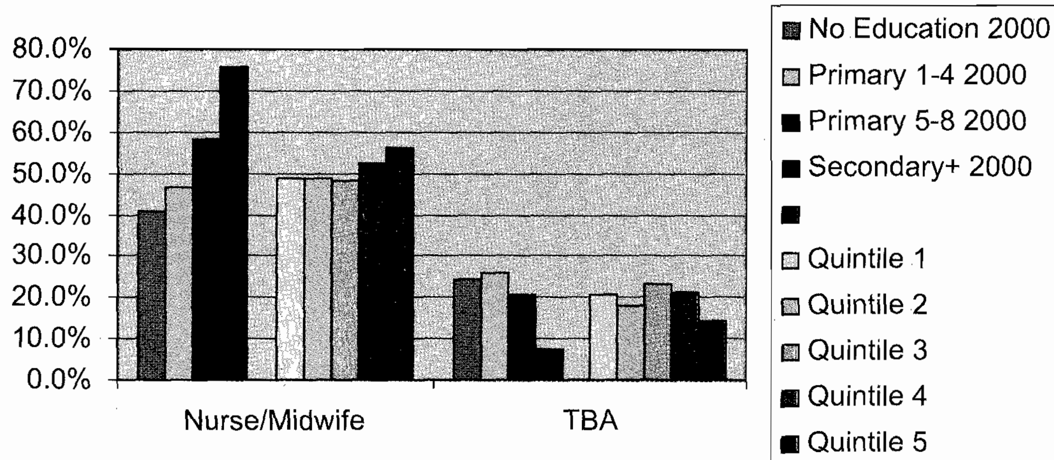




Source: DHS 1992 and 2000 SPSS data files

Figure 4 shows that in comparison to wealth, level of education has a stronger correlation with assistance by a nurse or by a TBA. The better educated a woman is, the more likely she is to deliver with a nurse. Women with a secondary education are nearly twice as likely to deliver with a nurse and are three times less likely to deliver with a TBA. Wealth, on the other hand, has a much more diminished impact with women in the highest quintile, being only one sixth more likely than the poorest to deliver with a nurse and one third less likely to deliver with a TBA.

Figure 4: Assistance During Delivery by Level of Education and Wealth Quintile (2000)



Source: DHS 2000 SPSS data files

Equity in access to antenatal care

The confidential enquiries found anaemia and AIDS combined accounted for about half of all indirect maternal deaths[11]; malaria is another important factor. All can be addressed through quality antenatal care (ANC).

Access to ANC appears to be fairly equitable, with over 90% of women from all wealth brackets reporting that they make at least one ANC visit (see Table 1). Once again, however, level of education has a clear impact on access to services as shown in Figure 5 below. In 1992 and 2000, those with at least primary education were more likely to have been seen by a nurse than those with no education. Access to services increased with the level of education. The likelihood of those with no education being seen by a TBA increased considerably between the 2 reporting years, rising from 0.8% to 4%.

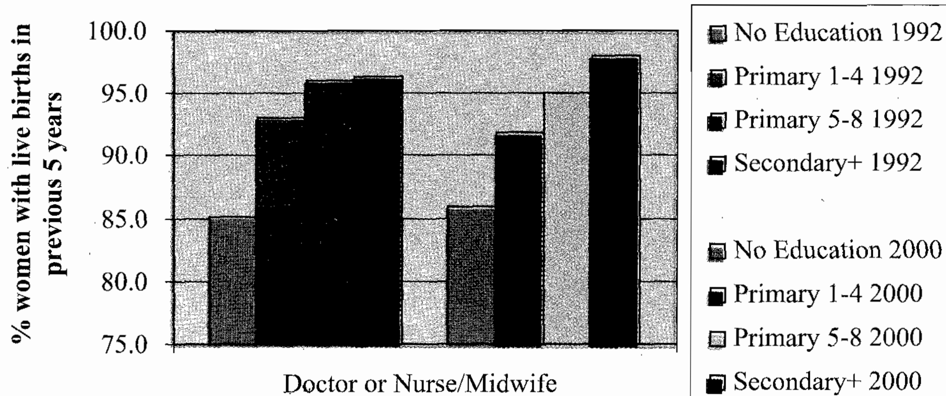
While access to ANC does appear to be equitable based on wealth and geography, the quality of ANC is not consistent between facilities or districts. It is important to differentiate between access to an antenatal clinic and access to antenatal care.

If quality antenatal care were being delivered, it would be expected that the number of women receiving iron, SP and tetanus toxoid (TT) should be proportional to the number of women accessing antenatal care during any trimester. However, according to the health management information system (HMIS) 2002-3, Balaka District had 122% of the expected antenatal visits, but only provided 82% of pregnant women with TT, 70% with SP and 26% with iron. Blantyre on the other hand saw 79% of the expected number of women, but provided 92% of the expected TT, 135% of the expected iron and 154% of the expected SP[15]. In other words, in some districts women are not receiving basic care, while in other districts women are receiving more than they need and perhaps travelling more frequently and incurring more cost than necessary.

Safe Motherhood project data from the southern region of Malawi provides a similar picture, showing that only 43% of pregnant women in the southern region had their blood pressure checked[16], fewer than 40% received the recommended two doses of SP, and the majority did not receive adequate iron supplementation [5,17].

[5] *There were inadesquate supplies of iron (with less than 36% health facilities having sufficient supplies), but adequate supplies SP at all levels (at that time). SP was not distributed largely due to confusion over the timing of the drugs and lack of education amongst health staff.*

Figure 5: Access to Antenatal Care by Level of Education: 1992 and 2000



Conclusions and Recommendations

The problem with maternal mortality in Malawi does not appear to be a lack of knowledge of the problem or a lack of strategies, but a lack of implementation of those strategies. The current strategy, The Road Map, therefore needs to be implemented more fully and equitably than past strategies, therefore resulting in a lower MMR for all women, regardless of their location, poverty or educational status.

This paper concludes with a number of recommendations for achieving this implementation. These recommendations recognise that a high MMR reflects the overall deterioration of health services within a country. A health systems approach is therefore required, but with a recognition that some specific maternal health interventions need to be incorporated. Given the correlation between education and access to services, linkages also need to be made beyond the health sector.

Recommendations to the Health SWAp point to the need for maintaining maternal health as the national health priority: without such commitment there will not be sufficient resources for implementing the Road Map. The Emergency Human Resource Programme needs to be implemented, focussing on the recruitment and training of nurse-midwives who will be prepared and able to work in rural areas, providing BEmOC services to those who currently have no access. In practice this is likely to require a focus on nurse midwifery technicians. Additionally efforts also need to be taken to ensure they have adequate resources to work with once they are in post, this includes the provision of essential safe motherhood drugs, BEmOC equipment and an effective infrastructure including transport and communications systems, water, and electricity; the last two of these should also be provided at the nurse-midwives accommodation, to minimise the disincentives for working in rural areas.

Infrastructure and equipment improvements will need to be made incrementally by districts prioritising on the basis of geography which facilities they would first select to provide full BEmOC. Other facilities would be improved over time. It may be that improvements need to be made more creatively, for example possibilities for public-private partnerships. Services within health facilities also need to be improved through effective infection prevention and control. Services could also be made more equitable, for example provision of food which would encourage and ease access for the poor to access skilled attendance at birth.

The major recommendation to policy makers is to discuss the legal impediments to safe abortion. Unsafe abortion is the cause of a high number of maternal deaths and treating complications arising from it is the most expensive single activity in the EHP. Currently such complications can only be treated at CEmOC facilities, and so are not accessible to more than 80% of the population.

The key system-wide recommendation is to ensure that CHAM facilities stop charging for EHP services, as cost is clearly a barrier for poorer women. This has already started to happen in some districts through service level agreements. District health personnel and decision makers also need to be more accountable for the equitable implementation of the EHP and of Safe Motherhood activities, thus ensuring that the current strategy has more impact than previous strategies. This can be achieved through advocacy to decision makers and politicians and interventions to enable communities to better understand and articulate their rights.

Specific maternal health recommendations focus firstly on the need for effective leadership and the need for an effective voice in the SWAp, through a Technical Working Group. Additionally there is an urgent need for nursing staff, particularly nurse technicians working in rural areas, to receive competency based training to enable them to provide BEmOC. Facilities need to be equipped to ensure the staff have the resources for providing services. This will help to reduce rural/urban and rich/poor inequities in access to services.

Given that visits to antenatal clinics are seen to be equitable, it is important to deliver focused antenatal care more effectively, to ensure that all women receive appropriate services during these visits. This should include the distribution of free insecticide treated bednets and of information regarding the importance of skilled attendance, as well as the current range of intended services noted above. Other equitable services, such as EPI, could also be more effectively used to disseminate safe motherhood messages to illiterate women.

Community structures need to be strengthened to refer and transport women with complications. They can also be used to engage household decision makers, often men, in discussions of maternal health issues to dispel misconceptions and reduce harmful practices, therefore reducing delays in women accessing appropriate care. Community structures can further be used to increase reporting of maternal death and maternal complications.

It is crucial that maternal health services are made effective before increasing demand for them, to avoid reinforcing negative perceptions about facilities held by communities. Links need to be made with the education sector, since level of education has a very high correlation with access to services. Support needs to be given to programmes encouraging female education and promoting health education in schools at all levels. Other sectors that should be liaised with include those providing infrastructure, such as water, electricity and roads.

To conclude, there are strategies that can reduce maternal mortality in Malawi and that can make services more equitable. While some are complex they are not impossible. A concerted effort by a number of stakeholders, however, is required to achieve them and so to give all women in Malawi a greater chance of surviving pregnancy and childbirth.

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Thanks also to Hannah Ashwood Smith for providing useful background documents and for her comments and contributions based on her experience with the Safe Motherhood Project. Also to Dr. Esther Ratsma for her contributions grounded in years of experience working at district level and with the Safe Motherhood Project and now as a zonal officer and to Dr Maureen Chirwa for her perspective from the Nurses and Midwives Council of Malawi. We would also like to thank staff at DFID in Malawi and the UK, namely Isabelle Cardinal, Dr Julia Kemp, Bernabé Sánchez, Katie Chapman and Fran McConville for comments from an international social development and policy perspective.

Stigma and discrimination experienced by TB patients - a gender perspective from urban Malawi

Sanudi L, Makwiza I, Kemp J, Weiss M.
Oral presentation at the European Tropical Medicine Congress, Marseille, France. September 2005

Background: Stigma is associated with diseases that are perceived to emanate from deviant or morally sanctioned behaviour, are contagious, and/or lead to physical disfigurement. Stigma for TB can be socially enacted, self-perceived or anticipated.
Objective: To identify gender-related stigma and discrimination faced by TB patients in Malawi.
Methods: Semi-structured in-depth interviews conducted with 100 TB patients (50 men and 50 women). Data was analysed using Epi Info v.6.04b and MaxQDA software.
Results: 61% preferred others to know about their illness. 28% reported experience of social isolation. 12% reported marital problems (3% reported spontaneously – all females) and 22% reported that their spouse refused to have sex. There is a strongly perceived TB and HIV/AIDS association. 54% men and 20% women reported that others would think that they have other health problems besides TB.
Discussion: Exaggerated concerns about the risk of spreading TB strongly influence stigma. Although 61% of the sample did not report stigma, qualitative responses revealed that stigma was widely felt. Sexual abstinence was in part due to traditional practice.
Conclusion: TB is not just a clinical problem; men and women tend to differently experience stigma and discrimination for having TB.

Gender analysis of perception of malaria and decision making in help seeking for malaria and fever: A case of two urban squatter settlements in Malawi

Nhlema Simwaka B, Nkhonjera P.
Oral Presentation at the European Tropical Medicine Congress. Marseille, France. September 2005.

Background: A study was conducted to assess perceptions, knowledge of signs and symptoms and decision-making in help-seeking for malaria.
Method: An exploratory study was conducted using focus group discussion and individual in-depth interviews in two urban squatter settlements in Lilongwe, Malawi. The interviews were conducted with groups of men and women.
Findings: The most commonly mentioned sign of malaria was fever. Men did not identify specific symptoms indicative of malaria in their children, but explained that their wives informed them about symptoms and illness. Older mothers advise the younger mothers of the symptoms of childhood fever.
Both groups of men and women mentioned that mothers know when a child is suffering from malaria, but decisions about help-seeking are made in consultation with the father. For married women the husband makes the decision about buying medicine or going to the hospital, although the drug purchasing or taking the child to the health provider is commonly done by women.
Conclusion and Recommendation: Although women are more knowledgeable about signs of malaria and are responsible for checking the sickness in the child, men are always consulted before making a decision to seek care. These gendered practices need recognition if policy and practice in this area is to be gender sensitive, equitable and sustainable.

Barriers to patient adherence to anti-retroviral therapy (ART) in Lighthouse Clinic, Lilongwe, Malawi: a gender analysis

Makwiza I, Neuhann F, Chiunguzeni D, Lalloo D, Kemp J.
Oral Presentation at the European Tropical Medicine Congress. Marseille, France. September 2005.

Setting: The Lighthouse is a comprehensive HIV/AIDS non-government service provider that implemented the Government of Malawi provision of ART. Drugs were provided 'at cost' during the time period of this research (2003-4).
Methods: 6 focus group discussions and 14 in-depth interviews were conducted with female and male patients on anti-retroviral therapy. The data was analysed qualitatively alongside data from patients' diaries, observation and informal discussions with staff.
Results: Most patients had a comprehensive understanding of their illness. Some gender differences emerged regarding perceptions of transmission. While only men reported transfusion of infected blood, women highlighted transmission through caring for infected persons, unhygienic practices in the maternity wards and traditional practices involving sex and blood contact.
The understanding of how anti-retroviral therapy works and the impact of non-adherence among patients was good. The high cost of accessing therapy was commonly cited as the major factor that could cause patients to stop therapy. Spouses and other people with HIV/AIDS were felt to be supportive. However, men felt more comfortable to disclose to their spouses than women, who were fearful of being blamed for bringing HIV into the family.
Conclusion: Though the understanding of the illness and the ART therapy is good, the high cost of accessing ART presents a threat to adherence for most female and male patients.

Theme 2 - Equity Monitoring

Application of a Geographical Information System (GIS) to examine the relationship between socio-economic status and access to care for TB in urban Lilongwe

Kemp J, Boxshall M, Nhlema B, Salaniponi FML, Squire SB.
International Journal of Lung Disease and Tuberculosis. 2001;5: Supplement 1, S166

Background and Objective: Routine health data rarely indicate the poverty status of patients. However, area of residence of TB patients is routinely collected to trace defaulters. In urban Lilongwe, census data identifies city areas as 'poor' in terms of low literacy rates, high population density and high population growth rates. The objective of this study was to assess equity in access to the DOTS TB programme, using area of residence as a proxy for poverty status.
Methods: A Geographical Information System (GIS) was established from an existing base-map of the city, and data from the 1998 Census were incorporated. National TB Programme (NTP) chronic cough register data were then entered, including age, sex, area of residence and TB microscopy result.
Results and Conclusion: High-density planned areas have much higher chronic cough and TB notification rates than adjacent high-density poor 'squatter' settlements. We propose that people from the poorest areas of Lilongwe face significant barriers to access to TB care and are not reached by the DOTS programme. The data suggests that up to half of the smear positive TB cases may be unreported from these poorest city areas.

Monitoring Equity in Scaling up Anti-retroviral therapy

Makwiza I, Bongololo G, Nyirenda L, Theobald S.
Oral presentation at the National AIDS Commission conference on HIV/AIDS. Lilongwe, Malawi: April 2005.

Objectives and Scope: The main aim of the study is to conduct an equity and health systems analysis of the provision and expansion of ART in Malawi: the results of which could then be used as a working example of country level monitoring and evaluation using available routine monitoring data. To meet this aim, information has been collated under the following thematic areas: the process of developing policy, equity in ART delivery, fair financing, public/private mix, integration of ART delivery within the health services and human resource capacity considerations. The study is being peer-reviewed by the Equity in ART working group (chaired by the Ministry of Health).
Methodology: Collation and analysis of pre-existing information and indicators from different Malawian stakeholders such as the Ministry of Health, National AIDS Commission and Ministry of Finance.
Analysis of sentinel site data from the Thyolo District
Results/Conclusions: Illustrative results are as follows. The process of developing a policy on ART was done in a participatory way and included perspectives from diverse groups, such as People Living with HIV/AIDS, civil society organisations and religious representatives. From data available there are some regional and district disparities in ART provision, with the northern region having the least number of ART providers. There is also an urban bias with more sites functioning in city areas.
Recommendations: It is critical to ensure that equity is considered in the process of ART scale-up, so that all groups – by age, gender, socio-economic status, and district - are able to access these life-preserving drugs. It is also imperative to make sure that ART provision is not having a negative effect on other health services through displacement of human resources or finances. A process of ongoing monitoring and evaluation that mainstreams equity concerns and shapes policy practice is therefore crucial.

Assessing the potential of routine data to promote pro-poor scaling up of TB control: insights from Malawi

Bello G, Nhlema Simwaka B, Theobald S, Salaniponi F, Squire, B.
Presentation at the International Union Against TB and Lung Diseases. Paris, France: November 2005.

Objectives: To explore the suitability of routine TB control data and available data on poverty for developing indicators for pro-poor scale-up up of TB control.
To assess the correlation of poverty with TB notification rates and adverse treatment outcomes, hypothesising that the expected positive correlation is masked by access constraints.
Methods: The suitability of national TB notification and treatment outcome data was examined. National datasets were identified that gave information on district-level poverty, HIV prevalence, and health service coverage. A correlation and regression analysis of the association between TB notification and treatment outcomes with poverty was completed, adjusting for key co-variates including gender.
Results: TB notifications (1998-2004) and treatment outcomes (2001-2003) were available in Excel spreadsheets.
The Malawi Profile of Poverty (2000), Atlas of Social Statistics (2003) and the National Census (1998) enabled estimates of district-level proportions of people living below the poverty line. Estimates of HIV prevalence and health facility coverage were obtained from HIV Surveillance (1998-03) and Ministry of Health (2003).
There are challenges in working with these disparate datasets, but initial analysis suggests no association between TB notification rates and poverty when adjusting for covariates (overall $r=0.007$, $p=0.97$; men $r=-0.1$ $p=0.635$; female $r=0.33$ $p=0.87$). There is a positive correlation between some indicators of adverse treatment outcome and poverty levels ($r=0.427$, $p=0.033$). However, controlling for HIV prevalence reduces the significance of this relationship ($F=2.65$, $p=0.093$).
Conclusion: The lack of correlation of poverty with TB notification rates and adverse treatment outcomes may support the original hypothesis, but the analysis needs further scrutiny. Locally available datasets can be used to develop crude indicators for monitoring the scale-up of pro-poor TB control in Malawi.

Theme 3 - Equity perspectives on TB diagnosis

The journey towards TB diagnosis: preferences of the people of Mtsiliza, Lilongwe

Kapulula PK, Chilimampunga C, Salaniponi FML, Squire SB, Kemp J.
International Journal of Lung Disease and Tuberculosis. 2001;5(11):Supplement 1, S167

Setting: Mtsiliza, a peri-urban community within Lilongwe, Malawi.
Objective: To assess which care providers people prefer to access for the treatment of chronic cough and TB.
Methods: 20 in-depth interviews and 8 focus group discussions (FGD) were conducted with adult men and women. FGD included the techniques of participatory mapping (to identify local care providers) and matrix ranking (to explore preferences for different providers).
Results: The first health action for symptoms of chronic cough is self-medication with drugs bought from local grocery shops. This is perceived to save both time and money. People visit traditional healers when health services fail to provide treatment, or when the illness is perceived to be caused by bewitchment or the breaking of taboos. People seek care from private clinics both before and after going to public services because they have 'strong' medication. People are reluctant to seek care from the public health facilities because of waiting times, lack of drugs and poor staff attitude.
Conclusion: The negative image of public health facilities may contribute to delays in getting a diagnosis for TB. To reduce diagnostic delays, the National TB Programme needs to collaborate with the range of private providers, including grocery shops and traditional healers.

Barriers and enabling factors to obtaining a diagnosis and adhering to treatment for TB: A Qualitative Study

Kabwazi ND, Kishindo P, Salaniponi FML, Squire SB, Kemp J.
International Journal of Lung Disease and Tuberculosis. 2001;5(11): Supplement 1, S167

Objective: To investigate patients' perceptions of barriers and enabling factors in accessing TB diagnosis and treatment.
Methods: A cohort of TB suspects from the month of June 2000 was followed through their diagnosis and treatment at Lilongwe Central Hospital, Malawi. From this group, in-depth interviews were conducted with 5 TB suspects and 12 TB patients to explore perceptions during both diagnosis and treatment.
Findings: Major barriers included the time spent and number of visits made during diagnosis and the lack of information about the process. Enabling factors were a desire to know what was wrong with them and encouragement to seek care by family members. Most TB patients cited time lost to collect drugs and a lack of information about the numbers and side effects of drugs as major barriers to continuing treatment. Feelings of isolation at home also had a negative impact on wanting to continue with treatment. Support by health care workers at times of difficulty with treatment enabled patients to continue with care.
Conclusion: This understanding of barriers and enabling factors in TB diagnosis and treatment should inform TB services on how respond to patients' needs and thereby reduce barriers to diagnosis and promote adherence to treatment.

Expanding DOTS? Time for cost-effective diagnostic strategies for the poorest in Malawi

Mann G, Squire S B, Nhlema Simwaka B, Luhanga T, Salaniponi FML, Kemp J.
Late-breaker Session. 33rd World Conference on Lung Health of the International Union Against Lung Tuberculosis and Lung Disease. Montreal, Canada: 6-10th October, 2002.

Objectives: To compare the relative costs associated with obtaining a TB diagnosis for poor and non-poor TB patients, and to project the cost effectiveness of possible alternative diagnostic strategies.
Methods: Patient and household direct and opportunity costs were assessed from a survey of 179 TB patients, randomly sampled from all health centres in Lilongwe. Poverty status was determined from the 1998 Malawi Integrated Household Survey (MIHS). Costs of alternative diagnostic strategies were projected from existing studies, and the effectiveness measure was the number of patients who start treatment within 5 days of diagnosis.
Results: On average, patients spent MK 972 ($13 or 18 days income) and lost 22 days from work while accessing a TB diagnosis. For non-poor patients the total costs equated to 124% of their total monthly income, or 174% after food expenditure. For the poor, this cost rose to 248% of monthly income or 584% after food. Cost effective diagnostic strategies would include a one-stop sputum smear strategy, improved service quality and community-based case finding.
Conclusion: The current DOTS programme presents barriers to diagnosis for the poorest populations. There is an urgent need to shorten the diagnostic process, improve service quality and bring diagnostic services closer to the community.

The feasibility of using a single "on-spot" sputum smear for TB case finding

Squire S B, Gondwe M, Michongwe J, Salaniponi F M L, Mundy C, Kemp J.
International Journal of Lung Disease and Tuberculosis. 2001;5: Supplement 1, S172.

Objectives & Setting: To examine the feasibility of implementing an 'on-spot', one smear diagnostic strategy in an urban microscopy centre in Lilongwe which handles more than 50 smears per day. To compare the proportion of true smear positives (using WHO definitions) starting treatment between the recommended 3-smear strategy and the 'on-spot' strategy.
Methods: Prospective data collection on all patients attending the 'on-spot' microscopy centre and comparison with equivalent data on patients attending a similar microscopy centre in the city that uses the 3-smear strategy.
Findings: By October 2000, 727 patients had been recruited through the 3-smear laboratory and 1704 through the 'on-spot' laboratory. Preliminary analysis reveals that 21/262 (8%) of TB suspects assessed through the 3-smear laboratory and 81/475 (17%) assessed through the 'on-spot' laboratory were true smear positives. Only 4/21 (19%) of the smear positives assessed through the 3-smear strategy had started treatment within a month of sputum submission, compared with 36/81 (44%) of smear positives assessed through the 'on-spot' strategy. Several constraints to implementing an 'on-spot' strategy have been defined, including problems with quality of microscopy in the 'on-spot' laboratory.
Conclusion: An 'on-spot' strategy appears no worse than the 3-smear strategy in this setting. This microscopy centre is now working towards serial, 'same-day' issue of results through a total quality approach, focusing on liaisons between chronic cough room, laboratory service and treatment registry.

Theme 4 - An equity lens on pathways to care for TB and HIV care and treatment

Financial problems and stigma for poor TB patients in urban Malawi

Sanudi L, Makwiza I, Weiss M, Squire SB and Kemp J.
International Journal of Tuberculosis and Lung Disease. 2002:6: Supplement 1, S142

Objectives: To identify gender differences in the reported problems and self-perceived stigma among TB patients in Lilongwe, Malawi.
Methods: Semi-structured in-depth EMIC interviews, a proforma for research in cultural epidemiology, were administered to 100 patients with TB (50 men and 50 women) at two urban health centres. Data was analysed quantitatively using Epi Info and qualitatively using Winmax software.
Findings: Financial problems figured prominently. Many respondents reported undependable and irregular income (48%). Many men and women were concerned about the impact of illness on family income. Men, in particular, were concerned about the possibility of losing their job and wages. Many patients (64%) had not discussed their problem with anyone and 34% preferred to keep others from knowing. Men were more likely to feel that others might avoid them because of their TB, while women were especially concerned about their marriage or prospects of getting married.
Conclusion: TB is not just a clinical illness, men and women TB patients face financial and social problems and, in an area of high HIV prevalence, stigma due to their illness. These social problems present barriers to access to TB care for poor people.

DOTS is not enough: Poverty is still an issue for TB control in Malawi.

Nhlema B, Benson T, Salaniponi FML, Squire SB, Kemp J.
Poster presentation to IV World Congress on TB, Washington, USA: June 2002.

Objectives: To compare the prevalence of poverty between TB patients and the general population, and the impact of TB on livelihoods of patients.
Methods: A proxy quantitative measure of poverty was developed from the 1998 Malawi Integrated Household Survey (MIHS) through regression analysis. A specificity and sensitivity test was carried out to assess the validity of the tool against the urban poverty line. The measure was then applied to a random sample of 179 new adult TB patients in urban Lilongwe.
A participatory poverty assessment (PPA) was conducted within urban Lilongwe to understand livelihood patterns and impact of ill health on livelihoods. In-depth interviews were conducted with twelve poor and non-poor patients.
Results: The level of poverty among the sample of TB patients was 62% (95%CI: 55-69%), higher than the poverty estimate for urban Lilongwe (38%). The impact of TB was greater on poor patients who lost wages, sold assets and took debts as major coping mechanisms. This affected their consumption activities like buying water and maize flour.
Conclusion: Poverty remains a key issue for the DOTS programme. TB patients are generally poorer than the general population and the impact of TB is greatest on the poor.

"Lost" smear positive pulmonary tuberculosis cases; where are they and why did we lose them?

Squire S B, Belaye A K, Kashoti A, Salaniponi F M L, Mundy C J M, Theobald S, Kemp J.
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Also published as full paper in Squire S B, Belaye A, Kashoti A, Salaniponi F, Mundy C, Theobald S, Kemp J. "Lost" smear positive pulmonary tuberculosis cases; where are they and why did we lose them? International Journal of TB and Lung Disease. 2005;9(1):1-7.

Objectives: Using a geographical information system in a rural district, to locate all smear positive tuberculosis patients identified in the first 6 months of 2000 but who never started treatment. To describe the pathways to diagnosis and determine reasons why treatment was not started.
Design: The Critical Incidents Narratives interview technique was used with patients or their carers. Emerging themes were triangulated with health care workers' perspectives through Focus Group Discussions (FGD).
Results: The laboratory registered 157 new smear positive cases. Twenty three (15%) of these did not start treatment and were traced through their nearest health centre. Interviews were conducted with 19 cases or their carers. Four FGD were held with 46 health care workers from 26 health facilities.
Most patients had died within a month of their smear positive status being established. Structural barriers related to the health care system were the major factors behind extended pathways to diagnosis - including delays in receipt of sputum results and the misconception that negative smears excluded the diagnosis of tuberculosis. Less striking were patient delays in seeking formal medical care.
Conclusion: Sputum smear positive cases can be lost in a passive case-finding system based on smear microscopy. The pathway to initiation and maintenance should be organised to prioritise the needs of patients rather than the needs of the service.

Improving access to DOTS for the poor in Malawi

Kemp J R, Mann G, Nhlema Simwaka B, Salaniponi F M L, Squire S B.
Invited presentation to the Poverty and TB Symposium of the 34th World Conference on Lung Health of the International Union Against Lung Tuberculosis and Lung Disease. Paris, France: November 2003.

Introduction: The National TB Programme (NTP) has been running a successful DOTS programme in Malawi since 1984. Despite a devastating HIV/AIDS epidemic and a case fatality rate of 20%, the NTP has consistently maintained high cure rates and low default rates. In 1999, the NTP and its' partners initiated an operational research programme to assess whether the poor have access to this model DOTS programme.
Results: In urban Lilongwe, research showed that relative to the non-poor, the poor face greater barriers and it costs them on average six times their available monthly income to get a TB diagnosis. The impact of TB illness on the lives of poor patients and their households is large. Further evidence suggests that poor TB suspects drop out of the diagnostic pathway, and up to half of all smear positive TB cases may remain undetected from the poorest areas.
Discussion: Through a process of feedback and policy dialogue, the NTP responded to these research findings by developing a strategy to improve access to DOTS for the poor in Malawi. This involves resting new interventions to reach poor populations; improving the overall quality of TB services; improved communications and better monitoring and evaluation of access by the poor. The NTP in Malawi is now implementing this pro-poor approach in order to improve the overall performance of DOTS.

Integrating patient voices into TB policy and practice in Malawi

Salaniponi F M L, Nhlema Simwaka B, Makwiza I, Kemp J.
Invited presentation to the Integrating Patient Voices Symposium of the 34th World Conference on Lung Health of the International Union Against Lung Tuberculosis and Lung Disease. Paris, France: November 2003.

Introduction: The Malawi National Tuberculosis Programme (MNTP) has run a successful DOTS programme since 1984, with a strong operational research component. From 1999, the MNTP embarked on an initiative to improve the implementation of the DOTS strategy from the perspective of its' primary stakeholders: TB patients and communities.
Methods and Results: Through an operational research project (TB Equity Project), qualitative and quantitative approaches were used to assess the perceptions and experiences of patients and communities of barriers to accessing TB diagnosis and treatment. The barriers experienced resulted from long pathways to care, requiring repeated visits to different health providers. Social and economic costs of diagnosis and treatment were high for patients and their households.
The operational research was coupled with a process of on-going feedback and policy dialogue, through fora such as the Programme Management Group and the Annual MNTP Review. In response to this initiative, policy changes to improve access to DOTS for patients and communities have been mainstreamed within the new MNTP Five Year Development Plan (2002-2006).
Conclusion: The experience of MNTP has shown that there is need to ensure long-term policy dialogue and responsiveness to primary stakeholders. This can be achieved through operational research and the sustainable interaction of TB programmes with peripheral, district and national civil society organisations. The DOTS element of 'political commitment' needs to be expanded to encompass the issue of 'governance' and MNTP's accountability to wider civil society and other stakeholders

Integrating self-sustaining community structures into TB control in Malawi

Willetts A, Kemp J, Nhlema Simwaka B, Joshua B, Lusinje A, Salaniponi FML, Squire S B
Poster presentation to the International Union Against Lung Tuberculosis and Lung Disease. Paris, France: November 2003.

Background: Poor urban communities have a high burden of TB. but significant barriers to diagnosis and treatment. Integration of storekeepers into TB and malaria control programs can improve access to advice and treatment, but their role in TB case finding has not been explored.
Objectives: To explore the role of storekeepers and community groups in TB control in a poor urban community. To empower an urban community and Lilongwe City health team to develop an intervention project.
Methods: In depth interviews, focus group discussions, key informant interviews and stakeholder workshops.
Results: Storekeepers already treat coughs and are willing to refer customers with chronic coughs, however direct discussion between patron and shopkeeper about TB is limited by the stigma of HIV. Community chiefs have a health promotion role and discuss sensitive issues such as HIV at public meetings, but lack knowledge and skills. Existing health education volunteer groups want to support storekeepers and chiefs and collaborate in a community-based program. The community and City health team jointly produced a proposal for a community health education intervention that is now funded.
Conclusions: Collaborating with storekeepers and chiefs with the participation of existing local health and community groups may lead to an equitable and sustainable community-based case finding strategy for TB control.