

Vulnerability, access to health services and impact: a gender lens on TB, HIV and malaria in Malawi

Bertha Nhlema Simwaka¹, Ireen Makwiza¹, Lifah Sanudi¹, Patnice Nkhonjera¹, Sally Theobald^{1,2}

¹ Research for Equity and Community Health Trust (REACH Trust), formerly known as EQUI-TB Knowledge Programme

² Liverpool School of Tropical Medicine, UK

Abstract

This paper synthesises the different research findings in Malawi to explore how gender roles and relations affect the way in which key diseases related to poverty are experienced at the community level. We highlight background information on Malawi with an overview of the three diseases:

HIV/AIDS, tuberculosis and malaria, and of the methods used; and provide a conceptual framework on how gender shapes (1) vulnerability to TB, HIV/AIDS and malaria, (2) access and adherence to services and (3) the impact of being ill on individuals and households

Section 1: Background on diseases related to poverty in Malawi

Malawi has a population of about 10 million people¹. It is one of the poorest countries. According to the latest Malawi Poverty Profile, 65 percent of the Malawian population is poor². Malawi's poor are not a homogeneous group but consist of a cross-section of the population including smallholder farmers with less than one hectare of land, estate tenants, urban poor and female-headed households. Their principal coping mechanism is 'ganyu'³ work. About 40 percent of the households in Malawi are headed by women, and most of these households are poor². Nationally, 21 percent more men than women can read: the national literacy rate for men is 74.9% while for women it is 54% (ibid).

Malawi's mortality pattern is typical of a developing country. It has very poor health indicators with a high proportion of deaths caused by infectious diseases like tuberculosis, malaria and HIV/AIDS.³ Malaria is the leading cause of outpatient visits (causing up to 30 percent of OPD visits) and is a leading cause of under five mortality (responsible for 40 percent of deaths⁴). Tuberculosis cases have risen from 5,334 in 1985 to 22,674 in 1998⁵, reflecting a rise from 82 per 100,000 per annum to 193 per 100,000 per annum (ibid). The increase in the TB incidence has partly been attributed to HIV/AIDS. HIV/AIDS constitutes a serious threat to the country as a whole as it has affected all the aspects of Malawi's social and economic fabric. There are approximately one million people infected with HIV in Malawi³. AIDS causes approximately 81,000 child and adult deaths annually and is the leading cause of death in the reproductive age group (20–49 years (ibid)). The Ministry of Health is the main health service provider in Malawi, accounting for 60 percent of health services, followed by Christian Health Association of Malawi (CHAM) with 25 percent.⁶ The remaining 15 percent of services are provided by private and non-profit organisations. In the government facilities, most services are free of charge at the point of delivery (ibid).

Section 2: Methods

In this paper we draw on research conducted by the REACH Trust in Malawi. At REACH Trust we have conducted research on access to health care services using multiple methods. Specific methods employed included focus group discussions with community members and tuberculosis, HIV/AIDS and malaria patients. Individual in-depth interviews were also conducted with tuberculosis and HIV/AIDS patients, key informants and other stakeholders. Follow-ups of patients who had defaulted from treatment were undertaken as well. Structured interviews using a questionnaire were conducted with tuberculosis patients to quantify costs and delay in seeking care. Gender analysis was carried out in all studies to allow in-depth analysis of the impact of power and social relations on access to services and adherence to drug regimens. A synthesis of the findings from these studies is presented in Section 3.

Section 3: Unpacking how gender roles affect the ways in which TB, HIV/AIDS and malaria are experienced at the community level

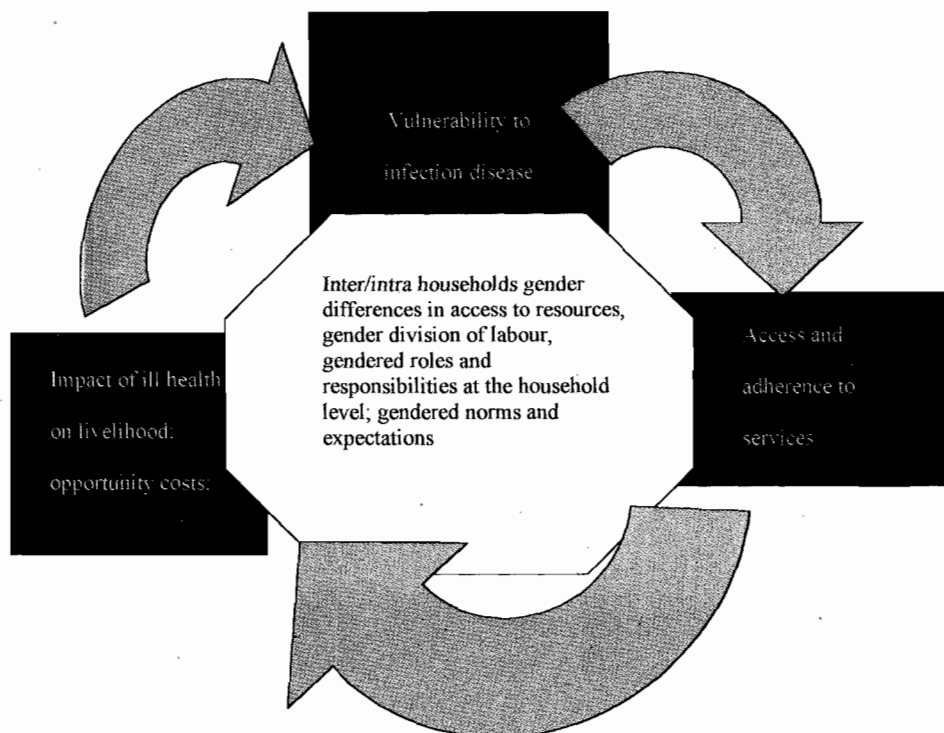
Gender analysis provides a useful tool for critically examining power relationships in society, and adds an important dimension in poverty and vulnerability analysis. Gender refers to men and women's characteristics, which are socially and culturally determined.^{7,8} It is related to how men and women perceive themselves and each other and how we are expected to think and act as men and women because of the way in which society is organised.

This section documents the inter-relationships between gender roles and relations and the key diseases of poverty in Malawi at the household and community level. To explore this inter-relationship we will discuss how they shape the following:

- Vulnerability to disease
- Access and adherence to services
- Impact of ill-health on individuals and communities

The most attention will be paid to 2 and 3 where much of our work has focused. The ways in which these relationships inter-link is illustrated in Figure 1.

Figure 1: Conceptual framework



Gender vulnerability to TB, HIV and malaria

Ill health has been and continues to be associated with poverty and vulnerability. These are multifaceted and shaped by gender roles and relations which impact on power, voice and participation in social structures.⁹ Biological factors, gender divisions of labour and the gendered nature of poverty lead to differential risk and vulnerability to HIV, TB and malaria for women and men.¹⁰

Gendered disparities in HIV infection are particularly stark in the younger age groups. For example younger women are more vulnerable to acquiring HIV infection than men, partly for physiological reasons such as an immature genital tract and the high rates of asymptomatic untreated sexually transmitted diseases occurring in young women. In sub-Saharan Africa, there are, on average, 13 infected women for every 10 infected men.¹¹ For example in Malawi the prevalence of HIV/AIDS amongst young women aged 15-24 is four to six times higher than amongst young men of the same age.¹² These differences have been attributed to the way in which gender shapes an individual's ability to negotiate safe sex against a backdrop of poverty and violence. With regards to gender differences in TB incidence, globally there are 1.7 times as many male pulmonary TB cases reported annually as female cases.¹³ Some evidence suggests that this may be due to gendered inequities in access to care, with women facing a number of barriers in accessing TB services,¹⁴ as is discussed below. The male:female TB ratio in Malawi is similar to the global notification rates trend, and is 1.08:1.⁵ However the trend varies from district to district, with some districts presenting high notification rates for women and others low.

Malaria is a major cause of illness amongst the general population in Malawi, with an estimated 40 percent of the admissions and 30 percent of all hospital deaths in under-five children being due to malaria and its associated complications.¹⁵ Women with lower levels of education are more likely to have fever than women with higher levels of education.¹ Gwatkin and Guillot¹⁶ demonstrated that 58 percent of the malaria deaths occurred in the poorest 20 percent of the world's population, a higher per-

centage than for any other disease of major public health importance.

Access and adherence to services: a gender analysis

Gender roles and relations result in differential access to resources at household and community level. The ability to make decisions over resources for accessing care is vital. In most developing countries men decide on the allocation of resources for the care of a family member in times of ill health.¹⁷ Analysis of pathways to seeking care in Malawi reveals that women take longer to report to health facilities than men. The delay period amongst TB patients showed that women took longer to be diagnosed with TB than men and had more repeated visits to health facilities. The barriers to seeking care are more complicated for poor women. This might be due to lack of power in decision making over resources to accessing care. The findings revealed that before visiting public facilities, patients shop around to different care providers such as storekeepers, private providers and public health facilities for treatment. The trend is similar for HIV/AIDS and malaria. Qualitative assessments of care seeking for malaria revealed that storekeepers are the first contact providers for treatment, though in most cases women need to seek permission to use resources for buying drugs for fever from men. In addition, repeated visits to health facilities due to long diagnosis process and also the lack of a proper diagnosis lead to huge costs to patients.

"We came back to wait for the result, we waited and waited but the result never comes out. We went to the health centre to find out about the result only to be told that the sputum was sent to the District hospital, if the result came we will inform you. We waited and waited then we went again for a second time, third time only to be told we shall be called. We stayed at home..." (in-depth interview, male guardian)

Financial and opportunity costs of accessing care have been identified to be major barriers to early diagnosis and treatment of tuberculosis and HIV/AIDS. These are increased due to the need for repeat visits to the health facility for diagnosis and treatment and lack of speedy laboratory diagnosis techniques.

In addition, access to resources at the household level also affect adherence to treatment and may lead to the dropping out of treatment and diagnosis. In depth interviews with patients on tuberculosis treatment and anti-retroviral therapy (ART) showed that patients usually have to bear transport costs for both themselves and their guardian. There was some evidence from qualitative research at the Lighthouse in Lilongwe, that where men are the breadwinners they are more likely to prioritise access to ART drugs for themselves, while women faced financial barriers in accessing care. In a context of limited resources and costly drugs, individuals and families have to make very difficult decisions about who should access ART.

'So the problem that is there is that we men are selfish, selfish in the way that we are only buying medicines for ourselves and denying our partners to buy the medicine as well. May be if it were halved but K2500, how much money do we get'. (Focus Group Discussion with men on ART)

'Like some of us are failing to have our partners at home to be getting the medicine as it is expensive and I cannot pay K5000, and then make sure we are eating and paying rent from the same amount. I can't manage, so it would help if the cost was lowered a little'. (Focus Group Discussion with men on ART)

In addition, social stigma associated with illness such as HIV/AIDS and tuberculosis sometimes acts as a barrier to seeking care and adhering to services. In Malawi, HIV/AIDS is stigmatised because of the strong relationship to sex, and by implication loose sexual behaviour, and tuberculosis because of its perceived relationship with HIV/AIDS. The fear of stigma can prevent patients who have symptoms suggestive of HIV/AIDS and TB from seeking care. Qualitative studies suggest that women suffer more social consequences from HIV/AIDS and tuberculosis. Disclosure of a positive HIV status has led to some women being divorced by their husband and to social isolation.

Impact of ill health on individuals and households

Measures to cope with the cost of accessing care push households into ultra poverty, especially those that are poor and are female headed. For example, information from individual in-depth interviews with TB patients revealed that poor men and women sell their assets and take heavy interest loans known as *katapila* to cope with the burden of ill health. There were notable gender differences between female-headed households and male-headed households, the problems being worse within the former. Besides selling assets, most of the female-headed households in urban settings had to stop buying water from communal taps and resorted to using water from traditional wells. This exposes them to other illnesses, such as diarrhoea and skin diseases.

"Since the illness we stopped buying a whole bag of maize per month, instead we buy a pail of maize. It is now several months since we stopped using the communal public water tap because we couldn't pay, we now use water from the traditional well after illness..." (Woman-Lilongwe2, in-depth interview).

Patients' families and households are directly affected in several ways when seeking healthcare. Firstly, someone has to act as their guardian at the clinic or hospital and secondly someone has to replace their activities in the home. The patient has to forgo his or her livelihood activity. As in most countries, women mainly do the role of caring in Malawi. Women have to make the decision to either escort the patient to the hospital/health

centre or continue with their livelihood activities. It is clear that a patient's female relatives spend significantly more time acting as guardians for TB patients (7 working days per month) than their male relatives (4.3 days per month). In total, females on the patient's side are used as guardians 60 percent of the time, males on the patient's side 37 percent of the time, females on the spouse's side 2.5 percent of the time and males on the spouse's side 0.5 percent of the time. Women are thus more likely to lose income-earning opportunities than men.

While patients are seeking health care, often someone else in the household has to fulfil their everyday tasks. This person is frequently their spouse, potentially resulting in further income loss, or a child. Men were less likely to have their activities replaced than women (70 percent of men had no one replacing them, compared with only 30 percent of women). The poor were more likely to have no one replacing their activities than the non-poor.

For most of the parents who did not have older female relatives, their domestic activities were replaced by children, and mostly by female children. Many of those children who replaced the role of their mother had to miss attending school.

Gendered roles, relations and differential access to resources at household level not only lead to vulnerability to infections or diseases but also ability to access and adhere to a drug regimen. The impact of treatment seeking and ill health is also impoverishing; poor women and men may become extra vulnerable to ill health due to reduced access to clean water and food due to reduced income. Hence there is need to employ gender and poverty approaches across the whole spectrum of health responses: from prevention to cure.

Summary of how gender shapes vulnerability, access and impact of ill health

- Gender roles and access to resources shape the ability of men and women to access care and also the impact of ill health. In Malawi, women have less power to make decisions on resources for accessing services. In the qualitative assessments it was found that women have to seek their husband's approval or at least notify them before incurring any expense.
- Also affected by TB and HIV/AIDS are guardians who provide caring activities to patients.
 - Most of these guardians are women; it is a common trend in Malawi for men to leave caring activities to women.
 - Studies also revealed more financial costs for female guardians because they had to travel with patients more than male guardians.
- Opportunity costs were higher for women and girls who had to take up caring roles than men. Some of the girls had to drop out of school to concentrate on caring for their mothers.

Section 4: Concluding Comments

Gender sensitive research approaches help to highlight inequities in access to resources¹⁸ as well as highlight implications for health sector responses. The research findings synthesised in Section 3 clearly illustrate how gender roles and relations affect not only vulnerability to TB, HIV and malaria, but also access and adherence to services and the impact of disease on individuals and households in Malawi. The multiple ways in which gender and poverty intertwine to shape health experiences and outcomes need to be realised and acted upon if health policy and practice is to be equitable, efficient and sustainable.

Notes

^a *Ganyu* work is piece work or casual work, which in most cases is sought on daily basis.

^b Confirmation of full TRUST status is currently awaited. In Malawi this can take up to three months from the time of submission.

References

1. National Statistic Office and ORC Macro. Malawi Demographic and Health Survey 2000. Zomba, Malawi and Calverton, Maryland, USA: National Statistical Office and ORC Macro; 2000.
2. National Economic Council. Profile of Poverty in Malawi 1998: An analysis of the Malawi Integrated Household Survey, 1997-1998. Poverty Monitoring System, Zomba: National Statistics Office; 2000.
3. Ministry of Health. The Programme of Work, Sector Wide Approach. Lilongwe: Government of Malawi; 2004.
4. Ministry of Health. Malawi roll back malaria: five years strategic plan, 2001-2005. Lilongwe: Government of Malawi; 2004.
5. World Health Organization. Putting research into policy and practice: the experience of the Malawi National Tuberculosis Programme. WHO Report, Communicable Disease cluster. Geneva: World Health Organization; 1999.
6. Ministry of Health. National Health Accounts. Lilongwe: Government of Malawi; 2001.
7. Williams S, Seed J, Mwau A. The Oxfam gender training manual. UK and Ireland: Oxfam Publishing Unit; 1994.
8. World Health Organization. Gender and Health: Technical Paper. Geneva, Switzerland: World Health Organization; 1998.
9. Narayan D, Chambers R, Sha MK, Petesch P. Voices of the poor: can anyone hear us? New York: Oxford University Press Inc.; 2000.
10. Bates I, Fenton C, Gruber J, Laloo D, et al. Vulnerability to malaria, tuberculosis, and HIV/AIDS infection and disease. Part 1: determinants operating at individual and household level. *Lancet* 2004.
11. UNAIDS. Report on the global AIDS epidemic. Geneva: UNAIDS; 2004.
12. National Aids Commission. Malawi National HIV/AIDS estimates. Lilongwe: National AIDS Commission; 1999.
13. World Health Organization. Global Tuberculosis Control. WHO Report, Communicable Disease cluster. Geneva: World Health Organisation; 2001.
14. Hudelson P. Gender differentials in tuberculosis. The role of socio-economic and cultural factors. *Int J Tuberc Lung Dis*. 1996;77:391-400.
15. Ministry of Health and Population. Malaria Policy. Lilongwe: Government of Malawi; 2002.
16. Gwatkin DR, Guillot M. The Burden of Disease among the Global Poor: Current Situation, Future Trends, and Implications for Strategy. Geneva: Global Forum for Health Research Publications; 2000.
17. Taylor L, Seeley J, Kajura E. Informal care illness in rural South West Uganda: the role that women play. *Health and Transition Review*. 1996;6:49-56.
18. Baume E, Mercedes J, Hillary S. Gender and Equity in Health esource Guide. Gender and Equity Network. 2001.