TUBERCULOSIS: A DISEASE OF POVERTY; A QUESTION OF CONTROL? A CASE STUDY OF TB IN MALAWI.

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ABSTRACT

Tuberculosis (TB) has re-emerged as a major threat in the developing world and is one of the leading infectious disease killers globally (UN 1999; WHO 2005). In Malawi, one of the poorest countries in sub-Saharan Africa, the National TB Control Programme (NTP) is struggling in a setting where an HIV pandemic combined with extreme poverty is undermining its efforts. There has been an upsurge in TB case rates and falling cure rates. Despite such deteriorating statistics, this programme is nevertheless regarded as a 'model' by the World Health Organisation (WHO 1995; WHO 2001), which applauds the early and sustained implementation of the DOTS strategy - seen as the most effective strategy for TB control. This apparent 'disconnect' between WHO praise for DOTS implementation and the deteriorating TB outcomes suggests that further investigation should examine why this is the case, and what can be done to improve it.

This thesis, therefore, investigates tuberculosis and its control in the Malawian setting, and aims to understand it from the point of view of ordinary people who are most at risk, from the perspective of policy making and implementation, and from the experience of care providers. Using a qualitative case study approach in a severely affected country, it shows that the failure of TB programmes to understand in-depth the environment in which they operate will limit their ability to recognise and respond to the particular needs of their public with practical service provision options, thus contributing to continued poor TB outcomes.

One of the overarching policy implications concerns the common reluctance of TB control experts to allow systematic social science research to uncover the complexities of the context in which they are situated. Biomedical control is instead promoted as a means to contain and avoid complexity, yet in doing so, ultimately precludes what may bring positive change.

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CHAPTER 1: INTRODUCTION

"Lala is a young man but not a healthy one. Weight loss has pinched his face, giving it the shape of India; his silences end in coughs. Lala stopped taking medicine for tuberculosis (TB) because he started feeling better and ran out of money at roughly the same time. Now the disease is back and he can no longer afford treatment. He may be among the half-million Indians who will die this year from TB, which kills five times as many as malaria, striking mainly those in their prime." ('Joining the dots,' The Economist, June 22nd, 2002: 30)

With this personal story, an article in *The Economist* begins and then reflects on the overall TB situation in India – a country with a population of one billion people and 30 per cent of the world's TB cases. This story, in its vastly summarized form, contains the essence of the challenge posed by TB in the world today, both for potential patients and providers. For Lala, both individual behavioural elements and broader economic ones combined to prematurely end his treatment. His story suggests that this combination of factors is something that TB Programmes everywhere ought necessarily to investigate, understand and incorporate into their policy and practice – not only at the treatment stage for those who actually make it to diagnosis, but at all stages of the illness path. Reality, however, frequently tells a different story, and for many different reasons.

In Malawi, one of the poorest countries in sub-Saharan Africa (SSA),[1] the National TB Programme (NTP) is struggling with the control of the disease. This is seen in an upsurge in TB case notification rates and falling programme cure rates.[2] HIV/AIDS is often cited as the main reason for TB's continuing and increasing impact in this region. Indeed, TB prevalence data throughout areas with high HIV rates would support this clinically proven relationship. HIV is a key factor in increasing the numbers of people with TB disease. However, it may not be the only reason why TB control efforts are currently failing. The clinical impact of HIV on TB is serving to

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[1] 2001: GNI (GNP) per capita: 170 U$, ranked 197/205 countries listed. Total GDP: 1,826,000 U$, ranked 134/176 countries listed, in the World Development Indicators database, World Bank, 2002.
[2] In 1985, the case notification rate (i.e., those cases found and 'notified' to the services) for TB in Malawi was 5,334 cases. By 2000, this had dramatically increased to 24,846 registered TB cases.

highlight the potential failings of TB control in being unable to adequately reach and treat the high numbers of sufferers.

Despite this prevailing situation, the World Health Organisation's main strategy for TB control, DOTS,[3] continues to be promoted globally, with Malawi regarded as a 'model' programme (WHO 1995; WHO, IUATLD et al. 2001). While the WHO[4] has recently acknowledged worldwide evidence that, despite increasing implementation of DOTS for TB control throughout the world, case detection rates remain low,[5] the reasons why, and possible innovative solutions to remedy them, have still not been fully explored. In the meantime, despite the deteriorating indicators, DOTS as a model for TB control is still regarded and promoted as the best – indeed the only – means to manage the disease.

For these combined reasons, Malawi – a respected DOTS practitioner, yet still struggling against the TB epidemic – was considered a useful location to explore the dominance and effectiveness of TB control and the challenges facing it, in a particular context. Between 1970 and 1985 in Malawi there was a small gradual increase in notified TB cases in the country from 3,492 to 5,334. However, from 1985 to 2002 there has been a significant upsurge in TB case rates within the country, from around 5,000 to 26,000 cases. The Malawi National Tuberculosis Control Programme, while continuing its well-established and internationally guided practices of case-finding, diagnosis and treatment under DOTS, acknowledges the continuing challenges, with recent data both reflecting poorer outcomes for those that actually reach the health service,[6] and suggesting many more 'missing' cases that never actually make it (Belaye 2000; Needham, Bowman et al. 2004).

Using a qualitative case study approach, this thesis therefore investigates and aims to understand tuberculosis in the Malawian setting, from the point of view of everyday

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[3] DOTS = Directly observed treatment shortcourse. Not to be confused with 'DOT' – directly observed treatment alone – DOTS is a five pronged approach to TB control (including DOT), embraced by WHO as the most appropriate model for countries to adopt in the fight against TB.

[4] M.Raviglione, speech to the Stop TB DOTS Expansion Working Group, Annual IUATLD Conference on World Lung Health, Montreal, Canada, 6th October 2002

[5] Whilst the WHO target for case detection stands at 70%, annual worldwide case detection rates (2001) remain a low 30%, despite increasing adoption of the DOTS strategy. DOTS coverage (2001) is reported as 70% (148/210 countries).

[6] Cure rates have dropped from a high of 87 per cent in 1985 to 67 per cent in 2002/2001 (NTP).

people who are most at risk, as well as that of policymakers, and care providers working at the interface between these macro and micro levels. It is acknowledged that such levels are not exclusive and that while the research is framed within them, analysis will necessarily look beyond them at the complex web of relations and relevancies across the framework. As a chronic disease of poverty, TB is an appropriate area through which to explore issues of health, development and poverty, the international political economy of disease and its embodied and behavioural implications for those living with, and with the threat of, TB disease (Farmer 1999).

This thesis is structured as follows: Chapter 2 presents a review of recent relevant literature, describing the broader policy environment for health in developing countries and situating TB and its control within that policy context. Chapter 3 describes the methodology adopted, detailing the range of methods chosen and justifying why, in the light of the research aims. Chapter 4 sets the scene, giving more detailed information about TB globally and in Malawi. Chapter 5 presents findings from 'inside' the Malawi NTP with reflections on TB control policy from an ethnographic perspective. This view is complemented in Chapter 6 with the view from the 'outside,' with detailed findings and reflections on practice amongst the public most at risk and the health providers serving them. Chapter 7 looks in depth at the healing encounter, the site where policy meets practice for TB control; this chapter examines the theoretical dimensions of knowledge, power and TB control that underwrite actions at the micro level of patient/provider interaction, and also at the macro level of policy discussion and dialogue. These findings and themes are brought together in Chapter 8, the conclusion.

CHAPTER 2: LITERATURE REVIEW AND PROBLEM STATEMENT

INTRODUCTION

This chapter provides an overview of the literature relating to health, development and TB, in order to situate the research in the prevailing policy environment and within the region, and to identify gaps in existing literature where this work seeks to contribute. It is divided into five sections. In Section 2.1, issues of health and development are reviewed, including the relationship between health and poverty. Section 2.2 focuses more specifically on health policy and provision in sub-Saharan Africa, leading to a review, in Section 2.3, of contemporary approaches to health, the state and sector reforms. This is followed by a discussion of biomedicine, health and society in Section 2.4, including a preliminary focus on TB.[7] Finally, Section 2.5 introduces the dimensions of power and knowledge, which contribute to a theoretical background for the wider study.

2.1 HEALTH AND DEVELOPMENT

In the constitution of the World Health Organisation (WHO), health is defined as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO 1958, Annex 1). This definition has been criticized on a number of levels, not least because of the difficulty in actually defining 'complete wellbeing.' The statement, however, is helpful in indicating the complexities inherent in the use of the term 'health' and the differing interactions it implies between humans and their surroundings (WHO 1992): social and economic factors; geographical and biological environment; indigenous concepts and categories; issues of measurement, indicators and statistics. It is thus possible to see the challenges involved in addressing health issues in any given environment.

It is now widely accepted that the concept of 'health' varies from culture to culture. As noted in one anthropological definition, "Standards and concepts of health are not only geographically and culturally, but also historically variable, as they change over time in response to changing socio-economic and cultural patterns and also to prevailing systems and levels of healthcare" (Seymour-Smith 1986: 135). However, while recognizing such contextual diversity, the hope for health and wellbeing can be

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[7] This is further expanded in Chapter 4.

regarded as a unifying factor, across peoples and nations: "In our turbulent world, health remains one of the few truly universal aspirations (Frenk and Gomez-Dantes 2002)."

Debates have centred on the complex relationship between a nation's health and broader development, between illness, disease and poverty. A generally accepted understanding is that, not only do socio-economic conditions affect people's health, but conversely, that a people's level of health similarly affects the socio-economic conditions of a nation. This has been encouraged by the mainstream development economics perspective, where the contributory role of 'human capital' to growth is acknowledged and emphasised. Approaches to health policy and provision have therefore tended to share the assumptions of the dominant development models of their time (Asthana 1994).

Post-World War Two development theory appropriated and built upon earlier social theories incorporating evolutionary models of growth, and led to the whole-hearted embrace of modernisation[8] as the way forward, with economic development and industrialisation at the heart of this approach. In the 1950s and 1960s, post-war and for many nations, post-independence, the prevailing view was therefore of *poverty* as a state of being without or having very low income, and of *development* as economic growth through rising income. In privileging the goal of income-based growth, assumptions were made that this would automatically result in overall development, through enhanced economic opportunities for all, with benefits trickling down to also reach the poorest, and therefore those with poorest health status.[9] This period has been referred to as the 'Golden Years' of development (Hewitt 1992), with growth, measured by GNP or GDP,[10] used as the key indicator of development.

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[8] Approximately two centuries ago, the processes of what is now termed 'modernisation' began, catalysed by the start of industrialisation in the West/North. The changes brought about by the Industrial Revolution caused significant economic, social and political changes in the way people lived, worked, organised and created, that were not just restricted to the economic and technological developments more obviously linked to industrialised production. While the uneven and unequal development that has taken place globally is apparent, the dominant notion of modernisation is nevertheless associated with an increased pace of development, linked to industrialisation and expected to cause social and structural transformation on a significant scale.

[9] "Whether socio-economic status is measured by income, education, employment or housing tenure, people in lower socio-economic groups tend to suffer the worst health" (Hawe and Shiell 2000: 874).

[10] GNP = gross national product, defined by the World Bank as 'the total domestic and foreign output claimed by residents of a country,' and therefore used as a measure of national income. GDP = gross

However, this faith in growth and its assumed benefits began to be challenged as not all countries 'grew' and the anticipated 'trickle down' did not occur (Dagdeviren, Hoeven et al. 2002). Where growth did take place, unemployment, poor health indicators and limited access to food, livelihoods and social services often endured amongst certain populations, indicating that raised income alone would not contribute to overall social and human development. As early as 1962, the United Nations had cautioned against viewing development and growth as synonymous (Kim 2000). Dudley Seers' 1969 article '*The Meaning of Development*' also cautioned against a one-dimensional economic interpretation of growth as development, and instead argued for the importance of a contextualised approach which accounted for human capacity, employment and equality:

"The questions to ask about a country's development are therefore: what has been happening to poverty? What has been happening to unemployment? What has been happening to inequality? ... If one or two of these central problems have been growing worse, especially if all three have, it would be strange to call the result 'development'..." (ibid: 12).

This view was influential in shifting definitions of development and poverty reduction away from an increase in income/GDP alone, to a definition which embraced overall well-being through attainment of both economic and social development needs, and a reduction in inequality. From this perspective, economic growth is still essential, but alone, and without conditions for *redistribution* of that growth, it is not sufficient (ibid.).

Pritchett & Summers in their paper 'Healthier is Wealthier' (1996) – as the title might suggest – support a link between wealth and health. This assertion is based on their examination of data on infant and child mortality and life expectancy, in relation to income per capita. As a result of their estimates of the "pure income effect on health," they conclude that "over a half a million child deaths in the developing world in 1990 alone can be attributed to the poor economic performance in the 1980s" and

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domestic product, similar to GNP but distinguished by including the total output of goods and services produced within a country, regardless of the nationality of the producers. GNP is therefore the total *income* available for private/public spending, whereas GDP indicates the size of the economy.

that their findings "confirm that increases in a country's income will tend to raise health status" (ibid: 865).

However, they also acknowledge their exclusion of factors other than income. The relevance of these factors in determining health outcomes has been highlighted by various authors (Wuyts, Mackintosh et al. 1992; Cornia and Mwabu 1997; Bloom and Lucas 1999) and the evidence of divergent nations, such as China, Sri Lanka and Saudi Arabia, reiterate this point. As shown in the following chart (Figure 1), countries like Sri Lanka and China have low per capita income, yet high life expectancy. Conversely, countries such as Saudi Arabia and South Africa have lower life expectancy, despite higher incomes. There is a general relationship between GDP and life expectancy, but it is only one measure amongst many which influence health (distribution of income, inequality, education, etc), as seen in those countries where life expectancy is much higher than could be predicted based on solely economic criteria (Phillips and Verhasselt 1994).

Wuyts (1992) and Cornia and Mwabu (1997) examine the health/income relationship and, while acknowledging the positive association shown on average, both mention the inequalities within a population that also may be hidden in the use of macro-level data (Wuyts 1992). Wagstaff goes further in his examination of the available data from 42 countries to assert that large and rising inequalities in health are positively associated with rising per capita incomes (Wagstaff 2002). Thus, "economic growth tends to lead to increases in health inequalities, not reductions" (ibid: 23). Without successful anti-inequality or redistributive policies, such inequalities will continue to be enhanced by economic growth and, to cite Seers once again "it would be strange to call the result 'development.'"

In recent years, a more 'activist' group of scholars[11] have been trying to move this debate forward (Farmer 1999; Kim, Millen et al. 2000). Their concern has been to accept the relationship between poverty and ill health as a given, but then to examine

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[11] The 'activist' label here refers to academics who are actively playing a role as advocates, using their research and work to support an international social justice movement. This is seen in individuals such as Paul Farmer and Jim Yong Kim, who, in addition to teaching and publishing, are founding members of the Partners in Health charity, which both provides direct health care services and undertakes research and advocacy activities on behalf of those who are sick and living in poverty (Farmer 2003).

the political and economic forces that exacerbate poverty and ill health, and to explore and trace the causal linkages that can be drawn between global economic changes and resulting health crises across the world.

Figure 1: World Health chart table: life expectancy vs. per capita GDP 1960 –1994.
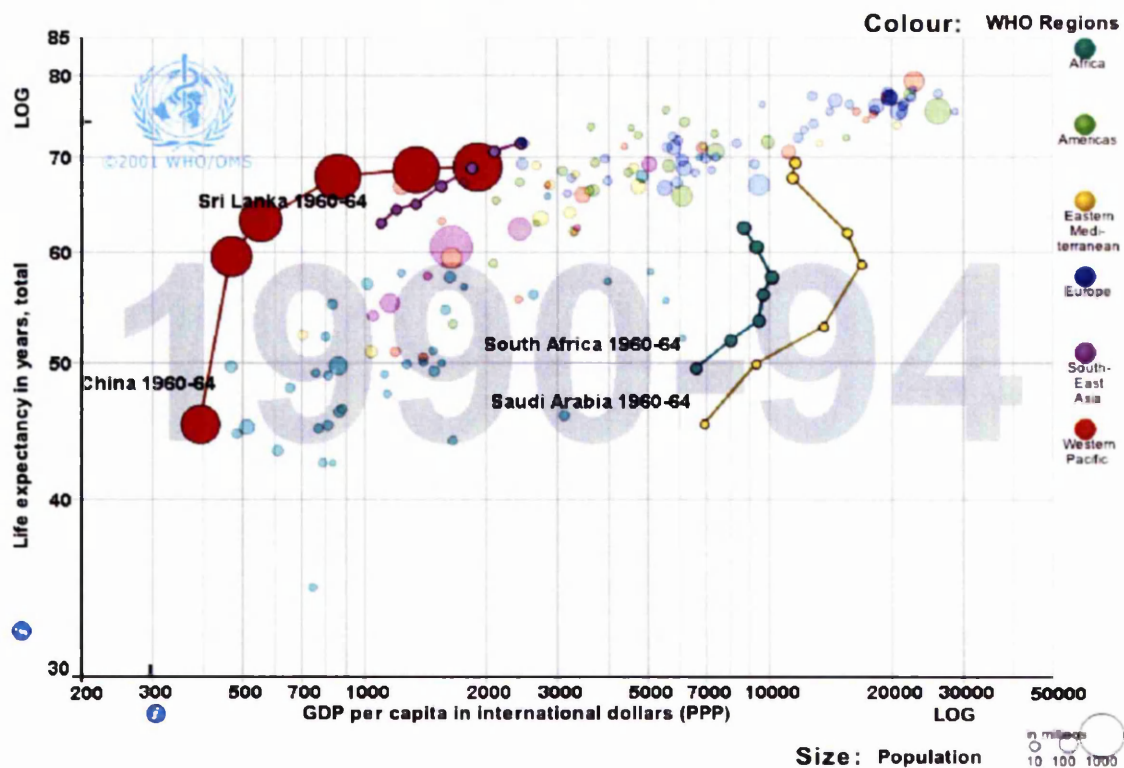
Source: WHO World Health Chart 2001 (www.whc.ki.se)

As part of their introductory evidence, they cite the uneven development that has taken place throughout recent history, and how this is clearly reflected in the uneven picture of health, once disaggregated from the standard global indicators. Therefore, while we may celebrate the fact that average life expectancy in the world has increased from 48 years in 1955 to 66 years in 1998, and that the worldwide infant mortality rate (IMR) is now 59 per 1,000 live births, in contrast to 148 in 1955, if we look beyond such aggregate statistics we find that there is a 16-fold difference between the present IMR in the 26 wealthiest countries (6 per 1,000) and the rate in 48 of the least developed countries (100 per 1,000) (Kim, Millen et al. 2000). Similarly, life expectancy in those least developed countries is decreasing, with the impact of HIV/AIDS, itself compounded by poverty and lack of resources in those

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countries. Life expectancy in Malawi is currently estimated at *36 years* by one source (WHO 2001), in stark contrast with the worldwide average of 66 years.[12]

Figure 2: Differences in Life Expectancy.
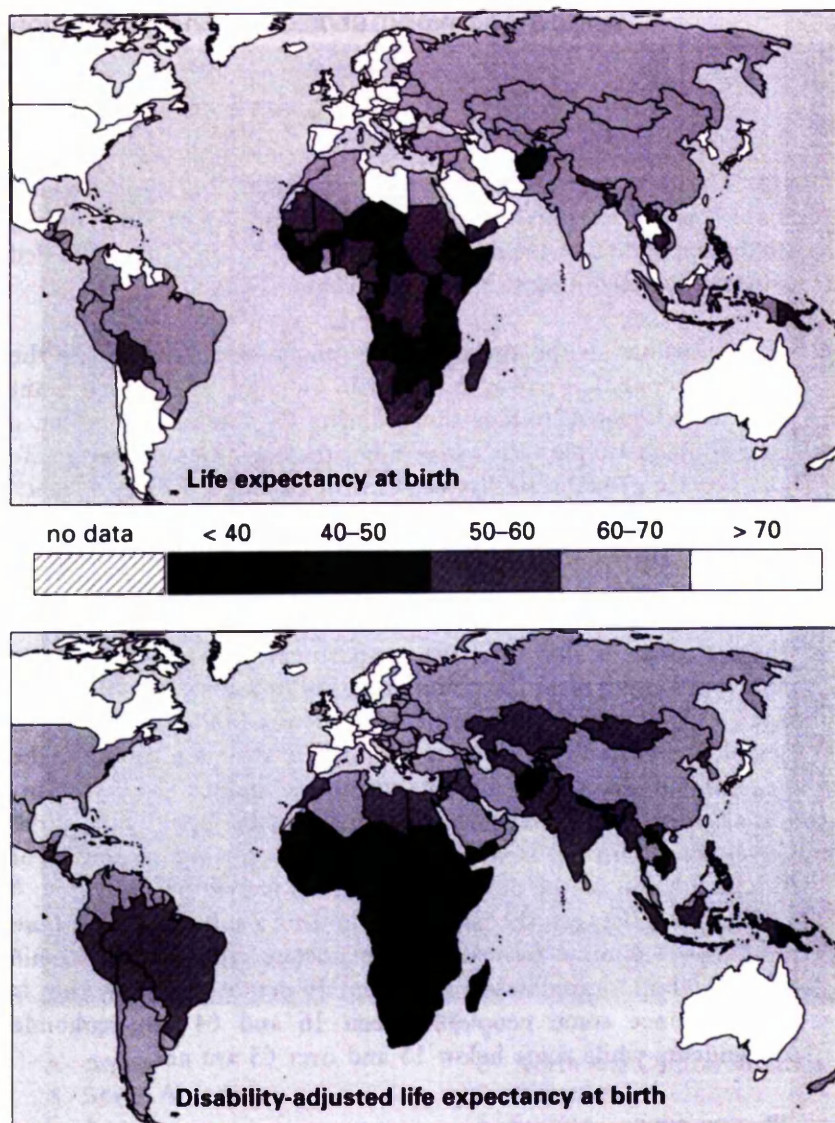
Reproduced from Bob Sutcliffe 2001, Table 23, '100 Ways of Seeing an Unequal World' (sources: UNDP 1999; WHO 2000).

The recognition of enduring health and socioeconomic inequalities has been represented in different schools of development thought that challenge the dominant

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[12] As the then-Director of WHO Gro Harlem Brundtland stated in 1998: "Never have so many had such broad and advanced access to healthcare. But never have so many been denied access to health. The developing world carries 90 per cent of the disease burden, yet poorer countries have access to only 10 per cent of the resources that go to health." (WHO Press Release, December 8th 1998)

growth model; e.g., dependency theorists; the argument for 'basic needs'; subaltern movements, etc.

In the work of Amartya Sen, the notion of human capabilities and how to promote them through development efforts was, and remains, influential in mainstream development practice (Sen 1985, 1993). Rather than judging a nation's development by the average level of income, Sen argued that development should be seen as the expansion of peoples' choices and capabilities, through addressing social and economic determinants of their overall 'substantive freedom,' in addition to civil and political rights (Sen 1999). This encouraged a shift in emphasis from outputs in terms of income or growth alone, to those that value people's ability to read or be healthy as relevant outputs in themselves (UNDP 1999) – a shift from income poverty to capability deprivation.

Sen does not ignore the role of economic growth, nor does he support an opposition between economic and social policies for development. Instead, he highlights their relationship, but proposes that social or political policies should not only be seen as contributors to growth, but as 'constituent components' of development themselves.

This perspective contributed to the 'human development' approach, which attempts a more inclusive understanding of poverty, and a translation of this multi-dimensional understanding into mainstream development policy and practice. It identifies "three ways to create desirable links between economic growth and human development: direct investment in human capabilities such as education, health and skills; more equitable distribution of income and assets; and empowerment of people, especially women" (UNDP 1999: 2).

The approach has been incorporated into the United Nations Development Programme's (UNDP) Human Development Index (HDI) – a quantitative measure of a nation's 'human development,' which goes beyond the traditional variables of

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income or consumption based growth to include a composite of indicators such as life expectancy, literacy, education and GDP.[13]

The human development approach gained momentum following the 1980s, when, with the growing debt crisis and increasing debt service obligations of many nations, economic adjustment was prescribed by the international financial institutions[14] (IFIs) as the solution to this crisis. As the impacts of subsequent austerity measures and structural adjustment packages (SAPs)[15] on the poorest became evident (e.g., rising prices of essential consumer commodities; reduced per capita public spending, including on social services;[16] rising unemployment and a decline in real wages), the model of economic growth alone was the subject of serious challenge. In addition, economists started to see human development issues as affecting economic growth rates, and therefore embraced the need also to focus on issues such as education and health in order to enable and support growth (The World Bank 1993). Acknowledging the limitations of macro-economic reforms alone, a recent World Bank report has concluded that growth of per capita income for a typical developing country in the 1980s and 1990s was zero (Easterly 2001), with growth actually dropping while World Bank and IMF adjustment lending increased (Easterly 2002).

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[13] In 2002, Malawi's HDI was a very low 0.388, ranked 165/177 listed countries. In comparison, the UK is 0.936, China is 0.745, Uganda is 0.493 (UNDP, 2003). There has been some debate over the value of a composite index versus a set of discrete indicators, such as the World Bank's 'development diamond' – comprising life expectancy, primary school enrolment, GNP per capita and access to safe water. The HDI index allows countries to be ranked according to their development achievements, whereas, with the diamond, countries can only be compared against the average for their income group (low-income, middle-income, etc). However, with a composite index, it is impossible to judge the relative importance of contributory indicators or to see which causes shifts in the overall score over time.

[14] For example, the multilateral and regional development banks, including the World Bank and the International Monetary Fund (IMF).

[15] The principles of adjustment include *fiscal austerity* - governments spending/consuming less and reducing domestic subsidies; *financial liberalisation* - increasing exports and liberalising markets and pricing; and encouraging *privatisation* – with the aim of correcting trade imbalances and government deficits: "World Bank and IMF adjustment programs differ according to the role of each institution. In general, IMF loan conditions focus on monetary and fiscal issues. They emphasize programs to address inflation and balance of payments problems, often requiring specific levels of cutbacks in total government spending. The adjustment programs of the World Bank are wider in scope, with a more long-term development focus. They highlight market liberalization and public sector reforms, seen as promoting growth through expanding exports, particularly of cash crops" (Colgan 2002).

[16] A study of SSA countries which experienced adjustment in the 1980s showed that the average reduction in real per capita spending was 14 per cent (Jayarajah, Branson et al. 1996). In the 42 poorest countries in Africa, spending on healthcare fell by 50 per cent during the 1980s (Inter-Church Coalition on Africa 1993: 17); in Nigeria, per capita expenditure on health fell by 75 per cent between 1980 and 1987 (ibid: 19).

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However, despite a stated near-consensus amongst the international donor community that the goal of development is 'poverty reduction' – in its broadest sense – rather than simply raising income,[17] donor and government efforts have resulted in mixed impact in terms of real health outcomes for the poor and tensions remain between the IFIs' continuing economic adjustment policies, poor countries' debt service burdens and the health needs of their people.

Before further exploring these tensions, and how they have been played out under the umbrella of Health Sector Reform (HSR) in Malawi and other developing countries, the development of healthcare in sub-Saharan Africa will first be reviewed.

2.2 HEALTHCARE DEVELOPMENT IN SUB-SAHARAN AFRICA

The evolution of biomedical health care in sub-Saharan Africa (SSA) can broadly be said to have followed the establishment of colonial administration in the region, in that the location of facilities followed the path of the colonial administrative centres – primarily to serve the needs of the European population stationed there. As colonizers undertook 'selective development' in order to serve their own political economic agenda (Akhtar and Izhar 1994), this was reproduced in the selective and unequal distribution of health facilities. This legacy was then built upon following the independence of the colonised African nations, thus further reproducing the unequal distribution of biomedical health facilities.

Not only was the *geographical* weighting of healthcare unequal, but additionally inequality was reproduced in the emphasis on curative, rather than preventative care (ibid; Turshen 1999). Western health care also ignored or discounted the existence of indigenous healing practices, preferring to reify the notion of scientific medical discourse, which in the European colonial imagination was represented by the 'white doctor in dark Africa' (Vaughan 1991).

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[17] "Human development is about much more than the rise and fall of national incomes. It is about creating an environment in which people can develop their full potential and lead productive, creative lives in accord with their needs and interests... Development is thus about expanding the choices people have to lead lives that they value. And it is thus about much more than economic growth, which is only a means – if a very important one – of enlarging peoples' choices." (UNDP Human Development Report 2001: 23). This approach is also reflected in the Millennium Development Goals.

While the impact of such colonially introduced health care was discriminatory, there were some contradictory and incidental benefits to the local African population, both owing to the work of missions in the region and as health care was extended to some African employees (Iyun 1994). In addition, as colonialism and capitalism spread, so too did the need for an essentially healthy labour force to fuel such expansion (Sender and Smith 1986). Thus, in many locales (e.g., northern Rhodesia, to serve the copper mines), efforts were made towards maintaining healthy 'labour reserves' in the rural areas (Cooper 2002).

While without the significant natural resources of its neighbours, the evolution of Malawi's health services reflects the colonial pattern. As Wendroff notes (1983), the arrival of both British colonial government and Christian missionaries influenced indigenous health practices and also led to the introduction of western-style 'allopathic' healthcare.[18] While the colonial administrators were attempting to develop the structure of a state system based on political, administrative and economic elements, their needs led to the development of a basic health infrastructure which serviced their very particular demands, and, in effect, favoured these settlers' interests over those of the local population. Gradually, African public servants and employees were accommodated within the system, but, essentially it developed along highly racial lines, and also included a distributive bias to those more urban areas of administrative settlement (Iyun 1994).

As in other settings in the region, missionaries made efforts to reduce the disparity of provision by setting up facilities in more rural areas. And indeed, pressure began to be exerted on government by both local communities organised in political agitation and the missionaries themselves. Thus, by the 1930s, the government had begun a programme of setting up district hospitals – 21 of these by 1964, in addition to a number of dispensaries and health centres (Ngalande-Banda and Simukonda 1993). Missionary activity continued to co-exist alongside this government provision, and,

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[18] The term 'allopathic,' deriving from the Latin terms *allos* (opposite) and *pathos* (suffering) originally means a "system of medical therapy in which a disease or abnormal condition is treated by creating an environment that is antagonistic to the disease or condition, i.e., antibiotic for infection" (Mosby Medical Dictionary). However, it has now assumed popular reference to 'Western,' biomedical or 'modern' scientific medicine and its healthcare system, as distinct from any alternative or traditional practices.

by the time of Malawian independence, several tiers of medical services existed. Ngalande-Banda claims that "the provision of district hospitals by the government at this early stage can be construed as complementing mission activities in providing facilities for patient referral as well as providing health services in areas that missionaries could not reach" (Ministry of Health and Population 1998). On the other hand, Iyun takes a more critical approach, observing that these tiers of provision were "largely divided along socioeconomic status lines." (in Phillips and Verhasselt 1994: 251)

Today, the Malawi government itself delineates hospitals at the central, district and rural levels, with rural hospitals supported by health centres and health posts extending into the rural areas. This system is supplemented by private/mission-run not-for-profit institutions, and by facilities privately run for-profit. In parallel with this allopathic provision, there exist traditional healthcare delivery systems, often accessed by the user simultaneously with biomedical health provision.[19]

Today, most countries in Africa, and particularly the eastern sub-Saharan region, still show fairly severe health indicators:

Table 1:Selected health indicators in SSA

Country	Infant Mortality Rate (per 1,000) 2002	Life expectancy 2002	HIV/AIDS prevalence (adults 15-49, %) 2003
Kenya	78	47	7
Tanzania	104	43	9
Zambia	102	37	17
Mozambique	128	41	12
Malawi	113	38	15
UK	5	77	0.1

Sources: World Development Indicators 2004; UNAIDS 2004.

Post-independence, health care was high on the agenda of most governments as part of the overall commitment to national development. However, imbalances in resource allocation; continued urban bias with investment in curative, technology-rich

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[19] This area will be further explored in the presentation of findings in chapters 6 and 7.

techniques; political whims and demanding demographic and economic conditions – nationally and globally – had their effects, and health care provision remained fairly weak after an initial strengthening in the 1960s and early 1970s. Since the introduction of SAPs in many of these countries, and the associated reduction in public health expenditure (Kim, Millen et al. 2000), many of these indicators have worsened in recent years.[20] It is acknowledged that, in settings of recession, it may be difficult to specifically draw out channels of attribution. In addition to the effect of adjustment policies, high drug prices, the 'brain drain' of trained practitioners, poor maintenance of water and sanitation facilities and the resurgence of communicable infectious diseases have all contributed to static or declining indicators (ibid.) – compounded by and contributing to continuing poverty.

African countries comprise 29 out of the 30 countries with the highest under-5 mortality rates (at an average of 155 per 1,000 live births across the continent and 170 per 1,000 in SSA) (The World Bank 2004). In addition, reports show that infant mortality rates (IMR) in SSA average 106 per 1,000, as compared with 5 per 1,000 in the developed world (UNICEF 2004). Maternal mortality (MMR) remains high, and indeed has worsened dramatically in some countries, including Malawi.[21] Crude death rates are still high, but have reduced considerably in many countries since the 1960s. On the other hand, crude birth rates and total fertility levels, on the whole, remain high, and have associated impacts on the health of women. (ibid.)

Health development cannot, however, be judged only on the basis of simple statistical measurements. They are very useful as general indicators; but such indicators need to be both contextualised and often disaggregated in order to give a more accurate representation of health status across different groups. An indicator such as IMR (deaths in the first year of life) is generally acknowledged to be a sensitive indicator of health status, focusing as it does on a sector of the population that is particularly vulnerable to health risks. Yet even this indicator can be further disaggregated by sex

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[20] It is important to acknowledge the continuing debate on the extent of the impacts of SAPs on health outcomes. In a review of the literature carried out by Breman and Shelton (2001), regional differences were found, with Africa more commonly cited in empirical examples of deteriorating health expenditure and outcomes, but with mixed findings – both positive and negative – characterising the Latin American and Middle Eastern regions.

[21] The Demographic and Health Survey of 2000 revealed that Malawi's MMR is now 1,120/100,000 live births – one of the worst in the world.

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or by specific cause of death, to further identify who is facing the greatest risks and from what. On the other hand, the crude death rate is arguably less informative as an indicator, as it looks at total deaths across the population without reflecting age or sex differences, and it may be influenced by the proportion of the population in these different groups.

The past misrepresentation of the health status of many African countries, based on a narrow interpretation of available indicators, has been described as "Africa's superficial epidemiological transition" (Kalipeni and Thiuri 1997). In standard epidemiology, the dominant model for viewing changes and patterns in health over time is 'the epidemiological transition,' a term used by Omran (1971) to illustrate the shift from a population characterised by infectious disease, to one characterised by chronic diseases (Phillips and Verhasselt 1994; Moon and Gillespie 1995). It seems ironic that it is now widely agreed that the 'epidemiological transition' in the developed world — while rightly criticised for being an over-simplistic linear model — was brought about through sanitary reform and associated improvements in living conditions between 1850 and 1950, rather than as a result of biomedical curative medicines (McKeown 1979), which came in a later phase. On the other hand, Kalipeni and Thiuri highlight how this evidence has been bypassed and attack the post-colonial emphasis in Africa on a multi-tiered system of health care provision, emphasising the urban, curative and drug-dependent Northern model, ignoring the subsequent uneven health development and failing to address issues of politics, poverty and power; communication, culture and control.[22] As will be reviewed in the following section, recent attention to reform of the health sector is regarded by some as a way to overcome this narrow historical focus.

2.3 HEALTH, THE STATE AND SECTOR REFORMS

As there was increasing recognition in the 1970s that the growth-dominated development paradigm was having little impact in terms of 'trickle-down' effect, focus began to shift towards social and community targeted interventions, aimed at

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[22] "Poverty manifests itself in many forms impacting on health, including poor housing, environmental sanitation and water supply, uncontrolled vector occurrence, unemployment and underemployment, low education achievement, high morbidity and mortality and poor access to health services....In the absence of adequate health services, economic factors, education and government infrastructure become the major determinants of health status." (Kloos, in Phillips and Verhasselt, 1994: 200)

creating a minimum standard of living for all. Whether from a neo-liberal perspective, rooted in continuing ideas of 'growth' and the view of an unhealthy workforce as an unproductive one, or the opposing standpoint of 'basic needs' and rights, as put forward by the International Labour Organisation (ILO), levels of health became a focus for much greater concern.

The Alma-Ata Declaration of 1978 built upon the themes of 'basic needs' and resulted in endorsement of Primary Health Care (PHC) as the way of achieving the WHO goal of Health for All by the year 2000. While Alma-Ata related specifically to PHC, it is significant in having had much broader and more political implications for general health care and provision, espousing as it does, a very particular philosophy and approach (adapted from Green 1992):

- The importance of equity
- The need for community participation
- The need for a multi-sectoral approach to health problems
- The advocation of use of appropriate technology
- An emphasis on health promotional activities

The fact that the Alma Ata declaration was accepted and celebrated by many in the health and social development fields belies the tensions that still existed in the policy-making arena. The notion of 'basic needs' itself came under criticism, not only from the orthodox free-market economists and IFIs, whose faith lay in rolling back the state rather than increasing its public service responsibilities, but also from those who felt that the concept of 'needs' was an outside imposition, based on an assumed and artificial 'Western' concept (Ferguson 1990; Illich 1992).[23]

In spite of such arguments about the definition and implications of terms, and owing to the priority given to such ideas in applied development, if we accept the prevailing

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[23] Illich attacks the use of notions such as 'needs' as an "insidious legacy left behind by development" (1992: 118). His view is that of a "traditional poverty," where an individual could always rely on a "cultural hammock," even in extreme circumstances, but which has been destroyed by development intervention, which lifts people out of their "traditional cultural commons." While it is possible to see intellectual value in what he is saying as a critique of 'basic needs,' his view that people would be living necessarily better lives on an apparently untouched and pure "cultural bedrock of poverty" appears as guilty of the naivety and 'masked compassion' that he accuses all 'needs-led' development efforts of.

notions of both increasing 'demand' and 'need,' questions might then be asked about whose role or responsibility it is to provide, in this case, health services. In today's development locations, the need to recognize and involve actors at all levels, i.e., state, market and civil society, is largely accepted (Walt 1994). However, much discussion continues as to the appropriate role for each of these in both financing and delivering health care (The World Bank 2003). In addition, the role of donors as a significant actor cannot be ignored (Cassels 1995).

Accepting in principle the notion of 'basic needs' or capabilities, it may be argued that health is both a basic right and additionally a global public good,[24] and that, despite the increasing role of economic players and global forces of capital in determining health policy and provision, the role of the state remains a significant one. Others counter this with a view of health as a commodity, and thus, health care as a privilege to be paid for, rather than a right to be expected (Turshen 1999). The focus is then on the economic value of a given service, and the appropriate deliverer of that service: private or public (Sen and Koivusalo 1998).[25]

In sub-Saharan Africa today, with international development assistance and financial aid contributing significant proportions of many nations' GDPs,[26] the question is not *only* over the role of the state or the market, but also over the role of donors and aid in determining policies relating to this. The World Bank began direct lending for health in 1980, and their increasing financial contribution from that time, supported in 1987 by the *Policy Study on Financing Health Services in Developing Countries* (The

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[24] In economic terms, public goods are those commodities which generate non-rivalrous consumption, which are non-excludable and non-rejectable (Bannock, Baxter et al. 1998). In health terms, depending on application, this may translate into those public health interventions which have 'positive externalities,' i.e., immunising a child will bring wider disease prevention benefits to the population, or, applied to health as a whole, there are population-based benefits to social and economic development of public health.

[25] This debate has not been restricted to the developing world, but has been informed by changes taking place in the North as well. The UK's own recent history has seen significant reform of the National Health Service (NHS) over the period from 1979. Rising costs and inefficiency were cited as one of the reasons contributing to the need for reform. However, while the Royal Commission set up under the Labour government of 1974 had identified the need for organizational change within the NHS, it had concluded that an open-access and free service, which made little use of market mechanisms was in fact better at containing costs than a more market-oriented system (Moon and Gillespie 1995).

[26] In 2002, net aid received in Malawi was 19.8 per cent of the country's GDP. For neighbouring Mozambique this figure was 57.2 percent; for Zambia 17.3 per cent and Tanzania 13.1 per cent of GDP.

World Bank 1987), indicated their interest in promoting a distinct policy position in health.

This position initially focused on reformed financing mechanisms, deriving from a belief that problems in the health sector were rooted in the inappropriate allocation of expenditure, the internal inefficiency of public health programs and inequity in the distribution of health service benefits (ibid: 3). This approach in turn was rooted in a conviction that prevailing economic circumstances of slow growth and increasing debt "make it difficult to argue for more public spending." The solution proposed was therefore to "reduce government responsibility for paying for the kinds of health services that provide few benefits to society as a whole" (ibid: 1), with a classification of goods and services into either 'public' or 'private.' Private goods are those whose benefit is received by the individual who consumes that service, and public goods, as already noted, are those whose benefits extend to all members of society (an example being treatment for a headache as opposed to immunization of children). The further assumption underlying this classification is that people are willing to pay for services with mainly private benefits, but are unlikely or unwilling to pay for those that benefit the community as a whole.[27]

The four policy reforms advocated as means to alleviate inherent health sector problems were the introduction of user fees, the promotion of insurance schemes, the increased use of *non*-government resources for health, and decentralization of government health services (ibid.). This package was at the heart of what is widely termed health sector reform (HSR). While HSR has been broadened beyond financing reforms to also encompass objectives of improved access to care and institutional reform, one of the central notions is that of reformed financing and a 'managed market' approach. The managed market approach is based on the view of traditional public sector bureaucracies as inefficient, but also recognises that markets alone will not provide for all health systems objectives. The role of the state is thus to regulate both public and private markets for care, with responsibility determined according to perceived 'public' and 'private' goods and services (Cassels 1995).

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[27] It is interesting to note that this classification only notes what is termed in economics consumer 'willingness' to pay, but makes no explicit observation of consumer 'ability' to pay.

The *1993 World Development Report 'Investing in Health'* (The World Bank 1993),
had an even more significant impact on donor and development policies for health,
putting so-called health reforms centre stage and promoting a distinct formula for
health policy in developing countries. The three principles outlined in the report were
to: foster an environment that enables households to improve health; increase
government spending on health; and promote diversity and competition (ibid.). This
not only builds upon the basic package of financial reforms, but combines an analysis
of health sector problems with a focus on understanding global and regional burdens
of disease and the cost-effectiveness of different interventions, resulting in analyses of
"health gain per dollar spent" (Cassels 1995).

While the prioritisation of health and many of the principles on which reforms were
based have been welcomed, there continue to be contradictions that many find
troubling (Loewenson 1993; Turshen 1999). The World Bank has now assumed the
role of the biggest player in world health, in terms of dollars spent – or rather, lent –
yet its prescription of economic adjustment and health reform policies, which
encourage marketisation of health through increased competition and a reduced role
for the state in provision, are seen by some as contradictory in their health outcomes
(Lurie, Hintzen et al. 1995). On the whole, such policies have had an explicit aim to
reduce public spending on health and other social services and have encouraged
diversification of financial sources, including 'cost-sharing' via user fees, yet this has
been shown to reduce utilization by the poorest and most vulnerable groups (Gilson
1997).[28]

In the United States of America, where health service provision is indeed based upon
a private market-oriented system, the extreme costs of this system to all involved –
user and provider – not to mention the inequities within it, would also appear to

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[28] It should be noted that the most recent position by the World Bank takes account of evidence of the
negative impact of user fees on access, and so, is one which "does not support user fees for primary
education and basic health services for poor people" (World Bank Issue Brief, August 2003). It also
"discourages user fees" for programmes such as immunisation, TB and malaria, which have large
public good implications. However, "in very low-income communities where the government's
resources are extremely limited, well-designed and implemented user fees can mobilize additional
resources from better-off groups that can in turn be used to improve services for poorer groups. Such
cost-sharing schemes can play a critical role in helping ensure essential services are available." This
position does not acknowledge the significant costs and challenges in targeting, identifying and
exempting the poorest from paying fees, and in reimbursing facilities for services provided to those
exempted (Kivumbi and Kintu 2002; Ridde 2003; Jacobs and Price 2004; Palmer, Mueller et al. 2004).

challenge the arguments in favour of a private market system for health care. As Polleys-Bunch (2002) is exploring in ongoing research,[29] the ideological debate on health as a right or a privilege, and healthcare as a public good or private one, is also expressed in either 'protective' orientations towards a population – where healthcare as a means to improve peoples' health is valued and prioritized regardless of economic costs to the provider – or 'exploitive' ones, where health care is a profit-producing commodity used to exploit peoples' resources, regardless of the health consequences to that population.

While such a categorizing framework can be flawed for its reductionism, the ethnographic evidence Polleys Bunch uses from differing health care settings in the USA clearly illustrate the costs of their prevailing market system, particularly to the user, and particularly to the poorest and most vulnerable within – or indeed excluded from – that system.[30]

This debate is not merely ideological, but economic. Cassels notes criticism made of the "uncritical promotion of market mechanisms by international agencies and the export of models from particular countries such as the UK" (Collins et al 1994, cited in Cassels 1995). While under the 'managed market' approach, whether a particular good or service is considered 'public' or 'private' identifies where responsibility for provision should lie, classification of goods into these categories is not a clear-cut procedure and areas such as communicable disease or vaccination are termed 'mixed' in their benefits by the World Bank (The World Bank 1987),[31] leading to mixed practices in financing, delivery and outcomes.

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[29] "Protective and Exploitive Value Orientations – Determinants of the Organisation and Delivery of Health Care Systems," S D Polleys-Bunch, paper presented at the Anthropology of Health and Populations conference, Brunel University, June 20-22, 2002.

[30] In 2002, 43.6 million people in the USA (or over 15 per cent of the population) did not have *any* health insurance. This includes 28 per cent of all young people aged 18-24 years, and 31 per cent of the poor ('Facts on Health Insurance Coverage,' National Coalition on Healthcare, 2004).

[31] Amartya Sen, in a recent interview for WHO (Mach 2002) describes markets as being particularly efficient for certain types of production, but not very good for others, particularly medicine. There are two reasons: "Many of the results of medical care have the feature of being what economists call 'public good' which affects not only the wellbeing of that person but also of others, for example with infectious diseases which are contagious to others. In dealing with public goods, markets are notoriously defective. Second, the pattern of risk in medicine makes the market less efficient because...it's always in the interest of private insurance to try and get out of covering those who are most likely to need medical care. But these are people for whom medical care is most important."

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It is timely that the debate on health spending and delivery has been furthered on the global stage by the WHO Commission on Macroeconomics and Health, and the subsequent report of their assessment of the place of health in global economic development (WHO 2001). The report stresses the link between poor health and poverty and argues that investment in health is fundamental to any hope of economic development. As this chapter has described, this association between health and development is not a new observation. However, the Commission has been notable in firmly supporting a role for governments and public spending on health at a time when health sector reforms frequently lead to a reduced role and spending on the part of the state. The panel was notable for the high percentage of economists and financial experts as members, rather than a technical health weighting, thereby giving greater economic "credibility" to its conclusions that investment in health is essential for economic growth (Smith 2002).

While the Commission's findings are widely regarded as deserving of support and action (Morrow 2002), their research raises issues of importance for health providers and policy makers about how to effectively approach not only the challenge of raising funds to increase health spending, but again about whose role it is to provide those funds and how they can be allocated effectively to ensure that the poorest, most vulnerable households benefit. The Macroeconomic Commission may be right in arguing for a massive increase in what is spent, but others remind us that in addition to *how much,* perhaps as important is *how* this is spent (Filmer and Pritchett 1997; UNDP 1999; Lanjouw, Pradhan et al. 2001) and *who* benefits as a result.[32]

In the light of this, some view as encouraging the argument in the World Bank's most recent key publication, the *World Development Report 2004, Making Services Work for Poor People*, that affordable access to services remains low. The report affirms public responsibility for improving health and education. However, critics point to the distinction made between 'public responsibility' and 'public provision,' and note the differences among financing, regulation and information dissemination: 'Social equity

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[32] In the World Development Report 2000/2001 (World Bank 2001), a study of public financing for health in developing and transition economies demonstrated that more of the government spending for health went to serving the richest 20 per cent of the population than to serving the poorest 20 per cent.

and fundamental human rights suggest a responsibility for government but leave open the *ways of discharging that responsibility'* (The World Bank 2003 - italics added).

Jack (2001) reflects on this in the context of TB control. His writings suggest that currently, private markets fall short of adequate provision and the public sector has been too resource-constrained to effectively address TB. Yet, such public intervention is essential, given the public health implications of TB, and the difficulties faced by suspects[33] in seeking care and patients in maintaining their therapy. While it is a specific illness, which might therefore be regarded as a 'private good,' it has clear public implications via the issue of contagion and therefore may be regarded as a 'public good.' He takes this further in raising the link with poverty, and arguing that it would be both efficient and equitable to expand public TB control services, as a redistributive measure that would directly affect the poor: "TB is a disease of the poor and public intervention in its detection and treatment could represent an effective part of an anti-poverty approach to development" (Jack 2001: 80).

In the current reform climate, this is a relatively rare voice – despite evidence that, in practice so far, implementation of a public/private mix has been patchy and the capacity of states has often not been enhanced through such a process. Mackintosh (in Walt and Leon 2001) argues that, rather than addressing inequalities, health systems reinforced by the reform process reproduce existing differences. Social inequality in terms of unequal *access* to care, unequal *claims* to care and unequal *experiences* of it, become further entrenched, particularly with the development of a two-tier privatized middle class market and a public system for the poor. In implementing system reforms, there has been a failure to consider the legitimate claims of all, or to consider how to encourage awareness of health entitlements and negotiation of those rights through people's engagement with the reform and planning process (Mackintosh 2001). Private provision has instead been celebrated as providing consumer choice, and therefore being equitable (Bloom and Standing 1999). However, evidence suggests that, in developing world contexts where extreme socioeconomic inequities already exist, the market tends to be *supplier*, rather than

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[33] Suspects here refers to TB suspects, or those with symptoms suggestive of TB (e.g., chronic cough) that may prompt care-seeking behaviour.

consumer-led. The role of the state as regulator, public health administrator and sanitation provider has been reduced, and issues of public participation, quality control and sustainable technologies have been forgotten. In addition, with the donor community's acceptance of the World Bank's push for reforms, power in the policy-making arena can arguably be said to have shifted from the national to international level, with the state's role being even further reduced and participation from other actors further marginalised.

Those that support moves to reform the health sector, including most multilateral and bilateral donors, would argue that where both previous extreme paradigms of predominantly state-led development *and* predominantly market-led development have failed, health reform tries to address that failure with a public/private mix. Prevailing theory proposes that the role for the state is slowly re-emerging, with capacity being built at national level to direct reform and act as regulator and purchaser. However, what this translates to in practice depends on how health and the breakdown of healthcare into varied commodities, public or private, is handled by a particular nation – or often the more influential international bodies (N. Druce, Institute for Health Sector Development, personal communication, October 2000).

Despite the original goals and initial achievements of Alma Ata, therefore, twenty five years later health care and services in both the developed and developing world are still facing significant challenges and are having to deal with similar issues of pluralised provision, regulation of standards and practice, distribution of services and, critically, financing and health sector reform. In the context of sub-Saharan Africa, where a multi-tiered and inequitable distributive pattern of provision has been largely the result of earlier colonial administrations (Phillips and Verhasselt 1994), often reinforced by post-independence governments, health planners are confronting complex problems. Malawi is no exception to this.

Although evidence to date suggests sometimes disappointing results, with rising mortality rates, reduced utilization of services, and lack of attention to preventive health measures,[34] health reform has been widely embraced by most donors and aid

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[34] For example, Zimbabwe, Zambia and Mozambique (Turshen 1999, and see also Pillay 2001).

agencies and the World Bank has supplanted WHO as the main international agency for health[35]. Therefore, in line with health reforms taking place throughout much of sub-Saharan Africa, the government of Malawi is currently elaborating a range of reform options.

As a donor-dependent nation attuned to the shifts in health policy thinking at the international level, Malawi pays a significant amount of attention to financing issues. The Malawian Government's own criticism of the present circumstances is that there is too much of a "big brother approach" (MOHP 1999: 134), with the Ministry of Health and Population itself assuming that role, in financing, policy formation and implementing collaboration among different providers. The state provides the health training for all health workers in Malawi. Even when its own services – currently still provided for free – have been in financial trouble, it has continued to provide assistance to the private mission sector. This is a situation regarded by many in the government as 'unfair,' and this view is echoed, or perhaps encouraged, by those in the international community who are in favour of ambitious health reforms, and who have the weight of their aid behind them, enabling their views to be taken seriously. However, the reform package also includes attention to institutional and organisational reform: changes currently being planned include decentralisation of administration and budgeting to the district level; consideration and possible introduction of user fees;[36] design and implementation of an 'essential healthcare package'; and the adoption of a sector-wide approach (SWAp) to facilitate both full integration of services provided and basket funding of those services, rather than the vertical programme system still being used.

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[35] World Bank loans to population, health and nutrition projects totalled nearly US$6.7 billion between 1986 and 1993 (World Bank Annual Report 1993) and currently total a cumulative $13.5 billion (2005).

[36] As already noted, the issue of fees for services is a potential minefield (Forsberg 1993, Gilson 1988, Mbugua 1993, Mc Pake et al 1993). While Bennett and Ngalande-Banda (1994) take a fairly conservative view of user fees having the potential to raise revenue and improve efficiency, it would be prudent to note the warnings that have drawn attention to the issues of distribution of existing facilities, effective means-based systems of 'exclusion,' safety net mechanisms, equity of access to patients from differing social groups and public perception of service quality. Evidence suggests that without a perceived improvement in quality of services and an effective and manageable system of subsidizing the poorest groups, the introduction of user fees in the public sector results in reduction in user numbers and increased marginalisation of vulnerable groups (Gilson 1997; Gilson, Kalyalya et al. 2001). Therefore, rather than implementing health reform factors such as user fees in isolation – if at all – there is a considerable argument for review of the evidence, as now acknowledged by the World Bank (see footnote 29).

Given that the National TB Programme is one of those vertical programmes likely to be affected by these plans, the development of health sector reform in Malawi is topical, challenging and will be explored in detail in Chapter 5.

2.4 BIOMEDICINE, HEALTH AND SOCIETY

One of the factors underlying the competing approaches towards the organisation of health systems and responsibilities for health care provision and financing is the longstanding tension between biomedical and social analytical approaches to health – sometimes represented as the opposition between 'cure' and 'care.' In looking more closely at the general relationships among medicine, health and society, critiques have been emerging over the past fifty years or so of an over reliance on biomedicine and medical intervention and a lack of attention to other, highly relevant contextual factors.

Rene Dubos, a microbiologist, was one of the first to challenge the increasing dominance of curative, interventionist approaches. His writings, based on a historical analysis of approaches to health over time, advocate a holistic approach to healthcare, recognizing that curative, disease-focused intervention alone is not the only approach, and that a full, contextualised understanding of people and their current environment is also necessary. The conditions under which individuals – and therefore their diseases – are living will also influence the path of those diseases, and their individual response. His work cites and indeed echoes the long-held opposition between 'cure' and 'care,' symbolized in the Greek goddesses Hygeia and Panacaea. Hygeia was the guardian of health through healthy living, and Panacaea was the healer, through her knowledge and application of plants; one symbolizing the preventive and environmental aspects of medicine and the other the curative intervention of disease-oriented medicine (Macdonald 1998). Dubos suggests that, as approaches to healthcare have developed over time, they have swung between these two points of view, maintaining such an opposition. More recently however, intervention has taken the dominant role.

Dubos soon turned his attention to TB, with his co-authored work 'The White Plague' (Dubos and Dubos 1952 (1992 reprint)). Developing his arguments in a historical analysis of TB from the nineteenth century, he and his wife state that TB's

development was closely linked to industrialization and associated urbanization, and that its subsequent decline in Britain and North America in the twentieth century was as a result of improved living conditions and socioeconomic development rather than the progress of medical techniques.

These ideas were taken further by McKeown in his work on *'The Role of Medicine'* (1979). He argues that the impact of medical intervention on the health of populations has been exaggerated, leading to over-investment in medical science and lack of attention to the role of social development and change. While his ideas have themselves been criticised on the grounds of an over-reliance on the agency of the individual – through individual lifestyle choices – and a Luddite stance that could actually help maintain the current inequitable distribution of both disease and access to health care (Farmer 1999), his views have been influential in demanding acknowledgement of the role of social change and improved living conditions on infectious diseases. As one of his main examples, he cites tuberculosis, where the industrialised countries achieved a 90 per cent reduction in mortality from TB through improvements in income, nutrition and living conditions (McKeown 1979). This was achieved *prior* to the arrival of specific antibiotic treatment for the disease in the 1940s.

John Grange, writing about TB half a century after Dubos first put forward his arguments, states, "Tragically though, the disease is still so prevalent that, in 1993, 111 years after the causative organism was identified and half a century after the introduction of effective therapy, the World Health Organisation (WHO) deemed it necessary to take the unprecedented step of declaring it a Global Emergency" (Porter and Grange 1999). Given this statement, it would seem that both Dubos' and McKeown's arguments not to rely on medical techniques of control alone, but to investigate all the human, socioeconomic and environmental factors, have not necessarily been heeded (Doyal 1979).

It is, perhaps, an even starker illustration of the inequities present in society and across the world that a disease for which there *is* a cure is still such a threat to so many lives. The evidence is seen in the available data: looking at where TB has 're-emerged' in the industrialized North and amongst which communities (homeless

people and prisons); and looking at where TB endures and worsens throughout the world (poor developing countries), the pattern is one of a disease affecting poor and marginalized people, whether in the rich developed world or the developing world: "TB could thus be regarded as a symptom of poverty, visualized by the unequal distribution of both factors in the world" (Diwan, Thorson et al. 1998:11).

For some writers, this scenario is not a surprise, but rather the inevitable effect of economic and political forces, driven by global capitalism and resulting in uneven distributions of wealth and power throughout society (Navarro 1976; Whitehead 1988; Packard 1989; Falola and Ityavyar 1992; Farmer 1998; Farmer 1999; Kim, Millen et al. 2000; Mackintosh 2001). From this perspective, it would be impossible to examine health, medicine and TB without placing them in this wider political economic context, and to recognize the implications of economies dominated by capitalism, where health systems reflect the needs of capital and class (Doyal 1979). The principal role of biomedicine is therefore to enable a healthy productive workforce, working in support of the needs of capitalism – a fact noted by Sender and Smith (1986), in looking at the issue of labour in Africa.

Under such a vision, those most vulnerable to the health-damaging factors built into the capitalist productive system (i.e., through shifts, overtime, industrial injury, poor environment, etc), are those in the lower social classes who make up the workforce (Navarro 1976). Only when capitalist class interests and those of the workforce converge (i.e., in maintaining a healthy workforce to maintain production) is access to medicine and healthcare enabled for these most vulnerable.

This is illustrated clearly in Packard's historical analysis of TB in South Africa (1989), where he argues that a reliance on medical technology actually deflected efforts to address the underlying causes of ill health and TB in apartheid South Africa. Writing about that country's TB Research Institute, he states that "…they have rather chosen to place their faith in the ability of medical science to solve health problems in the face of adverse social and economic conditions". This was not only owing to the apartheid policy and related poverty, but was specifically linked to greater political and economic transformations taking place with the rise of industrial capitalism.

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Packard notes that, in contrast to the industrialization process in Europe, which saw increased urbanization as workers moved to settle near their places of work and the development of TB in those urban centers, in South Africa, those in control of the mining industry encouraged *seasonal* migration in search of work, with workers maintaining their rural base. This saved the mining companies pension and health care costs, but contributed to a worsening health situation, with the hasty spread of TB from the urban epidemic areas out to the rural reserves.

As an uneasy alliance among poorer white workers, the state and the mine owners emerged, the racial divide and rule policy led to a worsening situation for African workers, with little chance for class, capital and labour interests to converge. It took until the 1930s, in the pre-World War Two era, for the white middle class, now fearing for their own health and recognizing the borderless nature of disease, to push for reforms. However, these reforms resulted in the Slum Clearance Act of 1934, ghettoizing people and disease, but removing the proximity of risk for the white population. Unsurprisingly, health worsened and TB devastated both the urban *and* rural black settlements.

As these areas increasingly became "reservoirs of disease and infection," the result was "no healthy labour supply" to the mines (ibid: 318). Finally, both state and industrialists were forced to recognize the need for improved living and working conditions. With different agendas, but the same desired outcome, the need for health and welfare for the workforce was finally acknowledged.

Greater political and economic forces continued, however, to map out the insubstantial nature of the resulting changes, leading to disease control based on segregation, and supported by medical intervention. Any attention to broader reform, or the need for social and economic change across populations, was therefore deflected (Packard 1989).

Such a political economic analysis can also be seen clearly in the worsening HIV/AIDS epidemic – closely linked to and partially fuelling today's TB situation – across Sub-Saharan Africa. Globally, the portrayal of HIV/AIDS in Africa has been as though the continent were the world's homogenous reservoir of infection. Sexual

and racial stereotypes have translated into political justification for policies and funding decisions, which restrict rights and access to resources (Seidel and Vidal 1997). An oversimplified early construction of the virus as a tropical disease, combined with an epidemiological focus on risk groups, has contributed to funding priorities biased in favour of medically defined priorities in the wealthier North, rather than on the needs of diverse Africans dealing with the effects of AIDS.

Even signs of hope, such as the relatively recent decision by the South African gold-mining giant Anglo Gold to provide anti-retroviral therapy (ARV) to its HIV-positive workers, are based purely on the convergence of the economic interests of the owners, with the health needs of their workers (Marks 2003). The attrition rate of staff through AIDS-related death and illness, and the stark projections of continuing attrition, can easily be regarded primarily as productivity lost. Anglo Gold, in its cost-benefit analyses, has thus calculated that it will be cheaper in the long run to provide therapy to its staff, interrupting and ameliorating the patterns of sickness and death, rather than continuing its recent approach of further recruitment and training. This clearly illustrates that any changing patterns of health and sickness are tied to the development of specific political and economic interests prevailing at local, national and international levels (Packard 1989). While welcome, it may be argued that the South African government's recent (yet overdue) announcement to introduce ARV therapy into the public health system (early August 2003) has been promulgated by similar figures of attrition and the related impact on the country's current and projected productivity and growth.

But what of current approaches to TB and TB control? As the historical analyses and critiques have shown, the swing more recently has been toward biomedical intervention and the desire for 'cure' rather than 'care.' Even with Dubos, McKeown and Packard over time identifying the limitations to such a single disciplinary approach, change has been both piecemeal and slow.

At the time of starting this thesis, the available literature showed some authors calling for a multi-disciplinary approach to TB control. Rubel and Garro (1992) make a strong call for socio-cultural factors to be considered in TB-related programmes and interventions. They emphasise that knowledge of the 'health culture' of patients is

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necessary if TB programmes are to be successful, and call for the use of social scientific methods to assess people's own knowledge and understanding of their symptoms/the disease, and how this knowledge is used at the health-seeking stage. Vecchiato (1997) supports this call, in looking at TB conceptualisation and management in a rural southern Ethiopian community. Acknowledging that a local model of TB is not something which will be explicit and bounded, he nevertheless recognises the value in trying to understand any *shared* knowledge structures and beliefs about symptoms, aetiology, treatment and prevention, and how these may influence therapeutic decision making. In addition to this however, he notes the role of the wider socioeconomic arena, through which any decision or action is mediated.

More analysts (Farmer 1997; Liefooghe, Baliddawa et al. 1997; Ogden, Rangan et al. 1999; Porter and Grange 1999) have all contributed to the broadening of this debate. Most notably perhaps, Farmer warns against the reification of such cultural factors to the exclusion of any others, thereby returning to the same narrow-minded focus on just one single perspective, for which biomedicine was criticised in the first place – a "conflation of structural violence[37] and cultural difference" (Farmer 1999: 9). Farmer tries to balance this out through a political economic approach informed by anthropology, illustrating the large-scale sociopolitical forces and structural violence at work. While the introduction of a social scientific or anthropological viewpoint is a welcome one, the *over*-emphasis on culture as the sole determining factor in peoples' health-related decisions and behaviour leads to an exaggeration of patient agency and the likelihood of 'victim blaming.' In this way, the role of poverty and surrounding structural factors are minimised, as is that of the health provider and health system. As Xu et al.(2004) have found in China, the costs of care-seeking – even when subsidised – may remain prohibitive to those groups most vulnerable to TB in the first place: the poor, the elderly – those that have little cash income. Socioeconomic status of the patient was identified by Xu as the main factor influencing care seeking for TB.

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[37] The term 'structural violence' was one originally used by Latin American Liberation Theologists to assert that the social inequalities which affect people's chances in life are structured along lines of race, gender, poverty, etc. Structural violence is exerted systematically through such structures, both directly and indirectly by those in positions of power and those who benefit most from the inegalitarian social order. This can be seen in the way in which mortality is structured by class, with outcome gaps in terms of who is dying/being affected/infected by, e.g., TB, HIV. "The distribution of both TB and HIV is sculpted by structural violence" (Farmer, Plenary address to the Conference on the Anthropology of Health and Populations, Brunel University, June 2002).

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Without acknowledging such realities, anthropology and sociology, which may have set out with valuable intentions to provide information about the socio-cultural environment, may be used by the medical establishment to support and reinforce an individualistic approach to disease control, rather than as one contributing element to an inter-disciplinary and holistic approach to healthcare.[38]

Both Liefooghe, Baliddawa et al (1997) and Ogden et al (1999) enlarge on this, advocating an approach that emphasises co-operation among disciplines, acknowledging the role of human behaviour, *in addition* to the social processes and environmental structures that both enable and hinder peoples' choices and access to care. Rather than victim blaming, attention should also be directed to the health settings and providers and "treatment failures" rather than "patient failures" (Ogden et al 1999: 858). Ogden proposes that a balance should be maintained, leading to a paradigm shift "away from the perceived need to control patients, to providing a health service and a TB programme that supports them to obtain what they and their communities most want: a cure" (ibid: 859).

Paluzzi has illustrated how, prior to the introduction of antibiotic treatment for TB, doctors in Chile worked towards a public health ideal that recognised the need for social reform, in order to address the causes of disease: overcrowded living conditions, malnutrition and poor working conditions (Paluzzi 2004). The then President of Chile is cited, from his own 1939 publication, *The Chilean Medical-Social Reality*: "Tuberculosis, a social disease, must be addressed with a program of social health; that is, a program of health for the masses whose application cannot be left to the individual or family; a program of health that, by remaining aware of the economic inequalities that arise from the very existence of rich and poor, tries to compensate for class differences." (ibid: 763). In this 'golden age' of social medicine, "action against tuberculosis became direct action against poverty" (ibid: 767) with advocates arguing for increased wages for the working classes, regulated working conditions, safe and affordable housing and clean public spaces. However, with the

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[38] This problematic use of anthropology is also illustrated in Seidel and Vidal's (1997) work on HIV/AIDS, where they explore the influence of the 'culturalist' discourse on HIV/AIDS policy, and highlight the tendency towards extreme relativism, where 'culture' is seen as a range of fixed, exotic practices, through which the failures of any intervention may be explained, and the exotic 'other' blamed as the obstacle to change and disease control (Seidel and Vidal 1997).

introduction of pharmaceutical agents in the 1940s, further strengthening the development of biomedicine, the discourse on TB became increasingly medicalised and defined by antibiotic treatment. Paluzzi ties this to the development of an individualised model of risk and accompanying stigma and stereotypes associated with TB. Critically, while poverty is often spoken of as a risk factor for the disease, TB control continues to focus on the individual and the biomedical cure, rather than the socioeconomic inequalities that encourage the disease and limit the ability of those suffering to obtain care.

As this literature suggests, there is a need to challenge the prevailing biomedical model with an approach that recognises the importance of culture and the need to allow peoples' voices and aspirations to be articulated (Appadurai 2004), while also seeking to investigate the broader social, economic and political forces at work, and how they promote or retard the development of TB (Farmer 1997). Farmer (1999) quotes Rudolph LK Virchow (1849), who, a hundred and fifty years ago, wrote "…if medicine is really to accomplish its great task, it must intervene in political and social life. It must point out the hindrances that impede the normal social functioning of vital processes, and effect their removal." For him, doctors were "the natural attorneys of the poor." Today, however, while this is still a relevant and worthy aim, it is one little realized.

One critical aspect which emphasizes the value of an inter-disciplinary approach to disease control is that of gender analysis. Until recently, a gendered approach to understanding health problems was a rarity. Even now, the literature on gender and infectious disease is relatively limited (Sen, George et al. 2002), although within broader development and health practice, gender has been receiving increasing attention (Crehan 1997; Visvanathan, Duggan et al. 1997; Standing 1999; Kulmala, Vaahtera et al. 2000; Warren and Hackney 2000; Quisumbing 2003). Since the strengthening of the women's movement in the 1970s, and recognition that women had largely been marginalized in the development process, various approaches to empowering and integrating women into development activities have followed.[39]

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[39] These are typically broken down into three phases: WID – women in development; WAD – women and development; and GAD – gender and development. WID attempted to bring women's issues into focus in development, primarily through targeted initiatives, to enable women to access the benefits of

More recent thinking is that the 'gender and development' (GAD) principle, which recognises not only women alone, but the relations between men and women, is the most valuable approach. Rather than further marginalizing women as a 'specialist' group, GAD advocates for the 'mainstreaming' of both womens' and mens' interests into all aspects of work, through a strategy of balancing the needs of both men and women throughout all development policy, planning and implementation.

Gender as a term has often been misinterpreted. It refers "not only to physiological differences between the sexes, but also the wide variety of behaviours, expectations and roles attributed by cultures and societies to women and men" (Hudelson 1996). Put simply, *gender* as a concept, in terms of "what it means to be male or female" (UNAIDS 1998) is different from that of *sex*, which refers to an individual's biological characteristics.

In terms of health and society, a gendered perspective is valuable, in understanding not only women's biological reproductive role, but also the cultural roles ascribed to and arising from this. As Vlassof and Manderson (1998) describe it, "The ideology of gender and its institutionalisation within the family underlie conventional notions of the household provision of health as womens' responsibility, and the burden of care that is allotted to women. But, in addition, gender determines women's access to information, health services and treatment; it defines women's domains and their vulnerability to infection, and it structures how men and women interpret and respond to disease."

Of the millions of people living in poverty worldwide, 70 per cent are women (UNDP, Human Development Report 1995) and, for these women, three-quarters of the burden of ill health is from diseases of poverty, of which infectious diseases are a major part (World Bank 1993). Thus, it would seem clear that the health risks posed

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development. WAD claimed that women were already integrated in development and so broadened the focus away from specifically targeting woman, to an approach that tried to address the sources and origins of both womens' and mens' positions in poverty. GAD looks at constructed gender roles in society, including implications for both sexes, with the aim of challenging existing power relations between men and women (Visvanathan, Duggan et al. 1997).

by poverty are much greater for women, than for men.[40] Yet, while such data, even at the aggregate global level, would seem to point to gendered implications for health and disease at all stages, relatively little effort has gone into exploring this issue, beyond the realm of reproductive health (and more recently, by association, HIV/AIDS).

Vlassof and Manderson (1998) set out a framework for approaching gender and infectious disease, drawing on anthropological studies. They highlight gender and prevalence of disease, gender and distribution of disease, gender and determinants of disease, and gender and consequences of disease, thus using familiar epidemiological categories to try and illustrate the utility of a gendered approach to deepening understanding and explain findings within each category. A similar framework is presented by Hartigan et al, in Sen (2002), in which both contributing male/female biological and social influences are identified, and their interaction traced in terms of susceptibility to contracting conditions, and the subsequent response and experience.

To take one example of distribution: worldwide, more men than women are diagnosed with TB and, in many developing countries, cases notified are significantly higher among men than women. In a country-specific case, the ratio of female to male cases notified in Vietnam is 1/1.5 – 2.1 (Long, Johansson et al. 2001). This may indicate that women are simply (biologically) less likely to develop active TB disease than men, and this has been the unquestioned epidemiological assumption. However, if a historical perspective is taken, in Europe and America in the mid 20th century, TB case notification was *higher* in women between 15 and 35 years than in men of the same group. This raises the possibility that cases of TB in women are now being *under-notified* in certain (developing) regions (Holmes, Hausler et al. 1998). This possibility has been further supported by a Nepalese study which, in comparing active and passive case-finding for TB, found higher notification rates for women in the active study group (Uplekar, Rangan et al. 2001).[41]

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[40] According to the IUATLD factsheet on Tuberculosis and Women: "TB accounts for 9 per cent of deaths among women between the ages 15 and 44, compared with war, which accounts for 4 per cent, HIV 3 per cent and heart disease 3 per cent."
[41] In this study, females made up 28 per cent of the passive cases found at a clinic in Nepal, yet with active case-finding, females were 46 per cent of the cases identified.

Using a gender framework to explore this issue, one might examine gender differentials in the risk of infection (i.e., through exposure to tubercle bacilli). Factors likely to increase the risk of exposure include those that favour the persistence of airborne droplets (e.g., poor ventilation, poor lighting) and contact with infectious cases (e.g., occupational contact, overcrowding, caring responsibilities). Overall exposure to such factors varies itself according to gender as well as by ethnicity and socioeconomic status (Hudelson 1996). Another avenue for gender analysis might be in looking at actual use of the health service and care-seeking behaviour for men and women, and the factors affecting this (in decision-making power within the household, in access to household income and resources, in changes in the labour market and (re)productive activities, in differing burdens of care, stigmatisation, etc).

Ogden identifies gender analysis as that which asks *how* and *why* inequity occurs in health (Ogden and Porter 2000). As Smith phrases it in his study of gender issues and TB in Nepal (1994), "Gender of itself is not the cause of morbidity and mortality in TB, but is a powerful indication of disadvantage, a marker of many factors that influence health and the utilisation of health services."

In the Malawian context, the validity of this kind of approach – one which recognizes the broader context of disadvantage – is slowly being recognised, with the 1998 inception of the TB Equity Study to provide social science input to the National TB Control Programme. However, at the time of starting fieldwork, the TB programme was still structured along largely vertical disease control lines, overseen by clinical TB specialists for whom such an approach is unfamiliar, and who are also faced with responding to pressures at both national and international level[42] which do not always allow space and time to develop such new ways of working. The opportunity to observe and analyse the international climate for TB control and its embodiment in a strong national programme where the possibility of innovative change existed was a useful one, particularly during a potentially important period of transition. Despite the calls made by the authors cited in this section – principally anthropologists and other social scientists – systematic investigation of the contexts of poverty where TB

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[42] At national level, policy changes, such as the decentralization of health provision nation-wide, and the challenges in resource-constrained service delivery; at international level, an academic and policy environment organized along the principles of biomedical disease control, rather than a broader engagement with issues of poverty reduction and development.

is found have rarely been undertaken, recorded or deemed important by disease control specialists, owing to prevailing 'terms of recognition' (Appadurai 2004) which privilege the clinical voice above all others.

2.5 DIMENSIONS OF POWER AND KNOWLEDGE: A THEORETICAL FRAMEWORK

Such a lack of systematic investigation has also precluded attention to the influence of power, its relationship to knowledge, and the workings of both in the area of disease control. Ideas about the workings of power in the world, how it is articulated and represented, have been and continue to be widely explored and debated. Current theories involve a broad analysis of dimensions of power, moving beyond the earlier binarily opposed categories of 'power' and 'resistance' to an examination of the mechanisms of power lived as a 'process' and its interrelationship with knowledge,[43] as espoused by Foucault (1975, 1980). However, this recognition of power as 'discourse,' in a more Foucauldian sense is criticised for lack of attention to the structural power constraints, advocated in a more post-Marxist or Gramscian analysis, which influence how people live.[44] Some social theorists have attempted to overcome the opposition between structure and agency, or subjectivism and objectivism – albeit in differing ways (Bourdieu 1977; Bourdieu 1984; Giddens 1984).

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[43] Such theoretical developments have been tied to broader paradigm shifts in social theory from modernity, through structuralism and post-structuralism, to post-modernism. Modernity (and modernism) generally correspond to the development of a 'modern' society, based on notions of legality, property ownership, labour, etc, rather than one based upon religion and customary relations. Post-modernism is said to be a movement against the certainties of modernism, in its search for 'truth' and the accompanying grand theoretical narratives that would explain society and progress. Rather, post-modernism is equated with notions of relativism and pluralism, recognising the diversity of human experience and rejecting the constraints of rationality.

[44] In the 1960s, structuralism was the dominant movement in social thought, originating from the linguistic theories of De Saussure and notions of 'langue' and 'parole' (where *langue* refers to the organising system or structure of language and *parole* refers to the individual speech acts). Such a relationship parallels that of structure and agency, where langue is an underlying ordering principle that is the precondition for any resulting action. Saussurre's ideas, including that of signifier and signified, were reinterpreted into a system of signs that could be applied to all cultural and social forms - in which the relations or differences between otherwise arbitrary labels confers meaning upon them, and where the underlying 'langue' or universal structures subconsciously govern the behaviour and actions of individuals, making up the web of society, structured like language. Structuralism has been criticised for placing too much emphasis on such determining structures, while downplaying the potential for human agency and change. Post-structuralists such as Foucault, Derrida and Lyotard, have tried to get away from the notions of constraint implicit in structuralism, contesting their claimed universality and bringing in the potential for doubt and challenge through more relational interpretations of power and society.

An early conceptual framework of power and knowledge was that of the three dimensions espoused by Lukes (1974), and expanded by Gaventa (1999). The three dimensions start with a traditional binary view of power and resistance, where a relationship of conflict between the power of 'A' over 'B' takes place in an established decision-making arena. Recognising that such a 'rational' vision pays little attention to *whose* knowledge is represented within this process and how that knowledge was credentialised, a second dimension brings in related aspects of power/exclusion and participation. Thus, "empowerment through knowledge means not only challenging expertise with expertise, but it means expanding who participates in the knowledge production process in the first place"[45] (Gaventa and Cornwall 2001: 3). The third dimension, however, builds upon this to further examine the ways in which powerholders, in their production/control of knowledge/information, shape consciousness of the agenda in the first place.

While this framework is a useful one through which to view the complexities of power and its inextricable link with knowledge, it is also limited in its reliance on attributing qualities of 'power *over*' alone (Nelson and Wright 1995). Power is constructed primarily as a resource held by others, which limits one's own capabilities and has to be challenged.

Gramsci's model of hegemony provides a more nuanced version of the traditional 'power over' model, while still building upon a Marxian view of society with an economic base and its cultural/political superstructure. The idea of hegemony stresses the political, cultural and ideological dominance of the ruling class, manifest in structures and mechanisms of power over other subordinate groups. The ruling class extends their dominance throughout all levels of society, and in any encounter or 'struggle' seeks to deny any differences of power (Hoare and Smith 1971; Ransome 1992). What is important to hegemony is the idea that the acceptance of one social group's dominance and control by another is done willingly, through the idea of

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[45] This very much ties in with understandings of power in both Gramscian ideas of hegemony and Freirean ideas of the internalised knowledge of the oppressed. "Countering power involves using and producing knowledge in a way that affects popular consciousness of the issues which affect their lives" (ibid.). Thus, transformation of consciousness is seen as leading to participation and social mobilisation, within the existing arena of the public (i.e., through something like Participatory Action Research).

consent – or the dialectic between consent and coercion: "Dominant groups in society, including fundamentally but not exclusively the ruling class, maintain their dominance by securing the 'spontaneous consent' of subordinate groups, including the working class, through the negotiated construction of a political and ideological consensus which incorporates both dominant and dominated groups" (Strinati 1995: 165).

When the hegemony is weak, the dominant class may use coercion or force to keep control. However, when the hegemony is strong, the dominant ideology is maintained through popular support and consent, as it is perceived by the subordinate classes to be the best scenario possible and one which will serve their interests too: it is seen as 'common sense,' in Gramsci's terms.

While the notion of hegemony has been criticised by some for failing to account for any serious potential for resistance or for the existence of contradictions escaping hegemonic control, the notions of consent and coercion point to the fact that hegemony is being constantly renegotiated through a process of struggle. As Fiske (1992: 291) puts it, "Consent must be constantly won and rewon, for people's material social experience constantly reminds them of the disadvantages of subordination and thus poses a threat to the dominant class... Hegemony... posits a constant contradiction between ideology and the social experience of the subordinate that makes this interface into an inevitable site of ideological struggle." Williams, too, argues that hegemony is never totally absolute, but is a dynamic and lived process, in which the dominant social order may not be infallible in its drive for control (Williams 1977).

Looking to Foucault (1976, 1980; also Eagleton 1991), power can also be seen as an even more diffuse force, distributed in a network of specific contexts of exercise. Rather than being a resource that individuals hold, hide or attempt to gain, it is a force formed within the texture of everyday lived experience – "a multiplicity of force relations" (1979:92). Not only coercive, but also productive, relational and *enabling*: "...individuals... are always in the position of simultaneously undergoing and exercising this power. They are not only its inert or consenting target; they are always also the elements of its articulation... the vehicles of power, not its points of application." (Foucault 1980: 98).

Thus, while Foucault has been interpreted by some as being overtly negative in his illustration of the effects of knowledge/power subjugating individuals through self-policing 'regimes of truth,' in some aspects, it may be argued that he actually opens the way to action and resistance, in arguing that where there is power, there inevitably is resistance: "These points of resistance play the role of adversary, target, support or handle in power relations. They are present everywhere in the power network" (Foucault, 1976:95). While his writings have been criticised for failing to fully illustrate such resistance[46] (Fiske 1993; Lupton 1997; Eagleton 1991; O'Hanlon and Washbrook 1992), his ideas allow discussion and exploration of whether particular circumstances can be more or less amenable than others to acts of resistance. However, as Cheater (1999) observes with respect to post-modern theories of power in general, "Conceptualising power as post-modern, warm-fuzzy, expansible not only conceals its hard edges; this cloak of opacity also discourages nasty questions of who benefits and how, and runs the danger of collapsing objective, processes and outcomes alike into an undifferentiated rhetorical empowerment" (ibid.: 7).

In trying to transcend the opposition between structure and agency, and avoid the danger to which Cheater alludes,[47] Bourdieu is notable for trying to bring together large-scale political and social workings of power/hegemony, with the potential for individual agency. His key concepts of the 'field' and 'habitus' are essentially theories of socialisation and the resulting social practice on the part of individuals, influenced by and interacting with the structural constraints surrounding them. Bourdieu uses 'a logic of practice' or 'practical sense' to convey the idea that individuals are agents who act according to both conscious and unconscious dispositions, through their 'practical mastery' of life. Such mastery is learnt and acquired through a life of engaging with and confronting diverse situations, circumstances and instances, both resulting in and influenced by the dispositions, desires and capacities of 'habitus.'

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[46] As Eagleton notes in a critique of Foucault, "What could conceivably protest against this condition, given that all subjectivity is merely the effect of power in the first place?" (1991:47).
[47] It is interesting that both the post-Marxist and the post-structuralist/modern perspectives have ultimately been criticised on the same grounds; i.e., that the overly deterministic homogenising nature of one and the overly-subjective relativism of the other may both lead towards reproduction of the status quo and both fail to pay attention to human capacity or interests.

Habitus is Bourdieu's key notion for transcending the principles of objectivism and subjectivism. As Jenkins (1992) writes, it is " a bridge-building exercise" between the two extremes of supra-individual structures and individual decision-making (1992: 74). It refers to the socially constituted dispositions acquired through practical experience in the 'field,' beginning at an early age. The habitus provides a basis for the actions of a 'social agent,' but these actions are then further shaped by the field in which they take place; i.e., the external constraints of their social environment. It therefore attempts to serve two functions: both as a structuring principle and as a producer of practical action, both producing and produced by the social world. In Bourdieu's own words, "...the most obscure principle of action...lies neither in structures nor in consciousness, but rather in the relation of immediate proximity between objective structures and embodied structures in habitus" (Bourdieu, 1996: 38).

Bourdieu also developed these ideas in looking at how relations of power and knowledge are reproduced in society. As noted, the field for Bourdieu is the social arena where people essentially engage in a struggle over available resources; e.g., education, land, political power. Rather than a tangible location, however, the field refers to a network of power relations or social positions. The resources over which participants are struggling are also categorised into different types of 'capital': economic; social; cultural; and symbolic. In each field, peoples' very struggle legitimises the 'symbolic capital' of the resource to which they are aspiring, credentialising the dominant cultural values, in a manner with parallels to Gramsci's notion of hegemony. These values are therefore reproduced without coercion, but through collusion, and are then made manifest in social institutions and objective structures.

While this model clearly outlines the potential for reproduction of the status quo, it is less clear how it can allow for transformation and challenge to the existing power relations,[48] or for the development and legitimisation of new knowledge, given that any struggle is occurring within such a hierarchically defined social space, with the odds seemingly stacked against those towards the bottom of the hierarchy.

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[48] His habitus concept is seen by some as overly deterministic, allowing for individuals to be constrained as the 'puppets' of structure, rather than possessing generative potential (King 2000).

Giddens' notion of 'structuration' attempts to address this (1984). His theory proposes that social life is not solely made up of random individual acts, nor is it only determined by inevitable structural forces, but by these two aspects in relationship with each other. For Giddens, people are habitualised by the structures around them, but they are never completely governed by these social forces. While he outlines how social practices are continued and reproduced by individual actions, the potential for agency and change is allowed, either through individual reflection or broader external changes.

This notion of reflection is raised by Baert (1998), in criticising Bourdieu for little attention to peoples' own ability to distance themselves from the field and turn their internalized knowledge of existence into theoretical knowledge. Rather, it is implied that this can only be done through external analytic intervention (i.e., through a mediating anthropologist). Baert suggests that, if it is acknowledged that people have the ability to distance themselves and theorise about their own situations, and, if that theoretical knowledge is able to enter the public-collective realm, it can be used either as a source of *change*, or to deliberately *maintain* structures (1998: 33). Critically, however, how and whether such knowledge can or does enter such a public-collective realm is a key question which will be explored practically in this thesis.

2.6 KNOWLEDGE, POWER AND BIOMEDICINE

As noted already, concepts of knowledge play an important role within this theoretical framework and consistently appear in health literature, whether in the more anthropological emphasis on local beliefs and knowledge and how these are used in determining behaviour and health outcomes, or the clinical privileging of scientific, objectified knowledge and the 'superior' role of the educated professional. Reproducing this dualistic paradigm, the acquisition of knowledge is often prioritised as an end in itself that is the key to changing peoples' behaviour, a view often promoted within information, education and communication (IEC) for health promotion purposes.

Rarely are these assumptions questioned, nor are boundaries between them crossed. Lay knowledge is opposed to professional knowledge, represented in the differential

use of the terms 'belief' and 'knowledge' (Good 1994); the two categories of user and provider are regarded as homogenous groups arranged in a hierarchical relationship based on this perceived knowledge; knowledge itself comes to be regarded as a fixed, obtainable category that is the key to behaviour change. And yet, while useful as broad-based concepts, these generalisations and oppositions may mask the complexities of reality.

In order to consider contemporary notions about information, knowledge and power in the medical world, a historical view is necessary. It is generally taken for granted today that medicine holds a position of high social status and intellectual dominance, with most people prepared to accept the authority of doctors (Hunter in Purdy and Banks 2001: 167).[49] The ascendance to such a position has its origins in the acceptance of positivism as the dominant paradigm for research and development of scientific knowledge. Historically, the Cartesian dualism of mind and body allowed for science and medicine to develop, leaving the social domain to theology/religion. This has had a longstanding influence on not just academic, but also popular conceptions of knowledge and understanding. Through its principles of empirical testability based on observation, science purports to bring knowledge of an ontological given: a pre-existing natural reality. It becomes not only positivist in this theory of objective knowledge, but also ideological through its attempt to subjugate other knowledges as false, owing to its prior claim to truth and its "ability to naturalise social reality" (Doyle McCarthy 1996: 7) – a view at odds with what may be termed a more social theory of knowledge.

Doyle McCarthy (1996) identifies two themes in the recent sociology of knowledge. The first was the idea of knowledge as socially determined (i.e., a Marxian-derived idea of human ideas as the superstructure, arising out of real life conditions, and changing as those conditions change). The second was an idea of knowledge constituting the social order (the idea that reality is socially constituted and that knowledge and reality exist in a relationship of mutual/dialectical constitution). Knowledge is thus not a reflection of a given reality, nor a bridge between people and

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[49] Hunter cites a survey undertaken by Heginbotham (1993), "Healthcare Priority Setting: A survey of doctors, managers and the general public," in which 61 per cent of the public put their faith in hospital consultants – over GPs (49 per cent) and managers (22 per cent) – as being the best people to determine healthcare priorities.

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such a fixed reality, but both are engaged in a process of mutual constitution, based on the experiences of people in that reality – not only as individuals, but as members of social groups. Knowledge(s) are therefore defined as "any and every set of ideas and acts accepted by one or another social group or society of people – ideas and acts pertaining to what they accept as real for them and others" (1996: 23).

This latter view was very much informed by Berger and Luckmann's influential 1966 text *The Social Construction of Reality*. In fact, even before this, in the 1930s, Ludwik Fleck's early sociological theory of *medical* knowledge had challenged the prevailing belief in objective scientific medicine and in 'natural' disease existing outside of and unaffected by society (Fleck 1979 (1935)). He felt that scientific 'fact' is itself not about discovering pre-existing nature, but our own *theories about nature*. Fleck felt that there are not natural facts or true knowledge, only social categories and our *representations* of our knowledge of reality. Those representations would be inevitably socially and historically conditioned and located (White 2002). He put forward the view that acceptance of any representations as 'fact' or truth comes about through interactions among groups, who compete with alternative definitions and representations. 'Facts' are therefore cooperatively constructed, not individually formed, discovered or 'thought.' Such thought collectives might coerce or shape the activities and interests of their practitioners, hence the robust and reproduced paradigm of positivistic medical science.[50]

As Jones and Porter (1994); Balen and Dormael (1999); Gray (1999) and Commelles (2000) have outlined, the process and practice of health care have been influenced and altered over time by these broader developments in the sociology of knowledge, the achievements of science and the new pluralism in medical provision. Historical records note the value originally given to the patient's perspective, with ethnographic notes made of the 'sick' environment and the perceived lower status of the physician

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[50] Fleckian ideas have informed later medical sociological ideas which challenged the biomedical monopoly, drawing attention to the social side of illness – as distinct from the physico-reality of disease. Critical works, such as that of Talcott Parsons' The Social System (1951) in which he elucidates the 'sick role,' were instrumental in highlighting the social effects of disease. His functionalist sociological stance was later further developed by medical anthropologists, such as Kleinman (1980), who emphasised the importance of the meaning and experience of illness to the sufferer, and tried to give voice to patient narratives.

in comparison to his employer, the patient (Commelles 2000). However, with the development of modernised health care and the increased faith in the apparent rationality and effectiveness of scientific measures, the patient has become increasingly passive and sidelined in decisions about their own health needs, as medical 'experts' have determined the health agenda. This 'medicalisation' process can be traced back through the development of medicine and its place in society. Emboldened by the new acceptance of the Cartesian mind/body dualism, particularly after the French Revolution, scientific medicine was able to push the boundaries, treating the human body as an empirical object and exploring anatomy. Organs were identified as the locations of disease and physicians gradually developed from those classically trained in Graeco-Roman medical theory, dependent on the patronage of their clients, to those skilled and trained in a depersonalised, more mechanistic and reified modern medicine. Identified with their body, the patient was reduced to a physical organism, subject to the expert 'gaze' of the rational scientist or physician (Foucault 1973; Moon and Gillespie 1995).

Evidence of this process of the professionalisation of medicine in the UK was seen in the mid-nineteenth century with the promulgation of the 1858 Medical Act – the same year in which the first copy of Gray's Anatomy was published (still in print and use today). This aided the establishment of the authority of professional medical expertise over the arena of 'healing' – traditionally the preserve of women – and the dominance of narratives of 'disease' over those of 'illness'[51] (Scambler 2002). Scambler also cites Grimshaw (1986) for adding the dimension of power to this process. Not only was the start of medical hegemony fuelled by scientific progress and development, it can also be seen as a politicised move to affirm and legitimate the power of white men in medicine. As Scambler adds (2002: 127), "modern medicine was from the outset gendered and racialised; and the principle of advantage has remained operative ever since."[52]

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[51] The distinction in use between illness and disease is attributed to Kleinman (1980; 1988). For him, illness refers to the "innately human experience of symptoms and suffering" (1998: 1), the lay or patient perspective and how such suffering is categorised, responded to and lived with. Disease, conversely, refers to the biomedical practitioner's perspective, which regards the body primarily as a machine, in which change in biological function causes disease. With this medical model, the correction of that change restores health.

[52] The gendered nature of medicine is still seen in the near domination of the profession by men, and, it would be argued by feminist theorists, in its construction of women largely in terms of their reproductive role in society. Professional medicine is therefore seen as a patriarchal system of control,

Other influential theorists have noted that the development of professional medicine worked hand in hand with the development of state power and institutions, in a process of mutually beneficial collusion[53] (Cant and Sharma 1999; Navarro 1976; Foucault 1973; Foucault 1976). While medicine was said to be autonomous and self-directing it was nevertheless tacitly supported by the power of the state (Purdy and Banks 2001). Freidson (1970) notes, however, the cooperation of lay people in accepting this medically managed state of affairs. Now redolent of both Bourdieu and Gramsci, he writes that medicine has not *forced* a position of authority, but that ordinary people, in their acceptance of notions of 'science,' progress and the natural body, have facilitated and reinforced the profession's position, allowing their illness experiences to be affirmed and defined in terms of scientific, medical knowledge. Real benefits have, of course, been brought by the development of medicine and also indeed the state. However, Foucault proposes that peoples' ready collusion is an inevitable outcome of medicine's role in social control: people have internalised medical discourse to the extent that they now even undertake 'surveillance of the self,' behaving in line with normative social and medical expectations (1975; 1980).

The claimed authority of the medical physician has endured, despite a range of possible 'threats.'[54] The medicalisation 'critique' (Lupton 1997) has cast the ascendance of modern medicine and its increasing social reach in a negative light. Such criticism highlights the overwhelming tendency for psycho-social problems to now be seen through a medical lens – and indeed to only have legitimacy if categorised in this way (e.g., addiction, Gulf War Syndrome). In addition, it highlights the construction of patients as vulnerable or passive recipients of expert medical care, disadvantaged by their lack of medical knowledge and indeed excluded from accessing such privileged knowledge. The credence generally given to the medical perspective at the expense of those of the lay community is one that has obscured lay concerns and indeed constructions of their own health and illness. This

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dominated by those groups with a vested interested in maintaining this situation where 'experts' determine the production of knowledge about our bodies and health.

[53] "A profession attains and maintains its position by virtue of the protection and patronage of some elite segment of society which has been persuaded that there is some special value in its work" (Freidson 1970: 72).

[54] For example, the growing managed health bureaucracy; knowledge development and public dissemination; new para professionals; citizens and user groups/patient charters.

is not to say that two pure realms of alternative knowledge co-exist. Lay narratives can be seen to have incorporated medical terms, as indeed doctors make use of 'lay' concepts and assumptions. However, the dominance of medicine, with the agency of the patient downplayed, is often demonstrated in an imbalanced interaction between doctor and patient at the micro level (Fox 1993), as well as at the macro political level of the professionalisation of medicine and the medicalisation of society.

In discussing the lay-professional encounter, Scambler (2002) takes up the arguments of Habermas, Mishler and Barry (Barry, Stevenson et al. 2001) that priority is "typically accorded to the voice of medicine over the voice of the lifeworld" (ibid: 124) and that, while doctor/patient interaction is indeed negotiated and dynamic, it is also structured in terms of (what may be unconscious) asymmetrical relations. This asymmetry is rooted in constructions of knowledge – with rational science accorded supremacy through its status as 'formal knowledge' (Freidson 1986) – and in the functional relationship between the two parties. This is demonstrated in the typical behavioural dispositions of the participants as the doctor objectifies the body of the patient through experiential observation to confirm/corroborate medical experience, which becomes 'knowledge' forming the basis of an informed diagnosis (Fox 1993).

In order to challenge the reach of medicalisation, other critics such as Zola, Freidson and Illich (2001 (1974))[55] have proposed the need to contest medicine's authority by enrolling the state as an ally, to increase regulation and control of medical professionals, and by empowering patients themselves to claim control, through the acquisition of knowledge with which to challenge their physicians. The potential agency of patients in this encounter has been emphasised, in addition to the need for them, as informed *clients*, to challenge the authority of the physician. Gray (1999) has identified the gradual development of 'postmodern health care' in response to the priorities of an increasingly 'postmodern' society concerned with values and risk, in addition to evidence and benefit. Thus, there has, in theory, emerged "the rise of the well-informed patient," (ibid.) with a view of patients as *active* participants who make

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[55] Illich's notion of 'iatrogenesis' is one of the more noted and radical critiques of modern medicine, which claims that medicine itself, its technology and practitioners, are actually the problem, rather than disease. He challenges the increased reach of medicalisation, claiming that the health system has in fact become counter-productive, obscuring socio-political causes and conditions of ill health and the voice and role of the individual.

use of their own knowledge and aspirations. Various movements to recognise and improve patient rights have been initiated in recent years, in line with the claims of the 'informed client' narrative and the associated discourse of 'empowerment.' The growth in user self-help groups and the promotion of patients' charters have been complemented by the increased use of 'alternative' therapies in preference or in addition to orthodox medicine. All have contributed to a growing plurality of knowledge claims that can be interpreted as a challenge to biomedical hegemony, through their defence of 'the lifeworld,' their challenge to the expert culture of medicine (Kelleher 2001, in Scambler 2002), and their attention to patient choice and voice.

In terms of global health care, this view – or aspiration – was manifested, in principle at least, in the Declaration on Primary Health Care of Alma Ata in 1978, and has continued to develop, with attention to notions of participation in the design and monitoring of health projects; the increased attention to empowerment, particularly in the discourse surrounding behaviour change for HIV/AIDS prevention; and the development of patients' charters and committees, through which providers may be held accountable. Following on from participation and empowerment, the 'new accountability' agenda in development (Anne-Marie Goetz, presentation to the World Bank, 14th November 2003) is one that prioritises the role of citizens and clients in setting health priorities and holding providers to account.

The notion of empowerment, which underlies much of this discourse, is not, however, unproblematic (Scambler 2002). Somewhat uncomfortable parallels may be drawn between the empowered/informed client narrative, and the concept of 'patient blame' through increased individual responsibility. As Scambler points out, the evidence of any link between the new medical pluralism and empowered or indeed increased public choice may be questionable. For this to be the case, he argues, the new medical pluralism would need to have arisen from 'knowledgeable accountability,' and be accompanied by a true increase in provision, whereas he proposes that it actually has origins in 'system rationalisation' and 'lifeworld colonisation,' accomplished through consumerism and clientalisation, in support of the capitalist system (ibid: 131).

Lupton (1997) also highlights that a focus on acquisition of medical knowledge to counter that of the physician merely extends and credentialises the reach of medicalisation, as Foucault has noted. Fox (1993), drawing upon Foucauldian ideas of the body as the site of ongoing historical and political discourse, proposes a more extreme deconstructed view of the 'discursive body.' From this perspective, the search for meaning in illness and empowerment in the healing encounter, put forward by medical sociologists and anthropologists, implies a search for biomedical 'legitimacy' (and complicity) (Williams 1999), rather than a total reconceptualisation of a physical body, which, in the postmodern view, only exists as a metaphor for society, which has constructed it.

As a reaction to this extreme post-modern position, a number of theorists have embraced the work of critical realism, drawing upon Bhaskar in their search for 'middle ground.' As Williams phrases it, the post-modern position suffers from a misguided "conflation of the ontological with the epistemological" (1999: 805), that is, a conflation of what *is* with what is *known about*. Williams (1999: 807) proposes a need to get away from the totalising social determinism of such a position and to bring back 'reality,' albeit cautiously, through an acknowledgment of the body as a real entity. Without regressing to all-out biological reductionism, he makes "an ontological defence of the body…as a pre-discursive entity." Yet, this entity and its experiences can and will be shaped by and in mutual dialectical response to its historically, politically situated environment.

Much has been written on these shifts in medical sociology in the industrialised north, as presented, but relatively little research has focused on these same issues in the developing world.[56] This research, therefore, aims to explore the relevance of such theories in the context of widespread poverty in Malawi, and analyses its findings to consider *practically* how such understanding can impact upon and influence medical policy and practice and the very real health concerns and conditions of ordinary people, with particular reference to TB and its control.

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[56] Delamont, in discussing the use of ethnography, observes the common and sometimes antagonistic opposition between the disciplines of anthropology and sociology (Delamont 2004). While such boundaries are increasingly being blurred in research and practice, the distinction between medical sociology and medical anthropology is still evident in the literature trail and foci for research.

While making use of a binary category of power/knowledge in investigating the Malawian context, the thesis will be looking both at very particular and localised articulations of power at the level of medical practice and individual encounters, in addition to those framed within broader centralised patterns of power, as structured by the dominant model of TB control, i.e., in issues of access to health services and information; and in being involved or excluded in the determination of state-run TB healthcare.

CHAPTER 3: METHODOLOGY

INTRODUCTION:

The aim of this chapter is to consider the methods used in this study, by outlining *how* the research problem was investigated, *why* particular methods were chosen and *what* the methods involved were. Following a discussion of the overall study design in this introduction, a brief description of the range of methods used will be given. In the next section, each of these methods will be described individually, giving the rationale for that method, the procedure followed, the process of analysis and efforts to assure quality. The study settings will then be described, followed by an exploration of ethical issues, dissemination methods and limitations to the overall approach.

3.1 AIMS AND OBJECTIVES

As described in the introduction to this thesis and the review of existing material in Chapter 2, the overall aim of this research has been to ask why TB is enduring as a significant developing world health problem and resisting the attempts of governments and control programmes to stop it.

A major hypothesis underlying this question is that current efforts at TB control, guided by the dominant clinical paradigm and represented in the WHO's DOTS strategy, may be flawed. Guidelines are implemented inflexibly and with little systematic attention to issues of both 'structural' and 'behavioural' importance in the complex settings of poverty where TB is most often found. Thus, even in settings with 'strong' TB control programmes, poor and worsening TB outcomes are being recorded.

A case study approach in a country with a significant TB burden, yet with a well developed and globally respected TB programme, was therefore adopted as the main methodological approach. The programme is operating in a country still severely stricken by poverty, with dire economic and health indicators,[57] a deteriorating health service, and where its government is heavily aid-dependent and struggling with the challenges of donor-driven health sector reform and the impact of the HIV crisis. As

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[57] For example, GNI per capita of U$160 in 2002 (World Bank African Development Indicators 2004) ; national HIV/AIDS prevalence of 15 per cent (UNAIDS 2002) and infant mortality rate of 104/1000 (MDHS 2000)

already noted in the introduction, using such an approach this thesis aims to investigate and understand tuberculosis in the Malawian setting, both from the point of view of everyday people who are most at risk, from the point of view of policy makers, and from the perspective of those care providers, working at the interface between these macro and micro levels. As a chronic disease of poverty, TB is felt to be an important lens through which to explore the linked issues of health, development and poverty, from the decision-making at policy level to the embodied implications of those living with the everyday threat of such a disease.

3.2 SCOPE OF THE STUDY

The study was undertaken during a 12 month period of fieldwork, from October 2000 to October 2001. During this period, the author was seconded by the UK government's Department for International Development (DFID) to work as Communications Officer for the National TB Programme (NTP) and the TB Equity Study.

The National TB Programme is the principle institution concerned with TB control in Malawi. It is organized as a vertical disease control programme, under the Ministry of Health and Population (MOHP), operating through the wider health service, but with its own separate hierarchy of personnel, supervision and monitoring structures. These will be outlined in further detail in Chapter 4.

The TB Equity Study, a collaboration between the NTP, the Department of Sociology, University of Malawi and the Liverpool School of Tropical Medicine, was initiated to promote equity in the delivery of TB care. Towards this aim, the project investigated patterns of care seeking for TB, and gender and poverty-related barriers to access to care during the period 2000 - 2002.

Both the NTP and the TB Equity Study are/were located within the Ministry of Health's public health facility, the Community Health Sciences Unit, in the capital city Lilongwe.

'Health promotion' is regarded as a key contributor to the NTP's main goal of improved case-detection and early in 2000 was recognised and prioritised by

management for review and redevelopment. As Communications Officer, the author's role was thus to oversee this process, working alongside a local counterpart to facilitate the evaluation and redevelopment of an information, education, communication (IEC) strategy for the National TB Programme. In addition, while managing the responsibilities of this position, field-based research was undertaken to collect data for this PhD thesis. This fairly significant burden of work had notable implications for the scope of the PhD study, both positive and negative. As an 'insider' to the NTP, there were obvious benefits to conducting an in-depth case study. However, the demands placed by the IEC work required constant negotiation of inputs and management of tasks. One mechanism to reduce this tension was to tie the complementary processes as closely together as possible. Thus, as the methodology is further described, it will be clear that some early methods served the dual role of gathering evidence for the IEC strategy design *and* for this thesis.

Responsibility for all data design, collection and analysis lie with the author alone, although NTP staff cooperated in its collection and the NTP's IEC Officer, in particular, played a vital field assistant role in the initial stages.

3.2.1 Study design
"An effective health policy requires a detailed understanding of local conditions – ecological, social, demographic, economic and political – that all affect health, and that need to be addressed in a public health strategy." (Sachs et al, 2001: 83)[58]

In choosing the overall approach and study design, the research problem was considered, alongside sentiments summarised in the above quote, and a predominantly qualitative approach to primary data collection was adopted, triangulated with secondary quantitative data.

There has long been a debate in the world of social science research, influenced by theoretical approaches to 'knowledge,' which has informed approaches to methodology. As the dominance of 'pure' scientific method began to be questioned (Fleck 1979 (1935); Barnes 1982; Kuhn 1996 (1970)), people asked whether the

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[58] Commission on Macroeconomics and Health, Macroeconomics and health: investing in health for economics and development, WHO 2001.

social sciences might require different methods and justification than the natural sciences? This debate is rooted in the philosophy of social science and the tension between the natural scientific versus the social scientific, a traditional distinction between epistemology and ontology (Mills 1959; Ryan 1973; Strathern 1987). In the world of natural science, the assumption is that the positivist, empirical search for a definitive reality is the only 'valid' and value-free approach to research – of any kind; the opposed view in social sciences challenges the existence of any 'real' set of facts that can be objectively measured and recorded, questioning the 'empirical' as an appropriate way to describe and understand complex social phenomena.

Thus, as the social sciences have developed, a central theme has been the extent to which 'naturalist' explanations are applicable, as opposed to 'humanist' ones. This has led to a division in methodology between the positivist, scientific method, stressing facts, figures and explanation, proving theories as determined/supported (or falsified[59]) by given facts; and the humanistic alternative, focusing on interpretation rather than explanation, intermediate meaning rather than cause. In this latter approach, theory was held to be a shifting product of process and presupposition, rather than a result of given 'facts' (Quine 1960).

Within social theory and the social sciences, this debate has continued and indeed, continues, to evolve. Influenced by the arguments of radical thinkers such as Feyerabend (Feyerabend 1975) the humanist reactions against natural scientific methods as being rigid, ahistorical, eurocentric and inappropriate for social analysis led to an emphasis, particularly in anthropology, on the ethnographic method. The 'unique' case study was embraced, treating cultures in their own terms and contexts,

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[59] Note that positivism rests on the principle of 'falsifiability,' as proposed by philosopher Karl Popper. Rather than just inductive reasoning or logical inference based on empirical testing, this approach asserts that logically, no number of positive outcomes at the level of experimental testing can confirm a scientific theory, but a single genuine counter-instance is logically decisive. Put more simply, it must be possible in principle to make an observation that would show a proposition to be false. Popper's notion of falsifiability lies at the heart of his philosophy of science and of what is and isn't, in his terms, genuinely scientific: a theory should be scientific if and only if it is falsifiable. However, many non-material or non-physical subjects of study or theories are of a form that is not logically falsifiable and therefore cannot be subject to the falsifiability principle. In Popper's view such theories (e.g., history, politics, etc) would not be 'scientific.' This classification in itself carried a value judgement in the division between 'science' – the highest form of knowledge – and 'pseudoscience.' In addition to dismissing those theories to which his principle is logically unapplicable, Popper also ignored the very unscientific responses of scientists when evidence contradicts their theories – but which were espoused by Fleck in the 1930s, as discussed earlier (1979(1935)).

through observation and interpretation of social action. The emphasis was now placed on 'meaning,' as distinct from the ordinary explanation of natural science and held to support this was the centrality of language, agency, and meaning to social interaction.

However, the inevitable backlash against social science and 'pure' ethnography has duly, and to some extent rightly, materialised (Fay 1975). While ethnography tried to move away from the restrictive approach of the natural sciences, in the early days of anthropology and social research it also proposed a purity and objectivity, placing the researcher in a position of privilege, presenting their ethnographic representations as somehow definitive, final and 'scientific.' While anthropologists such as Geertz embodied a shift away to 'interpretive' anthropology, emphasizing contextualised meanings and concepts, he too was guilty to a degree of the same naturalist method, looking to gather these concepts, made manifest through social acts, like empirical facts awaiting collection (Geertz 1973).

Rather, it is necessary to recognize that ethnography is merely representation: "rendering the foreign familiar (Crapanzano 1986). It is therefore an inevitably value-laden process with inevitable presuppositions both on the part of the 'observer' and the 'observed.' While Geertz tried to portray concepts of thought as intermediate carriers of meaning, he needed to be aware of the limitations to this approach. If social action is accepted as 'text' to be interpreted, the appropriate role for social science is a *mediating* one. Representation should be viewed as a dialogic process, with the researcher aware of their own presuppositions (and those of their study subjects), while framing their analysis within indigenous categories as far as possible. Yet, the researcher needs also to recognize the inherent constraints to any approach, and use this recognition to further their own 'critical' approach to social research (Olsen 1997). Through a process of reflexivity, assumptions can be recognized and challenged, through a holistic approach to methodology, which does not reify the value-free, but rather acknowledges the inevitable biases of social research, while seeking to reduce these where possible.

To cite Amartya Sen (1980), "description is choice," and therefore value-freedom – and indeed a separation of the academic and the personal – is not necessarily an

achievable or appropriate goal, and may even be detrimental in limiting the researcher's own sense of reflexivity and self-criticism. Through such a 'critical' social scientific approach, it is accepted that we are always in a world of rival theories and discourse, where it is overly reductive to try and objectify complex relationships or measure absolute reality (Feyerabend 1975). And where our position as researcher is one of problematic intermediary, acting in a specific political and historical context. It is therefore proposed that research methods avoid both the danger of realism *and* a reification of our interpretive abilities (ignoring our own presuppositions and those of the people we are observing). As Mies and Shiva's approach would describe it (1993), the aim is 'conscious partiality.'

However, if we are to accept such arguments for a reflexive and critical approach, how can this be translated into a workable methodology? One which is applied rather than abstract, and aims at relevant outcomes that can meet specific information needs and inform policy decisions and practices?

Bearing in mind this overview of theoretical debates and the particular objectives of this study, the methods chosen reflect an attempt to understand a specific historical, locational context, in more depth than has hitherto been achieved. The available methodologies were seen as 'tools' to describe, represent and, in analysis, negotiate meaning. An emphasis on primary qualitative methods was deliberate, aiming to investigate in-depth the gaps and problems thrown up by more routinely collected statistical data. This was not simply owing to a philosophical standpoint or commitment to the qualitative paradigm, but was a choice informed by the purposes of the research and the need to answer questions of 'why?' (Patton 2002; Hammersley 1999).

While good empirical evidence from NTP operational research indicates some reasons why diagnosis is low, particularly those structural or material factors such as distance to health facilities and costs of accessing care, this evidence is only one (important) part of answering the research problem. Such evidence, in its current state, is not sufficient to provide further insights as to why these problems have remained inadequately addressed and, in addition, what other barriers may remain undetected. Moreover, such research and its recommendations have typically focused on the

perceived roles and responsibilities of TB suspects and patients, yet without allowing their voices to be adequately heard. Surveys used have also been less internally reflexive in assessing the role and responsibilities of service deliverers and programme management, particularly in the resulting recommended actions. Therefore, in addition to allowing the perceptions and priorities of ordinary people and frontline providers to come out clearly, to further illuminate and explain the barriers to successful care-seeking and care provision, a research approach was chosen that would also try to examine what organisational, institutional and political aspects may be inhibiting a more systematised investigation and response to the range of challenges inhibiting TB control in such a poor context.

Although definitions are contested, reflecting the tension between positivist and interpretevist approaches, qualitative methodology can be understood to be a set of approaches, all of which are guided by an interpretive analysis. These might include methods such as participant observation, focus group discussions and interviewing techniques. On the whole, qualitative researchers can be distinguished by their attempt to study things in their everyday environment, attempting to interpret and represent a given setting through giving 'voice' to its members.

In disease control, owing to strong links with the medical and scientific world, the dominant approach to both recording data and investigating problems has been through 'real' scientific inquiry, with an emphasis on the measurable and statistical: the quantitative. While, as Hammersley (1999) has outlined, the opposition between qualitative and quantitative is not always helpful, it is a dichotomy to which many researchers subscribe, owing both to their stance in the ontology/epistemology debate and the purposes of their research, and it is therefore one that influences practice. This is seen to also influence approaches to disease control, where policy making remains largely within the hands of medical technocrats who favour 'hard science,' and regard qualitative methods as a 'soft' option and, in more extreme cases, "an assault on the tradition of positivist science" (Denzin and Lincoln 2001).

In an early desk review of available data relating to TB control in Malawi, a rich variety of statistical records were found, including records of cases diagnosed, started

on treatment and their respective outcomes – as suggested by WHO/IUATLD[60] guidelines. The Malawi NTP utilises rigorous recording techniques and attaches considerable value to maintaining comprehensive information and monitoring systems. However, this aggregate statistical picture, while robust and valid in and of itself, only measures the WHO promoted indicators of successful TB control, such as cases notified and treatment outcomes, and hides the complexities of the Malawian environment, raising questions which cannot be answered through these quantifiable methods *alone*. This is not owing to poor methods, or the 'wrong' data, but the fact that quantitative data – as long debated – may not be the most appropriate tool in the context of rapid social change and complexity to answer questions of 'why?,' and interpret *qualitatively* the possible underlying contributors to such a complex and deteriorating picture, as demonstrated in the statistics.

The statistics clearly support the statement that TB *is* enduring and indeed worsening. They also support that DOTS is being implemented throughout Malawi, as promoted by WHO, and with considerable commitment from the NTP. However, such statistics also leave many questions unanswered. Why is the incidence of TB rising? What is the environment in which the TB Programme is operating and how might this environment be challenging the DOTS model, reducing its efficacy? How effective then is that model in this Malawian – or any other – setting? What about those who are not reaching the health service and are not represented in the measurable statistics? Why are they not accessing care? Why are so many of those who *do*, subsequently lost along the diagnostic and treatment pathway? How might a worldwide model of control accommodate such detail in a particular context, bearing in mind the global political economic context in which it is operating?

Qualitative analysis is frequently absent from the dominant scientific approach to disease control, yet is potentially vital in informing policy makers of the richness and complexity of their operational environment, and this was felt to be the case in Malawi. To cite one example from the TB Programme's own experience, which demonstrates the differing use and interpretation of quantitative data, according to the

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[60] International Union against Tuberculosis and Lung Disease, the largest NGO dealing with lung health, with main activities of research, education and technical assistance carried out globally in support of TB programmes.

purpose and epistemological approach of the user: between 1995 and 1996, the NTP's own survey instrument showed that a large proportion (37 per cent) of smear-positive pulmonary TB patients had first sought care with a traditional healer, before turning to the formal medical service (Brouwer, Boeree et al. 1998). This was seen to contribute to a delay in diagnosis, thus having implications for both public health and individual treatment success.

In 1998, further operational research was carried out by the NTP, examining care-seeking behaviour of patients with smear-positive pulmonary TB that had made it through the diagnostic process, to identify what contributed to their delayed presentation at the formal health service (Salaniponi, Harries et al. 2000). The study used questionnaires with 1099 patients amongst whom the median delay between onset of cough and diagnosis was eight weeks. The NTP endeavoured to find out what factors contributed to care-seeking behaviour, and what choices their patients had made along their pathways to care.

Statistical analysis of the survey results demonstrated that there were variable patterns of care-seeking behaviour, and that local, informal sources of health provision were an important choice for TB suspects. Other factors such as distance from facilities and cost (transport, income lost) were also shown to be key influences. In addition, over 40 per cent of patients reported that they were unaware of the possibility of TB until the time of their diagnosis.

It is important to note that the methods used were likely to have compromised respondents' willingness to answer openly, restricting the space for full details to emerge, and leaving issues unrecognised. This was particularly true with regard to peoples' care-seeking with traditional or alternative providers.[61]

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[61] It was acknowledged by the authors that, even with a significant proportion reporting seeking care with traditional healers (37 per cent in the first study, 30 per cent in the latter), interviewing patients in a formal hospital setting and using staff as interviewers may have influenced responses. There was likely to have been *under*-reporting of previous care-seeking with informal providers. As Brouwer et al phrased it "The proportion of patients may in fact be higher because patients can be hesitant in admitting that they had taken traditional treatment for fear that the health staff would refuse to treat them" (1998: 232).

The limited conclusions thus drawn from the study by the NTP only identified 'education' of communities and informal practitioners as the appropriate intervention to address delayed care-seeking. While this survey had indicated a variety of influences on peoples' care-seeking behaviour and the importance of understanding their environment, it provided only some of the answers and was used to support the existing approaches to disease control that place the emphasis on the individual patient to 'do the right thing,' rather than to inform new approaches that took account of the findings. There remained an opportunity to follow up on the many interesting but unanswered questions about the full range of factors at play, the interaction between the material and the cultural constraints, the difficulties in the assumed attribution between improved knowledge alone and peoples' resultant behaviour - based on an unchallenged model of 'rational choice,' and also the role of the health service and NTP in responding to the identified contributors to delay.

These gaps were later acknowledged by the NTP and qualitative research was felt to be the appropriate tool to complement the quantitative work already undertaken, and attempt to flesh out the initial findings, involving communities in exploring these issues in more detail and depth.

The TB Equity Study was a major outcome of such unanswered questions, and was initiated to carry out multi-disciplinary research around key themes of poverty and gender. This thesis aims to complement such specific investigations by seeking to address the bigger picture of disease control for TB in Malawi. It seeks to emphasise the value of the qualitative in providing a more detailed and informed contextual approach to disease control, that can both complement and triangulate with quantitative findings. Existing quantitative data and secondary statistical materials were used to construct the overall research framework, and set up the questions to be investigated in greater depth through qualitative means. The methodology is thus pluralistic, seeking to describe the complexities of reality, through a variety of instruments.

Running through the entire case study was the author's role as a participant observer, while working within the NTP. The approach to observation was informed by a thorough review of secondary literature and an initial document and data search on

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arrival in Malawi. Following a series of stakeholder interviews, the next stage of primary data collection began with a rapid appraisal tour, followed by focus group discussions, a KAP survey, in-depth interviews, phased key informant interviews, and a final document and secondary data review. The preliminary analysis of each stage was used in an explicitly iterative fashion to inform the identification and design of the next phase of investigation.

The approach purposively started with group oriented methods on a nationwide scale, useful for throwing up more thematic data, and used preliminary analysis of this data to then refine a choice of two specific locations for in-depth follow up work, using interviews and observation. In addition, through early stakeholder interviews, a snowballing sampling technique was employed, seeking suggestions from key stakeholders as to the range and selection of interview subjects and criteria for FGDs. In order to gather information from ordinary people and health providers in high risk settings for TB, the groups purposively targeted included community members in rural and urban poor locations, village leaders, government health workers at both high and low cadre levels, and traditional healers. With these specific qualitative methods, statistical representative-ness was not being sought. However, the combination of tools, including a population-based survey to affirm and quantify some of the qualitative findings, and long-term participant observation at the programme and policy level, aimed at a triangulation of complementary methods that would promote reliability of data. Dissemination and discussion of findings in the community research sites also sought to validate findings.

As already outlined, this research hypothesizes that attempts at disease control, rooted in an exclusively clinical paradigm, are in danger of a continuing search for 'empirical laws,' actual and verifiable truths, upon which to base fixed mechanisms of 'control.' It proposes that, in the Malawian context, differing narratives and understandings of TB and disease control co-exist, in addition to a complex range of tensions and structures influencing people's ability to act, in accordance with the knowledge that they have. Without acknowledging such differing interpretations *and* the underlying tendencies (such as the influence of gender and local manifestations of power) (Lawson 1999) and more explicit structures (such as the economic and financial constraints of poverty), influencing people's behaviour and ability to make choices,

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the fixed mechanisms of 'control' will prove problematic, in the face of such a dynamic social realm. In addition, these issues and concerns are not restricted to this more 'individual' level of patient and provider alone, but also have relevance at the more 'macro' level of policy and decision-making in the wider national health environment. Thus, it is hypothesized that any central initiative will need to consider how to systematically address these competing paradigms, *at all levels,* if it is to move beyond a limited sphere of influence and restricted outcomes.

For the purposes of investigation, questions were therefore asked around two levels:
1. At the MACRO level of policy making, negotiations and influence within the national health context
2. At the MICRO level of individual knowledge, attitudes, behaviour and practices on the part of both patient and provider

It was acknowledged however that such levels are not exclusive and that while the research is framed within them, analysis would necessarily look beyond them at the complex web of relations and relevancies across the framework.

3.3 RANGE OF METHODS

3.3.1 Secondary document search and review

Rationale:

A comprehensive review of existing documents was undertaken on arrival in-country, with access to NTP and donor documents, in addition to wider governmental and civil society publications and data. Areas investigated ranged from TB specific epidemiological data to more general health sector planning and policy, and included a situation assessment of government, donor and civil society activities, with regard to health.

This built on a significant literature review process already undertaken on materials available internationally, via library and internet access, by supplementing this with much more up-to-date and country and programme-specific information, that was then used to further develop the research questions and inform the study design.

3.3.2 Participant observation

<u>Rationale:</u> "Once the field worker has gained entry, people tend to forget he is there and let down their guard, but he does not; however much he seems to participate, he is really there to observe and even to watch what happens when people let down their guard." (Gans 1968: 314)

Participant observation is the traditional basis for ethnographic fieldwork, originating, as already outlined, in the early days of anthropological fieldwork, when anthropologists traditionally immersed themselves in the lives of their 'subjects' - as Jorgensen phrases it: "becoming the phenomenon" (1989). However, as alluded to in the earlier section on study design, the total 'insider' interpretevist approach has long been criticised (Fay 1975) for researchers failing to appreciate their own limitations and presuppositions, and reducing themselves to the empirical 'fact-gathering' role they initially tried to move away from. The subsequent shift has therefore been toward appreciation that ethnographic 'representation' is just that: representation. And representation will be inevitably affected by the biases of the observer (Clifford and Marcus 1986).

However, as already outlined, social research is not framed within the positivist aims of value-free, quantifiable measurement, but rather those of making a valuable contribution to understanding social phenomena in a particular setting, as far as possible in their own terms. From this perspective, participant observation, though constrained, is a key tool in gathering detailed data on a vast array of, often, sensitive topics. And its 'validity' can be enhanced by a number of quality assurance mechanisms, which will be discussed.

In simplified, practical terms, participant observation involves establishing an accepted place and space within a particular (usually new) community, where people around you are able to go about their everyday activities, regarding your presence, if not as an 'insider,' then as an accepted neutral observer.

While the time and personal investment needed to establish such an accepted place is often cited as a significant constraint, the value of this method is in the increased understanding that can be gained through long-term exposure to a setting. Through the contextual knowledge gained, it is possible for the researcher to interpret

emerging themes and meaning in their data with confidence, and to use their developing understanding to continually review and guide further data collection, across all research methods used. In addition, the bias of 'reactivity' is reduced, i.e., people altering their behaviour when they know they are the 'subject of study' (Bernard 1995), and participant observation allows exposure to a wide variety of data and situations, not normally recorded using more conventional research tools.

For these reasons, and owing to the 'entry' to the NTP guaranteed by the author's formal role, participant observation was an appropriate methodology to use.

Process: Russell Bernard (1995) divides the observer roles into two types: that of 'participating observer' and that of 'observing participant.' The former type participating and accepted, however still as an observer (i.e., long term fieldwork amongst a group of chronic disease sufferers, yet you are not going through the disease process yourself); and the latter more a participant (i.e., fieldwork amongst a group of prison wardens, where you yourself undergo training and spend months employed and on the job).

The approach in this study can be categorized as the latter role: observing participant. As a working member of the NTP and TB Equity Study, my role was of a fellow participant in the programme's everyday working life, with my own discrete responsibilities. This working role facilitated daily access to 'the field' – in this case the TB Equity Project and the National TB Programme, within the Community Health Sciences Unit, and under the umbrella of the Ministry of Health.

Analysis: In order to give some structure to the observations, documentation of the process was kept in the form of a field diary. Descriptive notes were kept as soon as possible after the observation – generally at the end of the working day, with interpretive ideas and impressions noted at that time, and further analysis added by reading through on a fortnightly basis, highlighting emerging patterns or themes. These themes were then used to guide and structure the continuing observation. At the end of the fieldwork period, all notes were reviewed for a final time, recording and summarizing themes in a preliminary report.

3.3.3 Rapid appraisal

<u>Rationale:</u> As a relative newcomer to the Malawian context, and in particular, lacking familiarity with the service delivery environment, a rapid appraisal tour of health facilities within two districts was undertaken during the early stages of fieldwork, in order to gain an overview of the situation 'on the ground.' The overall aims of the visit – in addition to piloting a draft observational checklist for the NTP's IEC evaluation – were to gather preliminary data for both that evaluation and this research. Methods used were observation and informal interviews with staff and, where possible, patients, at district hospitals and health centres throughout the districts. The information gathered was analysed and then used to inform the selection and design of methodology for the rest of the study.

<u>Process:</u> This tour took place over a period of 2 weeks, in the two central districts of Dowa and Ntcheu. Both districts were purposively selected to be within Central Region and relatively near reach of Lilongwe, for logistical reasons. Both were chosen using NTP data to identify districts with significant TB burdens, with Dowa representing a more 'rural' area; and Ntcheu as a more densely populated district with a known high HIV rate.

The author was accompanied by the NTP's IEC Officer, with whom the work was shared, and from whose in-depth knowledge of structures at district level the appraisal benefited. Owing to weather conditions (rainy season) and poor roads, it proved far more difficult to access health centres in Dowa district, as many were along impassable dirt roads. Regretfully, this meant that many of the centres visited, though rural, were generally along the better roads/tracks. The fact that we were unable to reach a large number gives an indication of the daily transport difficulties those centres face.

The only place where it proved appropriate and possible to speak briefly with patients was in the Male and Female TB wards at Ntcheu District Hospital. At health centres, interviews were predominantly with medical assistants, nurses and health surveillance assistants. The first place visited in both districts was the district hospital, in order to introduce ourselves to both hospital and district officials and inform them of our intended activities. Using GIS maps of the district, several days were then spent

visiting as many health centres as possible, often accompanied by one of the district TB Officers (DTOs). The visit was intentionally unannounced, to try and ensure a realistic picture was gained of daily practices and environment, and to avoid increasing staff workload through any preparations they might make for us.

Analysis: Written notes were made at each health centre, and, at the end of each day, were reviewed and analysed for themes. At the end of the appraisal tour, findings were then orally disseminated to NTP staff at CHSU, written up in a preliminary report and used to inform the design of following methodologies.

3.3.4 Focus Group Discussions

Rationale: Focus group discussions (FGDs) were carried out with both health care workers and community members in four districts throughout Malawi, in order to gain a clearer picture of the existing understandings, behaviours and 'needs' around health and TB amongst these two groups. Areas investigated included community and provider understandings of TB, local models of healing and care-seeking, sources of health related information/communication and patient/provider interaction.

Focus groups are a useful method for gaining a broad understanding of people's perception, ideas and experiences. The group setting provides a forum where individuals are able to interact with one another, using the dynamic of dialogue to generate interest and responses, guided by a facilitator through a particular agenda (Spencer, 2000). Invariably, this type of group setting throws up a wide range of information and data, and is particularly useful for gaining a sense of prevailing norms and consensual ideas. Following analysis, these ideas can then be followed up *in more depth* via a more appropriate tool for exploring individual experiences, such as an interview.

Process: The FGDs took place over a period of two months, early in 2001, and were carried out in 4 districts throughout the country: Rumphi (North); Lilongwe (Central); Zomba and Mangochi (South). The selection of districts was done purposively, with the intention of carrying out activities in areas that were regionally representative, had both an 'urban' and 'rural' mix, and showed high TB prevalence rates. Ten days were

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spent in each district, and activities were arranged with the assistance of District TB Officers based there.

Within each district, two health centres were chosen, one more 'urban,' being based close to the district capital, and one more 'rural' being at some distance from the district capital (> 20km). Choices were made, as follows, using health systems data and Geographic Information Systems (GIS) maps of each district - Rumphi: Bolero and Mlowe; Lilongwe: Kawale and Nathenje; Zomba: Thondwe and Ngwelero; Mangochi: Mpondas and Chilipa.

The FGDs were used for gathering information, with both health centre staff and community members from the catchment area surrounding each centre. At each centre, four FGDs took place, two with health workers and two with community members (total number of FGDs = 32). With staff members, English was the language medium used; with community members, it was the main local language (Chewa, Tumbuka or Yao, according to region). Groups were disaggregated by sex and had a maximum of 10 participants. Verbal consent was sought from each participant before the start of the discussion, along with permission to make a recording. Each session was either facilitated by the author, and observed by the NTP IEC Officer, or vice versa, according to the language needs, using a topic guide to aid moderation. At the end of each session, an opportunity was given to the group for their specific questions and clarification regarding the research, while refreshments were provided.

Analysis: Each FGD was recorded using a mini-disc recorder and professional microphone. Each session was transcribed, as far as possible on the same day of the session, if not the same week - although logistics and field conditions sometimes obstructed this (ie: power cuts). Following word-for-word transcription, translation took place where necessary.

Analysis was carried out by the author using an indexed framework, devised based on the initial topic guide and according to recurrent themes and issues that arose during the discussions. Having indexed (coded) all transcripts, the resultant themes were

recorded on charts, and then summarized in a masterchart, prior to the writing of a preliminary report of findings.

3.3.5 KAP (knowledge, attitudes, practices) Survey

Rationale: Having used FGDs in a first qualitative stage of fieldwork to identify relevant issues and themes, these findings were then used to inform the design of a KAP survey, in order to try and quantify some of the responses and establish current awareness levels and norms statistically. The survey was also planned as a triangulation of methods, to inform further qualitative investigations and to use as a baseline for future impact assessment for the NTP's IEC strategy.

Process: A first version of a 'mini' KAP survey was designed by the author, translated and piloted amongst TB in-patients at Queen Elizabeth hospital in Blantyre, with the assistance of the NTP's IEC officer. Following revision and expansion, it was handed over to a team of interviewers at Statistical Services, a local Malawian agency run by Matthews Ngwale, and once again piloted in Blantyre amongst a random sample of the general public. This pilot took place in 2 urban areas of Blantyre – using the same interviewers who would later carry out the survey across the country – with the aim of identifying any problematic questions, or difficulties on the part of interviewer and/or interviewee.

Following final revision, it was then carried out on a 'nationwide' basis, returning to the 4 districts used in the FGD study. In total, a random sample size of 2,298 interviewees was used, with the calculation and distribution based on the 1998 Malawi Population Census. The distribution was as follows: Rumphi – 100 households; Mangochi – 600 households; Zomba – 600 households; Lilongwe – 1000 households.

Traditional authorities (TA) were randomly selected, using maps purchased from the National Statistical Office.[62] Within each TA, 5 Enumeration Areas (EA) were randomly selected, and within that EA, 20 households were interviewed. In the village setting, the first house visited was that of the Village Headman or Chief. Having obtained his consent to interview in that village, the supervisor would spin a

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[62] These maps show details of TAs, EAs, villages and some households for each district.

pen on the ground, in order to randomly select the direction in which to interview. Interviewers would then walk in that direction, interviewing intermittent houses, which fell in their path (i.e., having interviewed at a particular house, the next one would be skipped). Respondents were adult men and women, above the age of 16 and interviewers were advised to alternate sex when interviewing where possible. Owing to higher male migration and their occupation with activities outside the domestic sphere, women were more often found in the home, which resulted in 59.5 per cent of the sample being female. The practical implementation of the survey was carried out between April and May 2001 by Statistical Services, in close collaboration with the author.

Analysis: Data was checked in the field, by the group Supervisor and each evening by Matthews Ngwale, to ensure rigorous interviewing standards. On completion and once back in Blantyre, results were double entered into the Epi-Info 6.0 statistical package, validated and then cleaned. Analysis was then carried out with the survey's key objectives in mind, as instructed by the author and described in the survey protocol, involving frequencies for each of the variables, as well as cross tabulations of major questions with the demographics, to statistically test any associations.

A copy of the survey instrument is available in Appendix 3, with a summary of key findings in Chapter 4. Full findings were written up by Statistical Services, supervised by the author, in a separate report[63].

3.3.6 Semi-structured In-depth interviews

Rationale: The first stage of qualitative investigation, already outlined, involved a rapid appraisal tour and series of FGDs nationwide. This was in order to be oriented to a new environment and gain an initial picture of the state of service delivery and user and provider concerns in Malawi. However, having established an overview of the situation, the next stage was to use the insights already gained to develop appropriate interview schedules and topic guides in order to investigate emergent themes in greater depth with particular population groups. These included male and

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[63] 'National TB Programme KAP Survey for IEC Needs Assessment,' National TB Programme, Lilongwe, Malawi. Data collection managed by Mathews Ngwale, Statistical Services Consumer Research, May-July 2001.

female 'ordinary' community members, health care workers of different cadres and practising traditional healers.

In-depth interviews are one of the tools appropriate for enquiring more deeply into peoples' lived experiences, using the one-to-one setting to be able to probe their perspectives. The semi-structured interview, while not as fluid as an unstructured interview, uses a topic guide with a list of areas for questioning, to guide the interview and ensure that key themes are covered. Answers are left open-ended and may be freely probed for further information by the interviewer. The advantage of this method is that the topic guide brings some consistency to the range of interviews, and allows for comparability in analysis of the data. The disadvantage is if the interviewer is too rigid in application, not allowing for flexibility and openness on the part of the respondent, and therefore not gathering as much contextual information as the method can provide (Flick 1998).

Process: Bearing in mind the overarching research objectives, and having collated major themes and issues from preliminary analysis of the FGDs, these were sorted and organized into skeleton topic guides. These were then fleshed out with sub-themes and supplementary issues and possible prompts were added at key points. Using major themes as key sections, these were arranged in order, preceded by an introduction and 'warmer' section, where background information could be gathered. Guides were tailored to the population group and themes being investigated at each stage.

Having identified two suitable research sites in the central region and having sought access and permission to carry out research there, a total of 65 interviews were set up and carried out over the period April – August 2001, with community members (n=47), HCWs (n=12) and traditional healers (n=6). More detail about the site selection is included in section 3.4 of this chapter, with further detail about seeking access given in Section 3.5.

The author carried out each interview, using a prepared topic guide and with the assistance of an interpreter, Peter Kumwenda, in the local language ChiChewa. Respondents were informed about the purpose of the research and their verbal consent

was sought, while their freedom to stop at any time was made clear. With permission, recordings were made. While health staff or local leaders assisted in setting up each meeting, owing to confidentiality only the author and the interpreter were present for the session, and, at the end, an opportunity was given to the individual for their specific questions and clarification regarding the research.

Analysis: Each interview was recorded using a mini-disc recorder and professional microphone. Each disc was transcribed, as far as possible on the same day of the session, if not the same week. Following word-for-word transcription of the English sections, discs were handed over to the interpreter for transcription of the Chichewa segments and direct translation of highlighted key words and phrases.

Analysis was carried out by the author using an indexed framework, devised based on the initial topic guide and according to recurrent themes and issues that arose during the discussions. Having indexed (coded) all transcripts, the resultant themes were recorded on charts, and then summarized in a masterchart, prior to the writing of a preliminary report of findings.

3.3.7 Key Informant Interviews

Rationale: Key informant interviews took place in two phases. Upon arrival in Malawi and within a month of starting work for the NTP, a series of 'stakeholder' interviews was initiated. This was part of the attempt to compile a comprehensive profile of the NTP's current outlook and activities, to assess the NTP's future IEC 'vision' to direct the development of a future IEC strategy and to provide preliminary data on the themes of knowledge and communication to guide further research. The second phase took place in the last month of fieldwork, having completed the community-based qualitative work. This was to try and triangulate findings through interviews with a wider group of key informants, who would have relevant insights and opinions relating to the provision of health services in Malawi, both relating to TB and beyond. Respondents included local leaders in the two study settings; members of the NTP at both national, regional and district level; members of the Lilongwe District Health Office; representatives of civil society organizations active in the area of rights to health and healthcare provision in Malawi; representatives of WHO and other international donor organizations.

<u>Process</u>: For both stages, sampling of key informants was purposive, identifying key personnel in NTP's Central Unit in the first phase, in order to gather data that could be said to represent the views of the NTP. And selecting key figures in the study settings and across government, donor and civil society arenas for the latter stage.

Semi-structured interviews of approximately one hour in length were conducted, following a pre-prepared topic guide for question areas. The language of interview was English in all cases. Most (though not all) interviews were recorded with permission and transcribed in order to prepare them for analysis. Others relied upon note-taking only.

<u>Analysis:</u> Analysis was carried out by the author using an indexed framework, devised based on the initial topic guide and according to recurrent themes and issues that arose during the discussions. Having indexed (coded) all transcripts, the resultant themes were recorded on charts, and then summarized in a masterchart, prior to the writing of a preliminary report of findings.

3.4 QUALITATIVE STUDY SETTINGS

3.4.1 Selection of sites

Having carried out the first phase of fieldwork nationally, findings were then used to identify themes for further in-depth exploration in two particular study settings: one urban poor, one rural poor. For reasons of accessibility, these settings were in the central region, Lilongwe district, but satisfied certain deliberate criteria in their selection. Lilongwe district carries the highest burden of TB throughout the country, with 1999 data showing 4,454 cases within the district. Both were demonstrated to be poor, based on available data from the Integrated Household Survey (NEC 2000; NEC 2001; NEC, NSO et al. 2001) and Malawi Population Census (NSO 1998).[64] Access to private piped water (in the urban setting) and education/literacy levels were

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[64] In the poverty mapping analysis carried out by NEC, Lilongwe rural was shown to have 79.4 per cent of its population as poor, and Lilongwe urban 45.5 per cent. The poverty headcount of the two selected research areas (by Traditional Authority and urban administrative ward) were 85.2 per cent and 50.3 per cent respectively.

taken as proxy indicators of poverty levels.[65] Both were areas in the southern part of Lilongwe district, for a degree of comparability between urban and rural locations. Both were within the catchment area of established public healthcare facilities, but also had both a range of traditional and private providers offering their services locally.

Lilongwe district is divided into two parts: Lilongwe Urban and Lilongwe Rural. For purposes of primary health care delivery and local government organization, the two parts come under separate administrative structures, with the Lilongwe City Council in the urban areas, and the District Assembly and District Health Office managing rural concerns. However, this decentralization of administration, at the time of carrying out research, was a fairly recent phenomenon that had yet to be strictly clarified, and so there were concerns about respective responsibilities, many overlaps and noticeable gaps. Central government remained responsible for the bulk of most service provision across the district.

The total population of Lilongwe district was estimated by the District Health Office to be 1.4 million in 2000, with a conservative annual growth rate estimate of 1.6%. Of that, approximately 500,000 are within Lilongwe Urban.

3.4.2 Gaining access and securing collaboration

Negotiation of access is a critical part of carrying out research in any location. For this study, access needed to be agreed both formally and informally: formally in the sense of seeking official permission and ethical clearance to carry out research, from the Malawi Health Science Research Committee (see section 3.4); and informally through seeking collaboration with key 'gatekeepers' in the relevant areas.

For the urban study setting, Area 24 of Lilongwe, also known as Ngwenya, access was sought via a meeting with the traditional chief and group village headman, Chief Joshua – known already to TB Equity Project via earlier research experiences – to

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[65] Analysis of the IHS data showed a strong correlation between high levels of educational attainment and being non-poor. "High educational attainment is probably an important determinant of the fact that one is non-poor... Consumption levels go up with increasing education, while all poverty measures consistently go down. Education of the head of the household would appear to be one key determinant of whether a household is living in poverty or not." (NEC 2000: 20)

discuss the research and the possibility of working in his community. Having secured his agreement and that of the area's sub-chiefs, interviews were organized with his assistance. A few days in advance of the interviews, a visit would be made to the Chief, to outline the types of individuals to be met. Based on purposive selection, according to different criteria supplied by the author (i.e., age, sex, occupation), the Chief would then identify volunteer members of the community and facilitate their choice of location for the interview – usually their home, or the chief's compound.

For the rural study setting, a different means of access was negotiated. Initial contact was made via the National Initiative for Civic Education (NICE), a civil and political rights organization created with the advent of multi-party democracy in 1994. Since that time, NICE has developed into a key non-governmental institution promoting democracy and civic education across all of Malawi's districts, via a network of offices in the district headquarters, staffed by both rural and urban officers responsible for community mobilization and education. Owing to NICE's well-developed links with traditional leaders in parts of Lilongwe Rural, contact was made with their representative Blessings Nkhoma, who facilitated a meeting with one of their officers in the area of Nathenje, a trading post located approximately 30kms from Lilongwe city, to discuss 'entry' to the surrounding rural community.

During early discussions, the NICE officer in Nathenje handed over responsibility to staff based at Nathenje Health Centre, in particular Mr Charles Benala, Senior Health Surveillance Assistant. Owing to Mr Benala's recent laboratory training under the NTP, the assumption was that he would be the appropriate contact person for TB oriented research and would be able to facilitate interviews, using the network of field-based Health Surveillance Assistants (HSAs) located throughout Nathenje's large rural catchment area.

Therefore, in contrast to the access via local political 'gatekeepers' in Lilongwe Urban, rural access was gained via local level health service infrastructure. As in the urban location, however, selection of respondents was made according to purposive criteria and would be communicated in person to Mr Benala some days in advance. Volunteers would be sought by HSAs in their respective villages, and meetings set up at the respondents' homes.

Both these means of access had inevitable limitations. As Jan Breman (1985) has observed, following extensive fieldwork in rural India, "when introductions take place via the locally powerful, such research faces formidable obstacles: both because of the mistrust of the poor and the opposition of the dominant classes." While his setting in the Bardoli area of Gujarat state can be seen as an extreme example, being an area of stark local inequalities between landowners and the landless, with strict social and economic demarcation influenced by both caste and control of the means of production, the issues he faced also have relevancies elsewhere – including Malawi.

The decision to gain 'entry' via local leaders in Malawi held inevitable risks, with the researcher perhaps being seen to take 'sides' with the local elite. However, in the urban setting, where provision of services is managed by local leaders, where few alternative networks of power exist and where the study area was relatively small, such an approach was unavoidable from a practical point of view. In addition, while chiefs in such an unplanned urban setting are accorded respect and the many 'informal' benefits of status, the financial benefits, while present, are not as stark or obvious as in the Indian setting. Life is harsh for *all* in Ngwenya. The chief's house may be marginally more comfortable, his diet slightly more stable, his opportunities for income generation more frequent, however, he is not distinguished by considerable material wealth.

However, in spite of this, it would be naïve to imagine that his position within the community is neutral in any way. And therefore, association brought risks. The alternative risk however – other than not finding appropriate means of access – was possible obstruction by these locally powerful, should their cooperation not have been sought. In addition, it would have been impossible to completely circumvent the local chiefs, owing to their central position to both social and political organization in the area and therefore, some sort of cooperation was essential.

Interestingly, in the rural setting, owing to the larger geographical area, and an alternative network or infrastructure (health services), local chiefs were not the main means of access. While their agreement was, by necessity, sought, arrangements were not made through them. However, the alternative choice held its own risks, in the

researcher being associated with the government health service and the medical establishment, as perceived by the local community. Such a perception could then influence respondents who felt that they must demonstrate 'sympathetic' views of the public health service, in addition to 'correct' clinical understandings around health.

In both settings, urban and rural, the author attempted to limit such biases through a clear explanation of her role and purpose, through a slow build up of questions in the interview encounter, allowing the respondent to lead the discussion as far as possible, once they felt comfortable. Interviews were also sought with a cross-section of individuals, including both young and old, men and women, and with those who openly sought care with a variety of health care providers, in addition to interviews with those working in the government health service and those engaged in the informal, traditional sector.

The urban setting - Ngwenya: Area 24, otherwise known as Ngwenya, is located within the Traditional Authority of Tsabango, in Lilongwe city. The Lilongwe City Council classifies residential areas according to the type of housing found there, using the following categories: low density planned housing; medium density planned housing; high density permanent housing and high density housing traditional. Area 24 falls within the last of these categories, being considered traditional, informal and unplanned – a socalled 'squatter settlement'. As Mr Mumba of the City Dept of Planning and Development put it, "Five years ago it was bush."

In fact, this is not strictly true, as 5 years ago, there was already a quarry run by an international construction company, mining stone in the area. Following the company's withdrawal, the deserted land started to be occupied by migrants from all over the country, coming to the city and seeking land upon which to build and rent homes.

As Ngwenya is a traditional housing area given a 'layout' classification by the City's Planning Department, it is thus not provided with services by the City Council. The Council sees its role as merely to 'facilitate' such an unplanned area to be capable of managing its own services and improvements, through NGOs, CBOs and parastatals,

'when funds become available.' (Council 1992) Thus, with some irony, the poorest areas are expected to meet the costs of their own services.

In the past 5 years, Ngwenya has grown exponentially, with the continuing increase in migrants coming to the city. While its population comprises a mixture of ethnic groups (Yao, Tumbuka, Lomwe, Chewa, Ngoni, etc), the dominant majority are the Yao from the south, traditionally considered more mobile and commercially oriented traders than their northern compatriots. It is also notable that the ruling government party, the UDF, is associated with the south and the Yao ethnic group in particular.

Services have not however grown to meet the needs of the expanding local population (estimated at 25,000 in the 1998 Census). There are no public health facilities in the immediate area, although Ngwenya is considered to be within the catchment area of Kawale health center, some 6kms away. Until this research started investigating, there was no community health worker (HSA) active in the area. Until recently, there was no primary school, although a new building has recently been completed and opened. There is no piped water and community members have to organize to drill their own wells, paying contractors to do so. Roads are untarred and public transport is via private minibuses, ploughing set routes into the city center at a cost of approximately 20 kwacha one way (in 2001, U$1 was equivalent to 85 kwacha).

In terms of economic and income generating activities, some people are involved in agriculture and grow maize, beans and potatoes on tiny pieces of land neighbouring their houses. Others are involved in small-scale businesses such as selling second hand clothing or groceries. Perhaps the most common form of income generation is the crushing and selling of quarry stones and other casual labour, paid by the day or task, and known as 'ganyu.'

The rural setting - Nathenje: Nathenje is a trading post within the Traditional Authority of Mazengera, located approximately 30km from Lilongwe city along the southern Blantyre road in Lilongwe Rural. At this trading post, the Ministry of Health and Population operates a primary health center, offering both dispensary and maternity facilities to a rural catchment population of 92,711 – the largest population of all rural health facilities in the district – living in over 400 villages. The center is

staffed by one medical assistant, supported by two Enrolled Nurse Midwives, and thirty HSAs, the majority of whom are stationed out 'in the field.'

Most families in the Nathenje area – and indeed, across Malawi where over 85% of the population is rural – are smallholder subsistence farmers. Cultivation is manual, by handheld hoe, with the principal crop being maize – the household's main food and staple diet of the region. Cash income is low, generated by sales of supplementary crops, such as burley tobacco and vegetables, as well as maize. As the maize harvest rarely lasts a household for the entire season, most families are also purchasers of the crop in the 'lean' pre-harvest period. Poorer households supplement their agricultural cash income through 'ganyu' or piecework, for cash or food.

Unlike the migrant population of the urban areas, the ethnic composition of Nathenje is almost entirely Chewa, the main tribal group of the central region. Services are the responsibility of central government and the district assembly.

Housing is organized in traditional villages of thatched, mudwalled houses, built up around family lineages. Other than the main Blantyre road, off which the trading post itself is located, the roads in the area are untarred tracks and cycle paths. Principal forms of transport are foot, bicycle and oxcart, with minibuses available on the tar road into the city.

3.5 ETHICAL PRINCIPLES AND PERMISSION SEEKING

Ethical considerations are a vital part of any research. In the UK, the Economic and Social Research Council (ESRC), the main funding body for social science research, is sponsoring a project shared by York and Oxford Brookes Universities to develop a framework for social science research ethics, in order to document and institutionalize 'best' practice in UK academic institutions. While no mandatory rules exist[66] requiring social researchers to observe particular practices, there is wide agreement in academia that any research involving people – and not just medical

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[66] Note that there is different practice in the medical and social science research communities, in part owing to the nature of respective research methodologies. While medical research bodies typically have ethical committees who must review and approve all proposed research, social science research is not subject to any mandatory or imposed standards. There continues to be an active debate on issues such as covert research and the principle of informed consent, and the extent to which guidelines can and should be followed, in the light of a study's methodology and aims (Gilbert 1993).

research – is duty bound to 'do no harm' (Booth, Colomb et al. 2003 (1995 first edition)). Detailed guidelines for ethics in research are available from the UK's Association of Social Research and British Sociological Association. Existing ESRC guidelines encourage honesty, confidentiality and impartiality as guiding principles for ethics in research. For this study, clearance was sought at the appropriate institutional level in-country, through the Malawi Health Science Research Council, prior to any community-based fieldwork taking place – both for the IEC strategy needs assessment and this linked PhD.

However, ethics are not restricted to this formal authority, but also extend to the treatment and handling of all participants in the study. The overriding principle is that any participants should not sustain harm as a result of cooperating in the study, and also that informed consent should be given by each (Bowling 2002). The author was mindful of observing accepted protocol in this regard, by informing participants fully as to the nature of the research, obtaining their explicit consent, outlining their freedom to withdraw at any stage and maintaining strict confidentiality throughout the process.

While all data and recordings made will be kept for a period of 3 years after completion of this thesis, identifying codes have been used, so as to maintain confidentiality.

3.6 DISSEMINATION OF FINDINGS

Relating to the ethical principles outlined above, dissemination of findings was felt to be one way of increasing the trustworthiness of the data and involving participants in this process. It was felt to contribute to reliability by feeding back to community and staff members, to assess whether they were satisfied with the accuracy and representation of the data. In addition, the dissemination methods chosen involved presenting findings to peer review in national and international settings, for critical comment and discussion.

At the community level, in both sites of Lilongwe district, dissemination days were organized, involving local 'gatekeepers' and community members in the planning process. In Ngwenya, discussions were first held with Chief Joshua and the sub-

chiefs, reviewing the main findings with them, and consulting them as to the most appropriate way to organize dissemination in their community.

Drama was agreed upon as both an entertaining and informative medium, and so, two afternoons were planned, in different parts of Area 24, during which a themed drama written around the research findings, would be acted out by a local, popular drama group (the 'Paulendo' drama team). Following this, group discussions with the audience would be facilitated by the chiefs, with the researcher observing, and a final element would involve questions and answers directly to the researcher. Contact was made with a drama team, guidance given as to the themes to be included, rehearsals were overseen and dates set for performance.

This took place successfully over two consecutive Saturday afternoons, in the early part of 2002, some months after completion of the last interviews (see photos in Appendix 2). The first session was held in the grounds of the former quarry – a recognized public space for community events. The second session took place in front of the new primary school, along a main thoroughfare to the market.

In rural Nathenje, a similar process was adopted, working with health centre staff in the planning and organization of a day for dissemination. A Tuesday was selected, as this was local market day, when people come to the trading center from the outlying rural areas. As no drama groups existed locally, the health center agreed to using the same urban group, Paulendo, and a similar afternoon of themed drama and group discussion was held first of all in the health center grounds, facilitated by HSAs, rather than by Chiefs – although their permission had been sought and they were in attendance. This was then repeated next to the market in the trading center. In this way, as wide a local audience as possible was attracted, with mainly women and children at the health center, and a wider mix, including young men and traders at the market site. In addition, following these community-oriented dissemination activities, further discussion took place with assembled staff members at the health center, feeding back findings to them from their own FGDs and interviews.

At national level, the first stage of dissemination took place after the focus group discussions had been completed and analysed. This was in the form of a workshop,

organized as part of the NTP's IEC strategy development, at which oral Powerpoint presentations of findings were made to NTP stakeholders, including District TB Officers from the four districts where fieldwork took place. Plenary discussion sessions allowed opportunity for comments and discussion of accuracy and relevance. In addition, copies of final findings reports were circulated to all participating health centers with feedback requested.

Further presentation of preliminary findings was made at the annual March Review meeting of the NTP in 2001 and final findings at the Gender and Equity in Health Conference, held in Lilongwe in February 2002, to local and regional audiences of up to 150 people. At the 32nd Annual Conference of the International Union Against TB and Lung Disease (IUATLD), in Paris in November 2001, a poster presentation of the first stage of the needs assessment was accepted for display and discussion, and was thus seen by a wide international audience of several thousand. During 2002, abstracts for presentation were (successfully) submitted for consideration to the Anthropology and the Health of Populations Conference, held in June 2002, and the 33rd Annual Conference of the IUATLD, held in October 2002 in Montreal, Canada.

3.7 QUALITY ASSURANCE

As already outlined, dissemination of findings at all levels from the grassroots to international academia, was considered one method of quality assurance. However, for each methodology adopted, quality was considered throughout the investigation and accepted 'best practice' was followed, in terms of appropriate steps, wherever possible:

- triangulation of different methods (qualitative and quantitative) and data was used to increase reliability of findings and reduce bias;
- in qualitative techniques, the principle of 'saturation' was employed, carrying out discussions and interviews until no new material was emerging;
- through long-term participant observation, 'reactivity' on the part of the 'observed' was reduced;

- through 'conscious' awareness, observational bias on the part of the author - though to a degree unavoidable - was reduced through reflexivity and critical analysis of notes

- an experienced interpreter was identified through a personal recommendation, and was thoroughly briefed as to issues of appropriate practice, ensuring ethical principles were accepted and clearly understood;

- the same interpreter was used throughout the fieldwork process, to ensure a comfortable working relationship and familiarity with the issues;

- topic guides were piloted before use;

- with each participant's permission, data was recorded and then transcribed as soon as possible after the interaction, with a proportion of scripts checked by independent peers;

- quality recording equipment was used and checked on a regular basis;

- early analysis of preliminary data was carried out to allow iterative revision of topic guides where necessary

- for the KAP survey, the questionnaire was informed by qualitative findings, and piloted twice before use, with revision at each stage

- all questions were translated into Chichewa and back-translated to check meaning

- quantitative data was double-entered and cleaned thoroughly before analysis

However, despite taking such steps to assure quality, the research was subject to some unavoidable limitations, which are worth describing.

- having a full time position within the Malawi NTP had clear benefits in terms of participant observation within the programme, and access to government and donor circles. However it introduced limits in terms of the community-based work. A sympathetic line manager ensured significant regular periods of protected time in the field, however this research in the urban and rural settings, while necessarily 'applied,' was, in some ways more 'extractive' than originally hoped for. Had the author not had additional work commitments, more time overall would have been spent in each setting, observing and

participating in day-to-day life, and using such time and familiarity to further mitigate the biases that entry via local gatekeepers introduced

- in an increasingly tense political environment, which developed as the fieldwork period progressed, working with the local chief as entry point in Ngwenya had the advantages of ensured, sanctioned access by the locally powerful, but the disadvantages of the link with local politics and a particular 'side' with government connections

- similarly, working with MOHP staff as entry point in Nathenje had the advantages of ensured access to a broad rural catchment area, but the disadvantages of the link with public health facilities and a particular 'medical' association

- while an appropriately skilled, sensitive interpreter was identified, the process of on-the-spot translation, and working in two languages also brought inevitable limits. While basic language capabilities on the part of the author enabled some breaking of barriers and allowed her to follow the interpreting process carefully, ensuring it was comprehensive, the subtleties of language could easily be lost and the clumsiness introduced by this process was not ideal. Using an interpreter introduced an additional barrier, which could interrupt the flow of conversation, and also served to highlight the researcher's distance.

As a last observation relating to methodology, the delay between conducting of fieldwork in 2001 and the completion of this thesis in 2004 has in many ways been a productive one. When work on this study began in 2000, the Malawi NTP was regarded as a 'model' TB Programme, for its commitment to delivery of DOTS (and, indeed, in its original part in development of that very strategy). However, as noted already, the TB indicators in Malawi were grim, and stood in sharp contrast to this accolade.

In 2004, the Malawi NTP, while still committed to DOTS, is now regarded as a model and pioneer for other reasons: in particular for its attention to the relationship between TB and poverty, the use of social science research in unpacking this relationship, and the responsiveness of policy makers in piloting new initiatives.

This thesis seeks to provide an examination of part of its journey. It argues why a new approach to TB is needed; gives contextual evidence to support this; and shows the difficult process of how to get there, as demonstrated by the Malawi experience. It is hoped that other TB programmes, and health programmes in resource-poor contexts everywhere, may learn from this story, that they may appreciate the value in not only listening to their clients, their patients, their health workers and their public, but in then responding to them.

CHAPTER 4: TUBERCULOSIS IN MALAWI – SETTING THE SCENE

INTRODUCTION

This chapter introduces the issue of tuberculosis, including its critical relationship with HIV/AIDS and poverty, both relevant concerns in the Malawian context. It then fleshes out that Malawian context, giving a brief background to the country and an overview of the health situation, health service provision, and TB control provision. The issue of TB control is taken a step further in the following Chapter 5, which presents a critical analysis of the global development of today's TB control framework and the implementation of such a framework at the policy level in Malawi.

4.1 TUBERCULOSIS

In recent times, tuberculosis, or TB, has evoked images of a *distant* historical disease, often based on the dual narrative of either the idle, consumptive rich, or the slum-dwelling, infected poor of the nineteenth century (Herzlich and Pierret 1987); a disease which has now largely been controlled and no longer concerns us or affects our every day lives. However, this perception is very much a false one, as shown in the resurgence of TB epidemics in urban centres of the developed world, and its persistence throughout many developing countries. Public health specialists agree that, once again, TB is a very real threat to millions of peoples' lives (Kemp 1999; Netto, Dye et al. 1999; Porter and Grange 1999; Gandy and Zumla 2003).

However, for most of the world's population TB has *not* been a distant disease nor has it 're-emerged.' In fact, TB has persisted in causing suffering and death in the developing world, yet, in spite of this, has long been neglected on the international health agenda. Only recently, and perhaps with the growing realization that communicable diseases are without borders and that such suffering, death and *cost* can also touch the developed world,[67] has TB once again hit the news and been prioritized on the global health agenda.[68]

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[67] As in the New York 'outbreak' of TB in the 1980s-90s, and also similarly increasing TB in the UK (Bhatti, Law et al. 1995; Tulsky, White et al. 1999; Barr, Diez-Roux et al. 2001).
[68] For example, with the setting up in 2001 of the (UN proposed) Global Fund to fight AIDS, TB and malaria (GFATM).

Recent estimates show that TB contributes to a massive burden of ill health worldwide, causing somewhere around 8 million new cases each year, with 1.8 million deaths (WHO 2002). Eighty per cent of these cases are to be found in just 22 countries, themselves to be found in South Asia, sub-Saharan Africa and Eastern Europe. TB remains the leading infectious cause of adult death in the world.

Table 2:Estimated TB incidence and mortality across WHO regions, 2002

Estimated TB incidence and mortality, 2002						
	Number of cases (thousands)		Cases per 100 000 population		Deaths from TB (including TB deaths in people infected with HIV)	
WHO region	All forms (%)	Smear-positive	All forms	Smear-positive	Number (thousands)	Per 100 000 population
Africa	2354 (26)	1000	350	149	556	83
The Americas	370 (4)	165	43	19	53	6
Eastern Mediterranean	622 (7)	279	124	55	143	28
Europe	472 (5)	211	54	24	73	8
South-East Asia	2890 (33)	1294	182	81	625	39
Western Pacific	2090 (24)	939	122	55	373	22
Global	**8797 (100)**	**3887**	**141**	**63**	**1823**	**29**

source: WHO TB Factsheet 104, March 2004

In Malawi, these global statistics are clearly borne out. General health indicators have recently worsened, rather than improved (e.g., life expectancy and maternal mortality rate) and the overall health situation remains severely constrained, with the needs of a growing population as a considerable challenge for the future. TB remains one of the leading causes of death and cases have more than quadrupled in the last twenty years. Reported TB cases have risen dramatically from 5,334 in 1985, to 26,632 in 2002 (NTP 2002). There has also been a related decline in the national cure rate from 87 per cent in 1985 to 67 per cent in 2002 (ibid.). The deterioration is linked to continuing, and some would say increasing, poverty and also the spread of

HIV/AIDS. This thesis later discusses in more detail these and other contributing factors.

Table 3: Selected TB Indicators, as reported by WHO, for Malawi

TB in Malawi	1990	1995	2000	2003
Reported Cases total		19155	23604	25841
Cases per 100,000 pop		191	208	213
Estimated Incidence per 100,000, per year	263	390	419	444
Case detection (%)		39	42	35

Source: WHO TB database

Tuberculosis infection is caused by the bacteria *Mycobacterium tuberculosis* (tubercle bacilli) which mainly affect the lungs, but which can affect other parts of the body. Pulmonary (lung) TB (PTB) is the most prevalent form of the disease, spread though the air by close person-to-person contact, and, in cases of 'active' infection, is highly contagious. Although an otherwise 'healthy' individual can contract and carry the TB bacillus for years, in a dormant, inactive form (termed TB 'infection'), if that person's normal immune defenses become compromised in any way (ie: through malnourishment, exhaustion, another infection, or general weakness, etc), the formerly inactive bacteria will develop into active disease. Over time, this active disease will also become contagious, as the numbers of bacilli found in the lungs – and therefore coughed up with sputum – become more concentrated.

All types of TB in Africa are closely linked to both conditions of poverty and the development of HIV infection. Where people live in cramped or badly ventilated areas, with poor sanitation and susceptibility to a variety of illnesses, and where they may be over-worked in intensive and physically strenuous labour with poor nutritional status, an airborne infectious disease, whose development is assisted by the breakdown of one's normal immune defences, thrives. This situation is further complicated by the spread of the HIV virus, which attacks and disables the immune system. People who are HIV positive are more likely to develop the active disease than those who are HIV negative.

4.2 TB AND HIV/AIDS

In 2003, UNAIDS estimated that 38 million people worldwide were living with HIV/AIDS, including 2.1 million children. In that year, 5 million people were newly infected. Sub-Saharan Africa accounts for 25 million of the global total, with national prevalence rates now up to 38 per cent of the population (Botswana and Swaziland, UNAIDS, 2003): the region with less than 10 per cent of the world's population is home to almost 70 per cent of people living with HIV/AIDS.

In Malawi, most recent data indicates that there are 900,000 adults and children living with HIV/AIDS nationally (UNAIDS 2004). In 2001, an estimated 18 per cent of young pregnant women (aged 15-24 years) in the capital city Lilongwe were HIV positive.[69] National estimates indicate 15 per cent of the population aged 15-49 is infected with HIV, with 13 per cent sero-positivity in rural and 25 per cent in urban areas (Mwale 2002). AIDS is now the leading cause of death in the most productive age group (20-49 years). In 1999, there were 70,000 adult and child deaths due to AIDS (Malawi National AIDS Commission, 2001). By 2003, this had risen to 84,000 (UNAIDS 2003). HIV/AIDS related diseases such as tuberculosis and bacterial infections contribute substantially to AIDS related mortality.

These are alarming statistics, although today, in the context of southern Africa, they are tragically common. It is accepted that Malawi and other countries are facing a massive pandemic, the effects of which socially and economically are, and will continue to be, far-reaching and devastating. Even ten years ago, the Government of Malawi in UNICEF's Mid-term Review, called AIDS "a communication challenge, which will grossly overstretch the capacities of any real or imagined health system" (UNICEF 1994: 8). This prediction has been unfortunately accurate.

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[69] It is worth noting the considerable challenges that lie in accurately estimating seroprevalence data for HIV. The original reliance on reported or estimated AIDS cases and a back-calculation to estimate HIV rates has been discounted owing to the difficulties in obtaining reliable estimates of actual AIDS cases, and an appreciation that the HIV to AIDS ratio changes rapidly over time, depending on the 'maturity' of the epidemic. Different approaches are now used, based on sentinel surveillance techniques, with sample groups adjusted according to the nature of the epidemic. National, regional and local capacities for monitoring and surveillance at identified sentinel sites, and the associated quality of available data remains a challenge.

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Government data shows that awareness of AIDS is high amongst the public with 98 per cent of men and 95 per cent of women claiming to know of the condition (NSO 1994). More recently, 84 per cent of women and 89 per cent of men were reported as knowing that a healthy looking person can have the HIV virus (UNAIDS, 2003). In addition, it is reported that the majority of adults know that transmission of the virus is by sexual intercourse - heterosexual intercourse being the dominant mode of transmission globally. However, more critical investigation of the Malawi Demographic and Health Survey statistics shows that complacency should not be an option: while in a survey, interviewees might answer that they know about AIDS, what exactly this knowledge and understanding is, and how and whether it informs their sexual behaviour is an entirely different matter (Craddock 1996). In the same NSO report that recorded 98 percent awareness amongst Malawian men, 30 per cent of rural women stated that AIDS *cannot* be prevented (NSO 1994).

It is widely accepted that one of the reasons for the dramatic rise in incidence of TB in Malawi is the link with HIV/AIDS. Owing to their compromised immunity, individuals infected with the HIV virus are more likely to develop active TB disease than others (Girardi, Raviglione et al. 2000). TB is the most significant opportunistic infection of people with HIV/AIDS - yet, if identified early enough, the TB can be successfully treated and managed, enabling further years of life. In some countries in Sub-Saharan Africa, including Malawi, more than 70 per cent of patients with TB are HIV-positive (Raviglione, Harries et al. 1997; Harries, Hargreaves et al. 2001), with most TB programmes recording rising death rates, in line with the spread of HIV infection in the past 15 years.

TB control globally is based on the principle of reducing the number of *smear positive* active PTB sufferers. This approach was largely based on epidemiological evidence that detecting 70% of smear-positive, i.e., the most infectious patients, and curing 85% of these could reduce TB incidence by 10% per year – reducing TB cases and deaths by over 25 per cent in 10 years (Dye, Garnett et al. 1998). More recent estimates have posited a possible reduction in the TB burden of 50 percent in 10 years, if such targets are met (Dye 2000). With the advent of HIV/AIDS, however, in many of the same countries that already have high TB infection rates the increase in smear *negative* PTB has been considerable, in addition to the mortality rates amongst

those smear negative sufferers. This is not yet reflected in the goals of TB control, which continue to centre on the detection and cure targets for infectious smear *positive* cases. Not only are the targets prioritised in this way, but public funding too is reserved for treatment for smear positive patients, owing to the positive 'public good' externalities attached.

With the increasing dual burden of TB and HIV, however, smear negative TB is having an a increasing impact which cannot be ignored – not only in terms of the suffering, morbidity and mortality associated with it, but in the implications of smear negative disease for wider TB control. As those working with TB in high HIV-prevalence settings have observed, "HIV infection complicates the problem and adds its own set of difficulties to implementing the WHO-DOTS strategy" (Harries 2000). These complications are seen in a clinical sense, represented in falling cure rates through high HIV-related mortality, but are also affecting delays in diagnosis and quality of diagnosis and care for TB, all of which are related to factors both within the health system and in patients' own community settings (Harries, Hargreaves et al. 2001). Conventional diagnostic and treatment tools used in resource poor settings are less effective for smear negative TB, leading to an increasingly fearful response amongst a public who see more death, less treatment success and who are turned away from health facilities with incorrect diagnoses of 'no TB.'

One of the other related problematising factors in TB suspects coming forward for treatment, is the stigmatisation of HIV/AIDS in the wider community, and the close association between the two diseases (Kemp et al 2000). The stigma attached to HIV/AIDS has extended to TB at a time when the previous rejection of TB patients was reported as decreasing (DFID 1999). As the public become more aware of the link between TB and HIV, society is making judgments according to assigned stigma and portrayal of patients as 'perpetrators' rather than 'victims,' and this has led to danger of losing jobs, accommodation and friends, with significant economic and social costs to the sick individual. This potential stigma has prompted avoidance behaviours, such as care-seeking in the private and traditional sectors, where standards can be lower, but confidentiality more likely assured, or in non-compliance with resulting treatment.

There is also widespread fear and the belief that TB, like the HIV virus, is *not* curable. Owing to fatalism and a feeling that death is inevitable, people sick with what they fear is TB or HIV/AIDS, may not come forward for treatment. The TB/HIV relationship is thus something which cannot be ignored in terms of the potential degree of influence of this 'variable' on the NTP's aims and outcomes – not just in terms of the clinical and epidemiological implications of the HIV/TB relationship – which are well recognized – but in the wider social and economic implications. The multi-faceted impact of AIDS, in many ways, has therefore served to highlight some of the current weaknesses of accepted TB control methods (Girardi, Raviglione et al. 2000).

4.3 TB AND POVERTY

TB is not only a disease of the poor. However, the evidence available strongly affirms an association between TB and poverty and its disproportionate burden on both the poor countries of the world and on poorer populations, wherever they are situated.

More than 95 per cent of TB cases and deaths occur in the poor countries of the developing world (Dye, Scheele et al. 1999). In industrialized countries or wealthier urban settings in the developing world, TB typically affects poor and disadvantaged social groups in those wealthier areas, whether the US, the UK, the Philippines or the former Soviet Union (Spence, Hotchkiss et al. 1993; Tupasi, Radhakrishna et al. 2000; Frieden, Sterling et al. 2003). Studies in the UK have shown how London has overtaken New York as a centre for TB since 1996, with the determinants of disease found in "increasing wealth inequality and social deprivation, homelessness, co-infection with the HIV virus, migration, the neglect and consequent failure of public prevention and control services" (Story and Citron 2003:147). As Farmer has written, "the poor have no options but to be at risk from TB" (1997: 349).

A valuable illustration of the TB/poverty relationship comes from one country location where, unusually, systematic national prevalence surveys are conducted every 10 years (1979, 1990, 2000), including a socioeconomic profile of those surveyed. The fourth national epidemiological survey undertaken in China in 2000 (Ministry of Health of the People's Republic of China 2002) showed that over 80 per

cent of identified TB sufferers had a family income that was lower than the average for their communities. Notably, only about 40 per cent of those identified with TB through the survey had already been identified through routine TB control channels, i.e., a significant majority of TB sufferers were remaining undiagnosed and untreated in their communities.

The disparity between low case detection rates (30-50 per cent) and high cure rates (80 per cent) reported by the NTP in China is also indicative of the constraints on those suffering TB symptoms to initially access care. Specific categories of the population were identified in the survey as less able to access health treatment for TB, including ethnic minority groups, migrants, the uneducated, prisoners, those living in more remote areas, the elderly, and HIV/AIDS patients. These characteristics were associated with financial variables, such as income and access to health insurance coverage: the national TB prevalence survey showed that 92 per cent of the TB sufferers identified lacked *any* medical insurance. Geographical influences were also seen: the prevalence of pulmonary TB was higher in poorer western and central China than in wealthier eastern China. These aggregate differences, while indicative of macro level poverty differentials, also hide further urban/rural differences. Prevalence of active, sputum smear positive and bacteriological positive TB was consistently higher among village residents than the township or city residents.

The survey reported 1340 cases of TB nation-wide. About 35 per cent of these cases had *no* occupational income. 62 per cent of women were housewives reporting no income. Among those who had occupational income, more than 805 were involved in agriculture related work and almost all TB patients who had agriculture related occupations had no medical insurance. More than 50 per cent of female and 30 per cent of male TB patients were illiterate or semi-literate. Only about 1 per cent of the TB patients had education at college or above level.

While the Chinese prevalence survey provides a wealth of data typically unrecorded in other country settings, it also indicates the difficulties in actually measuring the TB/poverty relationship, owing to the multifaceted nature of poverty. Material deprivation is one element only, whereas social exclusion or cultural deprivation are

more difficult to account for, although often associated with material poverty. The China survey and its analysis attempts to combine both financial and non-financial elements, but a broader range of variables would ideally make up a composite index, including, as Hanson (2002) notes, not only income, but knowledge, nutrition, power and access limitations for poorer populations.

In her paper on tuberculosis, poverty and inequity, Hanson reviews the evidence for the association between TB and poverty at the macro societal level and at the household and individual level. As already suggested, she finds that evidence shows that the world's TB burden weighs most heavily on poor countries and that, within countries, TB prevalence is higher among the poor versus non-poor sub-populations. At the micro household level, however, she found that the existing literature is less conclusive in illustrating the association between poverty and an individual's risk of TB infection or disease. In US and Malawi based research, such an association was highlighted. However, in South African and Thai studies, no significant association was found. It is notable that all these studies were based on TB patients who had successfully obtained diagnosis and treatment, and that any undetected TB suspects were not included. It is difficult to evaluate whether those cases not accessing services are among the poor, though a reasonable hypothesis based on macro data might suggest that this is so.

Other Malawi-based research undertaken in the capital Lilongwe has investigated these so-called missing cases. In comparing notified chronic cough and smear positive rates in two adjacent urban areas, one a relatively comfortable planned settlement (Area 18), and the other an unplanned 'squatter' settlement (Area 56), the study found that notification rates were higher in the planned settlement. Given that the macro evidence shows TB prevalence to be higher amongst poorer sub-populations, a reasonable assumption was made that rates in the poorer area should be as high as the adjacent neighbourhood. Applying the rates from Area 18 to Area 56, it was found that 42 cases of smear positive TB were 'missing' from the poorer neighbourhood (Kemp, Mann et al. 2003). This may be considered a conservative estimate, which highlights the current failings of available TB control services in such poor areas.

Hanson also reviews the role of poverty as a determinant of TB and/or vice versa. Again, at a macroeconomic level, the strength of the association is illustrated in historical reviews, such as those looking at the former Soviet Union, South Korea or Europe, with levels of TB reflecting socioeconomic conditions and poverty indicators. While a direct causal relationship from poverty to TB is difficult to prove conclusively without large-scale longitudinal studies, nevertheless, various studies in diverse geographical locations affirm the relationship between TB and indicators of deprivation (Hanson 2002).

A study in Malawi identified 62 per cent of Lilongwe-based TB patients who had successfully sought care as 'poor'.[70] This was against the urban Lilongwe population poverty profile of 38 per cent (NEC, 2001). The same study also explored the role of TB as a determinant of poverty by calculating the costs to a patient of getting a TB diagnosis in Lilongwe. It was found that, for poor patients, total costs of seeking care made up 248 per cent of their monthly income, or 584 per cent after food expenditure. For non-poor patients, these figures were 125 and 176 percent. It should be noted that these costs occur in a setting where TB diagnosis is provided free in all hospital/health facilities. Nevertheless, the direct costs incurred (transport, food, fees and drugs) in combination with the indirect costs (approximately 20 days lost income) placed a significant burden on all patients. It can be seen that, even for the non-poor in a setting where TB services are 'free' the experience of seeking diagnosis and treatment for TB exceeds their available income, thereby causing an economic shock to the family. This shock is dramatically worse for the poor, thereby hitting already vulnerable populations and rendering them even poorer.

While the association between TB and poverty has been observed anecdotally and historically over time, at the time of commencing this research, it was notably absent from the international TB control policy agenda and in the design and application of TB control in practice. During the course of conducting fieldwork in Malawi and in subsequently writing up, changes have been emerging in the rhetoric, and, slowly, the actions of the global TB institutions – as seen in the Global Stop TB's Symposia

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[70] A poverty assessment tool based on regression analysis of the 1998 Integrated Household Survey was applied to the random sample of 179 TB patients to classify them as poor (few assets, food insecurity, unskilled labour and piecework, poorly constructed housing) and non-poor (food secure, regular income or employment, better housing).

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on TB and Poverty. This is owing to the increasingly vocal call from a number of TB specialists and, in part, to the very particular Malawian experience.[71] The following chapters and analysis record and present a critical transitional stage in the TB and poverty agenda, as reflected in the Malawi TB Programme.

4.4 TB CONTROL IN MALAWI

In Malawi, the National Tuberculosis Control Programme's (NTP) stated aims are to eliminate TB as a major public health problem in Malawi and to reduce the burden of ill health due to tuberculosis in the population of the country, through improved case detection, quality of diagnosis and TB treatment outcomes (Salaniponi, Kwanjana et al. 2000). These aims and means are based around the internationally accepted principles of TB control – about which more will be written in the following chapter.

Briefly, however, the two main problems acknowledged by the biomedical community in TB's rapid spread are *delay in diagnosis* and *(non) adherence to treatment*. The delay in seeking diagnosis and treatment leads to an infected person remaining in the community, suffering longer themselves, and spreading the infectious disease to greater numbers of people.[72] For TB, the prevailing approach to 'case-finding' (i.e., identifying cases of active tuberculosis as early as possible) is 'passive.' This leaves the initiative to seek care for suspected TB with the individual, rather than using active tests for TB amongst local communities.

The problem of adherence to treatment is a widely debated issue, blamed on a range of related factors; one of which may be the fact that treatment must be continued for a period of *at least* six months,[73] and that each – often daily – dose may be as many as ten or fifteen tablets. As with all antibiotics, even when the patient feels better, the therapy must be followed completely, and if not, the disease will return in more virulent, drug resistant varieties (the worst of which is MDR TB – multi drug resistant

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[71] http://www.healthinitiative.org/html/conf/paris/
[72] The average number of people infected by one infectious patient depends on location and varied socio-economic factors (e.g., living conditions). The figure – known as the 'contagion parameter' – may vary from 2-20 persons (Porter and Grange 1999).
[73] In Malawi, the current standard regimen lasts for 8 months.

tuberculosis, when the bacillus is resistant to two or more of the regular treatment options[74]).

This focus on adherence presents a dual problematic: first, the fact that it is the main issue prioritised and, secondly, the subsequent approach to that issue. On the one hand, the focus on adherence alone may be questioned, given that it tends to lay the blame exclusively at the patient's door and shift attention from other aspects of TB care and control. On the other hand, if this is accepted as a key issue by the TB community, the lack of research attention given to the influences on patient adherence is equally problematic. The success of both passive case-finding and treatment adherence are closely influenced by peoples' behaviour and actions, in addition to the wider socio-economic and health service environment that enables or constrains those actions. Yet those influences and environments have traditionally received little attention by the TB research community. Even the expected search for a biomedical technique or 'cure' to regain control of the disease, "a pharmacological solution to a far more complex problem", (Rubel and Garro 1992: 627) has been surprisingly limited – owing to the political economic reality of pharmacology businesses largely uninterested by a disease of poverty.[75]

Nonetheless, as this thesis commenced, a number of researchers were attempting to shift the TB control focus, calling for a wider inter-disciplinary perspective to complement that of biomedicine (Rubel and Garro 1992; Liefooghe, Baliddawa et al. 1997; Vecchiato 1997; Ogden, Rangan et al. 1999) reviewing both the principles of TB control and the contexts in which such principles are implemented. Malawi presents a unique case study for how and whether a traditional public health programme is incorporating such calls in their work.

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[74] The fear and danger of MDR TB, written about extensively by Paul Farmer (2003; 2001; 1999), was recently highlighted in a national newspaper article in the UK's Guardian (Bird 2003) and in the book 'The Return of the White Plague' (Gandy and Zumla 2003).

[75] As Trouiller and Olliaro put it, "few [drug] developments are need driven." The average cost of developing and marketing a new drug is U$ 224 million. The view of pharmaceutical companies is that such costs would not be recovered for diseases endemic in the developing world, where countries are not rich enough to buy them and cheaper generic versions would enter the market (Trouiller and Olliaro 1999).

4.4.1 The Malawian Context – Geography and administration

Malawi lies in southern central Africa, to the east of Zambia, south of Tanzania and to the north of Mozambique. A landlocked country with no maritime coastline, it does however contain the sizeable freshwater Lake Malawi. Its total area is approximately 120,000 sq. km of which 24,400 sq. km is lake water. With a current population estimate of approx. 12.3 million (UN 2004), it is a small but densely populated state.

Administratively, Malawi is divided up into the Northern, Central and Southern regions, which are further divided into 27 districts: (6 in the north, 9 in the central region and 12 in the southern region).

These districts are sub-divided into 'Traditional Authorities' (Tas), headed by a chief, who holds legitimate authority directly under the Office of the President. Such local government organization has been maintained in various differing forms, from before Malawi's days as a British protectorate when the colonial administration "maintained the power of traditional authority, even while subordinating it to the colonial bureaucracy" (Cross 2001), to the period under the dictatorship of President Banda, which further verticalised the nature of political power, and incorporated the patrimonial authority of chiefs within the party-state's similar approach of elite control (ibid.).

In spite of the new spirit of multi-party democracy introduced in 1994, many old structures remain or are re-emerging. Traditional authorities retain their position and have been incorporated into recent plans for decentralization, passed in the Local Government Act of December 1998. This proposes nationwide decentralization of administrative authority to the district level, with the creation of multi-sectoral District Assemblies (Das), who will ultimately function as complete local government institutions, with autonomous planning and budgeting capabilities. At present, while the new Das are encountering challenges in function, capacity and structure (ibid.), Tas and the network of group and village headmen over whom they hold authority have enduring legitimacy at the village level, maintaining their role in mobilizing their communities and their ability to thrive despite the changes being introduced around them. Villages are the smallest administrative units.

Figure 3: Map of Malawi showing Administrative Districts
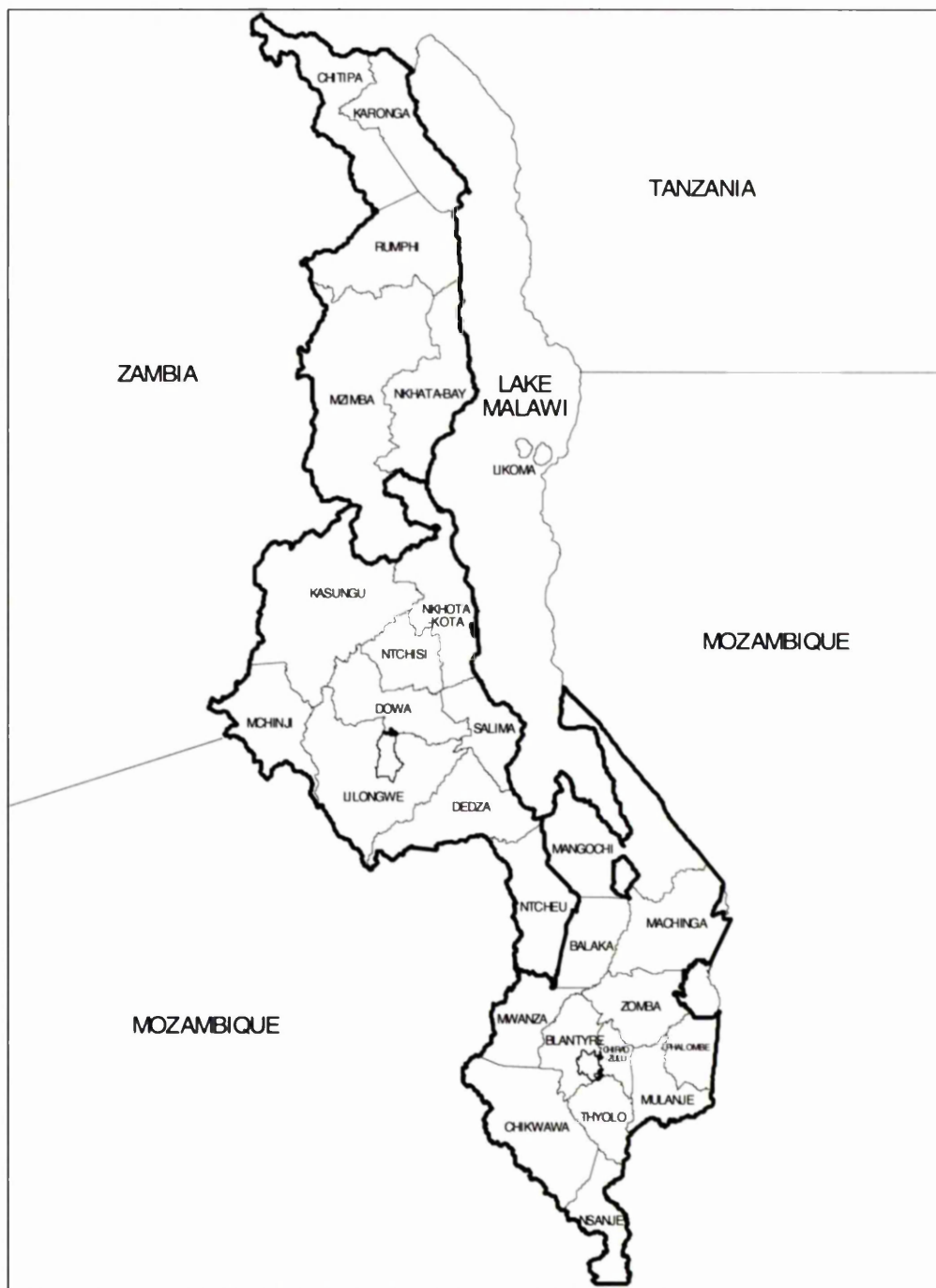
Source: NTP 5 Year Development Plan 2001

With its high population density, pressure on land and environmental resources in Malawi is fairly significant. 40 per cent of the land is reported to be suitable for agriculture (FAO), and this is primarily divided between family smallholdings (maize, cassava, tobacco) and estates (tea, tobacco, and sugar). Approximately 1,400 estates cover 9 per cent of Malawi's land area (850,000 ha); with more than half of all smallholders occupying less than one ha of customary land (NSO 1998). Land tenure is principally along customary lines – controlled by the chiefs – but this system is coming under pressure to change, owing to the effects of high demand, environmentally degraded land, and resulting threats to security of tenure in the struggle over productive land.

4.4.2 People

The people of Malawi are made up of several ethnic groups (Chewa, Nyanja, Tumbuka, Yao, Lomwe, Sena, Tonga, Ngoni, Ngonde) owing to regional migration and settlement said to have begun in the 16th century (Peltzer 1987). White settlement dates from the founding of a Mission in Zomba district in 1861, and the founding of the colonial African Lakes Company in 1878, but today is a small population made up of those mainly involved in diplomatic, missionary, voluntary and agricultural sectors. In addition, there is a small, economically active Asian community.

The first population census for Malawi, post-Independence, was carried out in August 1966. At that time, the population was just over 4 million, and even then, the population density of 111 people per sq. mile was high, being exceeded by only 3 other African countries (Rwanda, Burundi and Nigeria) (Msukwa 1981). Since then, population growth rates for Malawi have remained high, and today's estimates are around 2.0 per cent (MDHS 2000). Population density is now 105 per square *kilometre,* with 14 per cent of people living in the urban areas and the majority as rural smallholders. The staple food crop farmed is maize, although cassava features in some localized areas.

The age structure of the population is heavily weighted to the young, with 45 per cent of the population aged below 15 years of age. Fertility estimates are high: 6.3 births

per woman (Malawi Demographic and Health Survey 2000) although this varies between rural and urban areas (6.7 / 4.5) and also with socio-economic status.[76]

The population is believed to be 55 per cent Protestant, 20 per cent Roman Catholic and 20 per cent Muslim, with other minority religions represented, in addition to traditional indigenous beliefs (mainly ancestral and animistic). Languages spoken include the two official ones of English and ChiChewa, in addition to many other regionally and tribally significant languages.

4.4.3 Political history

Following a relatively peaceful and brief political campaign, 'Nyasaland' attained independence from Britain in 1964 and formally became the Republic of Malawi. Hastings Kamuzu Banda, who had trained and worked as a doctor in the UK, became president, and his party, the Malawi Congress Party (MCP), established itself as the only party permitted. In 1970 Banda was elected 'President for Life' as part of an increasingly powerful concentration of power around himself and his party. The regime became more and more despotic and totalitarian, and human rights were systematically violated.[77]

Resistance to this regime grew gradually, but accelerated in the early 1990s, both internally and internationally. In 1992, the country's bishops catalysed the turning point in Malawi's political history, with the publication of a strong critique of the government, who responded with further repression and arrests of political antagonists. The donor community responded with holding back of assistance to the country and many international governments and donors totally suspended their assistance by 1993. Within Malawi, the opposition too came together and increased pressure until the President finally accepted that a public referendum would be held in June 1993, to decide on the introduction of a multi-party system. The result of this referendum was a strong 'yes' and preparation followed for Malawi's first free elections in May 1994.

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[76] Women with no formal education give birth to an average of 7.3 children, compared with 3.0 for those educated to secondary level or higher (NSO 2000).

[77] See Amnesty International reports: http://www.amnestyusa.org/countries/malawi/index.do and Article 19: www.article19.org

In these elections, three parties were elected to parliament, and a coalition government was formed between the United Democratic Front (UDF) with 84 seats, and the Alliance for Democracy (AFORD) with 38 seats, with the UDF's Bakili Muluzi as President. The MCP took up the role of opposition with 55 MPs.

In 1996, the UDF/AFORD coalition broke down and, prior to the 1999 elections, the UDF were the sole ruling party, with AFORD and MCP in opposition. In June 1999, after a somewhat bumpy lead up to the elections with allegations of fraud from the parties in opposition, Bakili Muluzi was returned to the Presidency.

Suffrage is now universal, at 18 years, and the normal term of office is 5 years. Malawi's relations with regional neighbours have improved significantly; international donors have returned with a significant presence; and freedom of speech, of the press and the assembly have been written into the new constitution, which was adopted in 1995. However, during Muluzi's second term, the political scene grew increasingly unstable, with in-party and inter-party disputes. Freedom of speech is felt by many to be rhetoric rather than reality. Parliamentary processes are still underdeveloped and underutilized, while the patrimonial model of presidential rule is increasingly demonstrated.[78] After a second term, in which little changed in Malawi and after a failed attempt to amend the constitution to allow him to stand for a third term, Bakili Muluzi stood down at the May 2004 elections. However, his nominated UDF successor, Bingu wa Mutharika, won the election – once again amidst allegations of fraud from the opposition.

Statements of concern are once again being published by the local clergy in local press, while some donors have made decisions to withdraw budgetary support, both as a critique of macro-economic performance by the government, and as an expression of governance concerns.[79] During the writing up of this thesis, the country has experienced significant food insecurity, following drought weather conditions and compounded by internal corruption in the handling of national grain reserves

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[78] For example, with the suppression of peaceful anti-government and third term protests in Zomba and Blantyre, where police fired on students, injuring several and killing one, in December 2001.
[79] Following an IMF decision to suspend programme aid in 2001/2, significant bilateral donors including DFID, NORAD, CIDA, etc, made the same decision. This pattern has recently been repeated in early 2004.

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(Devereux 2002; Kydd, Dorward et al. 2002). Life for the majority of the people does not reflect the optimism expressed in 1994.

4.4.4 Economic & Social Background

Malawi ranks among the world's least developed countries, with a GNP per inhabitant of U$ 170, and an unequal distribution of wealth seen in a Gini coefficient of 0.62 (World Bank 2002). By any measure, poverty is widespread. In 1990, the World Bank estimated that over half the population was living on an estimated annual income equivalent to U$40 per adult. More recently, the 1998 Integrated Household Survey identified 65.3 per cent of the population as poor (NEC 2000). This was based on an analysis of consumption and expenditure data to identify an appropriate consumption basket 'poverty line,' and then a comparison between such a poverty line and household income. The research also showed poor households to be larger than non-poor households, with a disproportionate number of female-headed households classed as poor, and the poverty headcount higher in rural areas.

Table 4: Poverty Indicators

	Poverty headcount (Per cent)	Per cent of Malawi's poor
MALAWI	65.3	100.0
Southern region	68.1	49.2
Central region	62.8	40.2
Northern region	62.5	10.6
Rural	*66.5*	*89.7*
Urban	*54.9*	*10.3*

Source: PMS Policy Brief no.2, I 1997-8

Social development indicators are poor with illiteracy estimated at 38 per cent (80 per cent amongst rural women), life expectancy of only 38 years and an infant mortality rate high at 113/1000 live births (World Development Indicators 2004). Overall, the country is ranked a very low 165th in the Human Development Index used by the UNDP.

Malawi's economy is predominantly agricultural, with nearly 90 per cent of the population living rurally. Tobacco is the main export crop – accounting for over 65

percent of export earnings (World Bank 2002) – supported by other industries, including tea, sugar, sawmill products and cement. Agriculture accounts for 45 per cent of GDP and 90 per cent of export revenue. The economy depends on substantial economic assistance from multilateral agencies and individual donor nations. In 2000, total economic aid (ODA) amounted to U$ 445 million (OECD/World Bank).

Under the former government of President Banda, official policy was to follow the principles of a market economy. In practice, the national economy was dominated by a group of monopolies controlled by the state, or rather Banda himself. Selected commercial farmers were favoured with land, credit, beneficial pricing policies and labour, while the peasant majority were left with little assistance, either technical or financial. In the 20 years following independence, estate production rose at a rate of 17 per cent per year, whereas majority smallholder production grew by only 3.2 per cent per year, a rate barely sufficient to keep pace with population growth (Malawi Social Indicators Survey 1995).

During the 1980s and early 1990s, the former Government agreed on a series of reform programmes with the IMF and World Bank. These programmes pointed in the direction of increased market liberalisation, but did not achieve much in the way of anticipated growth. From 1992, the economy was further affected by several factors: successive years of drought (1991/92, 1993/94); political pressures and changes during the transition to multi-party democracy and after; the flotation and devaluation of the Malawian currency, the kwacha, in 1994; and greatly increased inflation. Further agreements with the IMF and Bank have required deeper structural reforms, tighter controls on public spending, privatisation and public service retrenchment, and the aggregate affect of these measures, in addition to earlier state policies which left out the smallholder majority of the population, have impacted severely on the poor.[80]

In its more recent policies, the government's stated aim has been to alleviate poverty through changes in macroeconomic policy, with the setting up of a stable market-

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[80] Chinsinga writes that government expenditure declined from 36 per cent to 29 per cent of GDP between 1987 and 1996, while at the same time the debt-servicing burden doubled. He also notes that expenditure shares for education and health (social sector) reduced in the adjustment period (1981 – 1996) from 15.5 to 10 per cent and 6.53 to 3.17 per cent respectively. In addition, unemployment and prices of essential commodities rose (Chinsinga 2002).

oriented economy. In addition, the Government claims to be addressing anticipated problems, with increased efforts within the social sector and improved management of public spending. Indeed, there appears to have been an attempt to maintain recent social sector public expenditure – despite shrinkage in the overall national budget in real terms, with the depreciation of the kwacha, rising inflation and growing population.[81] However, capacity and impact has been limited in many areas, with recent years' erosion of public sector wages, and the impact of AIDS at an official level, leading to loss of key personnel and thus a weakened, understaffed public social sector.

4.5 HEALTH IN MALAWI

Health indicators in Malawi remain stubbornly poor, as the table below demonstrates:

Table 5: Health indicators

Indicator	1977 National census	1987 National census	1992 MDHS	1998 National census	2000 MDHS
Infant Mortality rate	165	159	134	121	104
Maternal Mortality rate	-	-	620	-	1,120
Life expectancy: Male: Female:	39.2 42.4	41.4 44.6	- -	40.0 44.0	- -
Crude birth rate	48.3	41.2	-	37.9	-
Crude death rate	25.0	14.1	-	21.1	-
Total fertility rate	7.6	7.4	6.7	6.2	6.3

Source: Malawi Demographic and Health Survey 2000

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[81] In FY 2001/2 the Ministry of Health and Population (MoHP) approved recurrent budget was MK3,340 million. Using MK75=1US$ this is US$44.5m. Assuming a population of around 11 million, this is US$4.04 per capita recurrent government expenditure on health. Adding in the 'development budget' for health (donor programme aid) of MK1,937 million, the total MoHP budget was around MK5.3billion, or US$70m, or around US$6.4 per capita. For FY 2002/3, the recurrent budget was approved for MK 3,600 million, but the development budget was lower at 943 million. However, if you look at the recurrent health *and* education budget for 2002/3, they together add up to MK8.66billion. The total discretionary recurrent budget (excluding statutory payments such as the presidency and debt repayments) is MK24bn (e.g., social sector expenditure = 35 per cent of this) and the overall total recurrent budget is MK37bn (e.g., social sector expenditure = 23 per cent of this). Social sector expenditure is thus in excess of international targets as a proportion of overall government resources, and this proportion has increased over the last few years (MoHP Planning Unit and Malawi Public Expenditure Review, 2002).

The MOHP itself acknowledges that these figures are "among the worst in the world" (MOHP 1999). From most recent estimates, life expectancy has now dropped to 38 years (World Bank, 2004). As detailed in Chapter 2, the infant mortality and under five mortality rates,[82] while declining at a better pace than in the 1980s and early 1990s, are still decreasing slowly and remain very high -- even when compared to other countries in the region. These are internationally used health indicators, which are felt to be sensitive to poverty and indicate the relationship between poverty and poor health status, particularly amongst the more vulnerable in the population.

Malaria continues to be the biggest cause of out-patient attendance and morbidity in both adults and children. Malnutrition remains endemic and 49 per cent of children under five are reported to be malnourished and stunted (MDHS 2000), a situation almost identical to that reported in the 1992 DHS survey. Diarrhoeal diseases and upper respiratory infections contribute significantly to illness across the population, recorded by the MOHP as the next major causes of patient attendance, after malaria; and the maternal mortality rate has dramatically worsened to a figure of 1,120 per 100,000.[83]

HIV/AIDS is now considered the leading cause of death amongst the most productive age group (20-49 years). MOHP estimates in 1999 note that it accounts for over 40 per cent of all in-patient admissions. However, that figure is likely to now be significantly higher. As noted, tuberculosis has also seen a huge increase.

Research looking at the burden of disease amongst the poor and the rich (rather than the more common global aggregates) suggests that communicable diseases are concentrated among the poor. Globally, respiratory infections and diarrhoeal diseases account for the highest percentages of both death and DALYs[84] among the poor

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[82] U5 mortality 1992 = 234/1000, 2000 = 189/1000 (MDHS).

[83] Reasons suggested for this dramatic rise include an original underestimate in the 1992 MDHS, or an overestimate in 2000, through misclassification of deaths; and the impact of high fertility, AIDS related deaths and deterioration in maternal health services.

[84] DALY = disability adjusted life year. An economic tool used as to quantify the burden of disease in terms of time lost to illness/morbidity and therefore to measure the cost-effectiveness of healthcare interventions, in terms of DALYs prevented at low cost. Since the early 1990s, this has been one of the preferred measures used by the World Bank in its prioritization of resources for health. It is however

(Gwatkin and Guillot 2000). While the relationship between health and poverty is complex, as noted earlier, the situation in Malawi appears keenly to reflect the global pattern, distinguished by a high proportion of the population living in poverty, with poor health status, and seen in the disease profile of those that are accessing the formal health services.

4.5.1 The health sector in Malawi

Taken in its entirety, the health sector in Malawi is comprised of both traditional and allopathic sectors. The categories of healers included under the umbrella of traditional medicine are broad, including traditional birth attendants (TBAs) and *sin'ganga* (traditional healers). While *sin'ganga* can be further broken down into a diverse range of herbalists and spiritual practitioners, the Government of Malawi recognizes them only as a homogenous body of herbal practitioners, who they require to be licensed. This stance hints at the large numbers of unlicensed healers, who independently practice both herbal and magical healing techniques, and continue to play a very significant role in health service provision, owing to their physical and cultural accessibility.

In the allopathic sector, there are three main service providers: the MOHP and the Ministry of Local Government (MOLG), are the largest service providers (up to 60 per cent of the total services), with MOHP assuming overall responsibility for formal health policy in the country and Ministry of Local Government managing public service delivery at district level and below. The Christian Health Association of Malawi (CHAM) makes up much of the remaining 40 per cent, through its network of not-for-profit mission hospitals and clinics. Other providers, including smaller private-for-profit businesses and Army and Police facilities comprise a very small share.

4.5.2 Overall approach to health care in Malawi

Malawi's fourth National Health Plan (1999-2004) outlines Malawi's endorsement of the Primary Health Care (PHC) approach as the main strategy for health service delivery in the country. Using this strategy, three areas have been selected as the

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contested by some, owing to is inequitable nature, which values the life years of children, the disabled and the elderly lower than those of economically productive adults.

main focal conditions: maternal and child health; water and sanitation; and early treatment of common diseases. In order to make delivery of PHC possible, primary level infrastructure, in the form of peripheral health facilities (rural hospitals, health centres and health posts) and paramedical staff cadres, such as clinical officers and medical assistants, were established. They are now supported by a cadre of Health Surveillance Assistants (HSAs), who, following six weeks training, are stationed in the community to carry out basic health promotion activities, supported by a particular health centre.

Health services are also available at two further levels. The secondary level comprises government-run district hospitals and CHAM hospitals. At tertiary level, principally in the urban centres of Lilongwe, Blantyre and Mzuzu, central hospitals provide similar services to those at district level, in addition to a further range of specialist interventions, such as surgical procedures.

4.5.3   Organisation of health services

With the implementation of the national decentralization policy, organization of health services under the MOHP has recently changed from the more traditional structure premised on a central Ministry, acting through its sectoral regional and district offices, to one where the central MOHP adopts a coordinating, policy making role, rather than being directly involved in managing service delivery at the secondary level.   In theory, through the decentralization process, the vision is for the MOLG, acting through District Assemblies (DA), to be responsible for the more mundane aspects of health service provision[85] in the districts.

These assemblies report to the MOLG and to the MOHP. Actual health services at district level are managed through a two-tier system of a Community Health Office, responsible for all PHC services outside the district hospital, and a District Hospital Office, responsible for secondary level care in the hospital itself. Both offices, headed by a Community Health Officer and a District Medical Officer respectively, report to an overall District Health Officer who, in turn, reports up to the DA. It should be

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[85] Functions to be taken on by the DAs include human resources (eg: hiring/firing of staff); supply of water; public health inspection; management of secondary level hospitals; management of all peripheral health facilities; control of communicable diseases; provision of ambulance services.

noted, however, that fieldwork for this research was undertaken as these new systems were coming into effect. In many districts, including Lilongwe, much health delivery was continuing to be directly overseen by the DHO, supported by a District Health Management team, rather than the newer CHO/DMO positions.

In Lilongwe, at the time of fieldwork, two DHOs were in position to manage health services throughout the district. The situation was additionally complicated by the shifting organisation in urban settings under the decentralization plan, and the division of responsibilities between the (urban) City Assembly and the (rural) District Assembly. In an interview with one of the then DHOs, it was acknowledged that these split responsibilities and roles remain confused – "it is still halfway developed" – leading to some gaps in provision of services, particularly in some urban areas or for certain health issues,[86] as responsibilities and funding requirements were not met by either body.

The MOHP remains the central headquarters, headed by the Minister for Health, assisted by the Principal Secretary (PS) and Chief Technical Advisor. Under their leadership are six divisions: clinical and population services, preventive health services, nursing health services, health technical support services, health planning services and finance/administration services. These divisions are run by a cadre of Controllers, all of whom report to the PS and Minister.

At the time of carrying out this study, the Preventive Health Services division was responsible for disease control programmes in Malawi. Ten of these,[87] including the National TB Control Programme (NTP) were based at the Community Health Science Unit (CHSU) and, at the time of fieldwork, one was becoming independent under the MOHP (National Aids Commission).

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[86] For example, funding of Health Surveillance Assistants at urban health centers is split, with some coming under the City, and others under the District. Those District HSAs consider themselves responsible for outreach only in more rural outlying areas, whereas City HSAs have been given health center-based responsibilities, resulting in no HSAs working in the urban areas and a complete gap in outreach provision there.

[87] The ten disease control programmes are: tuberculosis, malaria, diarrrhoeal diseases, acute respiratory infections, schistosomiasis (bilharzias), onchocerciasis, trypanosomiasis (sleeping sickness), leprosy and skin diseases, and a cancer registry. The two biggest programmes are malaria and TB.

CHSU came into existence following the development of a national public health laboratory, initiated in 1976. In 1983, this laboratory was formally linked with communicable disease control in the country and CHSU was conceived as a kind of national public health institution, geared towards the prevention and control of communicable diseases, in addition to the provision of specialized national laboratory services.

4.5.4   Health service personnel

In Malawi, the main cadres of clinical staff include Medical Officers (fully trained doctors), paramedics known as Clinical Officers and Medical Assistants, State Registered Nurses and Enrolled Nurse Midwives. The technical assistant cadre includes laboratory, pharmacy and radiography staff, and environmental health staff include environmental health officers, health inspectors, health surveillance assistants (HSAs), etc.

Table 6:

Health workers to population ratio by staff category

Staff category	1992	1996	1998	2000
Population per health worker				
Medical Officer	140,880	131,413	136,645	117,647
Clinical Officer	66,992	46,892	47,992	25,246
Registered nurse	19,198	25,223	25,959	33,333
HAS	19,314	3,014	N/a	2,832
Nurse/midwife	9,419	7,538	7,783	6,042

Source: GoM/UNDP 2002

There is, however, a chronic shortage of staff at all levels, with 40 per cent of available posts unfilled in 1998.[88] At that time, in a country of 10 million people, there were 72 doctors – *if* equitably distributed, this approximates *less than one* doctor, 0.72 of a doctor, for every 100,000 people, which compares with 56.3 per 100,000 in South Africa, 13.9 in Zimbabwe, and 6.9 in Zambia (WHO). Of those doctors, however, 50 were working within central hospitals in the three urban centers (MOHP 1999), while 86 per cent of the population lives out of reach in the rural districts.   The more recent Health Facility Survey cited by Kemp and Aitken (2003) show that 96 per cent of clinical officers are based in urban health facilities.

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[88] Note that determining exact numbers of existing positions filled/unfilled is difficult, owing to the absence of routine records or any centralized data system.

The same dismal situation applies to nurses, as recently recorded in a lengthy front page *New York Times* article (12 July 2004), which described the high level of migration by qualified staff to other better-paying countries, both within the region (South Africa) and further afield (UK). Only 1,842 out of 6,620 nursing positions were filled at the time of the 2002 MOHP Stock and Flow analysis.[89] "There are approximately 28.6 nurses per 100,000 population, which compares to 471.8 for South Africa, 128.7 for Zimbabwe and 85.2 for Tanzania" (Aitken and Kemp 2003).

Reasons behind the shortage and attrition of staff were explored in a report by UNDP with the Government of Malawi (GOM/UNDP 2002). The early 1990s saw the impact of public sector reforms, which streamlined the civil service overall and encouraged 'retirement' across the sectors. In the mid 1990s, liberalisation of health services opened up private sector opportunities for health staff and further influenced losses. As already noted, this is not just restricted to private sector opportunities in country, but extends to active recruitment by wealthier nations to supplement their own health personnel.[90] However, from the mid 1990s onward, the main cause of attrition amongst health staff (50 per cent) has been death, with a much higher than average mortality rates seen, particularly amongst frontline workers and laboratory staff.[91] A further (smaller scale) study has showed that TB (and HIV/AIDS) are the primary cause of deaths (Harries, Hargreaves et al. 2002).

The poor distribution of staff throughout the country, with significant weighting to the urban areas and secondary/tertiary facilities, compounds this overall shortage in total numbers. No fully qualified doctors are working below district hospital level, and those that are in the district hospitals occupy the position of DHO (or DMO), with a heavy management and administrative burden, rather than engaging in clinical practice.

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[89] In that same analysis, only 9 per cent of specialist positions were filled in the country (i.e., 1 out of 24 surgeon positions).

[90] Since 2001, the UK government has adopted a code of practice, which states that NHS trusts should not recruit health staff from country's unable to meet their own needs (in 2003, the Dept of Health published a guidance list). However, this practice does not extend to the private sector recruitment agencies who still actively source personnel in countries across SSA and Asia.

[91] 'Abscondment and resignation' were also contributing factors. Low salaries, heavy workload and safety at work/infection prevention are reported to be other reasons why staff leave.

In a government review of staffing requirements, a significant need to increase overall position requirements was recognized in 1999 (MOHP 1999), and again in 2003. Adding these requirements to the current vacancy levels gives a picture of 6,252 posts filled, out of a total of 15,713, or only 40 per cent of positions. This does not include the additional needs of other providers, such as CHAM.

4.5.5 Organisation of the National TB Control Programm (NTP)

As already described, the NTP is one of the ten disease control programmes based at CHSU, reporting to the Controller of Preventive Health Services in the MOHP. The organization of the NTP is along vertical lines, with its own budget, staff and management structure. This follows three tiers from central level, to the regional (or zonal) and district levels. At district level, the delivery of TB control services is fully integrated within the general public health services, but is supervised and monitored by a District TB Officer (DTO). This DTO is in turn supervised by the Zonal TB Officer for their region (north, central or south), who reports to the Central Unit at CHSU. With the advent of increased donor financial support in 1996, staffing of NTP's central unit was expanded. The Programme Manager (PM), is supported by a two Deputy PMs, and, until late 2003, by an expatriate Technical Advisor. In addition, the position of NTP Coordinator has been created, filled by a former PM of the NTP, who is now the main Medical Officer for lung health at Lilongwe's Bottom Hospital[92] and an advocate for the NTP within the MOHP.

Integrated under the umbrella of the NTP are/were two projects: the TB Equity Project and the ProTest project.[93] The TB Equity Project was a collaboration between the Liverpool School of Tropical Medicine (LSTM), the NTP and the Department of Sociology, University of Malawi, funded by DFID. It aimed to promote equity in the delivery of TB care, through the investigation of patterns of care-seeking for TB and

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[92] Bottom Hospital (so-called because it is at the 'bottom' of Lilongwe in relation to the 'top' Central Hospital) is LL's district secondary hospital. It is the base for TB activities in the capital, to where patients are referred for x-rays and difficult diagnoses, and where many TB patients register for treatment.

[93] TB Equity ran from 1999 until early 2002, from when it developed into the DFID supported Equi-TB Knowledge Programme. ProTest ran from 1999 until late 2002, after which it was planned to roll out its services through the NTP's TB/HIV initiative, as a pre-cursor to wider provision under the Global Fund.

gender and poverty related barriers to access to care, using a multi-disciplinary research team. The team consisted of an expatriate social scientist, four Malawian trainee social scientists, a clinical research officer and an LSTM based doctor. In addition, from October 2000, DFID seconded the author to the project for one year, to assist both in the development of the NTP's health promotion strategy and to carry out this PhD research. The NTP appointed a Malawian counterpart to assist in the health promotion work and ultimately to assume responsibility for its implementation.

Figure 4: National TB Programme Organogram
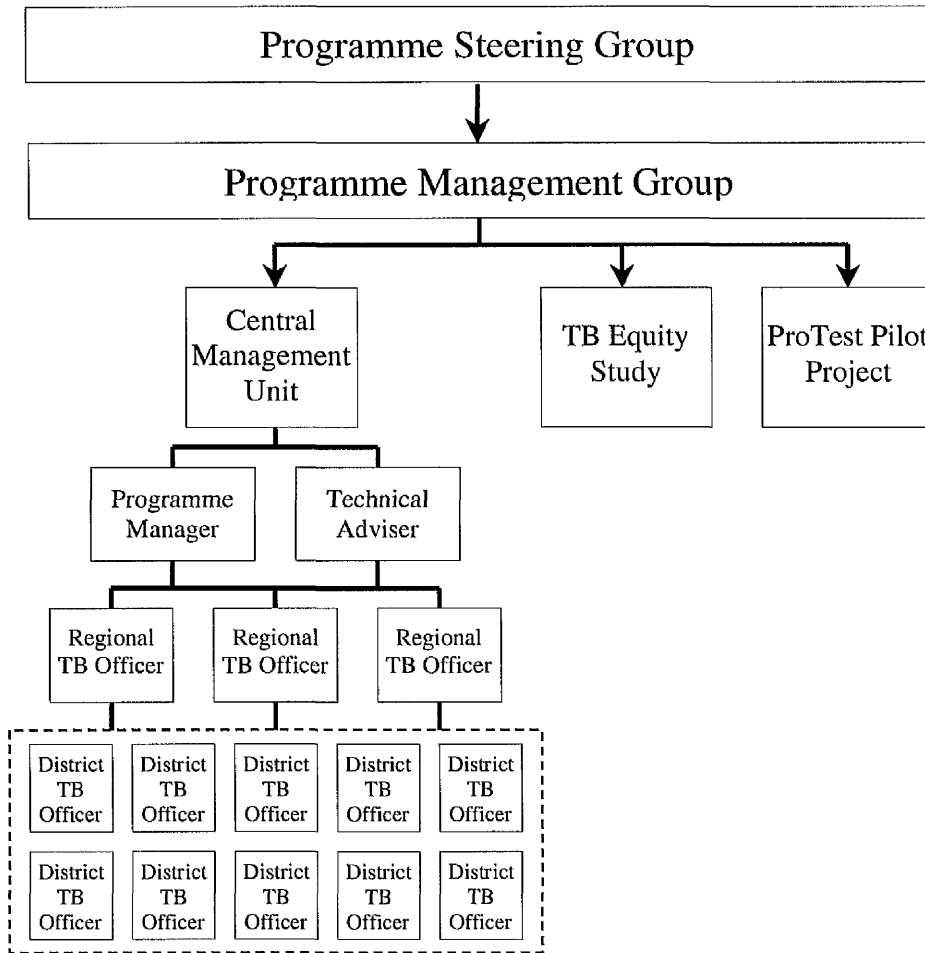
The ProTest project was a WHO pilot initiative, funded by NORAD, aimed at reducing the burden of the dual TB/HIV epidemic within Lilongwe, Malawi's capital, by increasing collaboration between different service providers (formal and informal) and piloting new initiatives to address joint TB/HIV management. It was staffed by an expatriate doctor and a local Malawian counterpart (originally trained as a Clinical Officer).

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Representatives from both these projects were members of the NTP's Programme Management Group (PMG), which was established in 1997 to oversee the strategic planning and direction of the NTP. In addition to these two and with the PM as chair, further membership includes the technical advisor, a College of Medicine representative, a district health officer and a WHO-sponsored TB officer, attached to the NTP. This group meets every 4-6 weeks to monitor progress, make planning decisions and ensure smooth implementation of the programme.

Above this group the Programme Steering Group (PSG) meets every six months, comprising the Controller of Preventive Health Services, Controller of Clinical Services, Officer-in-Charge of CHSU/PM NTP, the National TB CoOrdinator and a representative from each donor organization supporting the NTP,[94] in addition to invited members from the PMG and WHO. It sits in order to review PMG planning, oversee finances and provide leadership to the PMG in terms of policy, strategy, etc.

4.5.6 Organisation of TB care and service delivery

The main principles of TB control, agreed and promoted internationally,[95] are based around a path of diagnosis, registration, treatment and follow-up of cases (referred to in TB terminology as 'case-finding' and 'case-holding').

The NTP uses what is termed 'passive' case finding, where TB suspects have the responsibility of recognizing their symptoms as problematic and presenting for care to the formal health services. There, if recognised by the clinician as a chronic cough and so a potential risk, the condition is investigated to determine whether it may or may not be TB. Chronic cough is defined as somebody having symptoms of cough for more than three weeks. In Malawi, TB suspects will be asked to submit three sputum[96] specimens for smear microscopy.[97] The first sample is given on the spot. The suspect then returns home with a sputum container and first thing the following morning is asked to cough up an early morning sample before returning to the hospital

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[94] DFID, NORAD and KNCV.
[95] By organizations such as IUATLD, the International Union Against TB and Lung Disease, and WHO, the World Health Organisation.
[96] Sputum is the substance brought up from the lungs with a bad cough.
[97] Smear microscopy is the staining of slides with the suspect's sputum, which will then be examined under a microscope for acid-fast bacilli (AFB), or notable visible numbers of TB bacilli.

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(or health centre). Again, at the health facility, when submitting the second container, they will give a third, on the spot sample.

If a patient is found to be sputum smear positive for acid-fast bacilli (AFB) on at least two of their samples, they are classified as smear positive pulmonary TB (PTB) patients, and the next step is to register them for treatment. For those who are smear negative,[98] diagnosis is more complicated and usually should involve referral for x-ray. Should abnormalities be found, smear negative TB may then be diagnosed.

Ordinarily, both sputum microscopy and radiography take place at the district hospital. For a patient at a rural or peri-urban health center (HC), they must either travel to the district or central hospital to submit sputum, or do it at the HC, from where transport must be found within a day or two[99] to transport that sputum to the district center. In order to receive those sputum results after some days (and obtain an x-ray if needed), further visits to the hospital or health center are needed. Often, results are meant to be radioed back to the HC – if the equipment is functioning – to where the patient must also travel to collect results. This process often causes severe delays and places obvious demands on the patient in terms of time taken and the direct and indirect costs incurred through repeat visits to the health facility.

However, once diagnosed, each TB patient is then registered, noting their name, age, sex, date of diagnosis, address, type of TB and category of patient,[100] along with a TB registration number, in the District TB Register. Treatment is then begun according to the current regimens,[101] which for PTB follow a pattern of two months intensive phase (three times a week, under direct supervision either in hospital, or as an outpatient at a nominated health centre,) and six months continuation phase (daily, under indirect supervision at home). The exact number of drugs taken is calculated

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[98] If sputum is smear negative, this *does not* confirm that TB is *not* present, owing to the risk of smear negative PTB. In these cases, the concentration of bacilli coming up with the sputum is not enough for a conventional positive diagnosis, although the patient may still be suffering from TB. X-ray is needed to look for any abnormalities in the lungs, suggestive of TB.

[99] In order to be accurate, examination of sputum must be done within a week of collection, at the *latest.*

[100] Category refers to the type of case, eg: new, relapse, transferred in from another location, etc.

[101] Anti TB drugs used for PTB in Malawi are: isoniazid (H); rifampicin (R); pyrazinamide (Z); and ethambutol (E). For new Smear Positive PTB, the regimen is $2R_3H_3Z_3E_3/6EH$. For new Smear Negative PTB: $2R_3H_3Z_3/6EH$.

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according to the individual's body weight, but may be as many as 10-15 tablets per dose.

While it is accepted that, once on treatment, most smear positive patients become non-infectious within 2 weeks, standard practice is to have follow-up sputum smears at 2 months, 5 months and 7 months during treatment. The treatment outcome definitions used within international TB control classify treated patients according to the following categories: cured (treatment completed and smear negative), treatment completed (when smear results are not yet available), failed (remaining or again smear positive), died, defaulted and transferred out (those who have moved to another registration unit/district).

'Defaulters' are those who have not collected drugs for two consecutive months or longer. Health centre staff, usually HSAs, have responsibility for tracing defaulters, finding out why they have not come and trying to encourage or enable them to restart. Reasons for 'default' frequently given to staff and cited during data collection were weakness and inability to travel to the HC, lack of guardians to either come and collect drugs on their behalf or to look after the home while the patient visits the health facility, no money for transport, inability to leave work or daily labour to come and collect, etc.

The issue of supervision or observation of treatment has been a contentious one in TB control for some years. As Chapter 5 will show, Malawi was involved in pioneering trials in the 1980s that explored new treatment regimens and also the practice of observing patients taking their medicine – now the so-called DOT or Directly Observed Therapy. This arose out of the medical establishment's conviction that adherence was the critical plank of successful TB control and that, to ensure compliance with their treatment regimen, TB patients needed to be strongly guided.

Initial 'best practice' required that the observation had to be undertaken by qualified health personnel – reflecting the overall climate of TB control, in which control was only valid when in the hands of medical personnel. Subsequently, and primarily owing to the costs (to the provider, rather than the patient) of hospital-based observation, pilots for alternate forms of DOT were carried out. Now, accepted

practice in many settings is for the continuation phase of treatment to be observed by a nominated 'guardian,' who need not be a health worker. In the initial phase, DOT is still largely in the hands of health workers, but 'ambulatory' DOT has meant that patients need not remain in-patients, but must show up at the health facility on treatment days. In the Malawian context, such practice requires treatment at the health facility three times a week. This is still a considerable burden to patients who may be weak in the initial stages of treatment, and who must bear the costs of getting to and from the health facility (transport, time off work or away from the family home, etc).

CHAPTER 5: FINDINGS – TB CONTROL IN MALAWI. THE VIEW FROM 'INSIDE' THE NATIONAL TB CONTROL PROGRAMME

INTRODUCTION

The next chapters of this thesis present further detailed findings from the fieldwork undertaken in Malawi, during the year October 2000 to September 2001. This chapter starts by providing the view from the *'inside'*: the National TB Programme (NTP) perspective on disease control.

In the preceding chapter, the situation of health service delivery in Malawi at the time of the research was presented. In addition, TB service delivery was described in some detail. In this chapter, attention focuses on the development of TB control globally, and in the Malawian context, to the current internationally accepted standards of 'best practice.' This approach to disease control in a developing country is then explored against the wider national health policy context, including the backdrop of international aid and changing approaches to healthcare organization and delivery in Malawi.[102] Through an ethnographic approach to policy processes at this level, the NTP's response to this changing environment and their vision for the future of TB control is described and critically evaluated.

It is proposed that TB control is regarded, by most of those working within the field, as a bounded realm whose integrity must be protected from ongoing or future 'threats.' The success of managing TB and obtaining positive outcomes is equated with strict maintenance of the existing TB control components and delivery structures, based on principles of medical authority and successful patient treatment. At the time of fieldwork therefore, and with regard to policy formulation and programme management, *defence* rather than *dialogue* has been the watchword associated with the NTP. While the principles of TB control are used to justify such a stance, the response is both a reflex of desperation[103] and a defensive and uncritical attachment to orthodox disease control. With the authority of the NTP largely in the hands of a

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[102] It should be noted that this research was undertaken during a period of significant change in the organization of health service delivery and management across the sector and also in TB control.
[103] Desperation owing to the dire TB indicators, the impact of HIV and a genuine commitment on the part of programme staff to ameliorate suffering from TB.

medically trained elite, this protective stance precludes change and innovation, and instead indirectly and unwittingly perpetuates the interests of a biomedical hegemony, at the expense of improved access and treatment for the vulnerable populations they are trying to help.

5.1 WHAT IS TB CONTROL?

The organization of TB service provision already described closely follows the internationally recommended model for TB control. This DOTS strategy is based upon five core elements:

> government commitment to ensuring sustained TB control activities, e.g., through a national TB programme;

> case detection of TB through 'passive' case finding, using sputum smear microscopy;

> short course chemotherapy[104] for all smear positive PTB cases, with directly observed therapy (DOT)[105] in at least the intensive phase;

> a regular, uninterrupted supply of all essential anti-TB drugs; and

> a standardized recording and reporting system to allow monitoring, evaluation and programme supervision.

This strategy is recommended as the best means to control TB and achieve the TB control targets set by the World Health Assembly (WHA) in 1991: to detect 70 per cent of the estimated new sputum smear-positive TB cases; to cure 85 per cent of the sputum smear-positive TB cases detected.[106]

Given that, as Ogden and Porter (1999) note, this policy package has rapidly become the international gold standard for TB control, recommended worldwide by the WHO

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[104] The term chemotherapy refers to the "the use of chemical agents in the treatment or control of disease or mental illness" (Merriam Webster dictionary). Here it refers to the taking of antibiotic therapy for TB, and does not imply a similar process to the chemotherapy known more commonly to treat cancer.

[105] DOT, directly observed therapy or direct observation of treatment is the practice of observing a TB patient swallowing their dose of tablets. International guidelines recommend that the observer is a 'trained and supervised person' (WHO, IUATLD et al. 2001), ideally a health worker, although alternative strategies are being practiced in varied locations for the continuation phase of treatment, e.g., family members.

[106] These targets were originally to be achieved by the year 2000, but this was changed to 2005 in 1998, as it became clear that they would not be met in time.

and supported by their ambitious Global DOTS Expansion Plan (GDEP), which aims to expand coverage to all countries,[107] it will be useful to consider how such a strategy has developed both globally and in Malawi to become 'best practice' and the associated implications for successful management of TB and improvement of outcomes for the Malawian public.

Epidemiological work which informed the basic tenets of TB control stressed the need for good 'case management' for identified patients, leading to high cure rates (Styblo 1989; Murray, Styblo et al. 1990; Styblo 1991; Styblo and Bumgarner 1991) – an essential part of the epidemiological logic for bringing down incidence rates for TB. As this area fell within the realm of biomedical therapy and the physician's reach, there has been a tendency to focus on this treatment stage alone – with an assumption made that case detection will automatically be taking place in parallel.

At the time that this research began, it was clear, however, that case detection rates were falling well short of the WHO 70 per cent target – the optimum level in combination with 85 per cent cure rates to bring TB incidence down. This included those areas implementing the DOTS strategy.[108] There has since been a gradual realisation amongst the TB community that attention urgently needs to be given to case detection rates as well. For the epidemiological models to work, case detection and cure must go hand-in-hand (Frieden, Sterling et al. 2003; Elzinga, Raviglione et al. 2004).

5.1.1 The 'need' for compliance and cure: The development of DOT

Historically, however, since the discovery of germ theory in the 1880s, the tubercle bacillus in 1882 and antibiotic drugs in the 1940s, treatment of TB patients has been the focus of attention. While these were indeed significant steps in the history of disease control for TB,[109] McKeown has demonstrated that the fall in TB mortality in

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[107] In 1999, 23 per cent of infectious TB cases were detected and treated under the DOTS strategy. The Global DOTS Expansion Plan, formally launched in 2001, aims to create 100 per cent coverage worldwide, with conviction that this is the essential means to successful TB control.

[108] Case-detection rates – under DOTS – in 2001 were 20 per cent in China, 21 per cent in Indonesia, 31 per cent in the Russian Federation, and 47 percent in Kenya and Tanzania – all high burden countries (WHO).

[109] The conventional view supports this with the opinion that "in most technically advanced countries, the disease has declined very rapidly over the four decades since the introduction of effective chemotherapy" (Enarson 1991: 195).

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England and Wales took place *prior* to the availability of anti-TB drugs, but at a time when overall living conditions and nutritional status were improving – factors to which he attributes TB's decline (McKeown 1979). This hypothesis is further supported by TB's persistence in the post-antibiotic era (Farmer 1998) – if the cause is known and the drugs to treat that cause are available, why is TB enduring as such a significant problem?

Those involved in TB control have tended to answer this question through a focus on the issue of *compliance*, which has been regarded as the major obstacle to effective TB control. Compliance, or adherence, refers to a patient's successful following of a given drug regimen, taking all doses required to complete treatment. While antibiotic drugs for TB are indeed available, the regimens are demanding with even the so-called 'short-course' drugs requiring TB patients to take therapy (daily and/or thrice weekly) for 8 to 10 months. While the arrival of effective chemotherapy in the middle of the 20th century certainly transformed TB's treatment, problems have endured in that patients have not always adhered successfully to their therapy for the required length of time. If therapy is incomplete, this results in the patient later succumbing to TB once again.[110] In addition, incomplete therapy contributes to the development of drug resistance, and, overall, epidemiological theory suggests that low cure rates could actually increase disease transmission and thus the number of cases, as in the long term, these 'failed' patients will become infectious again (Dye, Garnett et al. 1998). Conversely, successful treatment will help reduce transmission and is thus a main plank of prevention upon which TB control rests (Styblo 1991).

The terms compliance and adherence have been used in subtly differing ways by the medical community, with compliance becoming associated with the regulation or control of patients, who should (without question) follow the treatment regimen authorized by their doctor. An attempt was made to acknowledge patients' agency in the relationship and level the power imbalance by a semantic shift and using the term adherence, instead of compliance (Sumartojo 1993). Adherence has also been used in the context of understanding patients' lack of ability to control forces which may influence whether they maintain a treatment regimen, e.g., living in poverty, the

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[110] Known in TB terminology as a 'relapse' case.

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constraints of gendered decision-making or caring responsibilities in the household. However, as Ogden argues (Ogden 1999), in infectious disease control, the public health implications of non-compliance/adherence have more often than not allowed control of the disease, in the name of protecting the wider community, to legitimize an institutionalised lack of respect for patient agency.

The concern with treatment is rooted in the biomedical epidemiology that characterises disease control, and focuses on the interaction between the disease 'agent,' 'host' and 'environment' (Hurtig, Porter et al. 1999; Jaramillo 1999). The dominant approach is thus to attack the source of the problem, to interrupt transmission and, as a result, protect the wider population. Disease control therefore becomes control of the infected individuals, seen in rigorous 'patient management,' which is expected to lead to successful treatment.

Figure 5: Epidemiology of TB
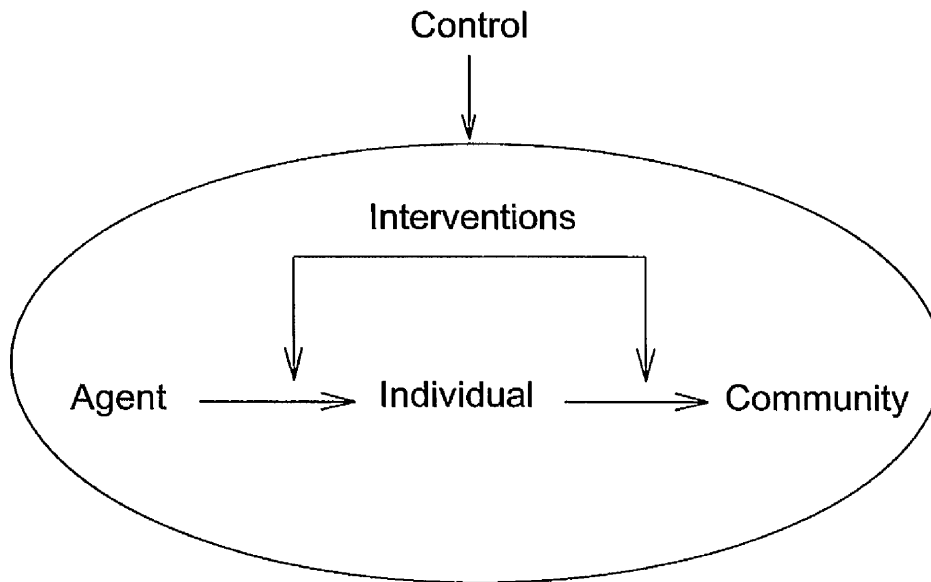
Source: Hans L. Rieder. Epidemiologic basis of tuberculosis control.
Paris: International Union Against Tuberculosis and Lung Disease, 1999

Within this biomedical framework, the focus upon this *treatment* stage has been reflected in TB related research, and indeed policy development.[111] Studies were undertaken in the late 1950s and early 1960s, in Madras and Hong Kong (Bayer and Wilkinson 1995), which explored the efficacy of differing approaches to patient

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[111] Most recently affirmed by the work of Styblo in the 1980/90s (Styblo 1989; Styblo 1991).

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management – 'ambulatory'[112] as against hospital-based therapy. Hospital-based care for TB had long been the standard – building on the sanatorium isolation model used since the 1900s. However, this placed a significant burden on hospital resources, in the availability of beds and staff time,[113] and led to an exploration of the feasibility of ambulatory care, particularly in developing country settings where the TB burden remained greatest.

The conclusions of Fox's work in Madras were that self-medication by ambulatory patients was irregular and encouraged non-compliance, despite staff efforts to monitor patients. He thus began to explore supervised therapy, i.e., patients being supervised in the taking of *each* dose of medication, and became an early advocate of the benefits of such supervised therapy for TB (Fox 1962). Similar work was undertaken in Hong Kong by Moodie and also in London by Stradling and Poole (cited in Bayer and Wilkinson 1995).

All such work was driven by a strong behavioural emphasis and a belief in "a general tendency... on the part of patients to cease taking medications when they no longer felt ill" (Bayer and Wilkinson 1995). Patients were considered 'unreliable' in the first instance and doctors were placed in a position of professional opposition, tasked with ensuring their problematic patients would 'do the right thing.' At this time, however, Fox's supervised approach, which treated all patients uniformly, was atypical. The prevailing approach to the issue of treatment compliance in TB control had been grounded in a similar paradigm of patient blame, but had tended to try and identify determinants of individual 'unreliability' and to predict individual troublesome patients who would warrant supervision.[114] Therefore, despite the shared motivation,

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[112] This refers to the taking of drugs while in the community setting, as opposed to being hospitalised.
[113] While this also placed a significant burden on patients, in removing them from their family support network and their ability to carry out any income generating activities, this patient perspective was rarely recognised at the time of this research.
[114] For example, Barnhoorn and Adriaanse's study in India (1992) set out to find the determinant factors amongst a cohort of compliant and non-compliant TB patients, comparing the influence of patients' health beliefs, socio-economic variables, degree of social support and levels of medical knowledge. The assumption of this study was that the resulting determinants could be addressed through 'educational interventions.' While an association between income level and compliance was observed (the compliant group's average income was 837 rupees and the non-compliant group's average income was 671 rupees), this finding was downplayed, and findings relating to "accurate medication knowledge" and "faith" in doctors were instead highlighted, emphasizing individual behaviours and beliefs. In a later article in favour of supervised treatment by Sbarbaro, he notes however that "scientific studies from all parts of the world have repeatedly confirmed that at least 30

the TB establishment was largely *against* supervised therapy. While some arguments were rooted in the notion of patients' rights and identified a problem in treating all TB patients as 'guilty',[115] Bayer and Wilkinson note that the main argument was the fear of "extraordinary and unjustifiable expense" (ibid.).

Throughout the 1970s, Sbarbaro is notable for continuing to pioneer and promote supervised treatment, and, as with his predecessors, this was based on a belief that most patients are inherently unpredictable/unreliable and likely to become "recalcitrant patients" (Lerner 1997). The emphasis continued to be on their problematic behaviour and the difficulties in maintaining effective TB treatment, as against the wider public health benefits to be gained, if treatment was successful – according to the accepted scientific model.[116] His work did, however, finally bear fruit, in pilots guided by the International Union Against Tubercle and Lung Disease in the 1980s, in settings including Malawi, and subsequently influencing the development of 'directly observed therapy' as a key pillar of DOTS.

The privileging of DOT by a trained health worker as one of the central components of DOTS has not however been without its critics. While cost-effectiveness has been a key factor, for some concern has instead been owing to the placement of compliance, and its concomitant association with the authoritarian doctor, maintaining control of the recipient patient (Trostle 1988), back at the centre of the TB control agenda. With this strategy, TB control is remedicalised through an individualised focus on a passive, potentially 'defaulting' patient, who can only be redeemed with the assistance of medicine's healing qualities (Ogden 1999).

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per cent of patients will not remain true to treatment; and, equally important, no personal or disease characteristics have been found to indicate which patients are likely to abandon treatment" (Sbarbaro 2001).

[115] Moulding (1966) was one of the few medical voices arguing for faith in patients, rather than patient blame. He has maintained this stance and recently presented at the IUATLD World Conference on making use of diarised 'drug delivery systems' which can assist patients in self administering treatment (Moulding 2002).

[116] Lerner, in a review of 'compliance,' looks at patient (mis)behaviour, the privileging of doctors armed by the authority of antibiotics, and their search for interventions to manage such problematic patients, all of which he felt reflected the prevailing positivistic paradigm of the scientific establishment. Lerner was unusual in highlighting the social context in which the notion of compliance gained ascendancy and the perjorative use of such terminology in the medical literature (Lerner 1997).

The WHO guidelines that observation must be undertaken by a trained health professional reinforces the authoritarian role given to medical staff, in controlling the behaviour of TB patients.[117] While this stance has gradually been reinterpreted more flexibly in several settings, adaptation has taken time, effort and significant evidence to challenge the accepted norm that only medical personnel are endowed with the capacity and legitimacy to ensure (the desired) compliance. This is even despite clear cost-reducing implications (Khan, Walley et al. 2002) and also the wider shifts in health and development practice towards beneficiary 'agency,' 'empowerment' and 'participation.' The strength of such a dominant stance is shown in Malawi where a piece of operational research that examined the efficacy of non-health staff – community 'guardians' – in supervising TB treatment was interrupted before the final results were available. While the study sought to compare findings between in-patient DOT, health centre-based ambulatory DOT and guardian-based DOT (in the home setting), "…following external consultation and before any results of this study were available, it was felt that DOT could be given at health centres, but *not* from guardians because of the perception that guardians might be *unreliable* and this would be a risk in smear-positive patients. No further guardian-based DOT was offered to smear-positive patients" (Manders, Banerjee et al. 2001: 6, italics added).

Once the initial study findings were available however, it was seen that, of the three options, home-based guardian DOT was a close second in registering 94 per cent adherence, as against 100 per cent in-hospital, and 84-89 percent for health centre based supervision. Findings were deemed robust enough to finally introduce guardian-based DOT throughout the Malawi National TB Programme. However, the removal of this option part way through the trial was a stark illustration of the automatic trust in health workers versus an assumption of 'unreliable' lay guardians, rooted in the hierarchy of medically trained staff over lay community members. It also highlighted the presumption that all patients are essentially non-compliant and need therefore to be controlled by health staff, in addition to the medical view which tends to focus on the *individual* health worker, guardian or patient only, rather than recognising wider constraints that would influence the success of different DOT delivery methods: while patients would be supervised at a health facility by a

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[117] "Compliance is successful as a descriptive term in clinical practice precisely because it assumes that physicians legitimately control patient behaviour" (Trostle 1988: 1305).

qualified staff member – the important factor in the eyes of NTP staff – health centre based DOT expected TB patients to be able to make their way from home to the health facility three times a week, in spite of distance, expense, weakness and work commitments. None of these factors were considered important as the trial got underway, yet their impact was clearly seen in the poorer figures for adherence.

Similar potential for supervision has been found amongst traditional healers in South Africa (Wilkinson, Gcabashe et al. 1999), amongst non-TB programme NGO community health workers in Bangladesh (Islam, Wakai et al. 2002), and in community-based DOT in Tanzania (Lwilla, Schellenberg et al. 2003), Uganda, Nepal (Wares, Akhtar et al. 2001), Pakistan (Khan, Walley et al. 2002) and Thailand (Akkslip, Rasmithat et al. 1999), amongst other countries. Nevertheless, the model of compliance implicit in DOT – whether undertaken by a traditional healer or a nurse – remains: TB patients must be adequately controlled to ensure treatment success.

5.1.2 From complacency to control: The development of DOTS, in Malawi and worldwide

Despite recent research projects looking at alternative models of DOT, it has been argued that, up until the 1980s, there was widespread complacency about TB, as it was considered under control in the industrialised world and thus of little concern (Bayer and Wilkinson 1995; Walt, Lush et al. 2002). This lack of attention on the global stage was reflected in the lack of TB-related papers published in scientific journals (Walt 1999) and in staff numbers within WHO: in 1989, only 2 people occupied TB related positions in Geneva, in what was at that time also considered a weakened institution (Walt, Lush et al. 2002). While the organization had paid significant attention to the disease in the fifteen years following its 1948 creation, with eight expert committees (Leowski 1988), the next twenty-five years were notable for their lack of activity and the shrinking of the TB Unit. As Walt observes (1999), despite the TB burden continuing in many of the poorer member countries of the WHO, the institution instead reflected the "public health complacency" (ibid: 76) of its richer member nations, influenced by the developed world's scientific and medical 'epistemic' community, from where its key advisors were drawn.

The International Union Against TB and Lung Disease (IUATLD or "the Union") was, and is, the main non-governmental organization in the TB field and, despite the wider complacency,[118] was instrumental in supporting smaller scale, technical and scientifically oriented research around TB. Perhaps the most influential in the subsequent development of DOTS was a series of pilots in the new short-course chemotherapy,[119] carried out in a range of countries: Benin, Kenya, Malawi, Mozambique, Nicaragua, Senegal and Yemen, following on from earlier success in Tanzania, under the Mutual Assistance Programme of the IUATLD. In discussion with the current Programme Manager of the Malawi NTP, who was, at the time of the pilots, the NTP's Regional Manager for the South, he describes the criteria for selection of the African countries as being on the basis of size and stability. The IUATLD was interested in testing the feasibility of TB control using short-course regimens in such differing environments. In the immediate region, Malawi and Tanzania represented both small and large peaceful settings, whereas Mozambique provided a contrast in being a conflict zone. Kenya was a setting where the pilots focused primarily on nomadic pastoral populations.

The Programme Manager at that time has outlined how, following a meeting called in Harare, the Government of Malawi (GoM) entered into discussions with the IUATLD about Malawi's potential involvement in the pilots. GoM were keen to bring in the new shorter drug regimens and set about creating the appropriate conditions, through the appointment and training of a new Programme Manager (PM) in 1984 and subsequently, in 1985, the appointment of 3 regional TB Officers. Dr Karel Styblo was then the Scientific Director of the IUATLD and took the lead in providing technical support to the pilot country initiatives, with the Union also providing financial assistance. Through regular consultancy visits, he is said to have guided the development of the fledgling NTP, introducing the Malawi team, as the present NTP PM has said, "to the backbone of TB control." As is apparent from both Styblo's own writings (Styblo 1985; Styblo 1991; Styblo and Salomao, nd) and the Programme Manager's comments, he was an advocate of the prevailing interest in treatment.

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[118] In the 1970s with the decrease in the involvement of the WHO in TB, and its shrinking Central TB Unit in Geneva, the Union therefore considered that their best role "was to try and make up for the decreasing interest of WHO and international agencies and the increasing neglect of governments towards tuberculosis" (Rouillon 1991: 162).
[119] Short-course chemotherapy was a series of new drug combination regimes which reduced therapy from a previous 12-18 months, to 6-10 months.

According to Malawian reports, he was a strong-minded individual with similarly strong convictions about TB control. For Styblo, the main issue in TB control performance was compliance. He is reported to have been emphatic that the approach of a TB Programme should centre around successfully treating the patients you have, managing compliance and reducing default in those individuals, rather than expanding case detection. As he later published, low cure rates could actually increase the rate of transmission in the long term as those patients who become 'treatment failures' start to again transmit TB (Styblo and Bumgarner 1991).

This approach was seen in the areas pioneered by the Malawi NTP and later to be standardized under 'DOTS.' Short-course chemotherapy with hospital-based DOT was introduced in Malawi in the second half of 1984 in three pilot districts, but within three years, was being used country-wide. Treatment results improved from a 50-55 per cent cure rate to an 87 per cent cure rate (Nyangulu 1991). Other areas in which Malawi played a pioneering role included the use of a Chronic Cough Register and the Transfer Out system to strengthen reporting techniques, and the institutionalization of a vertical TB supervisory system with built-in training mechanisms. These practices, in addition to the use of short-course chemotherapy with hospital-based DOT, led to the guidelines for the NTP model promoted as 'best practice' today. Other elements, which later supplemented this approach, included an efficient laboratory system and reliable drug supplies.

Those working for the NTP at this important time have been keen to emphasise that, while IUATLD's support in those early days was critical, Dr Styblo's approach was not a prescriptive one, but was mindful of the context and needs of the Programme. The then Programme Manager stressed that the ideas piloted came out of in-country experience and personal commitment on the part of the early programme staff. Nevertheless, in terms of organizational structure, the Malawi NTP subsequently developed along lines proposed by WHO in 1974 and outlined by Styblo himself (Styblo and Salomao, nd).

Styblo's support was the start of a period in which the Malawi NTP strengthened and developed until it was perceived to be, in the current Programme Manager's words "a star performer" on the world TB stage, demonstrated in its high cure rates. Following

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the Dakar IUATLD African Regional conference in 1989 and the Boston IUATLD world conference of 1990 during which early findings were presented, and after the Karel Styblo Symposium held in the Hague in 1991, a special WHO meeting was convened at which selected programmes were recognised as potential 'leaders' in TB control, based on their cure rates and well developed programmatic systems. Malawi was subsequently visited by a WHO evaluation mission, led by Dr Arata Kochi, which resulted in the NTP's recognition as a WHO 'model' programme – a recognition that remains to this day.

During this period of IUATLD technical assistance for the short-course/DOT pilots, changes were also occurring in the wider international environment, which prompted a move away from previous complacency toward a new concern with TB. In the late 1980s and early 1990s, the advent of HIV/AIDS caused rising numbers of TB cases in the USA and a related increase in drug-resistance. Wider interest amongst developed nations was therefore catalysed and resulted in a dramatic increase in attention and funding. Bayer and Wilkinson (1995) cite a rise in US domestic federal funding for TB from U$ 25 million in 1991 to U$ 104 million in 1993.

In the global arena, this was matched with WHO's restructuring, the appointment of Arata Kochi as head of WHO's newly augmented TB programme[120] and publication of his 'classic' article based on WHO's 1989 review of TB control worldwide (Kochi 1991), an article described as having 'changed the public health focus of the WHO, national governments and leading voluntary organisations' (Sbarbaro, 2001: 69). Following the success of the IUATLD supported short-course pilots in the late 1980s and Arata Kochi's redefinition of WHO's TB strategy in 1991, DOT was made federal US policy in 1993, the disease was declared a Global Emergency in 1994 and DOTS was launched as the WHO approved policy package for TB control the following year. The World Bank too was instrumental in the attention being brought back to TB. As the lending institution assumed greater influence in setting international health policy, it resumed lending for TB programmes in the early 1990s

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[120] Chief Medical Officer, TB Unit. The structure of WHO has since undergone many changes and, currently, TB activities are organized through the Stop TB Department, within the Communicable Diseases Division and, until 2003, was headed by Jong Wook Lee – now Director General of WHO.

and included TB as part of the essential health services package in its 1993 World Development Report (The World Bank 1993).

It is notable, however that, for TB to re-emerge as in issue of concern for 'policy elites' (Walt, 1999: 92), it took a combination of self-interest and self-defence amongst developed country governments and multilateral institutions, and depended on the knowledge production and dissemination of the scientific and biomedical community in those same developed countries. Such knowledge production and dissemination has continued to be closely associated with the 'control' of TB control, still managed globally by the policy elites at WHO and IUATLD and reproduced by their immediate followers in the TB medical hierarchy: NTP managers in countries worldwide.

Following the IUATLD trials overseen by Styblo in the 1980s, two other pieces of research were influential in mobilizing global support for DOTS. The first looked at cost-effectiveness, concluding that treatment for TB was one of the most cost-effective interventions for health to date (Murray, Styblo et al. 1990).[121] The second followed on from Styblo's assertions that short-course chemotherapy brought a positive epidemiological outcome and assessed quantitatively the likely impact DOTS[122] would have on improved rates of TB and death (Dye, Garnett et al. 1998), concluding that it had potential to reduce both the incidence and death rate. The resulting consensus across the majority of the international TB community is seen not only in individual country programmes such as Malawi, but in the published statements of the leading bodies and at the regional and global TB gatherings. The 2002 IUATLD World Conference on Lung Health, the biggest TB gathering in the annual calendar, was jointly held with the 3rd Stop TB Global DOTS Expansion Working Group meeting. One of the main objectives of this closed meeting was "to

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[121] Although, as Saunderson has noted, this and other studies have largely failed to examine the costs to the patients, and have only looked at the cost-effectiveness of the new drug regimens (Saunderson 1995).

[122] It should be noted that this research assumed ideal 'performance' under DOTS, using the WHO targets of 70 per cent case detection and 85 per cent cure rate in its mathematical models. Its findings are based on such assumptions that DOTS would already be successful in achieving such targets. Like Styblo (1991), Dye et al state that the first priority of DOTS programmes is to achieve high cure rates, with the second aim to improve case detection.

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review the status of TB control and DOTS expansion in the world" in line with their global commitments.[123]

Walt et al (Walt, Lush et al. 2002) have outlined how the 'policy transfer' for DOTS has operated successfully in several iterative loops: at the field level, through a process of knowledge generation, which coincided with a global search for workable solutions to the TB threat; at the global policy level, through promotion of one simplified strategy as the appropriate intervention; and at a level of international mobilization, through worldwide marketing and dissemination of information and resources.[124] For the first time, WHO recruited an advocacy officer in 1993, and in 1995 the DOTS 'brand' was launched. Such international institutions continue, in the main, to represent the interests of TB affected populations who, being poor, are typically disempowered and voiceless groups. DOTS continues to be advocated as the main strategy for TB control, based on unchanged principles of individual control and compliance. Whether these principles can or should remain unchallenged or unchanged is emerging as a matter of international debate.

5.2 CHALLENGES TO TB CONTROL: PROTECTING THE POPULATION OR PROTECTING THE PROGRAMME?

5.2.1 Reform of the health sector

In Malawi, one of the original field sites for DOTS development, the country programme has remained a strong advocate for and practitioner of DOTS, while also testing and evaluating complementary new interventions. As a programme, it is perceived to be one of the most technically sound, exemplifying the IUATLD model (Enarson 1991), and providing something of a mentoring role to more emergent programmes both regionally and internationally. An example of this was the 2001 Hague meeting for high-burden countries,[125] to which Malawi was also invited to

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[123] A Ministerial Conference held on 24 March 2000 in The Netherlands, adopted the Amsterdam Declaration to Stop TB. Ministers of Health of the 20 high-burden countries, comprising 80% of the global TB burden, called for an expanded coverage of the populations of these countries with the DOTS strategy, detecting at least 70% of infectious cases by the year 2005.

[124] This has been regarded as a remarkably successful global marketing campaign, while also being criticized by technical 'purists' for its oversimplification of science, and others for its dogma and rigidity in practice.

[125] 22 countries are identified by WHO as 'high-burden,' including India, China, the Philippines, South Africa, the Russian Federation, Peru, Brazil, Ethiopia and Kenya. They are the worst affected

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attend, in an advisory position. The Programme Manager, Technical Adviser and other staff are clearly proud of this role and recognition. In the 2001 annual Output-to-Purpose review,[126] however, the Programme Manager outlined the challenges to the programme, which included raising case detection, improving diagnostic practices and maintaining good treatment outcomes. His final statement was how to maintain TB control in the face of health sector reform (HSR).

As already described in Chapter 2, HSR is taken to refer to a package of financial and institutional reforms, ideally, to improve both efficiency and equity in the delivery of health care, through an integrated 'total systems' perspective. In Malawi, reforms envisaged by the government in 2001 included decentralization of administration and budgeting to the district level, design and introduction of an 'essential healthcare package,' and adoption of a sector-wide approach to both coordinate donor funding through the government's own health budget and facilitate full integration of health services. A key part of integrated service delivery would involve the dissolution of vertically organised disease control programmes, such as those for malaria, TB, schistosomiasis, etc, and provision for those conditions through integrated PHC.

With the bilateral donors active in Malawi being advocates of the principles of HSR (including the move to sector-wide planning and financing for health), at the time of fieldwork the NTP clearly felt that the model vertical programme which they had established would likely be threatened and that the principles of TB control might be damaged. Core activities that would need to be 'protected' were outlined, including drug procurement, staff training, IEC/health promotion and operational research. At the annual TB research review meeting[127] in March 2001, the opening speech given by the MOHP's Principal Secretary – and written for him by the NTP management – referred to "how to maintain the integrity of the existing NTP in the face of HSR."

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countries in the world and are explicitly targeted with advocacy and technical support to try and facilitate government commitment, resources and planning to control this burden.

[126] A joint review by the principal donors, DFID, NORAD, and external KNCV consultants Tone Ringdal and Jeroen van Goerkom.

[127] In recent years, the NTP has timed a meeting in March, to follow on from the donor project review. The research review meeting attracts a regional audience, with some international delegates (e.g., KNCV, WHO,) and provides a chance for the NTP and invited presenters to share operational research results and explore TB control issues.

The Deputy Programme Manager later observed how HSR presented a significant threat: "we don't want what happened in Zambia to happen here."

WHO and mainstream TB control experts regard the recent case of Zambia as a disastrous test case. Owing to their shared culture, history and health issues, a comparison is often drawn between Malawi and Zambia, as neighbouring countries. Recent years, however, have led to major differences in the status of TB control in each. As already outlined, Malawi has had a coherent history of TB control, which has resulted in a robust active NTP. While Zambia too had a national programme, the combined National Leprosy and TB Control Programme or NLTP, this was partially integrated in 1993 to become the NASLTP, adopting HIV/AIDS and STD control under its umbrella, prior to its complete collapse in 1997. TB technicians frequently cite the incredibly fast move to decentralized and integrated health care provision which occurred in Zambia, as the sole factor in the national TB programme's demise (M. Malukutu, NTP Zambia, presentation at the TB Accessibility Study, Research Dissemination Workshop, Harare, Zimbabwe, 22 May 2001).

In 1997, with the Zambian Ministry of Health's adoption of decentralization, the TB programme's vertical management and delivery structures were dismantled and secure financing for TB related activities was lost. Given that districts were unused to managing the planning and implementation of TB services and were struggling to cope with their new responsibilities,[128] a vacuum opened up, with nobody assuming responsibility for TB care and control in Zambia. Related to this reform process and further compounding the situation was the sudden withdrawal of donor funds with no alternative provision in place and a drug shortfall as the result.

The common response to this scenario is that health sector reform is the 'scourge' of TB control (Miller 2000). In Zambia, "systems for TB control which had painstakingly been crafted over many years were seemingly being decimated with the stroke of a pen" (ibid: 593). "Disease controllers" placed themselves in opposition to "health reformers" (Bosman 2000) and decried the loss of organized TB control and

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[128] In addition, due to budgetary constraints (these reforms were initiated during a period when Zambia was facing economic crisis and massive external debt), the Ministry and Central Board of Health did not fulfil their financial commitment to the district health budgets, leaving districts unable to implement activities as planned (Bosman 2000).

the adoption of a system that did not sit well with the prescribed international standards for national programmes and DOTS. This tension between the integrated approach to health provision, advocated by both PHC and HSR, and the vertical nature of disease control advocated by experts in their fields, has been an enduring theme, resulting in mixed practice in countries, e.g., both PHC and selective delivery for some conditions. Such tension is translating into practical difficulties in places where reform processes are moving ahead, leading to conflict between bilateral donors, such as DFID and the Nordic countries who support such moves, and international technical agencies, such as WHO and the IUATLD, who propose delivery of DOTS through vertical programmes as the best means to control disease.[129]

However, opportunities presented by the reform process have also been described, particularly in the vision for increased capacity at district level and the delivery and planning of services closer to the community (ibid.). Some have noted that the resulting situation in Zambia, with NGOs and CBOs organizing themselves to fill the gaps, can also be viewed as a positive outcome (H.Ails, 2001, personal communication) and that neither vertical programmes, nor the Zambian situation offers a total solution.

Nevertheless, despite such tensions, internationally, the drive has been to 'convert' all countries to DOTS practitioners – as seen in WHO's Global DOTS Expansion Plan. Under the plan, monitoring is taking place of how many countries in the world have adopted the strategy thus far, using as one evaluation indicator how many TB patients have been treated successfully 'under DOTS.' The TB community, while fairly split in the early days,[130] has largely come together around such a strategy.

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[129] This tension also represents something of the 'old' versus the 'new' in aid delivery mechanisms. While vertical or selective health programmes have historically been favoured by donors – owing to easy targeting of funds and monitoring of outcomes (Walt 1999), the development of new programmatic approaches in international aid (e.g. SWAps and direct budget support) have shifted the favour and authority, and divided donors in their approaches to financing for sectoral specialisations, such as health.

[130] DOTS initially came under criticism from medics and scientists who felt the formula was over-simplified and not 'true' science, marginalizing proper research. Those more concerned with socio-economic issues have criticised the model for its rigid application in diverse country contexts, without adaptation to local needs.

5.2.2 Calls for a multi-disciplinary approach

However, while the support for the DOTS strategy is largely cohesive, and continues to be bolstered by the advocacy and marketing managed by the WHO,[131] there are still those who question its unchallenged ascendancy, in addition to its content and applicability worldwide:

"The WHO policy package for tuberculosis control, known as ... DOTS, presents interesting questions about the role of research in policy. This is because the precise relationship between the research evidence and the development of the policy has never been clearly established. Nor are there clear mechanisms for new research to feed into the strategy. Yet the policy rapidly became accepted as the international gold standard for TB treatment, and was widely lauded as the final word on TB control. Findings from an Indian research project... suggest that it is high time to reopen the debate on this TB control policy."

These comments from Ogden and Porter (1999) highlight a perceived need for continuing debate around DOTS. They go on to propose three problematic aspects of the DOTS strategy: the lack of transparency in the policy process; the focus of the policy on directly observed treatment (DOT); and the rigidity with which it is applied in national programmes. In the Indian setting, it was found that patients were being pre-selected for inclusion in the programme, based on their ability to comply with treatment, thereby contributing to the policy's prescribed targets of 85 per cent cure rate.[132]

Indeed, Ogden and Porter are not the only voices calling for the 'dogma' of DOTS to be challenged (Grange 1997; Rangan and Uplekar 1999; Needham, Bowman et al. 2004). Others have highlighted an over-emphasis on diagnosis and chemotherapy in a strategy that ignores any wider behavioural or socio-economic factors (Jaramillo 1999). Jaramillo singles out both the poor education of TB patients and their low-income status as important barriers to their accessing and completing care. He notes that in conventional TB control this and the cost to the patient are largely ignored, with the biomedical aspects of treatment emphasised at the expense of prevention. This is attributed to a one-dimensional biomedical model of causality, rather than a more multi-causal approach to tuberculosis.

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[131] And seen in events such as World TB Day held on 24th March. The slogan for 2003 was: "DOTS cured me – it will cure you too!"

[132] Criteria used to determine inclusion in the DOTS treatment programme included: proof of permanent residence; stable job with standard working hours and limited mobility/travel; no past record of TB treatment (Ogden and Porter 1999).

Jaramillo's paper points to the polarised opposition between individualized risk on the one hand and large scale socio economic forces on the other, grounded in the opposed epistemologies of a positivist scientific approach to health and a more critical social epistemology. The dominance of such positivism in the medical sciences and, hence, disease control can be seen in the Malawi NTP's own history.

In interview, both the present and past Programme Managers outlined how in its early days tuberculosis control in Malawi was not viewed as having status or credibility in the medical world, but was 'relegated' to the field of environmental health, and staffed accordingly. Perceiving that such a lack of clinical credentials would hinder its development as a programme in Malawi, the first Programme Manager described how he made a deliberate decision to bring in clinical personnel to give the NTP credibility within the Malawian health establishment, so that they could negotiate effectively with the Medical Officers in control of health policy and planning in the districts and MOHP. This situation was indicative of the extent to which the international biomedical and positivistic paradigm dominated medical and, therefore, health practice.

This is further reflected in current approaches to disease control, which are only considered 'valid' by that medical establishment, if they maintain the focus on the individual disease, and seek to investigate and respond to it using similarly 'valid' tools of scientific enquiry. Public health may be about "providing the conditions in which people can be healthy" (Hurtig 1999: 553) yet it is dominated by a biomedical perspective, supported by today's statistically driven epidemiology, which focuses on the individual body and "obscures the social forces that produce and reproduce the poverty and inequality which give rise to disease" (White 2002: 64).

Unfortunately, such an emphasis on biological inevitability, which pays little attention to both the political and social dimensions, has resulted in a disease control strategy, such as DOTS, which is itself inevitably weighted to the same individualized behavioural issues, thereby leading to particular results in practice: as already described in this chapter, the focus in disease control for TB has been almost exclusively on treatment, owing to its proven efficacy and its contribution to reduced

infection in the population - its public health impact. The prioritization of adherence to such treatment, however, has resulted in *control* and *observation* of that treatment being highlighted to the exclusion of patient care and support, and indeed, access to any such care in the first place. The human rights implications of such a focus on 'control' have already been explored (Hurtig, Porter et al. 1999), and a call made for a wider interdisciplinary perspective that accounts for the key dimensions of access in a given setting, and shifts the burden of ensuring programme success from the patient to the programmers (ibid: 558). The differences are, however, not only in policy semantics but often translate into dogmatic practice.

One example comes from recent research carried out in Ethiopia (Sagbakken 2002). Here, in keeping with the DOTS strategy, TB control was practiced with a significant emphasis on DOT and adherence to treatment. The sadly ironic result was that some defaulting patients were not allowed to restart treatment (after having missed a drug collection date) as " a punishment for breaking the rules of DOTS" – a result which went against all the epidemiological principles underpinning the value of DOTS and would lead to wider infection and drug resistance. In the researcher's words, "humans are adapted to the system, and not the other way around." [133]

As noted earlier, another country setting where the dogma[134] of DOTS has prevailed is India. DOTS coverage is not yet one hundred per cent in this country, however, significant efforts are being made by the NTP in partnership with WHO and IUATLD to change this, under GDEP. Since 1998, coverage has increased 25-fold, with half a billion of the Indian population now 'under DOTS' (J Kumaresan, Plenary lecture, 8th October 2002, Montreal 33rd IUATLD World Conference). Nevertheless, in some localised areas, innovative health services, while not following DOTS, are reported to be using their own mobile TB teams successfully. With the national move to full DOTS coverage, however, their drug supplies are now under threat of withdrawal,

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[133] Presentation at the Anthropology and the Health of Populations conference, June 2002, Brunel University.
[134] Ironically, in his 1991 article, Kochi himself noted that one of the failings of pre-DOTS TB policy was that "some of the technical policies appear to have been taken as dogma…so that there has been a tendency to discourage results-oriented and local innovative approaches" (1991: 73).

because they are not following conventional DOTS (Plenary discussion, Anthropology and the Health of Populations Conference, June 2002).[135]

The more politically minded have noted how WHO's engagement with the TB policy process was a timely one: following on from an era in which the institution was perceived to be weak and ineffectual, they were able to embrace Styblo and the IUATLD's 'short-course' research evidence to drive a new policy agenda, which would assist them in demonstrating their institution's own value and role in world public health (Walt 1999). Even prior to the introduction of DOTS as the WHO's TB control strategy, the pre-existing TB control objectives and policy were not that dissimilar: the objectives were to reduce mortality from TB; to reduce disease prevalence and to reduce disease incidence, through case-finding and treatment of infectious smear-positive cases and BCG vaccination (Leowski 1988; Kochi 1991). The shift to the 'new' WHO tuberculosis control strategy in 1991 – later marketed and launched as DOTS in 1995 – did not alter or broaden the epidemiological principles on which policy had already been based. While Kochi's 1989 review of TB control worldwide identified problems, these were in terms of a lack in standardized monitoring and reporting mechanisms, poor coverage of TB treatment services and low cure rates. He thus concluded that, "from a scientific perspective, this policy is basically sound." The new strategy was thus designed around improving the cure rate and expanding treatment services. No attention was paid to initial access to those services, or the needs of those population groups most vulnerable to TB. Instead, a major assumption was made that through improving patient management and treatment outcomes, this would have an automatic effect and "attract tuberculosis patients from even very remote areas" (ibid: 79).

Thus, while the DOTS TB strategy has been hailed as a 'classic' (Sbarbaro 2001) and indeed has drawn attention to important elements of successful case management and treatment monitoring, it also remains notable for its prioritization of treatment alone.

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[135] Both these examples highlight the difficulty in 'transferring' a global, one-size fits all policy. It is difficult to predict which aspects will be adopted or appropriated, and in what way. A package, which, in its initial conception may have suggested in-built adaptation to local needs, might be stripped down to bare instructions, which are followed in the manner of rules. The Indian, Ethiopian, and other examples suggest that, for DOTS, this is often the case.

While acknowledging the epidemiologic claim for cure rates to be prioritised in the first instance, the all-encompassing policy focus on this aspect alone has crowded out any counter-balancing attention to access and case-finding, or any concern with socio-economic context, encouraging a tendency toward dogmatic and contradictory results in practice, as in Ethiopia. As Hurtig et al (1999: 555) have observed, this approach encompasses an inherent contradiction in that, "While the interest of a programme is ultimately the good of the population, the strategy focuses on the individual patient, who is treated without reference to the social conditions that frame his or her life."[136] This includes the conditions, which may contribute to suspects accessing diagnosis, care and treatment in the first place.

Interestingly, more than five year's after Ogden and Porter (1999) and Grange's calls for critical reflection on DOTS (1997), not to mention many intervening articles[137] calling for an approach to TB control that looks beyond cases cured to patients' needs (Walt, 1999), the rhetoric has recently started to shift within the international TB community itself, with the realisation that treatment alone will not address the problem of TB.

5.2.3 The future of DOTS? Shifting the rhetoric?

In giving a brief overview of the history of DOTS expansion, Mario Raviglione, in his review of the GDEP[138] at the 2002 IUATLD World Conference, noted the milestones achieved, and described the pace of change as "rapid and impressive", with an increase from implementation in 10 countries in 1990 to 148 in 2000. India was singled out for mention with an increase in population coverage with DOTS from 18

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[136] In an email to the Stop-TB forum discussion list-serv on 17th July 2002, Tim Cullinan of the Merlin NGO writes "This over-simplistic approach enables us as health providers to stick with our measurement of health outcomes, and our beloved cost-effectiveness equations, which is about as much as we understand and can manipulate, as the only end-points with which we can be expected to be concerned. We can provide any amount of evidence of success and its cost in DOTS or other programmes, but all we are doing in the context, say, of the homeless, jobless, alcoholic pauper on the streets of Russia is to return him, temporarily disease-free, to the situation he came from and all the risk factors that led to his contracting TB in the first place." In an attempt to try and address this, some groups are already testing innovative approaches to TB control that try to address socio-cultural development initiatives in addition to TB control (Mittal, Tripathi et al. 2002)

[137] Hudelson 1996; Farmer 1997; Liefooghe, Baliddawa et al. 1997; Vecchiato 1997; Farmer 1999; Hurtig, Porter et al. 1999; Jaramillo 1999; Kemp 1999; Ogden, Rangan et al. 1999; Tanser and Wilkinson 1999; Wilkinson, Gcabashe et al. 1999; Ogden 2000; Wandwalo and Morkve 2000; Farmer, Bayona et al. 2001; Long, Johansson et al. 2001; Uplekar, Rangan et al. 2001.

[138] At the 3rd Stop TB DOTS Expansion Working Group meeting, on Sunday 6th October 2002, Palais des Congres, Montreal.

million in 1998 to 450 million in 2001. In comparisons drawn between treatment outcomes in DOTS and non-DOTS countries, figures were presented to demonstrate better performance under DOTS. However, it was then observed that progress in global case detection was not as impressive, with a move from 11 per cent in 1995 to only 30 per cent in 2001. Given the international target of 70 per cent, originally scheduled for achievement by 2005, there was cause for concern, and recognition that perhaps it is not only geographical coverage with DOTS that counts. This alone – despite Kochi's confident assertion that TB patients will be attracted from even remote areas (Kochi 1991) – would not ensure that all potential clients are accessing diagnosis and care.

This is gradually being reiterated in publications which highlight the need to "close the case-detection gap", noting that, in missing one of the global targets, there will be little impact on incidence rates. "Up to the end of the 1990s, national tuberculosis programmes have concentrated on implementing the DOTS strategy through government health facilities, in the expectation that increased availability of high quality diagnostic methods and care through government health facilities would result in increased case detection (Frieden et al 2004: 816)." This expectation has unfortunately fallen wide of the mark.

In his presentation, Raviglione went on to examine where the 'missing cases' might be, outlining that they might be at home or missed if the programme is inaccessible or unresponsive; or they might be in an institution such as prison, another part of the fragmented health system, or with a private practitioner or non-DOTS provider, if these were not integrated in any way. Such an acknowledgement of these wider issues and a raising in profile of case-detection was a new and candid stance from the core TB community and a response to the critiques already made.

At both this 'open' day of the GDEP Working Group meeting in Montreal, October 2002, and the plenary speech made on behalf of the Stop TB Partnership[139] at the same conference, the language was seen to be shifting, with an acknowledgement that,

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[139] By Jacob Kumaresan, WHO, on 8th October 2002. In addition, in an earlier WHO press release (UN Wire News Service, 10 June 2002) and an article in the Lancet in June 2002 celebrating the expansion of DOTS in China and India, Mario Raviglione and Jong Wook Lee again acknowledge the need to raise case detection and reach potential patients in their coverage areas.

while DOTS is clearly good for treatment success, it is less effective in raising case detection rates. It is now being acknowledged that, in order to meet the internationally agreed WHA targets, something will have to change. As Raviglione admitted, "Full DOTS coverage does not seem sufficient to achieve the detection target." He concluded with a request for innovative additional approaches, and even outlined some proposals of his own as to how to reach the missing cases: widening access to DOTS; improving quality of DOTS; enlisting all care providers to deliver DOTS.

This list, however, clearly maintains an adherence to the basic DOTS package and, having made an earlier call for innovation, places that innovation within the existing parameters of DOTS. The WHA TB targets were described by him as "non-negotiable" and, given the adherence to rhetoric in his suggested solutions for improving case detection under DOTS, it remains to be seen how prepared the TB community are to make the moves necessary to look *beyond* DOTS. Can DOTS be broadened or adapted to allow space for complementary innovation and response to such innovation?[140] Is that enough? How can and will national programmes respond? Can the Malawian experience with the TB Equity Study provide useful lessons?

5.3 GLOBAL RHETORIC AND NATIONAL REALITIES: TB CONTROL IN MALAWI

At this stage, it is useful to examine the situation in the Malawi NTP, owing to its somewhat unique position: as already stated, the Malawi NTP is a respected implementer at the forefront of DOTS development; a strong vertical disease control programme, regarded as a model example of WHO technical policy. It is, however, facing the significant epidemiological challenge of operating in an environment with high HIV infection, where the two diseases of TB and HIV arguably cannot be separated – as is demonstrated in the rise in cases and reduced cure rates.

In addition to this, from the NTP perspective, there are tensions on two other fronts, as illustrated in section 5.2: one is the perceived 'threat' to its vertical structure

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[140] Even in 1991, in describing the 'new' approach to TB control programmes developed by IUATLD in partnership with governments, Rouillon, then acknoweledges the scope for innovation on the part of individual programmes, but also warns that "caution is essential not to allow degradation of the results of deterioration of the method" (Rouillon 1991: 170).

through the changing health sector in this resource poor, donor dependent environment. The other is its cautious embrace of in-depth social science research that aims to be policy relevant and affect the course of TB control in a practical and beneficial way, but which challenges the existing biomedical paradigm and the sometimes rigid rhetoric of international discourse around TB: the DOTS dogma.

Responses by the NTP in Malawi to this situation during the fieldwork period have presented a useful case study that will help to inform TB control at the global level. The remainder of this chapter will therefore examine the first 'threat' of reforms in the health sector and the programme's responses. In Chapters 6 and 7, the groundbreaking, but also sometimes difficult relationship between the NTP and its umbrella social science study will be introduced, through a presentation and discussion of the community-based research findings gained using such an approach.

5.3.1 The Malawi NTP in its national health sector environment

While this research was carried out, the effects of an international vogue for health sector reform were starting to be felt in Malawi. Earlier chapters have described the development of HSR globally, largely led by the World Bank and inspired by the financial reforms and prioritisation deemed necessary to ensure efficient and effective health service provision.

Given the significant donor presence in Malawi[141] and their embrace of health sector reform, it is little surprise that moves in the health sector in Malawi have been consistent with this direction. The most significant developments seen during the research period were the development and costing of an Essential Healthcare Package (EHP), also used as the basis for the Malawi Poverty Reduction Strategy Paper (PRSP) health section;[142] a commitment by government and donors to move towards a sector-wide approach (SWAp) for health; and ongoing decentralization of planning and budgeting to the district level.

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[141] In 1999-2000, total net ODA was U$445 million, with the top donors being IDA, followed by the UK, EC, Japan, US, Germany, Denmark and Norway (OECD, 2001).
[142] The PRSP was developed by GoM as its outline of policies and programs to reduce poverty, and also as a conditionality of debt relief under the WB/IMF Highly Indebted Poor Countries initiative.

Parallel to these broader processes, the NTP was devising its next Five Year Development Plan (5YDP) – outlining the NTP's proposed strategy, activities and budget for the years 2002-2006. The NTP 5YDP planning process will therefore be explored against the national health sector environment, looking at donor, NTP, MOHP interaction and responses, during the fieldwork period of October 2000 to 2001. It is suggested that this ethnographic overview provides a useful insight into the negotiation of health care at policy level in Malawi, and the relationship between a vertical disease control programme, its key donors and the wider national context. It also gives an indication of the complex range of partners, interests and 'variables' which must be accounted for when considering disease control in any context.

The Essential Healthcare Package (EHP)

The idea of a package of essential health services was first proposed in the World Bank's influential 1993 *World Development Report*, as means of cost-effective prioritisation of health services. As Soderlund has outlined, the range of objectives associated with such an approach include: social risk pooling, improved allocation and efficiency of public funds, protection against catastrophic illness events, improved access and equity for users, and prevention of cost escalation for government (Soderlund 1998). While he notes the somewhat conflicting nature of some of these objectives, in practice the package concept has been influential in a wide range of countries, both low and middle income (Ensor, Dave-Sen et al. 2002), although little documented evidence yet exists on its impact – whether in terms of affecting peoples' health status or resource allocation.

In Malawi, the possibility of a basic minimum standard of care was first considered by Malawi's Ministry of Health and Population in 1995, in its Policy Framework Paper, and was further developed in a draft report in 1997 (MOHP 1997). After a quiet period, the process was rejuvenated in 2001, under moves to operationalise the current National Health Plan (MOHP 1999) and plan for health under the Poverty Reduction Strategy Paper (PRSP). An EHP Sub-Committee was set up specifically to coordinate the process, with involvement from key donors.

The EHP was conceived as a bundle of services delivered at primary and secondary levels (i.e., community, health centre and district hospital), supported by the necessary

administrative, logistical and support functions. It was aimed at achieving near-universal coverage of the population with a minimum set of health services. Epidemiological analysis of the disease burden, combined with resource utilisation within the existing health service, were used to set both priority conditions to be included in the design, and then cost the total package of service delivery, including support functions. It is thus a form of explicit rationing, but aimed at improving *access to* and *equity of* essential healthcare. Through providing a basic minimum for all, 'equity' is felt to be achieved by guaranteeing access to a minimum standard of care for everyone. The equity assumption inherent in this argument is that, through the design, costing and delivery of a (fully-funded) EHP package, near-universal access *will* be ensured for all, including poor and vulnerable groups.[143]

The biggest challenge acknowledged by the MOHP in taking forward the process was the design and costing of the EHP, a process coordinated by their Planning Department with significant support from UNICEF. From May 2001 for a period of nearly a year, UNICEF funded an external technical assistant who was also involved with the Zambian Basic Health Care Package development, to complete a costing and intervention model. This model included: an estimate of the current 'actual' cost of providing EHP services (under existing delivery mechanisms); an estimate of the cost of EHP provision at a desired 'standard' in 5 years time; the financial and service implications of moving from the 'actual' to the 'standard' model, and the interim resource gap.[144]

The final costing document of the EHP was completed at the end of 2001 and was then circulated to partners and stakeholders for their review. In February 2002, the MOHP convened a 'roundtable' meeting for interested stakeholders,[145] where there was opportunity for input, comments and revision, and at which the NTP Programme Manager and Technical Advisor were in attendance. The question of participation

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[143] The overarching 'equity' argument of an EHP can only be made on the basis that access *is* near universal. As Ensor, Dave-Sen et al found in Bangladesh (2002), however, while resources were being better targeted at key health services through an essential service package, the persisting barriers to accessing care experienced by poorer and more vulnerable groups remained, thereby constraining access and improved outcomes.

[144] Three MOHP reports are available which outline the methodology used and results along the way.

[145] Attendance was largely donors, a few international NGOs, MOHP staff, CHAM and representatives from the civil society health umbrella organization, MHEN- the Malawi Health Equity Network.

and consultation in the EHP development process had been a key one – particularly from the point of view of selective disease control programmes, such as the NTP.

The Health SWAp

Proceeding at a slower pace in Malawi was the move to a SWAp for health. Internationally, the concept of SWAps emerged within the health sector, largely out of a dissatisfaction with traditional project funding and the wastage, duplication and drain on government capacity to which such external assistance often led.[146] It also reflects the increasing attention to 'national ownership,' where governments are taking control for resource allocation and management, in line with their policy framework. Rather than numerous separately financed health projects, the SWAp vision is one of partnership between country governments and development agencies, who, having agreed jointly on priorities and a programme of work for the sector, make arrangements for pooled financing of the programme, to be managed by government (Walford 1998).

While the value of such a way of working is largely appreciated across the health sector, the reality of organizing such an approach has proved to be a challenge in most settings, requiring massive coordination between donor agencies, and a relaxation on conventional and usually idiosyncratic channels of accountability and evaluation that each donor uses. Agreement has to be reached between partners on all aspects of policy and resource allocation, with associated confidence in a stable macro-economic environment, institutional capacity and potential for common management arrangements with the partner government (Cassels 1997).

SWAps are still a relatively new aid delivery channel, and so experience remains fairly limited. In one attempt to document and review one bilateral donor's experience with projects and programmes (including SWAps) in East Africa,

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[146] In Malawi, donors have usually organized their financing and management of projects separately, via project units only partially integrated into the MOHP structures. This has included project offices within the MOHP entirely given over to supervision of donor-assisted health projects (e.g., World Bank), projects partially nested into particular district health offices (e.g., USAID, Netherlands, etc), or entirely separate vertical programmes organized around specific health conditions. Donor support for staff members and their requirements for specific recording and reporting methods have tended to ensure that such projects are not fully integrated within the MOHP's own mechanisms. In addition, a tendency to channel funds to particular geographic areas (and within those areas, often, particular health conditions) has led to uneven coverage of resources and services.

Anderson, Cramer et al (2002) note how "conflict and compromise" have characterised the SWAp development processes. Difficulties typically faced include the inability or unwillingness of some donors to participate (thereby undermining the overall purpose), differences in capacity – not only between governments and donors but among donors themselves; tensions between supply (donors and central ministries) and demand (districts and end users); and potentially disruptive links to other aid instruments, which may be less well 'owned' by government or attached to more donor conditionalities (e.g., PRSP, etc) (ibid.).

In Malawi, the explicit commitment by a 'critical mass' of donors (Mpazanje 2001) to such a delivery mechanism for channelling their funds to government was made clear to government and, subsequently, interest was expressed in moving towards such a way of working by government themselves.[147] Early in 2001, WHO supported a preliminary consultancy mission to Malawi, to explore and articulate a common understanding of the potential move toward a SWAp. Plans were then made for a joint SWAp design mission, to be supported by multiple donor agencies.[148] This would be to consider the necessary prerequisites for SWAp implementation, to identify any gaps and to design a process for implementation.

The MOHP set up an EHP/SWAp group, amongst their eight Joint Implementation Plan sub-committee task forces (MOHP Draft Joint Implementation Plan for National Health Priorities 2000-2001). The JIP taskforces were conceived as the main means by which the sector was organised to deliver on the National Health Plan. The EHP/SWAp group was reported by donors (JM Aitken, DFID, personal communication) to be one of the most active groups with membership extending beyond the usual donor and line Ministry membership to include Ministry of Finance and Local Government representation.

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[147] In a thesis undertaken by one of the MOHP's own Planning Dept members, he outlines how SWAps were promoted mainly by external technocrats, before generating an in-country push for change (Mpazanje 2001).

[148] While DFID, EU, the World Bank, Danida, SIDA and the Netherlands government have made their pro-SWAps stance clear in published policy statements, USAID, JICA and GTZ, whilst recognizing the limits of poorly coordinated donor aid, have not. The World Health Organisation and other UN-linked international bodies (i.e., GFATM) still support disease specific strategies and vertical programmes in the health sector.

5.3.2 Facing or fearing the future? The NTP Five Year Development Planning process

While these developments were taking place in the Malawi health sector, the NTP was considering its own plans for the next five years. The NTP's Five Year Development Plan (5YDP) development process is quite revealing of the tensions that existed between a traditional vertical programme, and these wider moves to reform.

<u>The early stage: talking to ourselves</u>

The 5YDP planning process began in November 2000, with a meeting organized by the NTP management for core central unit staff, regional and district TB officers, and invited external participants. The previous 5YDP was used as a template and, following a series of background presentations on different aspects of TB control in Malawi, participants were led through discussions on each area of the plan by the NTP's technical advisor, with rapporteurs recording proceedings. The core management team was then to be responsible for writing up the new 5YDP, circulating it for (internal) comment, before submission to the donors for approval and funding.

The discussions surrounding this first stage of developing the 5YDP revealed some dominant perspectives, shared by internal staff members. Wider Ministry personnel, being largely uninvited, were notably absent from the week's proceedings, which enabled blunt statements of 'fear' about proposed changes, but also symbolized the NTP's tendency toward inward looking debates on the subjects and their reluctance to invite external participation. Outward dialogue was not at this stage being sought, in order that management and staff members throughout the hierarchy could remain in a 'safe' environment, where admissions of concern could be made. This was seen in management's vocalised worries about loss of control and the likelihood of management failure, to be brought about by impending decentralization. There was a tendency to blame the wider MOHP systems, whose weaknesses impeded the NTP's own aims. The preferred solution was thus to bypass these structures entirely, so as to ensure that control remained within the NTP's own hands. Explicit statements were made that the NTP, rather than government, must handle drug procurement, must organize TB training for staff, and must continue to gather their own statistics, despite

government moves to initiate a wider Health Management Information system (HMIS) throughout the health sector.

In acknowledging and discussing wider reforms, the Programme Manager spoke of his fears of being 'pushed' in an unwelcome direction, in addition to his programme's lack of knowledge and understanding about the proposed changes, owing to the Ministry's "keeping silent" about such matters. This was indeed a fair point, however, at this time the NTP was accepting such silence, and retreating into statements about maintaining their own control and protecting their activities, while also mistrusting government capability. The HIV/AIDS situation and the lack of implementing activity undertaken by the National Aids Control Programme was also seen as further justification for continuing operations in a vertical manner. This was indicated in a presentation given about the NTP's consideration of a move towards providing anti-retroviral care for HIV-positive TB patients: "Otherwise, who will provide the care?"

Resistance was thus a clear theme at this stage in the NTP's planning, as was the notion of maintaining control. Capacity in the MOHP was seen as weak, in contrast to the Programme's own robust systems, and therefore further integration was regarded as potentially dragging down NTP performance – as in Zambia. The solution was thus to do it themselves – and in fact, to do even *more* by themselves, with the addition of clinical care for HIV positive patients. Through internal discussions and affirmation of the importance of a vertically organised TB control programme with like-minded practitioners, the reality of external shifts on the health sector could be avoided.

The next step: the donor response
Following eventual completion and circulation of the NTP 5YDP document, a first meeting took place with the programme's donors in March 2001,[149] at which they had a chance to respond to the draft document. Following commendation of the NTP's efforts in pulling together such a comprehensive piece of work, the overwhelming response was that such a document looked noticeably autonomous, with little

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[149] NORAD, DFID and KNCV.

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acknowledgement or detail of how it would work with both existing and proposed external mechanisms in the health sector. The lack of recognition of the SWAp development was raised as one key issue.

The response from the Programme Manager was a now familiar statement of concern for how TB control would fare "in the face of health sector reforms." Again, the need to protect activities was raised, in addition to the practical difficulties of operating in the changing, undeveloped district system. The donor response, however, was unequivocal: it appeared to them that the NTP was trying to distance itself from the MOHP. And yet, surely it had to be acknowledged that "all TB patients start as outpatients" within the wider health system?

Further comments made to the NTP about the proposed 5YDP were that the programme management appeared reluctant to lose control of any of their existing processes or components of TB control. It was acknowledged by NTP staff that often "they were seen as donors" by ordinary MOHP personnel, owing to the programme's strict vertical personality, supported by donors external to the Ministry mechanisms. This resulted in NTP staff and tuberculosis-related activities being perceived as separate too, by frontline health workers, with effects in terms of TB related activities being 'left to' TB officers, in terms of resource allocation within the PHC system and in terms of human resource issues, such as opportunity for promotion within the health service.

Despite these negative outcomes, the NTP response at this stage was still mainly defensive. There was a sense of mistrust of (changing) donor whims: "We have no answers. We don't know how fast the process will move and how." The stance therefore was to avoid the issues, with resistance – and also desperation – implicit in the lack of engagement with such broader issues, or the implications for TB control. As TB technicians, NTP staff were clearly of the school of thought that DOTS could only be delivered successfully via a selective programme – following in the footsteps of other vertically organised campaigns, such as child immunisation, polio eradication or measles control. Whether this stance was to better protect the programme or the population was, often, unclear.

One of the external consultants brought in to evaluate the programme on a six monthly basis[150], proposed that such a defensive attitude may not be the most beneficial. Instead, he proposed that the NTP needed to recognize what was happening and to plan strategically for their own part in it, reflecting this in the 5YDP. The TB Programme should advocate for their position and participate in the ongoing processes. The NTP's technical advisor, in acknowledging this advice, also reemphasised the previous NTP position of concern about maintaining secured funds to ensure the "principles of TB control" were not eroded.

Only a few days later, at the annual TB Review Meeting the MOHP's Principal Secretary himself – guided by the NTP in the words of his opening address – cited HSR as an equal challenge to TB control as that of HIV/AIDS. He was followed by the Programme Manager maintaining a defensive stance and describing his fears of loss of control, leading to increased risk of disease. This event was one of relatively few opportunities to air these concerns to senior personnel of the MOHP. However, once again, in the meetings which followed – and with MOHP senior staff no longer present, donors cautioned against such a resistant stance, and stated that, while still maintaining their core 'business,' the NTP could and should be more instrumental in advocating their position within the wider health sector.

Somewhat surprisingly to many participants, one external consultant referred to himself as "reformed from a DOTS dogmatic activist" to a disease control specialist who nevertheless recognized the need to engage and avoid being marginalised. His words supported those of donors, including DFID, who were in a position to financially support TB control, but who were also active in promoting reforms in the Malawi health sector. Therefore, the NTP needed to develop links beyond its vertical structure and into the wider health sector processes. As he put it, the NTP needed to consider how to fit into the surrounding health systems, from ground level right up to the Ministry. As the then DFID Health Adviser phrased it, in much stronger donor language – and indicating the tensions between 'donorship' and 'ownership'– they needed to consider how to be "SWAp compliant."

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[150] A strong proponent of TB control, who works for KNCV and was involved with the early IUATLD DOTS pilots in Tanzania.

Such comments reflect the ongoing tensions that the NTP has faced. As international health practice has changed over the years (outlined in Chapter 2), technocrats whose main concern has been a biomedical focus on treating the individual in order to address health across the wider population, have felt themselves swayed in differing directions by the changing, prevailing practices.

While 'fashions' have changed from PHC to HSR, and the enduring tension between selective and integrated programming has never been fully resolved in practice, the current situation in Malawi is a difficult one for the NTP: on the one hand, they have been groomed as a model disease control programme, by technically oriented organizations such as WHO and IUATLD, based on a strong vertical structure. On the other, trends in wider health systems practices have moved away from verticalisation, trying to build on PHC principles in recent decentralization and other reform manifestations. While the debate between those who favour integrated delivery through a strengthened health system and those who favour a technical focus on a single health problem has sometimes been characterised as a battle between the priorities of national governments (integrated approach) and external donors (selective approach), the changing modalities of international aid have altered the environment and redistributed the interests at stake.

The donors remain interested in supporting communicable disease as an important part of public preventive health and curative health service provision, but now wish to do so by investing in the health service as a whole, building capacity so that fully integrated service provision is a possibility. The NTP is thus caught between its own technical convictions, that a strong vertical programme is the only means of maintaining 'control' and delivering DOTS, and both adapting to and influencing changes in the wider health system for their own sake, and because this is what donors are asking for.

This tension is not only at national level with the Malawi NTP, but is seen in conflicting moves in the global arena. The setting up of the Global Fund to fight against HIV/AIDS, TB and Malaria (GFATM) is a recent example of channelling funds in a vertical manner that many perceive as conflicting entirely with moves towards sector-wide approaches and integrated health provision. National

governments are therefore seen to have little option but to 'court' funds, having few qualms if one donor's approach differs from the other. All are sources of funds to fill the resource envelope and may therefore be sought, by demonstrating the relevant stance. Informally reported views amongst government personnel hold that donors are likely to change policy and approach again in the future anyway...

At a debriefing meeting with donors and MOHP in March 2001, the NTP were told that they had until September 2001 to review their 5YDP in the light of comments received. At this time, the donors would make their decision.

Facing the future – and securing funds...

Interestingly, although perhaps unsurprisingly given the funding attached, the comments by both internal donors and external consultants prompted a noticeable shift in the NTP's stance. While still wary of the changes in the health sector, in June 2001, the NTP convened an internal meeting, with invited partners, at which to discuss the EHP and SWAp developments, decentralization and the implications for the NTP. Participants included key NTP staff, the Lilongwe DHO and staff from the Netherlands district support project office. In the introduction to the meeting, the Programme Manager spoke candidly of the donor response to the first 5YDP and their highlighting the lack of information relating to the SWAp and decentralization to districts. It was decided that advice was needed from district colleagues who were involved in these processes and with whom fruitful discussions could take place.

This opening up was a fairly significant step for the NTP and, while the ensuing discussions revealed that the concerns and fears remained, the meeting suggested an attempt to further engage with these processes. District staff were able to speak openly of the difficulties their own offices were facing and gave evidence of the kind of results the NTP feared. One example was from Ntcheu district, where although the district itself had made a health plan and budget, which was submitted to the MOHP for resources to be allocated, in terms of actual funds received there was an 80 per cent shortfall. However, in giving this example, the danger of disengagement was actually highlighted: in this year's plan, the district TB staff had had no input to the district planning process and TB related figures were therefore "very unrealistic." In addition, in the likely event of another significant shortfall in funds, the tendency of

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district health staff is to prioritise spending for conditions other than TB as "there's a National TB Programme – they have their own resources, they do it."

While some non-NTP staff at the meeting stated that they felt "TB lends itself to integration" – owing to its close links to other health conditions, such as HIV – other internal staff reiterated their reluctance to lose particular responsibility: "I can't see how integration will work effectively." Their focus was on the problems of joint supervision, pooled transport and less efficient use of time. Notably, all arguments were made in terms of the *Programme's* efficiency and control of all its components, with nothing expressed or analysed in terms of how this affected *TB sufferers'* needs.

However, the consensus from the district staff was that this process has started, and the NTP would be unwise to miss the opportunity to involve itself and have influence on the outcomes. In addition, while the Programme was worried about losing its control and "ownership",[151] many suggestions were that they needed to conversely consider how to encourage district ownership of TB control, to ensure that they were not left out of planning, budget setting or implementation.

In interview with the then DHO for Lilongwe, this point was reiterated. Owing to the unfinished process of decentralization and while there was still confusion over respective roles and responsibilities, vertical programming compounded this confusion and led to gaps in provision. Resources were unfairly allocated, with certain conditions receiving funds, and others entirely bypassed. Verticalisation also reinforced the tendency to only be concerned with your 'own' problems and avoid dealing with or being mindful of anything else. The NTP could easily be 'forgotten' at the planning and budgeting stage, and be a low priority when it came to spending on activities, as it was seen to be autonomous and externally supported.

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[151] The issue of national 'ownership' has recently assumed prominence in donor rhetoric. Such ownership is deemed the optimal aim of development assistance programs, which, while supported by external financing, should nevertheless be country-owned (i.e., directed by national vision and decision-making). Inevitable tensions emerge between this stated rhetoric and reality, reinforced by aid-giving mechanisms, which struggle to balance accountability for funds with 'donorship.' The increased attention to budgetary support and SWAps is related to the new 'ownership' agenda, reducing the transaction costs on the part of both government and donors, and channelling resources through the country's recurrent budget, rather than standalone, donor-designed/managed projects.

Yet, a later statement by him revealed the complexities of the situation. While encouraging the Programme to get involved, he also stated that the NTP for the time being are doing a good job, and while other processes of decentralization settle down, he was happy for them to maintain their activities. This highlighted the dangers of total disengagement, if even the DHO was happy at this stage to still "leave it to them." Timing, as he said, would be key. Things needed to be taken slowly, but with very open channels of communication.

5.3.3 Who is 'in control' of TB control?

A simplistic analysis of 'ownership' in development often presents donors on one side – pushing an external agenda – and recipient governments on the other, backed into a corner and forced to accept. More detailed analysis recognises the subtleties of aid giving: governments are not passive recipients but active agents with the ability to creatively utilise the aid environment; donors are not only interested in conditionalities and tied-aid but may have genuine objectives of facilitating development. In between, there are myriad nuanced scenarios where the political economic realities are played out. And in between, are also vertical health programmes, such as the NTP.

In July 2001, following wider consultations, the NTP reconvened internally to continue the 5YDP redrafting process. While acknowledgement of the sectoral changes around them was now unavoidable, there was something of a defensive stance taken at this meeting. Discussions still revealed a mistrust of "donor whims" by those more cynical of the fickle funding environment, and more protective of TB control. The technical advisor guarded his original proposals to extend the NTP mandate to include clinical care for HIV positive patients, stating that "they are within our mandate as holistic care."

However, he was reminded by the ProTest manager that the donors had told them it was not about individuals, but the programmatic approach. Finally, the Programme Manager proposed that aspects of the enlarged care for HIV positive patients should not be included – "against our own wishes, but we must make sure someone else does it." This evoked a strong disagreement from the technical advisor: "No! This is the NTP's 5 Year Development Plan, not a donor development plan!"

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These debates continued until a suitable response was agreed upon in the submitted 5YDP: one which emphasised the need for dialogue until an appropriate plan for all partners was agreed. In discussion of certain joint TB/HIV initiatives, such as adjunctive treatment with cotrimoxazole in HIV-positive TB patients, earlier drafts had been highly confrontational, containing phrases such as "The Programme Steering Group also has an obligation to support the NTP in this initiative, because the PSG and donors have supported intellectually and financially operational research on this subject over the last 2 – 3 years. Failure to support this initiative, if it is proven to be successful, makes a mockery of the operational research." (August 2001 draft of 5YDP, circulated for comment).

In the final submitted version, the NTP response to both HIV and HSR related issues was less strident and more open to discussion. E.g., " Suggested NTP Response (to HSR): 1. Up until now, the NTP has not been involved in the preparation of these district workplans. This will change with the new 5-Year Development Plan. The NTP in a phased approach will start working with districts to assist the District Health Management team plan and cost forthcoming TB control activities. Part of the budget for TB control in Malawi will be given to districts in order for them to undertake specific TB control activities. Districts will administer the funds, will take responsibility for implementation and will account for the funds which are spent. The NTP will monitor these district activities to assess whether they have been carried out and carried out well. The ultimate aim is to firmly embed the concept of TB control at district level, with the district taking responsibility for its own TB control activities. This cannot be done countrywide all at once because of limited capacity in the districts to carry out activities and to account financially for funds. A phased and monitored approach is therefore necessary."

On 19th September 2001, the donors met with the NTP to give their response. The MOHP, again, were notably absent from the meeting. The delicately balanced relationship between the three main partners: NTP, donors and Ministry of Health, was illustrated in the meeting's contents. Donors asked if, with the MOHP absent, their agreement with the 5YDP contents could be assumed. The NTP response was that, if the NTP have made a decision and the donors were happy with it, the MOHP would also

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agree. The donors were not happy with this position, and suggested to the NTP that issues that should be consistent with MOHP policy (e.g., human resource issues), were not ones that the donors could or should make final agreement on. A compromise was reached: the donors would raise such issues to the MOHP on behalf of the NTP.

Thus, while sometimes weary of donor demands, the NTP clearly perceived them as a useful resource, which could also work to their advantage. This perception hinged on their enduring worldview of themselves as a separate programme with separate needs, between the donors and the MOHP: a tripartite relationship which challenges the traditionally simple opposition of donors and government, but which illustrates the notion of negotiated interests and agendas.[152]

While the 'control of TB control' is often constructed – by the NTP – as being purely for the sake of saving patients and saving lives, this construction is one which portrays their medical moral high ground, but which fails to account for the political reality. In having to negotiate a pragmatic path through the changing heath sector environment in Malawi, the NTP was not only concerned with protecting the patients, but with protecting the programme *and all that it stands for*. Donors and government (as represented by the MOHP) are not the only political actors on the health stage. The TB specialists who hide behind the rhetoric of public health to promote and maintain the TB control agenda are also doing so with their own technical authority and legitimacy in mind. As Trostle has inferred, the ideology of TB control, as manifest in DOTS, merely helps to transform potential influence into authority, in order to legitimate biomedical control (Trostle 1988).

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[152] It should be acknowledged that this analysis presents the NTP as an internally coherent or homogenous institution. During the period of observation, the medical members of the management team certainly presented a united front, potentially strengthened by the shared reistence to the perceived threats. Similarly, the NTP's donors, while a heterogeneous group, were united in their support for sectoral reform, decentralisation and the move to a SWAp.

CHAPTER 6: FINDINGS – TB IN MALAWI, THE VIEW FROM 'OUTSIDE' THE NTP

INTRODUCTION

"It seems that the magic bullet of antibiotic treatment is only as good as the environment in which we place it." M. Houston, Review: The White Death, A History of Tuberculosis. *BMJ 1999; 318; 1705 (19 June).*

As an overall case study of TB in Malawi, this research seeks to describe and evaluate the dominant model for TB control, examining how it functions in practice, its strengths and weaknesses. Having already examined TB control at the institutional level in both national and international contexts through an ethnographic approach to policy in Chapter 5, the current chapter examines in-depth the service delivery environment where such TB control is being implemented. It aims to present the flipside of the coin, complementing the earlier examination of policy processes with an examination of the user and practitioner perspectives, in order to provide a comprehensive case study of TB in Malawi.

Such perspectives are typically unexplored by National TB Programmes. Malawi has proved an innovator in this regard, cautiously welcoming the initiative of the TB Equity Study, as an early application of social scientific studies to inform disease control. This researcher was associated with that study, and witnessed the challenges faced by social scientists in bringing the voices of ordinary Malawians to the attention of health programmers, in a manner that might ultimately influence policy. As indicated in Chapter 5 and detailed further in Chapter 7, the privileging of medical over other forms of knowledge and the struggle for voice and influence does not only affect behaviour between doctors and their patients, but between actors at the health policy level too.

Currently, TB control is predicated on both *passive* case-detection[153] and an assured system response to the passive care seeker. The success – or not – of control efforts largely rests on these two components. It is, therefore, necessary to examine closely such principles in practice, to examine the enabling and limiting factors to their

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[153] Where TB suspects have the responsibility of recognizing their symptoms as problematic and presenting for care to the formal health services.

success and to unpick the assumptions upon which they rest, through an in-depth exploration of one particular context.

Passive care seeking leaves the decision to seek care for problematic symptoms with the individual. Commonly, the medical establishment emphasises the role of peoples' 'correct' understanding of health and illness and assumes a link between their knowledge and subsequent care seeking behaviour, based on both a presumption of available information and an assumption of unhindered 'rational choice' (Zola 1973). Having made these first assumptions that, prompted by recognition of their symptoms, TB suspects will be in a position to seek care, the next assumption is that, on making contact with the health services, an appropriate response is made by health staff and a diagnosis for TB enabled.

The findings of this research suggest that in a resource-constrained African setting, such assumptions mask great complexities and potential obstacles to the successful operation of such a model.[154] Through a detailed exploration of the care-seeking environment, this chapter will explore the range of understandings existing around health, TB disease, transmission and healing among different groups, both lay and provider, in an attempt to challenge the assumption that the Malawian public necessarily share interpretations of TB that are similar to those clinical definitions held by the NTP and to illustrate the range of understandings that do exist. It will then describe peoples' care seeking choices and the factors that influence these, in an attempt to challenge the assumption that, were people indeed to share the clinical interpretations of TB disease, this would be the sole factor in determining their care seeking behaviour. It will explore the health systems' response to patients, the pressures under which Malawian health care workers operate, and the implications of a traditional healing encounter premised on a very different personal communication between patient and provider. This will be explored against the backdrop of the

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[154] Such a proposal is not a new one. In a developed country setting, the USA, Zola (1973) has explored the issue of care-seeking and the way in which a sick individual moves from being a 'person' to a 'patient.' He concluded that health providers make significant assumptions about peoples' care-seeking, based on a model of rational choice that assumes that 'sickness' will lead to a person seeking medical help, after an 'appropriate' amount of time. In fact, he proposes that this ignores the complex mix of physical, personal and social triggers to care seeking and how these may vary between social groups. He also suggests that physicians need to pay attention to such triggers, in order to effectively treat their patients.

favoured diagnostic pathway for TB with its emphasis on a successful personal encounter and history taking between patient and provider, in order to enable successful TB diagnoses.

Through such exploration, the complexity of the care seeking environment in Malawi will be illustrated, in addition to the fluidity of practices demonstrated in the pragmatic choices made by community members, formal and informal health care providers. Such complexity suggests that TB control and the assumptions and components upon which it depends may be premised upon an epistemological search for simplicity and workable interventions, which, while practically desirable, mask the complexity of reality. This is seen at the level of everyday practice, where poor systems responses and individual provider failings are ignored or excused through the paradigm of patient blame, citing peoples' poor understandings and inappropriate health seeking decisions, rather than investigating or addressing entrenched systemic problems; and at policy level, in the exclusion of socially oriented research, whose validity and usefulness in identifying such problems and informing policy is unacknowledged. A status quo is thus maintained, with 'knowledge' used to reproduce existing inequities reflected in the existing hierarchy of biomedical power, rather than reforming or addressing such problems.

Through an acknowledgement of the complex environments where TB thrives and where conventional TB control is especially challenged, there is, however, the potential for knowledge to serve instead as a flexible and responsive tool, informing both policy and practice. Questions might be reframed, unconstrained by the prevailing epistemological 'box,' and used to uncover the range of real obstacles, thereby informing strategies that both acknowledge and start to address these. This process in itself would confront the prevailing political economy of medical knowledge, which has served to delay any rethinking of the system, and would promote a re-evaluation of the very concept of 'TB control,' in terms of who or what is being controlled, and by whom.

This chapter is organised around two themes: understandings of TB and care seeking behaviour. Underlying both themes is a concern with the role of knowledge and power in maintaining the status quo of unimproved health outcomes for the poor in

Malawi, as seen through the lens of TB, at both policy level and in everyday practice. This will be discussed further in chapter 7.

6.1 UNDERSTANDINGS AROUND HEALTH AND TB

It is widely acknowledged that the field of health is medically dominated and that the institutions of health care provision and training, developed along biomedical lines, allow relatively little opportunity for other representations of health and health-related knowledges to be aired[155] (Good 1994). Even medical anthropology, an apparently reflexive social discipline, was accepting of and congruent with biomedical knowledge in its early days, building upon an opposition between 'traditional' and 'modern' medicine,[156] in its exploration of the practices of the exotic 'other.'

Good has since acknowledged the opposition between scientific *knowledge* and lay *beliefs* (Good 1994) – a notable linguistic differentiation, suggesting an implied value judgement. Many other writers have also noted the tendency to oppose 'folk' and 'modern' traditions and translate this into a hierarchy of knowledges with scientific medicine at the top and traditional or 'primitive' medicine – or beliefs – at the bottom (Brady 2001). In this was conveyed an implied evolutionism through the view of a "primitive magical strait-jacket from which empirical medicine would be progressively released" (Auge and Herzlich 1995: 29).

More recently, social theory and anthropology have tried to address this through an acknowledgement of the social construction of medical knowledge. The claim by biomedicine to be empirical, universal and 'natural' has been challenged by a range of

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[155] Good discusses 'how medicine constructs its objects' and focuses on the way medicine is taught and learnt in American medical colleges. He describes how students learn the formative dimensions of medical practice "in an extraordinary 'totalising' institutional setting", which he compares with Foucault's panopticon in its combination of observation, disciplinary control and teaching (1994:82). In his view, the norms and standards of practice contribute towards maintaining an unchallenged version of reality, supported by a strong hierarchy.

[156] Viewed through the western scientific paradigm, this early anthropological stance encouraged an opposition between traditional and western systems of medicine. Whilst this is unsurprising, given that it too is a socially constructed and temporally located academic field, it was also groundbreaking and necessary work. However, the outcome of such early anthropological approaches was not only the reproduced traditional/modern dichotomy, but also analyses of culturally differing medical systems based on further oppositions between 'naturalistic' and 'personalistic' disease typologies and also on individualistic behavioural concerns, rather than social ones – again taking the lead from biomedicine.

theorists (Fleck 1979 (1935); Good 1994; Strathern 1996; Scambler 2002), as discussed in Chapter 2, who instead have proposed that, as with all knowledge, medical science is also socially constituted.

Relating to the research findings, if it is accepted that all knowledge is socially produced and distributed, then it is necessary to consider not only the knowledge that is produced and used, but the social environment in which that occurs and the processes which contribute to knowledge formation. In this section, an attempt is made to present the range of 'knowledges' and understandings that coexist in Malawian society – among the peoples questioned and worked with. An attempt is also made to consider the ways in which such knowledges are perceived by differing groups, and also used by differing groups and to what ends. Ultimately, an implicit question throughout this thesis will concern how a particular knowledge assumes primacy over others and comes to be established as 'reality' and why – and whether that might be challenged, and how.

In exploring the range of understandings and 'knowledges' around issues of health and TB in particular, different groups of people were spoken to in both focus group discussions and in depth interviews. As described more fully in Chapter 3, respondents included ordinary 'lay' community members in both urban and rural poor locations; health care workers of all cadres (HCW), employed at government health centres in those urban and rural locations, and traditional healers (TH), offering their services in the same catchment areas.[157] A random selection of lay adults nationwide were also questioned in a knowledge, attitudes and practices (KAP) survey to try and benchmark some findings quantitatively.

6.1.1 TB signs and symptoms

In exploring signs and symptoms, open questions were used in order to elicit the full range of responses from groups and individuals, including those which were 'clinically appropriate' and those which were not. Lay group respondents all showed some knowledge of the clinically defined signs and symptoms of TB, with every focus group mentioning persistent or productive cough. Amongst individuals,

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[157] In this chapter, if an FGD or interview is referred to, it can be assumed that it is with lay community members, unless otherwise identified as a HCW or TH interview.

interestingly, although cough was very frequently cited, there were a few individuals who did *not* raise it as a symptom of TB.

Other frequently mentioned symptoms in both groups and individual interviews were weakness/tiredness and loss of weight. Loss of breath was more commonly raised in the group setting, while the other signs noted by several respondents in either setting were bloody sputum and pale or dull hair and skin. One individual noted, *"A TB patient looks very weak, and the face has what I can describe as a baby face. The face tends to something like a young person even though they are old"* (LLA004F).

TB signs and symptoms were an area investigated using the KAP survey. The findings triangulated well with the qualitative methods with persistent cough (with or without sputum) the main sign mentioned by 43.8 per cent of respondents. The next most common responses were weight loss, tiredness and breathlessness. If, on NTP advice, the two major signs of TB are taken to be persistent cough and weight loss, only 28 per cent of respondents were able to name *both*. Notably, knowledge of these two major signs was seen to be associated both with being part of an 'urban' population, with education and with sex. More 'urban' people[158] (40.9 per cent) were aware of these two major signs, than rural inhabitants (27.3 per cent) – p=0.00058.[159] And more than 88 per cent of those who knew these major signs of TB came from households with an educated head, compared to 76 per cent of those respondents who came from households whose heads had little or no education. Similarly, significantly more men (31.3 per cent) were aware of the two major signs of TB than women (26.1 per cent) – p=0.007.

6.1.2 TB transmission: How is TB spread?

When discussing how TB is transmitted, understandings were shown to be more wide-ranging, in both FGDs and interviews. While some individuals in the group setting demonstrated understandings based on 'correct' clinical interpretations, this was set against a range of other ideas amongst their fellow participants. In individual interviews, where this could be explored in more depth, the interpretations proved

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[158] Urban refers to those living within 10km of the district centre.

[159] p = the p value, or 'probability value.' This indicates the probability that a statistical result could have occurred by chance alone. Results with p values equal to or less than .05, .01 or .001 are deemed statistically significant.

even broader, with respondents not afraid to state their own ideas, nor lack of them:

F9: "That is the question that we should ask you, because I for one, am always at a loss as to how TB is spread" (08LRF).

There was some agreement that spitting and coughing were significant factors, but very few respondents went further to demonstrate an understanding of how this led to TB (i.e., germ theory). [160] Significantly, in two separate focus groups, one northern and rural, one southern and urban, it was said that if a TB patient spits and someone with bare feet steps in that spit, the barefooted person will contract TB. This perception was also shared by interviewees, who supported the other divergent methods raised in the group setting, including the widespread belief held by nearly all respondents, that TB is spread through the consumption of infected meat. Smoking tobacco and sharing utensils with a TB patient were causes also cited by several respondents – some of whom were said to have been *"told by the hospital"* (LLA001F). Drinking alcohol, eating pepper, general hygiene and consuming raw food were also identified.

Notably, and related to the TB/HIV relationship that will be discussed later in this chapter, it was felt by some respondents that promiscuity and sexual activity played a role in the transmission of TB: *"TB can also be contracted at the same time as HIV, through sexual intercourse"* (04LRC).

Thus, while respondents demonstrated moderate awareness of the principle signs and symptoms of TB, as clinically defined, their ideas about its transmission revealed very mixed understandings. As the discussions and interviews progressed, the extent of these mixed understandings and inconsistencies, particularly with reference to the TB/HIV relationship, became clearer.

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[160] In FGDs, most groups had a member who demonstrated understanding of 'germs' or something similar. One female respondent stated: "If a TB patient coughs and spits anyhow he contaminates the environment and infects other people" (02LRF). In individual interviews, such understanding was generally shown to be quite weak: one male stated "By spitting a lot, they are actually removing the bad things from the body" (LLB009M); another held a belief in catching TB from germs in food, "if it is not well-prepared" or through germs entering through the skin (LLB 001M). Germs were described as *nato tizilombo*, or tiny (invisible) animals.

In terms of transmission, as investigated in the KAP survey, 43.1 per cent of the respondents were able to correctly name coughing (droplet infection) as a way in which TB is transmitted. Other ways commonly mentioned were overcrowding, poor ventilation, and (incorrectly) sharing utensils with a TB patient.[161] Other 'incorrect' modes named were infected meat, sexual activity, treading barefoot on sputum and breaking sexual taboos.[162] Importantly, knowledge of 'incorrect' modes of transmission was strongly associated with distance from the district headquarters. People who mentioned these other modes were predominantly those who lived more than 10kms from the district centre: the rural population.

Table 7: KAP survey results

TRANSMISSION MODE	PERCENTAGE
Coughing/spitting (droplet infection)	43.1
*Sharing utensils with a TB patient**	14.9
Overcrowding	10.4
Poor ventilation	9.8
*Sexual activity**	7.0
Treading barefoot on infected spit	5.9
*Unboiled milk**	2.3
*Eating infected meat**	2.0
*Breaking sexual taboos**	1.6
Other	4.0

[*Italics indicates modes of transmission not accepted as clinically correct]

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[161] Many TB patients become non-infectious within 48 hours of starting treatment and most within 2 weeks. The common perception that they are still infectious during their entire treatment period – a perception reinforced by health care worker advice – is a false one.
[162] In Van Breugel's study of traditional religion (2001), carried out in Nathenje, Lilongwe district in the 1970s – the same area as one of this study's main research sites – he devotes a chapter to the notion of *'mdulo'* taboos. He notes that *mdulo* are always related to sexual activity, and are a form of punishment inflicted by ancestral spirits, as a result of a person's misconduct. Commonly, such punishment is not inflicted on the wrongdoer, but on another related individual. At the time of his study, Van Breugel asserts that belief in *mdulo* is deeply rooted in Chewa culture, governing their lives. In the field research for this study, it was clear that belief in such taboos was still evident, although, concepts were often shown to have been reinterpreted with the impact of contemporary events (e.g., the emergence of HIV/AIDS).

In discussions with health workers (HCW), urban staff in particular shared a preoccupation with the infectiousness of TB patients and their own safety: *"We are greatly worried...since we live and work with patients contaminated with TB, that's why we are much worried"* (01RS). Notwithstanding the high rates of HIV infection amongst staff as well as patients, this concern is understandable given the high patient contact time prior to diagnosis and treatment and the poor ventilation frequently seen in clinic rooms.

Staff generally showed a high degree of awareness themselves of TB's transmission route,[163] including germ theory, but did not demonstrate awareness that most TB patients on treatment become non-infectious and are therefore no longer a risk. As a result of this, they censured the behaviour of patients who, in their eyes, were moving around and spreading disease, instead suggesting that they be kept in isolation at home: *" As I was telling you last time that we do spread this type of TB in minibuses, moving here and there...Because if once I will tell the guardian, 'don't let this one [TB patient] move out!' If once he will move out, he will spread TB to that one, to that one, and we will see our country is going down and down, down like that."* (LLA HSA 001F)

6.1.3 Cause of illness: Types of cough

From a public health perspective, it is often felt more important for people to know the way that a disease is transmitted (e.g., coughing) and less important for them to also know the actual cause of that illness (e.g., TB bacilli). However, a number of researchers propose that disease aetiology is an important influence on patient's care-seeking behaviour (Peltzer 1987; Vecchiato 1997) and thus it is an area that should be explored.

Some argue that a concern with 'cause' places the enquiry firmly within the Western biomedical paradigm: "The whole development of Western medical thought is embodied in the endeavour to attain this coincidence between the interpretation of symptoms, the discovery of causality and the implementation of a therapy." (Auge and Herzlich 1995: 15) Others, however, posit that "the quest for the origin of ...

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[163] Excepting some rural groups who also mentioned infected meat, and sharing utensils with TB patients.

illness" affects *all* individuals, regardless of society (Sindzingre, ibid: 71). This research proposes that the search for a cause, while indeed a major concern, is not the dominant factor in the initial stages of care seeking, but, as the disease progresses and fails to respond to early therapies, *it assumes greater significance*. Indeed, this work also suggests that, when seeking care at the biomedical health service, Malawians do not expect to find the cause of their condition, but merely want treatment. If, however, at a later stage they seek traditional help, here a causal explanation will be sought. Therefore, the model that opposes the two systems and identifies the allopathic system with the western concern with cause, fails to account for the plurality of practice in different settings. In Malawi it is shown that the traditional system is more often seen as one which offers causal explanation and the western system is one which provides treatment only.

Nevertheless, this research posed questions that sought to uncover local notions of disease causation and, on a simple and almost abstract level, found a tendency demonstrated by people to categorise diseases as either 'natural' (i.e., coming from God) or 'social' (i.e., caused by magic/witchcraft[164] or a social transgression), according to their perceived aetiology. Following proponents such as Foster (1976), Peltzer (1987) and Chavunduka (1994), such a dualistic distinction is taken to an extreme in determining the disease's development, the sufferer's care-seeking choices and further extending to a clearcut opposition between allopathic and traditional medicines.

Throughout this chapter, however, while such a framework is clearly used by Malawians themselves, and was used by the researcher in initially framing the enquiries made, findings revealed the fluidity of such constructs in practice. More important than the classification into 'natural' and 'social' was a general awareness of a disease manifesting as the result of an action taken or a personal exposure. Whether that action or exposure was 'natural' or 'social' was not the overriding determinant in attempts to get well. The symptom of cough might first be perceived to be a 'common cough' and self-treated with cough syrup and lozenges. On

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[164] In the more probing interview context, the concern and conviction with 'witchcraft' (*ufiti*) as a cause of illness was clearly demonstrated. This will be more fully explored in a later section examining care-seeking for health problems, but reasons for potential bewitchment were said to mainly centre around grudges, land disputes and personal jealousies (Peters 2002).

persisting, it might then be taken to the health centre, where TB, or *chifuwa cha chikulu* (the big cough), might be suspected – either by the patient, the clinician or both. If however, diagnosis proved inconclusive and the patient returned home empty handed, having been told that 'nothing is wrong,' the suspicion might then arise that such an affliction – persistent and unidentified by the doctor using his modern tools – must likely be caused by witchcraft. However, naming the condition is secondary to taking action in an attempt to relieve or cure it, and the degree of success of each action. Indeed, the cause of a disease, or its name, is often identified or changed *in response* to events along the care-seeking pathway, prompted by the degree of success or otherwise, in finding help.

Therefore, despite claims by Peltzer (1987) and Chavunduka (1994) that illness definition or conceptual compatibility (with the healer/doctor) is the main determinant of care-seeking behaviour, in this research, it was found that the perceived cause and/or name are not sole or primary factors in directing each stage of that pathway. Rather they are one factor among many, and are a dynamic factor that also responds to and is shaped by events along the way.

It is also relevant that peoples' own analyses of their conditions do not always remain within either of the bounded categories. In a study commissioned by the researcher to explore lay understandings of TB and HIV in more depth in the central district of Ntcheu,[165] one respondent – a traditional healer – describing TB, outlined *"It starts in different ways...and it's true, there is TB from magic. If we take a closer look from our forefather's beliefs, some TB comes from magic. They called it tsempho..."* (UTHHM3). Another lay respondent stated that, *"Urban people take TB as a lung disease while many rural people think it is caused by witchcraft or something wrong with taboos..."* (UK11). Such responses illustrate that, while TB is commonly held to be a 'natural' disease, such a categorisation is not inflexible.

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[165] During the fieldwork period, the researcher was a 'client' to a Liverpool School of Tropical Medicine Masters in Community Health student, VL Karn, who was requested to undertake a piece of field research on the researcher's behalf, investigating lay understandings of TB and HIV/AIDS and their relationship to clinical definitions of the diseases. The findings have been submitted as his dissertation in fulfilment of his Masters. Findings supported those of this PhD research, but will be used as further explanation where necessary and in particular in the exploration of TB and HIV/AIDS (Karn and Chinyama 2000).

The interface between 'natural' and 'magical' is thus shown to be a porous one for individuals who, findings show, are mainly concerned with getting better and seeking help, whatever the cause of their condition. Such an interface is also being challenged by the emergence of HIV/AIDS, which has led to further blending of categories, in peoples' attempts to make sense of what they see and hear around them (see later TB/HIV section).

Nevertheless, discussions did reveal a diverse range of what can be classed as more traditional interpretations of disease coexisting with more modern conditions in the plural imagination of lay, HCW and TH respondents. Once again, it is stressed that such categories should not be read as absolute and examples will later be given of conditions, which have arisen out of the collision and collusion between pluralistic medical narratives, e.g., *TB ya mafupa* or 'TB of the bones.'

In discussing different types of cough, the most common range given by lay respondents were 'ordinary' cough; asthma; whooping cough and TB – and/or the 'cough that is associated with AIDS.' An ordinary or everyday cough was distinguished by its less serious nature, i.e., it would cure itself over time, and respond to symptomatic relief provided by syrups, lozenges, etc. Chichewa terms used to describe such a cough were: *chifuwa wamba* (ordinary cough), *chifuwa chabe chaching'ono chomatha* (literally: the small cough which finishes) or *chifuwa* – literally just 'cough.'

Asthma was also raised as a common type of cough. It was recognised as a more chronic, recurring condition, characterised by breathlessness, rather than persistent coughing. Some respondents felt that this type of chronic condition responded well to traditional herbal medicines and that allopathic medicine provided only temporary relief. The Chichewa term used was *befu*, although the anglicised *'chifuwa ch asima'* was also used interchangeably, with 'befu' sometimes used to describe breathlessness as a symptom (i.e., of TB). One traditional healer however, more unusually, distinguished between 'asima' and 'befu,' as separate conditions, requiring different handling and responses, although both were said by him to be common types of cough.

As for those conditions regarded as common 'traditional' diseases, one mentioned was *'tsempho.'* In FGDs, explanations varied slightly from region to region, but most agreed that '*tsempho*' afflicts family members in circumstances where a sexual taboo has been broken. In this sense, it corresponds to the notion of *mdulo* and, indeed, it is noted by Van Breugel (2001) that the same phenomenon has been called *tsempho* by other authors (Scott 1892). Further details provided by respondents also corresponded to Van Breugel's earlier illustrations. After a death, or a new birth, in the family, all relatives must follow a period of sexual abstinence. If someone fails to keep to this, and breaks the taboo, they become 'hot' – synonymous with an attributed quality of danger. If they then dine with other 'cold' family members – attributed with vulnerability, those others are placed at risk of the illness that is *'tsempho'*: an illness that is said to be characterised by cough, amongst other symptoms of facial swelling, chest pains and bringing up of blood. As one female FGD respondent put it:

F3: "Traditionally, there is a cough, which can occur if a husband (because most of you men are promiscuous) goes around with other women while his wife has a young child or if there has been a funeral, which has occurred within the family. The child or family members can develop a cough, which is difficult to treat with modern medicine. It can be treated with traditional medicine. We call it 'moto' or 'mdulo.' But this is a belief from us old people. You modern people do not believe in these things anymore. (01LRF)

Other respondents reported that if individuals added salt to peoples' food while in this 'hot' condition, the same result would occur:

M6: "Yes, we have a cough caused by salt. It occurs when people have not consulted each other concerning salt in the family. [Laughter]
Q: Please tell me more about that.
M9: For example in the event of a funeral within a family, you have to abstain from sex until the prescribed period expires, and if you violate that rule you can cause other members of the family to develop a cough.
M4: They also become anaemic.
Q: Is there treatment for such conditions?
M4: Yes we have traditional medicine, which if given to the patient, he recovers immediately, so long you discover what he is suffering from in time. " (09LRM)

Similarly, in informal discussions with Malawian colleagues, it was reported that menstruating women are considered to be 'hot' and therefore, traditionally, may not salt the food or brew traditional beer. As seen above, the term *mdulo* was used by

some respondents, rather than *tsempho,* in addition to other terms '*mlachilachi*[166]' and '*moto*' (fire):

F8: "Yes if one member of a married couple is going about with other women or men his/her partner can develop a cough. We call it 'chifuwa cha moto.'
F10: And also if there is someone suffering from measles in the house, there should be sexual abstinence in the family. And if some members cannot abstain, then they can cause other members in the family to develop a cough.
I: How does this type of cough differ from TB?
F2: It is the same only that our ancestors had no knowledge of TB, that is why they associated persistent cough with 'chifuwa cha moto.' (08LRF)

It was strongly felt that conditions like these could *only* be treated with traditional medicine.[167] However, several groups – particularly those of older members – said that such traditional beliefs were now the preserve of older people, and were not subscribed to by the younger generation:

M4: *"For us who were born in the past, we used to adhere to regulations laid down by society that whenever your wife was expectant or had a small child you had to avoid extramarital sex at any cost. If you did not, then your wife or child would develop a cough or swellings, which could lead to death. But these young people do not believe in these things anymore. So we do not talk much about it* (03LRM)."

Other groups supported this notion of *mdulo* being a "*thing of the past*" (04LRM), and religion was often cited as an additional factor to support that of age. Christians were identified as a group who do not follow such traditional ideas. Indeed, the relationship between the introduction of Christianity and western allopathic medicine has been explored by several writers. Both Chavunduka (1994) and Digby and Sweet (2002) have noted the important relationship between the introduction of Christianity and western medicine, via the missionary process. Digby and Sweet observe how western medicine was perceived by missionaries themselves to be a tool to assist in the religious conversion of Africans, with local nurses as culture brokers or "agents of substitution" (2002:121). The missionaries' simplistic perspective was of a dual

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[166] 4LUM: *"Mlachilachi is as good as 'mdulo' or 'tsempho' because it occurs after a funeral in the family, and you find that some members of the family, especially young men, go about fooling around with girls, and they come back to eat together with members of the family who are abstaining from sex. The result is that those members who are abstaining from sex, who are 'cold' they will develop this cough called 'mlachilachi.' And they can even develop swellings.... This kind of cough cannot be treated at hospital. They cannot detect it. It can only be treated through traditional medicine."*
[167] Although there was a distinct variation in one southern rural area (Mangochi district), when describing the condition *mlachilachi.* F6: *'These days such beliefs are less common though, because have found out that if they go to the health centre or hospital with signs of 'mlachilachi' they get cured."* (05LUF)

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displacement of traditional religion and healing beliefs, with the Western culture of Christianity and medicine. As both they and this research find, however, such an analysis relied too heavily on a notion of rationality itself premised on the innate superiority believed to be present in the Western cultural 'package.' It ignored the wider cultural meaning of illness in a given context as well as "the interpretive rationale for it, within a longer and wider framework embracing individual, family, wider social group and ancestors" (ibid:122). It failed to account for the potentiality of pluralism and alternative choices, or the resilience (and relevance) of local knowledges. Similarly, respondents in this research who identified that traditional beliefs are a 'thing of the past' and that religion forbids traditional ideas, may not have critically reflected on the diversity of practice that was revealed by both other respondents and their own later narrative exchanges!

Such contradictions were seen in that this same older generation, who still adhered to traditional practices, were said to have significant influence in the family's health care seeking decisions and were reported to be key advisors in matters of health and health care decision-making. In addition, the 'messy' nature of actual practice, prompted by pragmatic needs, was illustrated in both the words and appearances of individual respondents (e.g., a young Christian lad's tale of his bewitched leg responding to a healer's medicine, despite his stated lack of belief; an older woman's dismissal of traditional healing practices, despite showing a clearly tattooed face).

6.1.4 TB Diagnosis
Diagnosis for TB was examined both in terms of awareness of the available diagnostic means offered in Malawi, and in terms of issues raised by respondents themselves. These issues centred around the difficulty of obtaining a diagnosis for TB and the obstacles encountered along the lengthy pathway. People spoke in terms of their own experiences, if they had previously been suspects or patients, and in terms of friends' and relatives' experiences. Health care workers had much to say about their own roles, those of their patients and the environment in which they worked to try and enable diagnoses.

At present, the main method for diagnosis of pulmonary TB in Malawi is using sputum microscopy.[168] Three sputum smear examinations need to be done on each TB suspect and, should individuals have negative smear results, they should be investigated further,[169] as they may have what is termed smear negative pulmonary TB. These further investigations are through chest x-rays.

The diagnostic path is a long one, as previously described. It begins through 'passive case-finding' with a TB suspect presenting him or herself at a health facility. The first step is for the clinician to administer antibiotics and advise the patient to come back if this course of treatment does not prove effective. On a re-presenting suspect, the clinician is meant to confirm whether the cough has been present for 3 weeks or more. If it has, the patient is asked to submit sputum for examination, with three samples given over two days. All three samples are then passed to the nearest laboratory and the patient is listed in the Chronic Cough Register. Given that the nearest (or only) laboratory is generally at the district hospital, this may involve a wait of some days for transportation to the district centre from the health centre, although the recommended maximum time within which examination must be done is one week. As the NTP's TB manual states, health workers must "use any available means of transport" (2002: 23).[170] Once the results are available, if at least two out of the three samples are positive, the suspect is registered for treatment for smear positive PTB. If the patient has not come to claim his results, a DTO is expected to follow up promptly to ensure the smear positive sufferer registers for treatment as soon as possible. If one or no samples are positive, the patient should be referred for x-ray. If the x-ray is abnormal, patients should be treated for smear negative PTB. If the x-ray is normal, but the patient is still symptomatic, the clinician is meant to reconsider diagnosis and carry out further investigations.

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[168] Identifying TB bacilli in a patient's sputum by examining a smear on a stained slide under the microscope.

[169] In the NTP's current TB manual, it is stated that smear negative suspects "need further investigation and should never be told that there is nothing wrong with them before such investigations are done" (NTP 2002). This comment is important given findings, which suggest that suspects with negative smears are often told that 'nothing is wrong' with their diagnostic process halting there. Speaking about the difficulties of smear negative TB diagnosis, one medical assistant said: *" But they are just prescribed, go to the pharmacy, they get their drugs and 'Mulibe Chifuwa' 'You can go home. You don't have TB.' Go home, take the drugs from the pharmacy only."* (LLB MA001)

[170] During the course of this fieldwork, the researcher was regularly requested to carry back sputum samples to the district hospital, as her vehicle was the only one available.

In considering peoples' awareness of such a diagnostic process, responses were shown to be mixed. Qualitative findings revealed that people were aware of sputum tests and x-rays, but often cited blood tests as also having a role, and this was supported by the quantitative evidence gathered through the KAP survey. The most overwhelming finding qualitatively was that people puzzled over why TB was so difficult and lengthy to diagnose:

"Why do doctors take long to suspect TB in a patient who is coughing, why do they waste time giving out antibiotics rather than examine someone right away? Why does it take long to diagnose?" (04LUM)
"Patients tend to give up after making two or three follow ups to no avail." (04LRM)
"By the time they tell a patient to go for an x-ray and start TB treatment, he is already on the verge of death" (04LUM).

As one female community member phrased it,

"It's discouraging when people are told 'we cannot find the disease, we cannot find the disease' and sometimes it looks as if it is the doctor or doctors who do not want to be helpful". (LLB002F)

Health workers too spoke of the obstacles presented to patients by the lengthy diagnostic process. One medical assistant described this at some length, expressing his dissatisfaction with the existing system – and in spite of recent improvements with the setting up of microscopy facilities at his health centre.[171]

"[The problem] It's in the TB Programme. I feel up to this moment, our patients, even if they report to the health facility, it takes long for them to be diagnosed. Reason is the process which we follow. For example, somebody coughs for 3 weeks, they are supposed to submit sputum. And that takes maybe 3 days: first bottle, second bottle on the other day; to get examined, it's in a period of maybe 7 days. Then you find that maybe it's negative. Then, for a centre like here, we still refer them to Central Hospital. Central Hospital, they are referred not to a TB clinic, it's general, we refer. After referring, they are seen there. We find x-ray, and we find that maybe the chest is OK. They are given antibiotics like erythromycin, and they say go back. We find after 3 weeks again, patient is still coughing. They come back again, then you find that I referred this one to Central Hospital, and now he is back again. Then, because you have already taken the sputum. Then you ask him again, can you repeat the sputum? Then, what happens, this patient, he will either disappear. Or he won't submit the sputum, because you give the sputum containers and when they go home,

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[171] The difference a simple practical response can make has been demonstrated with the provision of a microscope and training to a senior HSA in slide preparation and reading at Nathenje HC. It now serves as the microscopy centre to all surrounding HCs. However, this is the exception to the rule and in virtually all other districts, microscopy is only available at the district hospital: *"We find it useful because as of now sputum examination is done right here as opposed to the past when the sputum used to be sent to Lilongwe, whereby the results took long to come and at times did not even come, and people had to resubmit sputum."* (06LRM)

they say 'aah, at first I was asked to submit this one. They find negative, I was sent to Central Hospital, they said the chest x-ray was normal. So, maybe I'm, I can't repeat. I'll go to a traditional healer.' You find after 2 or 3 months, they come. Maybe they have taken an ox-cart, seriously sick. Then you remember, this is my...I saw this patient in January. OK, you read the health passport, then you refer, and that patient gets admitted. While in the wards is when they say, they look, those clinicians, the physicians, oh, critically ill, then normally they suspect TB, because of the visible signs. Then, sputum, you'll find it's positive, or chest x-ray, with so many cavities. So they start treating them there."

Such views capture those widely expressed by other health workers of varying cadres, but particularly the HSAs and MAs/COs. The length of time taken in getting a TB diagnosis was constantly referred to, in addition to the money and effort needed by patients in getting to and from not only the health centre, but the district hospital. One particular tale was told of an educated teacher, who fully understood the implications of his TB diagnosis, but had no money to go to Ntcheu district hospital to follow up on his diagnosis and treatment and therefore remained in his village, untreated.

Overstretched staff and laboratory facilities were described, in addition to the lack of fuel and transport, which made transport of sputum samples a major challenge. The impracticality of the referral chain was illustrated clearly in one district setting (Dowa), where the only microscopy centre was in the district hospital, but where physically, the district was divided into two parts, east and west, with transport to the district 'centre' (in the east) costly, infrequent and impractical.

Staff also spoke not only of these difficulties from the patient perspective but of their own fears and concerns. The lengthy diagnostic pathway left them with increased exposure to TB suspects and those at their most infectious stage, prior to treatment. Staff candidly spoke of their concerns of being at high risk of TB themselves.

"Of course, there is fear, because some patients have died of TB. So if they know that someone was suffering from TB, has died, so it's the same like me – if I will be attacked with TB, I will die as he has done. So there's a fear." (LLB HSA 004)

"We need some space, because there are so many patients here. Just imagine 844 patients with that small room. It's not safe... and on the other hand, those people who are working there, they are not safe, you see." (LLA MA 002)

In the two microscopy centres (Kawale and Nathenje), the high workload and its effect on the quality of work done there was described, with lab staff handling not only TB samples, but malaria slides as well:

"Ai!! Go there and check, I was telling you last time that yesterday he had 96 patients, testing malaria. You can imagine, 96, one person can he manage?? Staining, lighting, focusing, everything. Can he manage? There's a shortage of staff there, sure." (LLA HSA001)

Amongst the public, there was also a persistent fear and misunderstanding that the diagnostic route for TB would involve blood tests which would also be used to identify HIV. Both staff and community members themselves spoke of people too afraid to come forward with a persistent cough to be investigated, owing in general to the joint TB/HIV perceived association, but also because of a specific fear that they will be tested for HIV. Female community members stated that if you go to the hospital or health centre, your blood will be taken for testing and,

"You will be told that you have AIDS, so they find it better not to know and they stay away"(LLA007F).

As one health surveillance assistant put it,

"Aah, I can say that nowadays, with this HIV, people are afraid. Their afraid mainly comes when they have started coughing, and they decide 'aah! As it is, maybe it is HIV. So, even I can go to the health centre for a sputum check up, maybe that doctor will tell me that I'm positive HIV. So, aah, as it is I can just leave it to see how I will live'." (LLBHSA001)

It was clear from responses that peoples' fears were of either an actual HIV diagnosis, or other peoples' assumption that they are also HIV positive if they were diagnosed with TB (and indeed their own fears that this is the case). This issue will be explored further in a following section.

Looking at the KAP survey's results, which tried to quantify diagnostic awareness levels, nearly half of the respondents, 49.5 per cent, said that TB was diagnosed through the testing of sputum. 30 per cent identified clinical examination as the diagnostic means, and 17.4 per cent spoke of x-ray. Of the remaining 3.6 per cent who gave other means, their responses included blood tests (65 per cent of the 'other' responses), checking breathing/cough rate (13 per cent), urine test (9 per cent) and those that did not know (13 per cent). There was a marginal association between

knowledge of TB diagnosis and sex (p=0.0366) with more men mentioning the correct method(s) of sputum testing and x-ray, than women. There was however a strong association between educational level and ability to name sputum testing. More people from households whose head had had some education mentioned this (65.8 per cent), compared to those whose household head had no education (51.8 per cent).

6.1.5 Responses to TB: treatment and cure; fear and worry

In continuing to explore peoples' understandings around TB, their awareness of the availability of treatment and perception of the likelihood of cure were examined. In addition, this led to an examination of their wider responses to the disease.

Following on from the FGDs, which suggested a great deal of fear and uncertainty about TB compounded by a common perception that it was incurable, people were asked in the KAP survey whether they felt TB could be treated and, similarly, cured. 73.7 per cent said that they felt there was treatment for TB and 73.4 per cent said that they felt it was curable. While these figures are fairly high, more than a quarter of respondents thought that TB could neither be treated nor cured.

In many ways, the qualitative evidence gathered in FGDs, interviews and through observation reveals much more behind the survey's closed responses, and suggests that the figures above may under-report the depth of peoples' concerns. In discussions, a repeated and common theme was peoples' heightened worry about TB. They emphasised how, compared to the past, increased deaths from TB are now seen:

"So, come today, death is everyday. It is a common thing, which is not how our parents lived."(LLA008M)
"Yes, there are many problems, many health problems. Like cough. You have people coughing, the next morning it is a funeral: they die. " (LLB008F)

Staff too shared such a perspective:

"Nowadays, we are seeing more and more deaths and that makes us scared. " (02US)
"These days, a lot more diseases are coming. In the past, [TB] treatment was OK. This time, drugs are not working. " (LLA MA002)

Those of lower cadres were not afraid to demonstrate their own confusion at what they were seeing and hearing around them,

"They say there is TB1, for which there is cure, and TB2, you cannot be cured. Is this true??"(LLB WA001)

As this ward attendant noted, a distinction was being drawn between the 'old' and the 'new' TB. With the new TB, the old treatment no longer worked and death was more likely, if not inevitable.

"At first people used to have hope that once someone was diagnosed with TB they will get cured. But this is not the case nowadays, where we see almost all TB patients ending up dying." (01LRF)
"In the past, it was different. TB of nowadays is very, very different, it's worse, because people cough and cough and cough. They go to the hospital, they get examined, they're told no, it's not TB, maybe it's something else. The next thing they die. So, no, these days it's really bad." (LLA 009F)

However, this distinction between old and new TB, while identified by differences in the disease's strength and response to treatment, was not as clear-cut as these particular quotes suggest. While many people spoke of an old and a new TB in the ways illustrated above, others added a new dimension, by identifying the 'new' TB as having an association with HIV/AIDS. The reasons for the perceived link were said to be owing to their shared symptoms, particularly cough and weight loss, and the increasing deaths from TB, suggesting an incurability like that of HIV/AIDS.[172] This idea of 'an association' is in fact appropriate, owing to the causal relationship between the lowered immunity of HIV/AIDS and the resulting predisposition in HIV positive individuals towards developing active TB disease (Raviglione, Harries et al. 1997). However, peoples' interpretations often reduced this complex relationship to a much simpler one: that the two are directly linked and, indeed, are the same disease:

"There are two types of TB; the 'old' and 'new.' The 'old' one is treatable while the 'new' one is not. Health workers call this 'new' disease TB but we know it is AIDS." (03LUM).
F7: "There are two types of TB, TB that comes with AIDS especially if the husband is promiscuous he contracts and infects his wife. We call this 'new' TB. Patients who suffer from this type of TB do not get cured even if they undergo TB treatment. And this is the type of TB that is common these days, that is why almost all TB patients these days end up dead. The 'old' type of TB patients used to get cured." (05LRF)

Such an understanding has precipitated a variety of effects, in terms of people's responses to TB. The idea of TB as no longer curable and/or closely tied to HIV has led to a great deal more fear surrounding the disease. Such fear, and the

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[172] In analysis, one might also consider the influence of 'mdulo' and the traditional notion of a cough caused by the breaking of sexual taboos, and how this may have influenced and interacted with peoples' ideas.

accompanying sense of hopelessness, was said by some to be so acute that people would consider suicide at a positive TB diagnosis, or would just wait to die in their homes and villages, rather than seeking care.[173] This hopelessness was as a result of not only the lack of available assistance in the health system for HIV-related opportunistic infections, but also the potential social stigma surrounding a TB/HIV diagnosis.

Much research has already shown the negative connotations and reactions, which surround HIV and people living with HIV/AIDS in many settings, from the US to South Africa (Herek and Capitanio 1993; Goldin 1994; Parker and Aggleton 2003; Stansbury and Sierra 2004). At the XIII International AIDS conference held in July 2000 in Durban, South Africa, the theme of the meeting was 'Breaking the Silence,' giving an indication of the reluctance of both governments and ordinary people to face up to HIV openly, largely owing to the negative and unacceptable traits attached to it. Its association with illness, death and promiscuity – events or activities that often carry stigma themselves – is one that has fostered the creation of strong social sanctions surrounding the virus.

Where previously the stigma of TB had been its association with poverty (Liefooghe, Michiels et al. 1995; Johansson, Diwan et al. 1996; Rangan and Uplekar 1999) and was arguably more limited in the Malawian setting than in others (e.g., South and South East Asia), now, in Malawi, the increased 'shame' of a sexually transmitted disease, such as HIV, is attached to TB. In talking of HIV and TB, people use the Chichewa term "*chiwerewere*" to describe the sexual activity that has led to people getting the disease(s). *Chiwerewere* is a term used for sex, with an implicit moral judgement: 'bad' sex, promiscuous sex. As one male respondent put it,

"Yes, there is fear. But also feeling shy, because AIDS is associated with...immoral behaviour. It means that this person was not living morally well, was going out with a lot of sexual partners, so... they feel shy. So, because of that, people just opt to leave town and go to the villages and maybe die there. So they are not seen to have AIDS." (LLA002M)

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[173] M4: *"There are some people who take 'termic'* (insecticide used in coffee fields), *if they are diagnosed with TB rather than face long suffering from TB.* (M8 chips in): *Others refuse to go to hospital when they suspect TB because they say 'ndafa kale'* (I am as good as dead). *"* (03LRM)

People are clearly labelled with a 'spoiled' identity (Goffman 1963), and are viewed by others as morally degraded. It has been acknowledged that the negative social reactions arising from such a disease label can affect a person's life and work. This may significantly influence the way in which they manage their response to a potentially stigmatising condition and, if a diagnosis is made, their own potentially altered identity (Williams and Scambler, cited in Moon and Gillespie, 1995).

In interviews, when discussing this issue, there was an interesting gendered aspect to peoples' responses. Men, especially in the urban area, emphasised the link and confusion between TB and HIV and the negative sexual connotations attached to both. The sex which spreads disease is perceived as invariably immoral, carried out by promiscuous individuals, and therefore deserving of the resulting social stigma. Women, however, emphasised the related lack of openness surrounding such topics. They were themselves sometimes unwilling to talk in detail because of the sexual nature of the topics, and described how socially it was unacceptable, shameful and therefore kept secret.

"People have died because they kept such kinds of illnesses to themselves."
(LLB003F)
"There is no admitting openly. We just look at how a person has been suffering. We don't want to spread the message that the person died of AIDS. They just say the person is 'unwell.'" (LLB010F)
"People do not want to admit openly because AIDS patients are regarded as unwanted people in our society." (LLA012M)

The negative judgements which contribute to such lack of openness were seen in the respondents' own statements.

"You can catch it through having sex with...er...women who are loose." (LLB009M)

6.1.6 TB and HIV

As noted in the previous section, the increased deaths seen in people having TB and the perceived symptomatic similarity between TB and HIV have reinforced a notion that the two are not only linked, but, frequently viewed as the same condition. A diagnosis with TB would therefore be seen as a diagnosis with HIV/AIDS.

F3: *"Whenever people hear that that person is suffering from TB, people automatically assume that the person has got AIDS. So many people these days are worried about TB because of this scenario."*
F5 agrees: *"At first people used to have hope that once someone was diagnosed with TB they will get cured. But this is not the case nowadays, where we see almost all TB*

patients ending up dying. So these days whenever you think about TB, you also think about AIDS." (01LRF)

Health workers supported this picture and, in speaking of their communities, described how people were putting the two diseases together and making the assumption that they are one and the same disease. While some individual male (mainly urban) respondents were at pains to point out that this general perception was wrong, most others voiced the shared perception that *"they are not very different"* (LLA011F), saying of sufferers that *"They look for medicine without success, looking for medicine without getting help, so you know it's the same disease"* (LLA009F).

As also noted in the previous section, people were distinguishing between different types of TB. At the simplest level, this was a perceived difference between an'old' and a 'new' TB, where the new version was no longer susceptible to the available drugs and led to many more deaths. However, with probing, the increasingly multi-layered narratives pointed to the complexity of peoples' understandings, as the impact of HIV/AIDS was revealed in their interpretations. A 'new' TB was thus often felt to be tied to HIV/AIDS, with peoples' models of disease causation and transmission reflecting this new conception.

F1: "Men are the first to suffer from TB.
Q: What do you mean?
F1: I mean men are promiscuous, they fool around with different women and in that way they contract TB. [Laughter from young ones]
Q: Do you mean to say that TB can also be spread through promiscuity?
F1: Yes, because TB and AIDS go together, so the way that AIDS is spread is the same as the way that TB spreads." (05LRF)

M3: "You can get HIV through sexual intercourse and you can get TB at the same time because these things are related.
Q: Do you mean to say TB and HIV/AIDS are the same?
M3: Yes
M5: No, they are not the same. They are two very different diseases. TB has got treatment while AIDS does not have any treatment.
M6: However their presentation is the same because both TB patients and AIDS patients lose a lot of weight and they all cough persistently. To us ordinary folks we take them as the same but doctors are able to differentiate them.' (04LRM)

One area where HCWs, like lay respondents, demonstrated their own confusion, was with this TB/HIV relationship. During the qualitative investigations, many questions were addressed to the researcher by health staff seeking clarification of the TB/HIV

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relationship. Interestingly, a related issue through which such lack of clarity was clearly played out was the common perception amongst HCWs and the public that TB patients, on treatment, should abstain from sexual intercourse. This issue had been identified anecdotally by the NTP some years previously and followed up in a short published report (Salaniponi, Christensen et al. 2000), where 94 per cent of TB patients interviewed (n = 384) said that they could not have sexual intercourse during the initial 2 month phase of TB treatment, and 58 per cent said sex should be avoided for the entire duration of treatment. While the report gave a variety of patients' reported reasons for this belief,[174] it did not explore whether health care workers were involved in promoting such an understanding, based on their own knowledge and understandings, but made the implicit assumption that such notions were the preserve of 'the community,' with their local beliefs.

However, in the KAP survey carried out for this thesis, 88.2 per cent of respondents also stated that they felt TB patients should not have sexual intercourse. When asked from where they had heard this perception about TB patients and sex, 48 per cent responded that it was in advice given by health centre staff or HSAs. This triangulated well with qualitative findings. As one FGD *health worker* put it:

"If she is a lady, she must stay away from her husband until she finishes treatment. The men must also do the same thing" (06RS).

As both male and female lay respondents expressed it:

"Doctors advise us to abstain from sex when on TB treatment, but if your husband demands sex from you how can you convince him not to?" (01 LRF).
"If I am a TB patient should I not have sex with my wife?" (04LRM)

It is difficult to identify the origins of this perception. It is possible to speculate on the relationship with more traditional ideas about sexual prohibition and *mdulo* taboos surrounding significant life/death events. However, it might also be useful to recognise the association with emergent ideas relating to the TB/HIV relationship. It seems likely that these notions of sexual prohibition for TB patients have arisen out of a dialectical relationship between prevailing and emergent ideas and knowledges,

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[174] Including weakness and fatigue owing to their condition; fear that intercourse would lead to recurrent TB; belief that intercourse would weaken the effects of the drugs; or lead to transmission of their disease to their sexual partner (Salaniponi, Christensen et al. 2000).

both reinforced by the contemporary TB/HIV link,[175] and furthering the common perception that these two diseases are one and the same:

F9: *"They are the same because doctors give people suffering from either of these diseases same instructions. For example, they are all discouraged to take alcohol and to abstain from unsafe sex."* (08LRF)

As can be seen in the questions about TB treatment and sex asked by lay respondents above, on overriding theme was peoples' confusion about the two conditions. Interpretations of the diseases were clearly shifting and evolving in response to what people saw and heard around them, interpreting the empirical evidence of increased sickness and death through both pre-existing traditional understandings, through the advice and information given by health workers and through what was seen, said and heard around them. Health workers shared such confusion, being members of the lay community themselves and often with as little access to any alternative clinical explanations or information as their clients, yet in a position of 'privilege' which required them to fulfil a role as health educators and promoters, disseminating health related information to their clients. Given their positions, they would be looked to by patients as reliable sources of medical knowledge and, as later findings will demonstrate, their advice would be largely respected and listened too, with people accepting the hierarchy of doctor (or any health worker) over patient and either privileging the apparent clinical knowledge over individual experience, or, reinterpreting that knowledge through their individual experience and knowledge, contributing towards a new interpretation, as shown here:

M4: *"These days there is another kind of TB whereby the patient does not cough, but develops large pimples on the face and loses weight. Such are usually diagnosed with TB when they go to hospital. I don't know what kind of TB this is.*
(Chorus from the group): *It is this new TB that is related to AIDS."* (03LRM)

6.1.7 TB of the bones

Given the actual picture of TB and HIV seen in Malawi, where research has shown the co-infection rates in some areas to be as high as 74 per cent (Harries, Maher et al.

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[175] Salaniponi et al (2000) observed how such a belief could contribute to a useful public health outcome, by limiting both TB and HIV transmission, particularly in those co-infected with HIV or those highly infectious Sm+ patients, who take longer than usual to become non-infectious. However, they also note the potentially devastating impact on personal relationships this might have and anecdotal evidence (J Kwanjana, personal communication, 2001) suggests that patients with TB might then be forced to look outside their marital relationships for sex, thereby increasing their own, and others, risk of HIV.

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1995), it is unsurprising that community members are drawing their own idiosyncratic conclusions. While NTP staff were aware of the 'no sex, we're on TB treatment' view (Salaniponi, Christensen et al. 2000), until this study, they had been unaware that their own health workers were promoting such a view in their advice to patients. In addition, another unpredicted and startling finding for the TB establishment – and one which seemed to illustrate the complex dialectic at play in the construction of local knowledges – was peoples' understanding and use of the term 'TB of the bones', *TB ya mafupa*:

F2: *"There are 3 types of TB: TB of the lungs, TB that is related to AIDS and TB of the bones.*
F3: *TB of the bones is as good as the TB that is related to AIDS. If someone is suffering from TB of the bones we know that that is AIDS."* (02LRF)

When talking about types of tuberculosis – other than the 'old' and 'new' – respondents commonly differentiated between TB of the lungs, *TB ya mapapo*, and TB of the bones. TB of the lungs was identified by the persistent cough, weight loss and the other signs and symptoms of 'normal' TB. TB of the bones, however, was, different. Sufferers did not necessarily cough, but lost weight. They might have chest pains and body pains, in addition to sores on the skin. The disease was difficult to diagnose – even for doctors. Consistent themes were its similarity to HIV/AIDS in its difficulty in being diagnosed and its difficulty in being cured. In many ways, such themes corresponded with peoples' earlier identification of the 'new' TB. However, the additional clinical signs mentioned, including joint and chest pains and diarrhoea were more suggestive of the AIDS stage of HIV infection. Perhaps most interesting, however, was the common response that health workers were actually using the term TB of the bones, to hide a clinical AIDS diagnosis:

"Why is it that you doctors do not tell us the truth when someone is found to be suffering from AIDS, you tend to say he has TB of the bones? You are the ones causing these deaths because you do not tell us the truth and people end up inheriting widows and widowers of relatives who have died from AIDS.[176] " (05LRF)
"People look at you and they know this may be AIDS. It's just that the hospital sometimes, they will not disclose exactly that you are suffering from AIDS, because it would be embarrassing. But, people know that this must be AIDS. It comes in together with TB of the bones, and TB." (LLA006M)
M2 (standing up): *"All the people that I knew to have been diagnosed with TB in the past 3 or 4 years have all gone, they died. The problem is with you doctors because*

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[176] This is a reference to the traditional practice of wife inheritance – when the wife of a deceased man would go to live as the wife of his brother or cousin – practised mainly in the patrilineal regions of Malawi in the north, and in the far Southern Shire valley.

you tend to say all AIDS patients have TB. You tell us it is TB of the bones, but though we are just lay villagers we know that it is AIDS. So you doctors should learn to tell us the truth. When it is AIDS just say so." (03LRM)

Owing to the great confusion displayed amongst respondents about TB and HIV/AIDS, and the frequent assumption that they are one and the same, it is difficult to evaluate conclusively to what extent it is the staff hiding AIDS with diagnoses of 'TB of the bones,' or the public perception that TB is the same as HIV, resulting in the belief that staff, when giving diagnoses of TB, must therefore be hiding a true diagnosis of AIDS. It is acknowledged by the NTP (AD Harries and NJ Hargreaves, personal communication, 2001) that clinical extra-pulmonary TB of the bones is a *very* rare condition, of which few cases have ever been reported in Malawi. And yet, the findings of this research show that ordinary people recognise and use the term 'TB of the bones,' thus presenting a very different picture to this clinical one. In further findings in VL Karn's study – commissioned by this author – it was shown that, when probed in interview, people did not have a clear idea of exactly what TB of the bones involved, but referred to what they had heard from health workers (Karn and Chinyama 2000). This suggests that lay respondents' reports of staff may be accurate and that, although the findings are not detailed enough to state where or by whom the term was first coined, what is undoubtedly clear is that there is *very* widespread feeling amongst the public that staff are failing to accurately diagnose AIDS, and that, when given a diagnosis of 'TB of the bones' this is assumed to be both AIDS and incurable.

In making such diagnoses of 'TB of the bones,' health workers are thus contributing to further confusion about the already complex relationship between the two diseases. And yet, the strong social sanction that exists around HIV, in addition to the lack of any available treatment to ameliorate the impact of such a diagnosis, are understandable contributing factors which may have helped staff towards such a trend. It is not only patients who feel helpless and hopeless upon receipt of an HIV (and/or TB) diagnosis. Health care workers are also feeling compromised by both the cultural[177] and structural limits (see later section) to their making such diagnoses.

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[177] Malawian health workers' reluctance to discuss HIV/AIDS openly in front of their patients has already been documented in the work of NJM Claessens, S Meijnen and MM Weismuller, three

These findings have highlighted the diverse narratives and overlapping discourses of those involved and touched by TB at every level. From the politically and officially 'accepted' expressions of knowledge about TB that tend to monopolise debates and decision making at policy level; to health service practitioners' own interpretations and constructions of that knowledge; to their clients, whose understandings and knowledge are affected not only by the (semi)medical constructions of health and disease offered to them, but by the social dimensions of illness and the biological realities of diseases experienced.

As Leigh Pigg has acknowledged, in her writing about health and development in Nepal (Pigg 1997), development knowledge, in a similar way to medical knowledge, presents itself as the dominant, logical and desirable mode of thought and practice, in opposition to the more limited and parochial local understandings. However, as she suggests, such knowledge gains further power through 'translation' and fusion with these other ideas – the same local knowledges and idioms of difference, with which it presents itself in opposition, yet through whose local significances (often highlighting difference and discrimination) further power is found. As she writes, "villagers are made marginal by a development discourse that turns them into 'targets'... and positions itself as an authoritative system that mediates numerous 'local' situations" (1997:284).

Such an analysis hints at how the opposition between the developmental and the local, or the clinical and the traditional, is not absolute, but often extends to a collision, and subsequent collusion, between these oppositions. Frequently, the resulting ideas from this collision, their appropriation and use are deliberately controlled by those in the position of authority. The findings here, however, illustrate that such a mixing of ideas between the dominant scientific and local social processes, cannot always be determined or controlled by the dominant sector. However, it is a concern that, if falling beyond that realm of control, any new ideas - such as TB of the bones - may instead remain unacknowledged.

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medical students from the University of Amsterdam, who undertook research for the NTP in 2001 – some of which has been published in the Malawi Medical Journal, volume 13, number 4, 2002.

There is therefore an urgent need for policy makers – those making decisions at NTP headquarters, motivated by the desire to control TB and genuinely improve the lives of Malawians, yet often unaware of the perspectives of those who they were aiming to assist – to appreciate all these aspects through inter-disciplinary investigations which can inform their policy and practice.

6.2 CARE-SEEKING PATHWAYS AND BEHAVIOUR

In Chapter 3, when discussing methodological approaches, the opposition between the natural and social sciences, and how this has translated into differing epistemologies, was highlighted. The development of differing theories of medical knowledge/practice has also been discussed in the introduction to section 6.1.

Nowadays, there is general acceptance that illness is undeniably a physical *and* a social 'event';[178] both individualising and social in its effects and experience. While a disease has a clear physico-biological effect on an individual, the very experience of that disease is constantly interpreted in relation to others, and others' interpretations of that condition. Parsons' theory of 'the sick role' (1951) was one of the earliest that recognised this aspect of illness and, while theorists have moved away from the rigid functionality of the 'sick role,' his ideas nevertheless proved pivotal in encouraging a recognition of the very social effects and implications of illness and disease.

The Western concern with 'cause' inevitably places a disease experience in a chain of events and a social context. The pathology of disruption to one's normal state – if socially sanctioned – may lead to action to remedy the situation. In taking that action, one encounters the social institutions set up to deal with such pathologies. Alternatively, if the condition is not socially sanctioned (e.g., post traumatic stress disorder, Gulf War syndrome) or is socially stigmatised (e.g., HIV/AIDS, STDs) and the Parsonian sick role is not well recognised by *others*, a whole range of social aspects may mitigate against the successful treatment of that pathology. This 'social' interpretation can also not be considered in isolation of the political economic context in which an illness is experienced, as this research attempts to highlight. The

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[178] When we say social this may refer to the effects on wider society of an individual being sick; the effects of that wider society on how an individual may interpret and express that sickness; the institutional structures and networks set up to deal with disease and illness, and the intellectual models of interpretation of which such structures are both basis and expression (Auge and Herzlich 1995: 3).

biomedical establishment's 'hi-jacking' of the social agenda is often used to deflect attention from the wider political economic environment, by using the paradigm of the 'ignorant' patient to explain away biomedical and systemic failures. This may be compared to the way that the social agenda of anthropology has been used in the past to demean indigenous knowledges, as being beneath the rational legitimacy of scientific medical knowledge, and, ironically, through the natural/personal dichotomy, to promote an individualised, behavioural view of illness. While attention to local level understandings was long overdue, unfortunately, the social was conflated with a reductionist view of the 'cultural' that focussed on the distant – and demeaned – other.

This has been paralleled in the development of approaches to health promotion interventions, particularly those aiming for behaviour change. With the advent of HIV/AIDS in both the developed and developing world, attention focussed on the risk behaviours of individuals. Applied medical anthropological techniques were increasingly combined with social cognition models in an attempt to interpret, predict and guide peoples' behaviours, in line with an individualised view of illness and risk. The initial focus was on understanding and improving peoples' knowledge as a means of changing their subsequent behaviour.

As Parker has illustrated, however, in looking at HIV/AIDS (2001), over time, recognition has gradually been accorded not only to peoples' individual behaviour, but the social context in which this occurs. In his view, this was demonstrated in the 1980s, with a focus by medical anthropologists on the cultural systems shaping sexual behaviours relevant to HIV transmission. More recently, in the 1990s there came an added emphasis on the structural factors and inequalities shaping peoples' vulnerability to HIV infection (e.g., the economic pressures influencing young womens' practice of 'transaction' sex with older moneyed partners – so-called 'sugar daddies').[179] Commonly now, attempts are made to integrate the two in any interventions, with what Coombes describes as the social-ecological approach to behaviour change and the most recent health promotion term: Behaviour Change Intervention (Thorogood and Coombes 2000) – both of which seek to recognise the

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[179] See Bruyn 1992; Bledsoe and Cohen 1993; Haram 1995; Silberschmidt and Rasch 2001.

multiple causes of peoples' actions and the flawed assumptions of a model based on rational choice and an automatic link between knowledge, attitude and behaviour.

In the light of this, the following section will explore the role of peoples' knowledges along their care seeking paths, and will try and raise their voices to be heard – as an end in itself – but also to illustrate the role of all other factors influencing their pathways to care. This will help to reduce the tendency for such knowledges to be interpreted solely through the biomedical paradigm of patient blame, instead contributing to the generation of practical policy and systemic health care responses that acknowledge and attempt to address such factors.

6.2.1 Pluralistic options

"This is how it happens. If I'm unwell, I will buy medicine from the grocery shop, and if after taking that medicine, I see that there is no improvement, I would decide to go to the hospital, where I would hope to get an injection. But if I go to the hospital, sometimes, they will not give me an injection, they will just give me pills, tablets, and if I get those tablets, I take them and I see there is no improvement, that's when I decide I will take my own medicine.[180] And at this point, I either get well, or if I don't I decide to go to other traditional healers to help me. " (LLA005F)

The above quote, coming from a lay community member, illustrates the range of treatment options available to most Malawians. Those in rural locations might encounter a greater degree of difficulty in physical accessibility – in terms of distance to their nearest health centre or hospital. However, despite varying degrees of challenge in accessing these options, the majority of respondents, lay and staff members, outlined their use of three main health care facilities: over-the-counter medicine from a grocery shop; health centre or hospital; traditional healer.

Within these options, there was also variation. The grocery shop might be an urban pharmacy, or more likely a local convenience store selling a range of goods from cooking oil and soap bars to cough syrup and aspirin. In more rural areas, it could be a market stallholder or itinerant vendor. Within the government sector, the health centre might be a rural government health post, a secondary level district hospital or the outpatient's department of a tertiary level central hospital. If in the private sector,

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[180] This particular respondent also practised as a healer herself, specialising in women's reproductive health and sexually oriented problems.

it could be a rural mission hospital or an independent practitioner's urban clinic. As for traditional healers, this could be a herbalist selling ready made preparations at the local market, or a spiritual-herbal practitioner, operating a 'clinic' from his village house.

Throughout the fieldwork process, this same range of options was highlighted time and again, emphasising the variety of medical approaches utilised by people, regarded by them as of complementary utility, and including both informal and formal, traditional and allopathic methods – affirming the observation by repeated commentators that plural medical systems co-exist in both Western and non-Western settings (Ernst 2002), and that such plurality should encourage us to look beyond the dualisms and binary opposites often used in analysis of such settings.

However, Ernst also sounds a note of caution by noting that, despite the attempt by the medical pluralism approach to break away from the restrictive categories and oppositions traditionally adopted in both medical history and anthropology – often based around an assumed superiority of a western scientific system – its arguments have also tended to be framed within the very categories it tries to challenge.[181] In addition, while encouraging a welcome shift away from the domination of biomedical superiority, its promotion of pluralistic systems and alternatives might also run the risk of ignoring notions of power, politics and hegemony[182] (Navarro 1976), by creating an alternative vision of a semi-utopia of free consumer choice from a range of accessible, mutually supportive therapeutic options.[183]

It is important therefore that this research finds that, in addition to the range of plural therapeutic options available to individuals, the final care-seeking decision and the ability to act on that decision is both limited and enabled by a wide range of competing factors. While the approach of scientific medicine has been to

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[181] For example, in talking of exchanges or interactions between one system and another, or notions of hybridity, synergy, etc (Ernst 2002: 3).

[182] As Cant and Sharma have stated, "The biomedical power which social scientists have wished to critique is no illusion. Historically speaking it has grown from ... biomedicine's political alliance with the state and ... its espousal of scientific method as the basis for its authoritative claims to knowledge and expertise" (1999: 11).

[183] A view such as that depicted by Bloom and Lucas (1999) in their discussion of pluralism and marketisation in the health sector.

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individualise disease, the nature of its cause and the response to it, this is seen by some as working in collusion with the capitalist state system to try and absolve responsibility from the wider economic and political environment as contributors towards peoples' health conditions (Navarro 1976; Cooper and Packard 1997). This therefore undermines the opportunity for any collective or systemic response, and seeks solution in either an individualised health education system (prevention) or individualised clinical treatment (cure)(Navarro 1976).[184]

As the following sections illustrate, however, the wider environment – encompassing economic, political, social and cultural dimensions – constitutes a context of great complexity in which care seeking decisions and actions are undertaken. While it is sometimes possible to identify patterns and occasionally to draw generalisations, perhaps most importantly such an environment demonstrates that seeking an individualised solution alone, merely ignores reality's complex challenges and maintains the status quo, which suits particular interests and downplays others.

In a study by Chilowa, Devereux et al. (2001), an assessment was made of users' access to and perceptions of social services in Malawi. The aim of the study was to examine the gap between provision of goods and services and the needs of Malawian users, in the areas of education, health and safety nets, using four criteria: access, quality, relevance and fit.

In the study, access referred to a range of barriers to utilisation including physical, financial and social factors, in addition to those of eligibility (i.e., targeting criteria for particular projects or programmes). Such barriers are also relevant for the presentation of this study's findings, although it was found that there were frequent occasions of overlap. For the purposes of presentation, two main categories will be used: structural influences on care-seeking and behavioural/cultural influences[185].

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[184] In examining the changing nature and role of public health, Berridge identifies three historical phases of environmental sanitation, bacteriology and finally education and personal hygiene. The latter two phases, precipitated by developments in bacteriology from the late 19th century, focussed attention on notions of individual cause, individual infection and individual patients and led to the concept of 'personal prevention' on which a 'new' public health was founded in the early 20th century. Prior to recent developments in health promotion, health education supported the school of prevention that was premised on individual responsibility and, by association, individual blame (in Thorogood and Coombes 2000).

[185] It is acknowledged that these are not mutually exclusive categories.

While playing a part as an underlying theme, the role of information and knowledge in influencing the care-seeking process will be addressed in the following chapter.

6.2.2 Influences on care-seeking: structural

As will be shown clearly in the upcoming discussions, the issue of structural influences on peoples' access to health providers – of any kind – was a considerable one. With a distanced observer's perspective, these influences could be seen as either enabling or limiting factors, i.e., the absence or availability of money; the closeness to or distance from facilities. However, such structural factors were commonly portrayed as limiting factors by the respondents themselves, highlighting the barriers to their access to care. This will be clear in the reports below, which reflect the negative phrasing in respondents' narratives, demonstrating their preoccupation with the difficulties that were consistently faced in seeking care for sickness.

As this research was predominantly concerned with the role of the TB Programme, where services are delivered primarily through the formal government system, the focus of questioning and responses concerned government providers. However, inclusion of perceptions of other providers was a necessary comparative device, illustrating the degree of 'choice' – or not – which Malawian 'consumers' have in their pluralistic care-seeking context.

Physical factors

When people were asked to discuss what factors influenced their decision of where and when to seek care, a recurrent theme was the physical factors, such as distance to and from the nearest provider and availability or means of transport in order to get there. These issues were common to both urban and rural respondents, and cited by both lay community members and health workers.

Grocery shops and traditional healers were discussed in a typically positive light, in that they were generally more conveniently positioned and much closer than their alternatives.

M5: *"Treatment for these ailments* [diarrhoea, pneumonia] *can be found at the health centre, it is only because we are used to the fact that these diseases can be treated using traditional medicine; and also because traditional healers are within our villages rather than the health centre, which is at distance."* (04LRM)

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This too was recognised by staff at government health centres, who were very much aware that alternative providers were often based closer to peoples' homes, with a more even distribution throughout both urban and rural locations.[186]

The problems in physically accessing services were repeated as much amongst the urban poor population, as within the rural areas. While rural areas might be seen as more immediately compromised in terms of distance and transport, poor urban areas were also disadvantaged. In the study site, Area 24 Lilongwe, the nearest government health centre was a distance of 6 kilometres away. If unable to travel on foot, a public minibus cost 15 Malawian kwacha (MK) one way. If travelling to the central hospital, two separate minibuses would be needed to cover the greater distance of 12kms, at a total cost of 60MK for the return trip. Given that typical daily wage rates for *'ganyu'* labour[187] were 50MK, it can easily be seen that for poor urban dwellers, any transport other than by foot, or borrowed bicycle, was largely prohibitive.

"From here to Central hospital is a long distance. And if you become sick suddenly, then things could get worse. There is a small clinic at Kawale. Also, it is somehow a long distance but not compared to Central. Because of lack of transport to town then you have to walk slowly and little by little. But, had it been it was possible to have our own (government) clinic in our area to assist those who are in problems, mainly women and those who become sick during the night. Because diseases come without notice in the night, and when this happens, it is difficult to walk to the hospital."
(LLA006M)

Private clinics were seen to be immediately available[188] in urban areas, and also mission hospitals were commonly found in rural districts – although distribution was still limited. However, the fees[189] charged at these private providers restricted access for those *"with nothing in their pocket"* (LLA006M).

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[186] In Chakanza's article on traditional healers in Malawi, this more favourable distribution of alternative providers is demonstrated in his figures: "In 1993, there was an estimated 65,000 traditional healers and the ratio of traditional healer to patient was 1:123, while the medical doctor to the patient was 1:50,000" (Chakanza 2000).

[187] Typically translated as 'piecework' and referring to casual labour, paid by the task or day. In Area 24, the most commonly available *ganyu* involved breaking stones from the old quarry by hand, to be used as building materials.

[188] At the time of research in Area 24, 3 private clinics were running in within close range of the central market area.

[189] A typical consultation fee with a private practitioner would be in the range 50-100MK. Drugs would cost extra.

Those in rural areas whose villages were close to the government clinic were mindful of the difficulties for those in further outlying areas, some suggesting that the government needed to extend the reach of its health centres and health posts. Occasional respondents were remarkably stoical in their attitudes, citing community support and the borrowing of bicycles and ox carts to transport the sick – particularly in rural areas – or even claiming that distance was no object,

"When you are sick, you don't look at how far a place is. It is like a very short distance. You just go." (LLA004F)

On the one hand, such a response symbolised the determination by ordinary Malawians to cope and find ways to manage, despite enormous obstacles. On the other hand, such responses belied the more common hopelessness displayed by those who were clearly limited by their circumstances, despite the will to do more. As one old woman in Area 24 revealed, having described her painful and swollen joints,

"I tell the people I stay with that 'I'm unwell, take me to the hospital.'[190] But the hospital here is very far, you cannot reach there. So, instead, the gentleman who was sitting here, my son-in-law, and his wife, my daughter, only say that 'now we pray for you.' And they pray for me. I get some relief." (LLA009F)

This situation was not atypical. For those without means and too weak to walk, options were severely restricted,

"There's nothing else they can do! They just continue being sick. What else can they do?" (LLB 005M)

Financial factors

Unsurprisingly, money was an overriding factor. *All* urban male respondents mentioned money as a priority issue, but it was a cross-cutting theme for groups, regardless of gender or location. In principle, poor households have access to public sector health services that are free of charge. The government network of facilities includes hospitals at central, district and rural level, supported by health centres and health posts extending into the rural areas. In spite of this public service provision, significant financial barriers to access to care exist for the whole population and in particular, the poorest and other vulnerable groups. Indirect opportunity costs, including time spent seeking care, income lost, etc, are also significant.

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[190] It should be noted that the Chewa word for hospital and/or health centre is the same: *chipatala*. In English translation therefore, the term hospital is commonly used to refer to any health centre or clinic, regardless of size or technical classification.

As already noted, physical barriers for the urban poor can be as great as for those in rural areas. While transport distances may not be so far, routes are frequently indirect, time-consuming and expensive. Opportunity costs to the urban poor are often greater than to the rural population, given their day-to-day earning needs and the vulnerability of a population dependent on work/money sought on a daily basis. Frequently, a decision to seek care – even in the 'free' public sector – will mean a day without income generated, a day when savings must be spent on transport and so a day, or days, without money for food. A choice to seek care in the fee-paying sector carries an even greater burden of multiple costs. The huge demands placed on individuals in such precarious daily positions was spoken of by one older woman:

"In our area, we break stones to earn our daily income. It's a tough job, but we need to continue – even when sick, or on TB treatment." (LLA001F)

Her statement was consistent with the overall picture of vulnerability. She was speaking as a former TB patient, who used to always walk to the health centre to collect her drugs, three times a week in the initial phase. *"Once in a while, my husband would give me money for transport."* This comment demonstrates the added dimension for women of who has control over household income, and the related degree of decision-making power. This was reflected not only in her response, but in those of other women, both older and younger:

"I have to discuss it with my husband first, because he is the one who gives me money." (LLA011F - younger urban woman of 23 years).

The gendered aspects of access to healthcare are here demonstrated not only in terms of control over household income, but the related control over health related decision-making. Enduring sexual divisions of labour and strong social norms in Malawi contribute to the maintenance of unchallenged gender roles, which may obstruct access to care for groups such as women and young people. Women's decision-making power and control of the household income is frequently compromised, with husbands, other male-family and even female elders remaining key gatekeepers.[191]

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[191] In matrilineal rural localities where the research took place, uncles and female elders also represent key decision-makers. Older women may represent as much of a barrier as male counterparts, in maintaining traditional ideas around health practices, in addition to supporting age and gender related decision-taking structures.

Despite this one area of gender difference – raised predominantly by women[192] – men and women concurred on the overall significance of money as a determining factor. *"Money is what tells a person which hospital they can go to get help."* (LLA002M)

Physical distance could be simplified with the availability of money, especially in urban areas; a decision between earning for food and seeking care would be made easier; fees for private providers would not be such an issue, if money were available,

"The problem is money. If we had money, we would be going there [private clinics], *but the kind of money that we make does not match with what would be required to pay at those clinics."* (LLA012M)

In rural areas, the seasonality of cash income increased vulnerability at particular times of year – for example, the lean pre-harvest rainy season period, where health problems were exacerbated by poor diet and wet unsanitary conditions. When no money is in the house, peoples' options are plainly severely limited:

"For those who have money, they straightaway go to the paying hospital... But how do you go if you have no money?...Even if they tell you you will find medicine in such-and-such a shop, but if you don't have money, you cannot buy." (LLB002F)

In the rural study site of Nathenje, much of the so-called 'catchment population' for the government health centre, lay well beyond 5 kms and up to 25kms away. Some villages were much closer to the well-known CCAP Mission hospital at Nkhoma – an institution with a reputation for good service, with drugs in stock and limited waiting time. However, for this section of the rural population, the purchase of services at Nkhoma hospital was highly significant, and would necessitate a choice between health care and other basic needs, if that choice could be made at all.

F10: *"If we had mission health centres only, most of us would be dead, because we do not have money to pay for the services."* (08LRF)

For the Malawian population, food dominates the household expenditure, and this proportion is highest for the poorest rural population (NEC 2000; NEC 2001; NEC, NSO et al. 2001), who have the least cash income yet often great food insecurity and a

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[192] The exception being in one male focus group discussion: *M3: "It also depends on who has financial advantage in the family. The one who has money can influence other members of the family on where to go for treatment with the patient because he is the one going to foot the bill for transport and other expenditures."* (10LRM)

need to buy seed and inputs to produce food, in addition to food itself.[193] The urban poor however, also have to meet additional urgent cash needs, such as housing, fuel and transport. The impact of the costs of care-seeking for a suspected disease such as TB, where the diagnosis will necessitate repeat visits to the health facilities – if indeed correctly suspected in the first instance – is therefore significant, and enough to precipitate a significant shock to the livelihoods of both rural and urban Malawians.

A study undertaken by the TB Equity Study set out to quantify the costs to the patient and their 'guardians,'[194] thus looking at patient and household costs directly amongst a sample of Lilongwe-based patients (G Mann et al 2001).[195] The study found that, on average, patients spent 972MK (approximately U$13, or 18 days income) and lost 22 days from work while accessing a TB diagnosis. For the poorest patients (classified according to data from the 1998 Malawi Integrated Household Survey), the total costs were equivalent to a massive 584 per cent of total monthly income, after food expenditure. For the non-poor patients, the total costs were 124 per cent. Relative to monthly income, it costs the poor twice as much to access TB diagnosis and treatment as the non-poor and as much as 6 times available (non-food) income. In the somewhat understated phrasing of a poor urban man and woman,

"Yes, it's very difficult. Sometimes you find yourself feeling sick when you have nothing in your pocket, so it's very difficult." (LLA006M)
"Diseases do not come at some expected time. They come in rather unexpected, sometimes when you don't have any money at all." (LLA011F)

Systemic factors

The Mann study illustrates how the present DOTS programme presents financial barriers to diagnosis for TB, especially for the poorest. It recommends an urgent need to shorten the diagnostic process, improving service quality and bringing services

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[193] As part of the monitoring and evaluation of the donor-supported Targeted Inputs Programme, which gave 'starter packs' of seed and fertiliser to poor families in Malawi, a nationwide survey in 2001 showed that only 5 per cent of farmers produced enough maize from their own gardens to feed themselves. 73 per cent had a food deficit of 1-6 months and 22 per cent had food deficit of 6-12 months. (P Sibale et al, Educ Consult, 2001, Targeted Inputs Programme Evaluation Module 1: Food Production and Security, for the Ministry of Agriculture and Irrigation, Malawi and the UK Department for International Development.). This is significant given that only 6.9 per cent of TIP recipients had salaries from employment. Others earned what income they could from *ganyu* labour when available and selling other crops (cassava, beans, tobacco etc).
[194] In Malawi, it is common practice for sick individuals to be accompanied by a (usually female) family member, as their helper and 'guardian.'
[195] Awaiting publication, but presented at the IUATLD World Conference in Montreal 2002 under the title 'Expanding DOTS? Time for cost-effective diagnostic strategies for the poorest in Malawi.'

closer to communities. This research presents qualitative evidence, which supports these recommendations.

When discussing the issue of 'patient delay' with NTP staff members, early qualitative evidence and the NTP's own studies were premised on a notion of TB suspects delaying their presentation at the formal government health services, owing to a decision to seek care informally and principally with traditional healers. Research evidence (Banerjee, Harries et al. 2000; Salaniponi, Harries et al. 2000; Claessens, Gausi et al. 2002) was cited in support of a narrative, which stated that TB suspects, owing to their traditional 'cultural beliefs' and lack of knowledge, were making badly informed care-seeking decisions and choosing to seek traditional help first. Only after they had failed with a traditional healer would they present at the allopathic services. And then, often, their history of care seeking would be hidden from the clinicians – for fear of scolding by clinical staff, dismissive of their 'traditional' ways – which would mask the actual length of their symptoms and perhaps delay investigation for TB.[196]   The conclusions of the NTP research carried out to date are uniform in their calls that, "More needs to be done to educate communities and non-orthodox care providers" (Salaniponi et al 2000: 327) in addition to the "need to address local beliefs in health education" (Banerjee et al 2000:1047).

The terminology used by Malawi's NTP staff, TB specialists internationally and indeed health workers on the ground is itself rooted firmly in the paradigm of patient blame: when TB suspects present well into the disease's progression, it is clearly a case of *their* delay – patient delay. Rarely is acknowledgement made of possible systemic failures or delays on the part of the health service in correctly diagnosing

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[196] In recognition of the importance of successful history taking and owing to the lack of any individual out-patient record system, CHAM worked with MOHP to introduce a system of 'health passports.' From mid 2001, all patients were required to purchase, for 20MK, a passport into which their details, diagnosis and treatment could be noted on each health centre visit. While the fee was set at an apparently reasonable level, it still proved to be a barrier for many patients, with clinicians observing that *"because of poverty, it's also a burden to our community, especially the rural areas...when you ask why they didn't come for immunisation, they say 'we had no money for the health passport.'"* (LLBMA001)

and addressing the problem.[197] And yet, other preliminary research evidence suggests
that this is often the case. In Zambia, a recent publication cites that, on average,
patients have 6.7 health encounters prior to being diagnosed with TB (Needham,
Bowman et al. 2004). In primary fieldwork in Ntcheu district, Malawi, an
investigation was undertaken into what became of smear positive TB patients who
had been diagnosed with TB, but had never started treatment (Belaye 2000). The
research found that most of the patients had died within a month of their diagnosis,
and that structural barriers relating to the health system – including delayed sputum
results, etc – had contributed to lengthy diagnostic pathways that resulted in the
suspects' poor state of health by the time of diagnosis. As the research abstract
concluded, "less striking were patient delays in seeking formal medical care."

In this research, taking place one year after Belaye's work, it was found that lengthy
diagnostic pathways remained the norm and peoples' encounters with systemic
barriers to successful care seeking persisted. There was much criticism of
government hospitals and health centres and a familiar list of reasons why: waiting
times were long; drugs were out of stock; staff were rude and dismissive; nepotism
favoured the wealthy and well-connected. Health workers too acknowledged exactly
the same themes mostly with a sense of regret, particularly amongst clinicians, but
also with a sense of powerless at being able to change their conditions. Frontline
workers spoke of the 'pain' at repeatedly being unable to give the right drugs or spend
as much time with their patient as they should. *"I understand that they are
complaining about a true thing."* (LLB HSA001)

Conversely, some individual community members showed appreciation for the
difficult conditions under which staff worked,

*"With these public hospitals, just because of congestion, so these doctors feel, 'If I
take 10 or 15 minutes to attend to this one, I'm wasting the time of 10 or 15 people
behind him,' which is a problem."* (LLA008M)

On the whole, however, community members tended to have more words of
complaint than sympathy, and with good reason, given their experiences. The
repeated refrain of 'no drugs, they tell you to go and buy' was one of the most

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[197] This same paradigm carries through the whole treatment process, which views patients as potential
'defaulters,' and commonly puts default down to poor motivation and behavioural reasons, rather than
recognising the additional constraints of poverty.

common – and confirmed by the staff. The long queues, sitting waiting all morning and sometimes all day, were another complaint, necessitating time spent away from caring and earning responsibilities, for both the care-seeker and often the accompanying guardian.

"And you have been on a queue since seven in the morning to twelve, and then they just give you aspirin" (LLA003M).

The TB diagnosis has already been considered specifically in the discussion in section 6.1. Once the diagnostic process is started, however, the pathway to care continues to present challenges to the care-seeker.[198] This research shows that the system frequently fails at key stages and it is this failure, which leads to significant patient delay, and death, rather than belief-led behavioural choices – as is often portrayed. Indeed, such systemic barriers themselves fuel a reliance on and need for socio-cultural alternatives, rather than such socio-cultural alternatives presenting an automatic challenge to the system.

What is perhaps a most significant finding is one that challenges the medical establishment's perception that patients tend to go to the traditional healer first and thus delay their presentation at the allopathic health services. While this undoubtedly happens, what was presented as a much more common pattern was for people to have sought formal health care *first*, to have 'failed' or 'found no help there' and therefore turned to the traditional alternatives. As this respondent explains, both patterns occur, but the following extracts reflect the fact that the more common pattern qualitatively cited was of the decision to seek care with a traditional healer, following lack of success at the formal health services:

"Either if the disease comes very suddenly, then you go to the traditional healer. Or, if you go to the hospital and the hospital fails to provide you with treatment, you go to the traditional healer." (LLB012F)

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[198] Amongst both urban and rural respondents, the length of time taken in getting a TB diagnosis was raised. Issues were the number of repeated visits made by the TB suspect, the problem of transport and fuel in taking sputum submissions to the district centre, the delays in results coming back from the district to the health centre, the further costs to the patient if further investigations were needed at the district hospital, the heavy workload affecting the quality of smear examination in overstretched laboratories, the impracticalities of the hierarchical referral chain and the challenges of smear negative TB to this entire pathway. Added to each element of that path is the time spent waiting at each repeated visit, the lack of drugs to temporarily manage the symptoms, the financial and opportunity costs at each stage, etc.

In interviews, nearly all respondents cited hospital or health centre system failure as a factor in their care seeking. Most suggested that if the health centre fails, then a traditional healer is the next step.

"But sometimes it's because, after you have been to the hospital, the hospital fails to give you treatment and you come back, you say 'why don't I try the traditional healer? Maybe it's something which has come as a result of being bewitched." (LLB010F)

Rural respondents were often more explicit in their portrayal of such a path, but both urban and rural, men and women described this tendency and affirmed the position that system failure reinforces traditional alternatives.

"Yes, because at the hospital sometimes they tell you that 'we are unable to find any disease in your body.' But you know that you are unwell! And sometimes it is true that it can be a bad spell from someone, so, yes, you need to go to a traditional healer, if the hospital has failed to give you a cure." (LLB006M)

It is also important to know that these ideas are very much recognised and even shared with hospital staff. Sometimes this was portrayed in an opposition between 'us' and 'them.'

"Yuh, the reason that maybe when you are sick for a long time, let's say you are coughing and you go to a clinic, they give you antibiotics, you go to another clinic, and then you start to think 'No. I have taken that medicine and I am not cured. I think it might be someone has bewitched me.' That's why patients go to traditional healers. So, they still take a long time before they are actually diagnosed, because they say 'I have tried my best, I went to Nathenje clinic, Ndethera clinic. No I am wasting my time, let me see a traditional healer.' Yeah, sure....There is a belief that any illness, if you are not cured, you have to think that maybe someone has bewitched you. So that's why so many people still go to traditional healers." (LLBMA001)

At other times it was an acknowledgement of the health system's failure, with staff mentioning the phrase *"mulibe chifuwa"*, 'there is no cough/TB, nothing has been found' as something that they themselves have used with patients,

"It is discouraging when people are told, 'we cannot find the disease, we cannot find the disease' and sometimes it looks as if it is the doctors who do not want to be helpful." (LLB012F)

Some community members pointed out that medical workers share their faith in traditional medicine, with staff themselves acknowledging its value for particular conditions,

"Sometimes, if I go to the hospital, like Nkhoma, if they fail to give you help there, they actually tell you that why don't you try traditional medicine?" (LLB009M)

What was also notable was that, where possible, patients were not the passive recipients of medical care, as biomedicine often constructs them, and as the formal health system in Malawi is sometimes successful in reducing them to. Patients do tend to hand over their control to the doctor or healer when in consultation, but then take back that control – as far as structural constraints such as finances will allow – in determining what the next step should be. Statements reveal their critical awareness that, despite the declarations of *"mulibe chifuwa"*, that they *know* they are unwell,

"At hospital they tell you that they can't find any disease in your body, but you can feel yourself that you are unwell. " (LLB004M)

As will be proposed in a later section, sick individuals follow a pragmatic and fragmented path of trial and error, which is limited by significant obstacles, but they are nevertheless active agents on that pathway "looking for help."

6.2.3 Influences on care seeking: behavioural/cultural

Severity, 'how you feel' & type of disease

As agents on this care-seeking pathway, respondents attributed a high value to their perception of the severity of their condition and their own critical judgement in assessing this. Repeatedly, it was stated that when and where they sought care 'depends on how you feel.'

"It depends how you suffered... It's because, you know, your body is like a vehicle. As you move, you feel it, as you sleep, you feel it, as you stand, as you walk, anything! ... My body tells me something: like, today I'm not feeling OK. " (LLA008M)

The normal first step reported when feeling unwell was to buy medicine, usually from the nearest grocery shop – available even in rural areas, although sometimes at more of a distance. Individuals were aware of the variety of brand name preparations sold for common ailments (Panado for headache and pain; Conjex cough syrup for coughs; Novidar SP for fever or malaria) and stated that they would ask for these products by name, rather than asking the shopkeeper's recommendation. However, if, following self-treatment, there was no response or the ailment returned and persisted, the next step would be to go to the hospital or health centre,

"If it persists is when you leave the medicine you bought and go to hospital. "
(LLB003F)
"But there are cases when you say, this is now more complicated, this is more serious, I cannot go and buy medicine. I need to go to hospital. " (LLA001F)

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When asked for further clarification of what a 'serious' case meant, or when a disease was perceived to be serious enough to result in visiting a formal health provider, typically, the ability to walk and transport yourself was raised,

"But, when deciding whether to buy medicine or whether to go, usually, it's to do with how seriously affected you are. If you think it's a minor health problem, the option generally will be to buy medicine, but if it's a serious health complication, generally you will go to the hospital. ...In cases where it is serious, you probably cannot even walk, you are down. But if you have a health problem, but you still can manage to walk, though you are feeling in your body that you are somewhat unwell, you go and buy medicine." (LLB012M)

However, as already noted, although it was the usual second step for a more serious problem, patients were not always successful in getting well at the formal health service. As described in an earlier section, it was then reported that failure with the doctor would undoubtedly lead to a visit to the traditional healer.

"If I am feeling pain, I buy tablets and take them. And if there is no improvement, then I decide to go to hospital. If there is no help there, that's when I decide that I will have to go and seek traditional help." (LLA005F)

"It depends on how a person is feeling. They will decide to go and buy medicine from the grocery shop, but if they think that the situation is more complicated, they will go to the clinic at Nathenje. If they fail at Nathenje, that's when they will start looking for help with traditional healers." (LLB008F)

The picture is clearly one where people use a combination of all three options, depending on where and whether they find successful treatment. A typical path is to start at the grocery shop, when the condition is not so serious; to go to the hospital or health centre if it worsens; and to then seek help from a healer if the hospital does not prove helpful. This latter stage is particularly common for chronic conditions including persistent cough, where the lack of response to conventional medicines or investigations, leads to suspicions of magic (*matsenga*) or witchcraft (*ufiti*).

In the same instance as discussing the perceived severity of a condition, the judgement of the nature or type of disease was often raised. People spoke of both 'looking at how you feel' and 'the type of the disease.'

"There are several factors. You look at the type of disease, which you are suffering from. If, for example, you have these strange symptoms, you know this might be a bad spell and you go to the traditional healer. But, if it's a disease which you know, you decide on the stage and condition of the person. If you are very seriously sick, you'll probably go to the private clinic, where you'll be welcomed and given help instantly. But if you're unwell but it's not serious, but it's a kind of disease that can best be

cured by modern medicine at the hospital, you go to the government clinic because at that stage you can afford to wait, the situation is not so bad and you will get help." (LLB007M)

"It's dependent on an individual. For some individuals, if you know that you do not stay well with people who are around you, if you have a health problem you begin to suspect that maybe it's people who you are not on good terms with. And then maybe you go to a traditional healer." (LLA012M)

It is important not to overplay this aspect, for fear of fuelling the 'rationality' argument, advocated in the biomedical professions – and done so successfully for many post-Enlightenment generations – that it is either the lack of any medical knowledge or the misguided habits and beliefs of uneducated peoples that lead to 'inappropriate' health related behaviours. This view presupposes that these inadequacies could and should be remedied through the dissemination of the correct medical knowledge. As Good has noted, while early medical anthropology went as far as to challenge the notion that people were 'empty vessels' (1994: 26), and identified the range of indigenous habits and beliefs that differing cultural systems incorporated around health and illness, it did not, however, necessarily challenge the assumption that such 'beliefs' or subsequent health 'knowledge' were the principal determinant of peoples' health related actions.

This research would appear to support the simplistic opposition between natural diseases and those caused by magic, and the related notion that belief in such a dual categorisation drives a person to seek allopathic or traditional care, according to one's perception of the type of disease. It is important to note however, that, in their narratives, and particularly when describing an actual experience rather than a hypothetical situation, people were careful to outline the influence of this categorisation *at a particular stage along the pathway*, and in conjunction with other determining factors. Thus, while recognising the role that the perceived type of illness plays in influencing people's care-seeking, this research also situates that perception in context and acknowledges the effects of associated factors on peoples' choices – including, critically, the persistence of their ailment and the treatment success found.

Many described freely moving between 'traditional' and 'modern' sources of care, without conflict, and dependent on a combination of not only perception of the type of

illness and the way they were feeling, but also the degree of help found. Some problems could *only* be taken to a traditional healer. Sudden unusual symptoms, which indicated witchcraft, would be taken to a healer straightaway. Long illnesses, which had not been helped at the hospital/other providers, would also be taken eventually to a healer. On the whole, this free movement between the 'modern' and the 'traditional,' was accepted and practiced across communities, but was more starkly demonstrated in rural respondents' comments, for whom access to 'modern' allopathic providers was more constrained.

One young male individual narrated his personal experience with being bewitched. He described how in the cold season month of June, for the whole month, he had not sat by a fire to warm himself. However, one morning, he awoke to discover that there was a pain, just behind the knee. Following his discovery of the pain, he noticed that the skin there turned black, as though burnt. When he showed it to friends, on closer inspection, they said they felt there might have been an attack by some kind of insect, which had led to this. Through contact with the insect, the skin had become itchy and so on. So, people thought that that this may have been the problem. But the following day, there were blisters, and then these developed into very bad wounds. His friends encouraged him to go to seek traditional help – owing to the sudden and curious onset of the problem. However, as the young man was a devout churchgoer, and his faith preached against such traditional practices, he was reluctant to go.[199] Under pressure from his friends, however, he went. When he saw the traditional healer, the healer said, no, this is a bad spell that's been cast on you. But the young man came back, still not believing, and decided to treat it like other wounds he had had before, putting some medicine he had bought on it every evening. But to his surprise, every time he put medicine on the wound, the following morning, the wound would be as it was before, without any medicine at all and no beneficial effects.

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[199] A few individuals – two older women most vocally – maintained that their strong Christian beliefs meant that they did not believe in witchcraft or subscribe to traditional healers. When probed however, they were able to talk freely about "other peoples'" beliefs and practices. As the young man's narrative shows however, peoples' beliefs and behaviour were not always consistent. One of the older women, who professed that her religion forbade her attending traditional healers, had clear 'tattoo' markings showing as evidence that she had indeed visited traditional healers, despite her response. Other individuals' narratives often started with one viewpoint and finished with another, proclaiming 'belief' in modern medicine as the only way to deal with ill health, and then later affirming traditional healer's value in treating 'magic' conditions - self-contradictory, but indicative of the complexity of the plural environment.

Finally, as his problem persisted, he went back to the witchdoctor, who put in his particular medicine, to fight against the magic and, despite his own lack of belief, from that time, up until now, he has been OK. (LLB012M)

Witchcraft/magic – or natural disease? Ways of knowing

As this previous example illustrates, there is a common understanding that if acute symptoms of ill health begin suddenly and without warning, some 'unnatural' social forces may be at work and, therefore, an individual might take such a problem straight to the traditional healer. This was an understanding held not only by lay members of the community, but by the clinicians working in their health centres too.

"Sometimes, people can just lose their sight, just suddenly, without any cause. And when they go to the hospital to be investigated, nothing is found. So such illnesses maybe could be believed to be associated with witchcraft. So sometimes such illnesses are cured by traditional healers." (LLAMA003)

"For those diseases that are the result of a bad spell, there are strange kinds of signs. Sometimes, a certain part of the body will just be burnt, or sometimes a person just faints from nowhere. So we know from these kind of symptoms that this must be a bad spell." (LLB007M)

This experience was less common, however, than the self-treatment of an early condition with shop-bought medicine, followed by a visit to the hospital or health centre if that condition persisted. Only after unsuccessful contact with this allopathic medicine would the first suspicion of magic or witchcraft normally arise.

It was, however, clear that respondents distinguished between diseases caused by magic/witchcraft (*matsenga*[200]) and those 'natural' diseases,[201] and used this framework of opposition between the 'natural' and the 'magical' to categorise the origins of ill health and the related treatment provider. If you think you are bewitched (*kulodza*), the consensus is that a traditional healer is the only treatment choice.

"Especially if diseases are coming as a result of witchcraft. For sure, that's an area where traditional healers can help. But for all these natural diseases, I do not believe the traditional healer can do a better job." (LLA012M)

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[200] The term '*matsenga*' is generally taken to refer to magic more broadly, including witchcraft and sorcery. The term '*ufiti*' is taken to refer to witchcraft more exclusively, with the implication that it is magic used for negative or destructive purposes.
[201] Often, a distinction was made between those diseases caused by man (*cha wanthu*) and therefore magical, and those caused by God (*kwa mulungu*), and therefore natural.

"For other diseases people become very weak and maybe it's as a result of some individual bewitching, casting a bad spell on the one who is sick. And for that, people will go to a traditional healer. But if it's a natural disease, because of God, the traditional healer will say that this is a natural disease" (LLA011F)

"Sometimes people say, when the deceased went to hospital, they said actually the disease was from fellow humans, as a result of being bewitched. Others say, no, in fact it was something natural, as in coming from God. So, what I see is some kind of competition." (LLB008F)

Health workers too confirmed such a distinction,

"In our culture, when you are sick, whether you have gone to school or not there is still this feeling that I might be sick, it might be malaria or any other organic thing. But, you also feel that maybe this is ..ah.. my friend has bewitched me, or some other people." (LLBMA001)

These statements illustrate the oppositional framework used to interpret and explain disease types and support the relevance and validity of plural treatment choices, allopathic and traditional, in treating different conditions. However, as previously suggested, it is important to note that, despite this apparently straightforward categorisation, interest in the cause of a problem is not always paramount, nor is it the overriding influential factor in peoples' care-seeking. If initial signs are not immediately indicative of any malevolent 'external' influence, peoples' concern is merely with getting treatment and getting better. As will be discussed at length in the next chapter dealing with the healing encounter, while people initially seek care with differing providers with the same superficial aim of getting better, if their problem remains and their care-seeking pathway lengthens, their later intentions may differ more subtly. On the whole, evidence suggests that when they go to a doctor, they merely want medicine and cure. They are not accustomed to finding the cause of their condition, nor do they seek to find it there. If, at a later stage they remain sick and turn to traditional medicine, at this point cause *is* a priority. In order to cure a condition for which modern treatment has failed, the causal agents must be identified.

"In terms of receiving help...in terms of help, you go to the hospital, you get help, as you get help from the traditional healer. But that is if there hasn't been anyone who's also playing their own witchcraft to try and prevent things. If there is someone, you can go to hospital, but there will be someone, who will try and make you not be cured. And you will not be cured. But if you then go to a traditional healer, who knows how to find and turn around the magic of those who practice witchcraft, you will definitely be cured." (LLA 005F)

Thus, interestingly, the western epidemiological concern with identifying and treating a causal agent, which drives the biomedical approach, is absent from the lay interpretation of biomedical practice in Malawi. Conversely, and yet parallel to western medicine, it is indigenous medical practices which are explicitly concerned with causal factors, and to which individuals turn when seeking such answers.

In contrast to the majority of respondents who acknowledged the utility of both allopathic and traditional medicine and their own use of both systems, a few individuals reified modern allopathic medicine to the exclusion of any other alternative providers. Theirs was an almost moralistic or religious conviction in medicine, usually supported by a stated strong Christian faith,

"To talk about witchdoctors, no, I cannot talk about that because I am a church person. But, yes, maybe others go there... If you are sick, the place where you can be cured is at the hospital. So you still go to the hospital. If it fails, it should fail right there at the hospital" (LLB002F)

Interestingly, the few male individuals who proclaimed the benefits of modern over traditional medicine, did not cite religion as their reasoning, but demonstrated a faith in the perceived scientific validity of such an approach, citing the 'evidence' of physical examination and laboratory tests,

"The hospital is better because they will examine you there. Examine and know the problem." (LLA006M)

Nevertheless, their 'belief' in modern medicine was stated as though it were a quasi-religious choice,

"Some people still go to traditional healers as you well understand. People have different beliefs and traditional backgrounds. But, for a person like me, I believe in hospitals, modern hospitals." (LLA012M)

"I believe in tablets. That's why, when I am unwell, I just go to a place where I can get tablets." (LLB005M)

And yet other respondents illustrated the overlapping, porous boundaries. While some women would not discuss traditional healing because of their belief in God, another woman saw no conflict in bringing God into her discussion of her experience with traditional healers:

"Yes they help me, but also it all depends on God. You can go to hospital, but if God has not allowed, you can't get cured. You can go to a traditional healer, but if God has not allowed, you cannot be cured." (LLA005F)[202]

Fear/stigma/HIV

Throughout all issues investigated in the fieldwork, HIV/AIDS endured as a significant crosscutting theme. This was and is most obviously seen in its clinical relationship with TB, where it pushes up the number of overall cases of TB in the country, and more specifically contributes to a raised smear negative TB rate (and therefore further over-stretching of basic diagnostic facilities, where appropriate guidelines are missing, and where individuals are told *'mulibe chifuwa'* 'there's no TB'). The very health care workers tasked with diagnosing and treating patients are themselves succumbing to the same HIV epidemic. They are amongst the individuals whose livelihoods are threatened and where TB may be just one element in an overall picture of AIDS related illnesses, which have reduced a person's ability to work and be productive. It is thus a contributor to increased vulnerability where healthy individuals' lives are lost and family incomes dwindle, putting pressure on remaining family members - increasingly children, who may leave school to help out, thus losing out on education and fuelling the overall cycle of poverty and illness.

HIV/AIDS is also a contributor, albeit in a less tangible or measurable way, to increased stigmatisation and discrimination against those living with and suffering from the disease. In the developed North, when HIV/AIDS was first recognised in the 1980s, it was largely associated with marginalized groups, such as homosexuals and drug users, which provided fertile ground for the development of increased prejudice and blame, and an association of HIV with 'risk groups,' rather than risk behaviours (Vliet 1996).

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[202] It is valuable however to note Van Breugel's writings on Chewa understandings of 'God' and how this may have shifted over the years, with the influence of Christianity in the region. He outlines a belief in the existence of a 'supreme spirit,' one who rules all other lesser spirits, traditionally known as *chiuta* or *chauta* (Breugel 2001). A notion compatible with that of a Christian God. In this research, however, the more common name used for God was *mulungu*. There is some debate over whether this is a term introduced by missionaries, or a pre-existing Chewa term adopted by Christian missionaries as the name for their God. In his analysis however, Van Breugel, observes how, with the long history of contact with both Muslim traders and Christian missionaries, it is difficult to say exactly what the original Chewa concept of God was and how it differs from the common interpretations of today.

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In Africa, during the early days of HIV's recognition, it was perceived by some to be introduced by 'the whites' as a means of further subjugating Africa and its nations, either as an extreme family planning tool or even a tool of genocide depending on your point of view. In Malawi, such an association remains in its nickname of 'the government disease.' Speculation on whether the disease had actually originated in Africa provoked strong reaction from those keen to turn around what was perceived as a racist response to a global issue. In the media and at the national political level, debates have raged about the true origins and nature of the HIV virus – most controversially with the South African President Thabo Mbeki's sympathy to a radical scientific viewpoint that challenged the link between HIV and AIDS.[203]

The same issues of blame, risk and discrimination are also being played out in every day peoples' lives. In Africa, where the dominant mode of HIV transmission is heterosexual, there is still great potential for labelling 'risk groups.' STIs, with their fruitful combination of sex and disease, provide an opportunity for moralising attitudes to flourish. Whether in the UK or Malawi, people typically use an 'us and them' framework to distance themselves from both the risk of infection and the associated blame and judgement that accompanies an HIV-positive diagnosis.

As described in section 6.1, the notion of stigma now plays an increased role with TB, owing to its close association with HIV/AIDS. The label of 'socially deviant', applied to those who are seen to have conducted themselves in an immoral manner, is now a potential reaction to TB patients. As has been noted by those examining stigma in more depth (MacRae in Purdy and Banks 2001), strategies may be employed by those in danger of becoming stigmatised, to manage or avoid the resulting labels. One which MacRae identifies, and which is supported in these qualitative findings, is that of concealing or covering up the illness. Both health care workers and lay community members felt that some TB suspects were avoiding seeking care, for fear of a TB/HIV diagnosis and the resulting social stigma. Some refused to accept the signs of their

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[203] Some commentators however have interpreted his stance as one which sought to highlight the critical influence of broader socio-economic factors in the spread of HIV/AIDS. From this perspective, his statements were key in initiating a fresh debate about the AIDS pandemic in SSA and its relationship to wider poverty and lack of development (Paul Farmer, 'AIDS Heretic,' New Internationalist, 331, Jan-Feb 2001).

condition, and others, particularly in urban areas, would reportedly leave their homes and jobs to return to their village, where they might suffer in relative isolation.

It is also necessary to acknowledge that it is not only the fear of the stigma of a TB/HIV diagnosis that may keep people away from health centres, but their very real fear of the sickness, suffering and perceived death sentence that both conditions were viewed as carrying.

Age/gender

Two more subtle socio-cultural variables, which were seen to have an influence on peoples' care-seeking choices and, particularly, the decision-making processes were gender and age. The role of gender norms has already been touched upon when discussing financial barriers and the prevailing norm of men controlling the household income and thus acting as gatekeepers to health care related decision-making and expenditure. Married women are in a position where their husband must be consulted in order for funds to be accessed. In rural matrilineal areas, maternal uncles assume this gatekeeping role, although it was noted that in serious situations,

"Some people rush to the hospital first without bothering with the formalities of informing the maternal uncle. They can inform him on the way back." (04LUC)

An arena in which age and gender intersect is in the role of female elders, who are reported to be key in maintaining traditional ideas around health practices, in addition to supporting age and gender related decision-taking structures. While traditional power structures dictate that a village headman is the most influential figure in a community,[204] and while he has two male 'advisers,' there also exists a circle of female elders who act as his village 'committee' and who are said to wield considerable influence in local decisions and arbitration. In both the local political and the family setting, age is accorded respect and, once old and female, in some arenas, power is augmented.

In focus groups discussions, there was some debate as to whether the younger generation continued to hold so-called 'traditional ideas' about particular illnesses and

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[204] In rural areas, this remains a predominantly male position. In urban Lilongwe, where a quasi 'democratic' system of elected chiefs/headmen is followed, rather than the traditional practice of inheritance via a descent lineage, out of 50 village heads, 6 were women.

conditions – such as *mdulo, tsempho* or *kaliondeonde* or indeed sexual relations and STIs, with older respondents saying they were now out-dated. However, interestingly, it was also reported that the older generation were key advisors in matters of health and health care decision-making within families, with grandparents cited as the family members most often consulted for information and guidance. Thus, despite comments made by those of the older generation that their traditional beliefs were no longer held by younger members, respondents affirmed that the older generation still have an important voice and a role to play within the family, in guiding or deciding where to seek help.

Pragmatic trial and error – the iterative care-seeking dynamic

In the introduction to his discussion of plural medicine, Ernst refers to the practice of 'healer hopping' or 'patients' strategies of consulting a number of healers in their pursuit of cure and better health care' (Ernst 2002: 2). While the term 'healer hopping' seems somewhat dismissive, the concept was critical in challenging the prevailing medical discourse by portraying patients as active agents on their paths to healing, rather than passive subjects, in addition to indicating the range of successful treatment outcomes found through alternative, non-biomedical providers.

This research presents a picture of individuals engaged in a similar process of *pragmatic trial and error*. Sick people are indeed active agents, despite odds frequently stacked against them, in the form of a repressive health system that seeks to reduce them to passive objects and also the range of structural and behavioural factors already described. Nevertheless, while the combination of factors influencing an individual's care-seeking path may differ on a case-by-case basis, what emerges as a consistent theme is that people are indeed 'looking for help.'

Where they look for that help may be with any or several of the available therapeutic options. The majority of lay care seekers reported their use of both traditional and modern sources of care without contradiction or conflict. Both clinical doctors and traditional healers were seen as providing treatment and cure of some sort and being equally valid sources of 'help.'

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As has already been touched upon in the previous section on care seeking, however, different providers may be sought at different stages along the pathway, and with different expectations on the part of the care-seeker. Undoubtedly, when visiting a clinician at a health centre or hospital, the patient goes expecting to receive some kind of treatment, which they will take unquestioningly in the hope that *"it is in accordance with that I am suffering from."* When seeking care with a traditional healer, patients are commonly looking for an explanation of what their problem is, how and why it is happening, in addition to receiving a cure. Overall, the motivation, fairly obviously, is to become well again. In Malawian terms, *to find help.* As one traditional healer phrased it,

"Let's paint a correct picture here. When a person is sick they don't know what it is. They're unwell and all they want is to be well again. They go to the hospital. But if after they've been to the hospital they are told by the hospital there is nothing wrong that can be found in their system in their body, that is when they think that maybe it has got to do with witchcraft. They decide to seek traditional medicine. And when they go to traditional medicine that is when they are helped. This is what happens."
(LLATH003)

Looking for help?

The phrase 'looking for help' was frequently used by people, in describing their varied care-seeking attempts. Wherever they went and whatever action they took was informed by an – unsurprising – desire to get well. Their search for help would be based on self-observation, interpreted through both individual beliefs and social norms. Any decision would be limited or enabled by a complex mixture of structural and social barriers, and would lead to a process of trial and error, involving both traditional and modern sources of care, without tension, and depending on when and where successful treatment is found.

Both health staff and lay community members recognised this range of factors, but also underlined the defining role of *practical possibility.* Patients' efforts were emphasised, against a backdrop of pragmatism, trial and error,

"I think when you're going there in the first place, it's more a case of trying to see whether you can get help. You don't know for sure that you will indeed get that help."
(LLB008F)

"You go from one place to another... And if the medicine does not work, then they decide 'I will try the traditional healer.' But it's different from... they are not... it's

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not <u>exact</u>. It's not like they are sure they will get well by going to these two places." (LLB001M)

An emphasis on medicine and treatment, often the 'help' people described, was not unusual - particularly when seeking allopathic care and in the early stages of a problem. The 'belief' in tablets and injections has already been described and this was supported by more general comments on the importance of *'receiving proper treatment'* or getting *'proper strong medicine'* – or indeed the common lack of such drugs. If such drugs failed, clinicians would tend to blame patients for not following instructions properly and these attitudes were also demonstrated by patients, whose faith in the efficacy of allopathic drugs, rather than themselves, was common, and was illustrated by an often dogmatic conviction that *"if we follow the instructions, we will get cured."* (LLB006F)

Patients expect treatment and cure

An overriding opinion amongst both health workers and their public was that patients came to an allopathic provider with a definite expectation of receiving medicine and would be disappointed to leave empty-handed. Lay respondents concurred with frequent emphasis on the importance of getting drugs, which were strong and effective. On the one hand, staff were regretful about the poor drug supply and the fact that, owing to stock-outs, they would often have to tell their patients to go and buy the correct medicine elsewhere, or even prescribe a wrong or ineffective substitute, simply to avoid disappointing their client yet again. They described themselves as *"nexperts, not experts."* On the other hand, they noted that, regardless of drug supply issues, patients would be unwilling to leave empty-handed, even if their condition did not require any medicine to be prescribed.

"Yuh, they expect to go away with at least something, not nothing. I have at least one example. This one was a patient who came from City Assembly clinic in town. He was prescribed Ibuprofen and Amoxy, Amoxycillin. So, he came here to say 'No, I was only given one drug, the other one I was not given because it's not there. So I have come here to get it from you.' So I said we also don't have the Amoxycillin. So he said 'Ah! Just give me something, because I can't just go away without nothing.' So I said 'No, but your condition does not permit me to just give you any drug. The one who prescribed for you knew very well that the right drug was Amoxycillin. So, I can't just give you any drug, just to satisfy you.' So, we talked for some minutes in fact, he was resistant to my sort of answer. Until at long last he went away, but disappointed. Yes, disappointed. And in most cases, women who come with their children here, you find that they also bring their own passports. Not because they are sick, but because they have come with that child, but they shouldn't just go away

without anything... Yuh. So, my experience has been people come here to get at least something." (LLAMA002)

Health workers outlined that they were under the dual pressure of both the patient's expectation to take something away with them, and their own unwillingness to yet again let down a patients because the correct drug is out of stock.

"In most cases, we advise the patient to buy, but other times you are forced to give a drug that you know maybe will not work, simply because maybe this one will also be on your neck to say 'no, for how long are you going to be telling us to buy the drugs?.' Because sometimes it's really pathetic: they come today 'go and buy,' tomorrow 'go and buy,' the other day 'go and buy'..." (LLAMA003)

The expectation of medicine is the only expectation that patients took to the modern doctor. There was faith that what they were given would be appropriate, and no concern about the lack of explanation about what their problem was. Conversely, at the traditional healer's, a full explanation of the cause of the problem would be sought. As summed up by one female respondent,

"The difference is at the hospital they will ask what you are suffering from. You have to say according to how you feel. Whereas at the traditional healer, they just tell you. You don't explain beforehand. They explain to you what you are suffering from." (LLA007F)

This will be explored further in the following chapter, which will look in more detail at the interaction between patient and provider, and seek to answer some theoretical and empirical questions about the role of 'knowledge', its construction, application and relationship to TB.

CHAPTER 7: THE HEALING ENCOUNTER AND BEYOND - WHERE POLICY MEETS PRACTICE

INTRODUCTION

The perceived difference in handling by different providers – traditional and allopathic – and in expectations on the part of patients was one that merited further exploration in the course of the research. While being wary of an over-functionalist interpretation of 'the healing encounter,' it was felt that a comparative analysis of what appeared to be two differing styles of practice between traditional and allopathic practitioners might be useful. The aim of the first part of this chapter is therefore to better understand the interaction between provider and patient and explore the implications – if any – of the arising similarities and/or differences in encounters for successful TB diagnosis and treatment. This is considered important given that, as already described, the diagnostic model for TB in the allopathic sector places great emphasis on successful communication and history-taking between patient and provider, hopefully leading to identification of TB suspects and a positive outcome of care.

Important themes which arose in considering the healing encounter included those of power, knowledge and communication. The latter parts of this chapter therefore adopt a more social theoretical approach to examine the influence of debates on these 'bridging' themes (Booth 1993) and their relevance not only at the micro level of the healing encounter, but at the macro level of the professionalisation of medicine.

In considering the Malawian context, arguably the biomedical model is an introduced paradigm that has worked very readily with a pre-existing acceptance of status and hierarchy. This status may be either ascribed/inherited – as for traditional chiefs – or learnt/acquired – as by some traditional healers or indeed clinicians – but once attained, it is a defining identity and the key to one's social mobility, defining to where one may move and justifying one's ability to do so. In such a hierarchical environment, people's own perceptions of knowledge, education and power will be explored and the implications for TB control and the Malawi National TB Programme will be discussed, leading into this thesis' conclusion.

7.1 THE HEALING ENCOUNTER

In examining patient-provider interaction, it should be noted that this was not an exhaustive study, but was one which relied principally on patients' and providers' own reported behaviour. While observation of healing encounters took place in both traditional and allopathic settings, this was not structured in any way using a quantitative checklist, but was informal and unstructured. Through observation of the settings, including the physical environment, behavioural interaction and activities, an attempt was made to add detail to what people had reported and to correlate the observations with their reported behaviour. Overall, the findings contributed toward a better understanding of provider attitudes and behaviour toward patients, and patient attitudes and behaviour towards different providers.

7.1.1 Theoretical background

It is notable that, in the light of the TB model's emphasis on successful history-taking for accurate diagnosis, Tuckett et al (1985) have found in their research that two-thirds of patients do *not* report all their symptoms to the doctor (cited in Moon 1995:114). A hypothesis might therefore be that in a resource poor setting, such as Malawi, with constraints affecting the actions of both doctors and patients, reporting of symptoms might certainly be as poor, or indeed, poorer. Accepting this as a reasonable hypothesis, it was felt appropriate to look at whether the 'ideal encounter' in Malawi was constrained and, if so, in what ways. In addition to an examination of broader patient and provider perspectives, this also included a comparative analysis of the allopathic and traditional healing models, including the differences in patients' norms and expectations of differing providers, and the implications of any findings for the success of the TB diagnostic model.

Clinical practice style has been the focus of theorists' attention – particularly Western medical sociologists – for some time. This was introduced earlier in the thesis with reference to Talcott Parsons' use of the 'sick' role, where he distinguished doctors as those with expert technical knowledge, and patients as those who defer to this knowledge in terms of diagnosis and treatment. In their relationship, Parsons felt that each party had ascribed social roles – and scripts: the doctor's being to use their skills in the patient's interests; and the patient's being to handover to the greater knowledge

of the doctor and cooperate with their advice. Each had respective obligations, with a duty on the part of the patient to strive to be well again and to defer to the expert knowledge of the medic, who would assist them to do so. The relationship was underwritten by an assumed consensus as to these roles, with the expectation that the patient would seek medical attention when necessary, in line with their social responsibilities, and would not challenge the accepted greater authority of medicine. The doctor in turn would provide appropriate advice and care.

Unsurprisingly, this model has been criticised for its unquestioning acceptance of medical authority and the related privileging of the expert doctor, over and above the voice of the patient. Stimpson and Webb (1975) increased emphasis on the role of negotiation between patient and doctor, with respective strategies on the part of each party, to assert their role and influence the outcome. In their interactionist interpretation, the patient is accorded a greater degree of agency than in previous interpretations. However, structural limits are identified on each individual's actions (including practical limits, such as the organisation of the care setting; and less tangible limits, such as peoples' perceptions of what may or may not be possible), which hint at tensions, but do not really address the issue of potential conflict between patient and doctor. Instead, the negotiated stance once again assumes a complicit consensus over a mutually negotiated and functional role, albeit moving further towards greater and more balanced communication between the two parties.

Byrne and Long (1976) outlined a continuum of practice, that varied from those encounters they termed *doctor-centred*, making use of the doctor's specialist skills and framed in biomedical terms, to those that were *patient-centred*, dwelling on patient experience and social context. The underlying assumption of such work is of a desired balance in control between the patient and the doctor and thus the move towards an ideal and desired equality between doctor and patient is continued.

The concepts of mutual participation and negotiation have also been fuelled in the developing world more recently with both increased attention to notions of participation in development generally and with the prioritisation of counselling for voluntary testing and behaviour change in high HIV-prevalent settings. A general model of improved IPCC – interpersonal communication and counselling – has been

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accepted as key to successful patient-doctor encounters, mirroring both medical sociological literature and discourses of participation and empowerment in wider development practice (Nelson and Wright 1995; White 1996; Chambers 1997). However, despite such ideal models being proposed and worked towards, as the following discussion illustrates, medical sociological research has shown that mutual participation and consensus may be rare – whether in the developed or developing world. Instead, a variety of models of interaction, with varying degrees of control or consensus from either party, may be more likely.

Barry et al, have used the phrase 'giving voice to the lifeworld,' to refer to a communication between doctor and patient that creates space for the terms, language and voice of the patient to be heard (Barry, Stevenson et al. 2001). They investigate these notions in the English General Practitioner (GP) setting, concluding that four main communication patterns emerge: strictly medicine; mutual lifeworld; lifeworld ignored; and lifeworld blocked. While acknowledging doctors' flexible use of different styles with different patients,[205] it was found that in many instances, there was frequent miscommunication with the dominant, technical voice of medicine excluding patients' experiences, and leading to poorer care and treatment outcomes. The need to pay attention to the organisational aspects of healthcare provision, in order to enable doctors to work using a more patient-centred approach, was also highlighted.

While much contemporary attention is focussed on the ideal communicative encounter, and the need to equip patients with the skills and knowledge to empower them in an otherwise medicalised setting, as noted previously in Chapter 2, the Foucauldian perspective provides a critique. A concept of holistic care that recognises the patient's lifeworld merely extends bio-medicine's power and 'control' to include an individual's personality and behaviour, as well as their body (Barry et al 2001). In this way, the medical reach or 'gaze' is extended, as it also is through

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[205] Their work did not however analyse any influence of socio-economic or cultural categories on the 'success' or style of interaction, i.e., gender, ethnicity, educational level, etc. Interestingly, YM Kim's study (cited in Piotrow, Kincaid et al. 1997: 166) shows significant differences in provider communication with women in Kenya. Providers were found to give more supportive and technical responses to men than to women, and ignored and disagreed more with women than with men. Female patients themselves were less likely to ask questions or disagree with the provider, but did give more elaborate responses to a provider's questions.

regimes of preventative healthcare, where people have been encouraged to adopt –
and have now internalised – 'rules' of healthy living, including diet, exercise and
other modes of 'self-discipline' (Lupton 1997).

Foucault's complex ideas have also been interpreted as opening up the perspective on
power and communication, not only between doctor and patient, but also between
staff in the medical hierarchy. While he has been criticised for failing to clearly
illustrate his ideas on resistance (Lupton 1997), Hansen's work exploring the
dominant pattern of power in the hands of the physician, also examines and illustrates
methods of 'resistance,' where power is shown to be more diffuse in nurses' strategies
on the wards (Hansen 1997), recalling similar means illustrated in Scott's *Weapons of
the Weak* (1985).

The findings presented in this part of the chapter therefore help to explore and
illuminate the relative value, application, and relevance of these perspectives, from
the 'ideal' communicative encounter, to the notion of unavoidable 'biopolitical'
control. Underlying the final analysis will be a consideration of whether these two
standpoints are irreconcilable, both at the micro and macro levels, and ultimately from
the practical point of view of improving service delivery and TB outcomes for the
Malawian people.

The chapter discusses the differing consultation styles of allopathic and traditional
practitioners. In weighing up the similarities and differences between the two models
of encounter, the implications for TB control are evaluated, before examining the
themes which bridge the micro level doctor-patient relationship with the macro
professionalisation of medicine and the associated organisation of care and,
ultimately, development of policy for TB.

7.1.2 Allopathic consultation
One of the main features of care seeking in Malawi, whether with an allopathic or
traditional practitioner, is the tendency for patients to be accompanied by a

'guardian'.[206] This is usually a female family member. In urban areas, this was said to be becoming less common, except in the case of children and extremely sick patients. Rather than a change in beliefs, this was felt to be the result of urban pressures on livelihoods and the expense and opportunity costs associated with two individuals seeking care. Contrasting with this, it was reported that the practice was still the norm in rural areas. Rural female respondents were therefore the most likely to talk about the importance of being accompanied and doing the accompanying. Interestingly, some respondents felt that it was not the role of the patient to interact with the doctor, but that this was the guardian's job. In this instance, somewhat unusually, an urban younger man felt that the role was still essential:

"But you have a guardian, and it's that guardian who finds out, who explains to the doctor, the history of the sickness, when it started and other details.... For me, I don't think it's good for a patient to be talking to the doctor, because at that time, he's very sick, and maybe cannot concentrate. So, it's better that someone speaks to the doctor on the patient's behalf." (LLA006M)

This stance hints at the later finding that Malawian patients may be less forthcoming in consultation with their clinicians, for this and other reasons.

In examining this further, questions were asked about the normal process followed in the healing encounter and the respective roles of both patient and doctor. Responses from both clinicians and lay patients built a consistent picture of practice. In a Malawian health centre, the process begins with a patient registering in the main clinic register. They are then given a ticket – or, if they have one, get their 'health passport' signed and dated. The patient then joins the queue waiting to see the doctor.

Once in the consultation room and following greetings and the noting of basic demographic data in the register, the doctor asks questions about the problem bringing the patient to him/her. The patient responds by describing their complaint. Sometimes, there will be a physical examination, or alternatively the doctor will just write a prescription on the patient's ticket, according to their 'working diagnosis.' The patient – assuming the drugs are in stock – then proceeds to the pharmacy to

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[206] Interestingly, in his research in the former Zaire, Fairhead notes that the accompanying guardian adopted a 'witnessing' role in the traditional healing encounter, where the guardian would provide protection to the patient from potential sorcery on the part of the traditional healer (Fairhead 1990: 314). This was not reported to be the case in Malawi.

collect them. For certain drugs,[207] the clinician hands them out directly to the patient, rather than writing a prescription.

Reports of this process given by both lay community members and clinicians matched each other at each stage. The only extra points mentioned by the health staff were that they greeted the patient and noted their basic ID details in the register.

"At first, we ask the history, yuh. We ask what is your problem, what can I do for you. 'Oh, I'm coughing, I'm having diarrhoea.' We ask them for how long, they state. Then, if there is need for to take some vital signs, like BP, temperature, then we do so – weight and some other physical examinations. So, later on, you come up to a working diagnosis... and give treatment." (LLBMA001)

Patients gave emphasis to the doctor asking questions, listening to the patient's response and then giving out medicine. Many patients also mentioned the physical examination as being a necessary step in finding out the problem. In the urban setting, there was additional recognition of the role of tertiary hospitals in carrying out further diagnostic tests to know exactly what the problem was, normally with an accompanying value judgement that this was 'better' than a diagnosis without such tests.

A further noted observation was the tendency of the doctor to dispense medicine or a prescription, with no explanation of the condition, which they were treating. Lay respondents reported this descriptively, without complaint that this should or should not be the case.

"After asking us questions, that's when we get the help. The doctor will tell us where to get our medicine and after we get our medicine, we start coming back home." (LLB007M)

"You don't know what they have written on the ticket, but at the pharmacy, they give you medicine, so you assume that the medicine they have given you is for the disease you are suffering from." (LLA006M)

"They don't explain, they just give you medicine." (LLB008F)

This was not to say that patients did not have complaints about the overall communicative encounter. While the lack of explanation of their diagnosis was not an apparent concern, where patients *did* complain was about the history-taking stage.

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[207] Either common drugs, such as aspirin or SP for malaria, or alternatively less common, low supply drugs such as antibiotics.

Several respondents reported that they were rarely given enough time to explain their problem fully, nor were they encouraged to give all details. As one focus group member phrased it, they, *"hand back your ticket before you have finished explaining what's wrong with you"* (05LUC). Others displayed obvious fear and apprehension about vocalising their problems to the clinician, asking questions of them or requesting more time to explain,

'What should you tell a clinician if you come with multiple signs and symptoms? Because I was once asked to present only one sign, rather than tell him all the signs and symptoms that were bothering me." (02LUC)

"There are none who you are really free to talk to." (LLB008F)

Contrasting views were, however, demonstrated. Where one older male rural respondent showed a very clear idea of what he felt should be appropriate practice, including time and attention paid to the patient, who should be encouraged to explain their concerns in detail – *"because if you give someone the freedom to explain, then he or she will tell you something good"* (LLB008M) – another man, already quoted earlier, and an older rural woman held that patients should not speak at all to the doctor, but should allow their guardian to report on their behalf, owing to their weak state and poor frame of mind. Correlating with these lay reports, doctors spoke of guardians who insisted on speaking on their patients' behalf. Two medical assistants insisted that, in such circumstances, they would try and encourage the patients to speak for themselves as well, although this was sometimes difficult.

Thus, a mixed picture is revealed, of some patients who are either fearful or unwilling to share issues with the clinician, of those who are too sick to do so, and of those who privately complain that they are not enabled or encouraged to do so by the doctor.

On the part of the clinicians themselves, findings triangulated well with the lay reports, but added the dimension of the constrained clinician, operating in a high-pressure environment. Staff also complained that their patients were generally not forthcoming and did not easily reveal a full history. It was said that they might 'hide' elements, often because they were frightened of the clinician's response. Rural clients were felt to be more likely to do this, particularly women, whereas urban people were portrayed as more confident and assertive. Rural patients in particular were reported as not asking questions or vocalising either their concerns or lack of understanding –

"Most of our patients, they don't ask when they don't understand. They just remain silent." (LLBMA001)

Some were said to fear revealing that they had already sought care unsuccessfully with other providers, in case they were castigated or less fairly treated by the government clinician. This included being 'told off' for seeking traditional treatments, or even for visiting a private provider.

"There are some who will say [explain]... there are some who hide. Because, they know that if they say they were at that place [another provider], they will not get treatment at this place. So, it's either way. There are some who really say, but there are others who really hide." (LLAMA002)

Another clinician identified the prevailing fear of HIV/AIDS as a factor inhibiting patients from giving their history. It was felt that if they gave a picture of an ongoing or chronic condition, an HIV diagnosis might be a possibility:

"We are treating as new patients because normally our patients, they don't want to say, you know, what is the real reason. They think, I was sick sometime back, but I have said, no, I started two weeks ago. They think they will be given the best treatment, because if they say they were sick sometime back, they feel you will say... they think the doctor will say 'aah, this one is chronically sick,' and they are afraid of being labelled, this is HIV." (LLBMA001)

The reluctance or lack of opportunity to give a full history is highly significant for TB suspects. In the ideal model for diagnosis, it is assumed that a full symptomatic, care seeking history will be elicited from the patient, thus revealing the length of time for which the suspect has been symptomatic and the steps already taken. If, as findings suggest, a clinician commonly misses the full picture, it is likely that commencement on the TB diagnostic pathway may be delayed for many suspects. Other research already presented further supports this (Belaye 2000).

On the whole, the picture is one of consensus as to the steps taken in consultation with an allopathic doctor. It is also agreed by both the care seeking public and care providers that the area of communication and history taking is problematic. Clinicians posit that their working environment and high burden prevents them from taking the time necessary. Lay people concur with reports of consultations cut short and little opportunity to explain. Clinicians also blame their patients for being shy and unwilling to talk freely, while lay people describe their fear of being outspoken and truthful and cite clinicians for not encouraging and enabling them to speak.

Others maintain a belief that they should not speak, but that guardians as their representatives should do this for them. While these are all contributing factors, the common outcome is of a consultation in which information is partial and working diagnoses may not be accurate, where the relational space between doctor and patient leaves much room for ambiguity and personal perceptions or practical interests to intervene or inhibit behaviour, rather than fulfil the biomedical assumption of an ideal exchange.

Following on from this, the acceptance, on the part of patients, that a verbal diagnosis and explanation of the problem is not as necessary as the receipt of drugs for that unnamed condition, was seen as a common feature of the allopathic consultation. While some clinicians stated that, again, time constraints led to this omission – *"In most cases we lack time to explain well about what they are suffering from, what is supposed to be done, or maybe side effects"* (LLA MA003) – others were less aware of a need to explain, in line with their patients' normative expectations and so did not consider this a problem. With the complex and multi-staged diagnostic process for TB, this tendency *not* to explain by doctors, nor for patients to demand explanation, is however significant. It may contribute to the number of suspects who leave part way through the diagnostic process, disillusioned and not understanding the steps necessary, or, those who, having been told 'there's no TB,' leave despite being potential smear negative cases, which should be further investigated.

7.1.3 Traditional model

In considering a so-called 'traditional model' of consultation, it is vital to recognise that traditional healers in Malawi are not of a single type, but can be distinguished into several categories. It is also important to appreciate that these categories are themselves broad and overlapping, and that a given practitioner may fall between categories, or adopt practices from one or another. Chakanza's (2000) delineation of healers identifies three types: a herbalist (*wazitsamba*), a diviner (*sing'anga wa ula*), and a spirit medium (*sing'anga wa mizimu*).

A herbalist, based on his or her understanding of the healing properties of local roots and herbs, makes up medicinal preparations, which are dispensed to patients

following examination, or may often be sold, ready-prepared, at markets as 'over-the-counter' remedies.

A diviner consults powerful sources – sometimes ancestors, God(s), or an unidentified oracle – through the use of a mediating divinatory channel, to find the nature of the illness, its cause and cure. Such healers commonly deal with witchcraft and magic, and through their sources, find the way to turn such magic around.

The last type, and one which was not personally met in the course of this research, was the spirit medium. Through being possessed by ancestral spirits, such mediums may understand the cause and cure of a particular illness episode – particularly if linked to the spirit world. Such practitioners, and the 'cults' of spirit possession with which they are associated, may vary greatly from region to region. One of the most reknowned is the *vimbuza* cult of spirit possession, mainly practised in the north of the country (Friedson 1996).

As Chakanza notes himself, these types of healers are not to be seen as practising exclusively in one way or another, but may adapt practice according to circumstances. Lay respondents in this study tended to distinguish mainly between two types of healer: those that administer herbal medicine and those that deal with magic and witchcraft, while also noting that some would do both. In the course of fieldwork, the traditional healers most commonly met identified themselves as 'diviners,' but also used herbal preparations and techniques in their work. Thus, the consultation process examined was that between a 'divining' traditional healer and his/her patient.

In exploring the healing encounter, three groups were spoken to: lay community members, practising allopathic clinicians, and traditional healers themselves. Six healers were purposively identified as those who offered their services within the catchment areas of the two allopathic health centres, in the urban and rural study sites. They included five men and one woman.

All of these healers offered their services from their homes. Two of the rural practitioners were well established and obviously popular, with both out and in-patient services offered. Compounds had been erected with small huts for the patients

and their guardians to stay while under the supervision of the healer. Others were much smaller scale, having patients visit them in their homes, but not offering any kind of inpatient care.

When lay respondents discussed their experiences with such traditional healers, the normal process identified was that a patient, commonly with a guardian, would enter into the healer's room and sit. Unlike at the hospital, where the patient would be asked to describe their problems, at the traditional healer's, the patient would remain *entirely silent* throughout the diagnostic and examination process. Unlike a clinical doctor, the healer would 'use their magic' to 'see' the problem, its cause and its cure. *"But with the traditional healer, if I go there sometimes, I will not even explain. He will get his own things and will tell me the problems I have."* (LLA003M) *"There, unlike at the hospital where we explain symptoms or signs – to say, for example, the child has fever – there, you don't explain anything. All the time, you don't explain anything, they find out themselves."* (LLA007F)

Different forms of 'magic' or divinatory tools were described. For some, a simple bowl of water would convey the information, for others, a gourd or calabash. Not only lay people described this process, but clinical workers too,

"But, most cases, just like, I would say like – how can I put it? – something like you just look into maybe a basin of water and you see what is wrong with the patient and you just tell them 'no, I can see your liver's not in good condition.,' such things. Yeah, more or less that way." (LLAMA003)

Some traditional healers would display an array of consultation aids, including stuffed snakes, dolls, and bottles of various liquids, each of which could be used to channel the divinatory advice. When asked themselves to describe the diagnostic process, variations on a very similar theme were given. One spoke of taking a bowl of water, adding his own special medicine and then using this *"the same way as you would x-ray a person, to know what is wrong with them"* (LLBTH001). Another described using a mirror in the same way, or on other occasions, just knowing from looking at the patient.

One tried to explain how he used his divinatory source, known as the *supa*. In this healer's case, there was a close tie to the magic of witchcraft and he himself admitted

having learnt the art of witchcraft from his grandparents, and having practised as a witch in his younger days. As he grew older, he decided to use his skills to help ordinary people address the effects of witchcraft in their own lives.

He spoke of gathering an old gold coin that had belonged to a witch, and then adding this to his special medicine in the divinatory tools. Once there, this *"starts talking...it's like a radio."* Through the voice of the *supa*, everything relating to the patient is explained. *"When the disease has been revealed, it's now up to me to say that this disease, this medicine is the one."* (LLBTH005)

All emphasised that, during this process, the patient would be required to sit, silently, without saying or doing anything. Only after the healer had completed their 'examination' would they then communicate. Commonly, the healer would report their findings to the patient, telling them everything: the nature of the problem, its cause and a proposed treatment. After telling them what they had found, the patient would then be given a chance to agree or to challenge the healer's diagnosis.

Lay respondents agreed that this was the case. After the healer had given a full explanation, their patient would be given an opportunity to discuss and ask questions,

"The witch doctor will say, for example, 'it's witchcraft coming from a relative,' so when we are given an opportunity to ask questions, we ask 'is it a relative on the woman's side or on the man's side?' Or 'is it just a neighbour from where we are staying?' So, we ask all sorts of questions like that." (LLA007F)

"He uses his medicine and his ways and then he actually is the one who tells you what you are suffering from. If you don't agree, you tell him you don't agree. But, if you do, he goes ahead to give you medicine accordingly." (LLB008F)

Interestingly, and in contrast to the few individual lay members who affirmed that their belief in God ruled out a belief in traditional medicine, several of the healers spoke of the role of God in their practice. Two of the male healers, invoked the role of God as their source, speaking not of ancestral spirits, but of spirits that come through prayer to God.

Of overriding importance in all healers' cases was their emphasis on using their intuition and 'magic' to identify the source of the problem, and to then explain this to their patients. Patients were also distinguished by their need to hear that explanation

and find what was causing their illness, unlike at the clinical doctor's. It is significant that patients were more likely to take a chronic condition to a traditional healer and find the apparent true cause there, than to a health centre where they had already been disappointed and where they would not normally go in search of the causal explanation:

"Sometimes they [patients] will go to the hospital, but they will be sent back that there is nothing, they have found nothing. They will go to the grocery and buy medicine, there is no cure. And later on they will come to us, the singanga." (LLBTH005)
"When they go to the hospital, when they are tested, after an x-ray, you people at the hospital say 'we are not finding any problem.' So, you say, go back home, because you are not suffering from anything. And those people come to us." (LLBTH001)

7.1.4 Similarities and differences: a comparative analysis

In comparing the two models of practice, both similarities and differences were drawn between the traditional healer and the clinical doctor. Interestingly, men tended to focus more on differences rather than similarities, with only one lay respondent looking beyond any differences to observe that, *"both provide cure of some sort."* (LLB009M). Women however, frequently commented on the obvious similarity that both were options for help in times of illness. Another area of similarity highlighted by female lay respondents was that both gave out medicines to help treat their patients. There was awareness that, of course, such medicines were different in origin, however, the aim would be the same: to treat and cure the ailment.

"There is a similarity in that both places give you medicine, which helps you to get better. If you go to a traditional healer, he will give you roots and, if you go to the hospital, they will give you maybe tablets. And then you will know that this root and this tablet are the same kind of medicine – only that they are different because they are from different sources. Yuh. But they are... they help cure the same disease."(LLA009F)

One traditional healer, however, when commenting on the medicines used, stated that

"this hospital medicine originated from traditional medicine... this western medicine originated from the roots and those medicines are our medicine!" (LLBTH005)

This element of competition was not unusual and traditional healers themselves tended to focus on the perceived differences between themselves and clinicians. Amongst health workers, the higher cadre clinicians tended to be more open-minded, acknowledging their similar role in both providing treatment, and having differing 'comparative advantages' in dealing with different conditions. They identified some logistical differences in the smaller queues and the fees charged at traditional healers

– thus highlighting those features, which bore similarity to the private allopathic providers, rather than government health workers. One health surveillance assistant distinguished between his preventative role and the curing role of a traditional healer, while readily equating the healer with the clinical doctor.

Lower cadres on the whole showed less open-minded opinions, making implicit value judgements about the efficacy of clinical medicine, as compared to traditional.

"It's just that I do not believe in traditional healers myself. But for what I know is you get better help at the hospital, because if you're sick... If you do not have enough blood for example, at a traditional healer, they will just put incisions in your body, they will not give you any blood, and you cannot be cured. But if you go to the hospital, they make arrangements and they will actually give you blood."
(LLBWA001)

Other critical comments focussed on healers' lack of training and 'proper' knowledge, their reliance on intuition or 'guesswork' rather than clinical evidence and their distribution of 'improper' medicine with no regard for dosage.

"There are great differences, because a traditional healer, they do guess. They do guesswork that, if I take this such type of herbs, maybe this one will be cured. Yet, the doctor sees that patients and clinically, he tries to find a better treatment, better drugs for the patient. Once he gets that one, he gets better, he is cured, the patient is cured. So, there is a great difference. This one has got training and a certificate, but, traditional healers, many of them don't even have certificates." (LLBHSA004)

In terms of differences, similar themes were highlighted by lay men and women. In a simple tabular presentation, this was as follows:

Table 8: Summary of differences between clinical and traditional practitioners

Clinical doctor	Traditional Healer
Patients explain the problem	Patients are silent
Hospital instruments used	Own "magic" and instruments used
Physical examination/ Diagnostic tests	Divination/intuition
Doctor depends on patient's explanation	Healer 'knows' the problem
Treats natural diseases	Treats magic/witchcraft – and natural
Modern medicine – tablets/injections	Traditional medicine – herbs/roots
Doctor prescribes without explaining	Healer explains cause and gives cure
Consulted earlier for treatment	Consulted later to find the cause

Healers themselves commonly focussed on the differences between them and the clinical school. Again, attention was drawn to the difference in instruments and medicines, and the nature of the diseases, which they dealt with, opposing the natural and the magical. There was acknowledgement of the types of tests which healers were unable to carry out,

"There are big differences. Our friends at the hospital, for example, will know if there is a problem in, to do with dialysis or a person's blood, if there are problems in a person's blood. They will be able to find out that there are viruses in the blood and so on. These are the things we cannot find, we cannot know. So there are big differences...." (LLATH003)

However, this was balanced by the view that, as healers, there were areas that they could manage, which hospital doctors could not:

"There is a difference. There are certain things that people in the hospital have, that we do not have. But there are also certain things that we can do, that they cannot do. I can give examples. The epilepsy that I talked about. At the hospital, they will tell patients to be going maybe every month to collect medicine and they take the medicine continuously. But with us, if we say we can cure, we give them medicine, it's a once and for all sort of thing. They are cured, they will not have to keep coming to take medicine." (LLBTH002)

The cure of chronic ailments, which would otherwise only be managed by hospital medicine was a consistent theme, with problems ranging from epilepsy and asthma to mental health conditions.

7.1.5 The Communicative Encounter: a valid ideal in a Malawian context?

Themes that cut across both traditional and modern healing encounters were those of power, knowledge and resulting communication. As already presented, these are key concerns in medical sociology, which commonly presents an equitable communicative encounter as the means of attaining the best health outcome for patients.

Research here suggests that, on the whole, communication is poor with *both* types of practitioner, when judged against the medical sociological ideal. While the allopathic model is predicated on a two-way exchange of information, and while male Malawian respondents in particular, seemed to understand and approve of such an ideal model, evidence suggests that this ideal rarely plays out. Findings show that there is constrained information provision on both sides. This is occasionally as a form of

active 'resistance' with patients withholding information from the clinician (i.e., to avoid being characterised as chronically ill and potentially HIV positive), or more commonly reported as a result of their limited opportunity to speak out and fully elucidate their history. Such difficulties also arise owing to the limited ability and/or interest on the part of clinicians to elicit more information from patients during the encounter.

With traditional healers, despite an entirely uncommunicative diagnostic stage, there was some evidence that healers gave more opportunity for their patients to discuss or question their findings later in the consultation. A natural space was created for the patient to either agree or disagree with the healer's conclusions and so, was explicitly felt by some respondents to improve patient-provider communication. However, the nature of the diagnosis itself, in which all power rests in the hands of the healer and the patient is notable by their silence and lack of contribution, creates an environment built around an explicit power imbalance, whereby it may be more difficult for patients to challenge the resulting diagnosis.

While less explored in non-allopathic settings, the clinical 'gaze' of Foucault (1973) is here seen to apply in both allopathic and traditional contexts. In Malawi, both doctor and healer are trusted by patients to have diagnostic intent and ability and are felt to have a wisdom (either learnt or inherited) that is not shared with or accessible to their client. All participants collude in the maintenance of such a hierarchy, with patients, on the most part, willing to invest trust in their carer and carers willing to take on the authoritative role.

This was confirmed by many female respondents who generally said that communication was poor in both the traditional and modern setting. While no women explicitly outlined what they felt would be an 'ideal' communicative encounter, in the way that some men did, tales of impatient doctors and intimidated patients were used as an indirect means for women to express their dissatisfaction. This was supported by the fact that a tale told of a positive encounter with time given to the patients to present their symptoms was presented as a rare, but welcome, occurrence.

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Such opinions were confirmed in observation of consultations with both types of provider. In the observer's experience, clinicians were extremely busy, seeing one patient immediately after another, being interrupted by nursing and other staff coming and going from their room. Privacy was minimal, as was time taken to take history and examine each patient. Traditional healers were far more relaxed, without the pressure of an enormous queue outside and taking their time with the 'ceremony' of their diagnosis. Nevertheless, patients were still reserved in manner and deferential to the healer's words and actions. The researcher is, however, mindful that, in both instances, the patients may likely have been affected by the presence of a foreign observer in the room, which may have further intimidated them.

All this must be considered, however, in the light of the normative expectations with which patients seek care at each provider and, indeed, with which they are received. It has been proposed that patients go to each provider at different stages of their illness pathway and with differing expectations. The fact that patients tend to seek care with an allopathic provider *earlier*, and generally expecting little more than to leave with some medicinal treatment may further mitigate against open communication. The fact that the patient may go to a traditional healer at a *later* stage and seeking the cause of their ailment, suggests that communication may be more active. However, findings suggest that as long as the healer provides an answer, the patient is unlikely to challenge their findings owing to their relatively disempowered position in the encounter. While patients have demonstrated their agency in their pragmatic and staged care-seeking paths and, it may be argued, some degree of subversion in instances when they deliberately withhold information from the physician, on the whole, they participate in a relationship of power with the diagnostician which accords them the position of authority. Thus, a final similarity between the two models is the imbalance of power in the encounter between patient and provider, facilitating poor communication, with each tradition reinforcing this tendency in the other model.

7.2 BRIDGING THE MICRO AND MACRO - BEYOND THE HEALING ENCOUNTER

The analysis of the healing encounter so far has explored the influences of knowledge and power on the instance of patient-provider interaction. It is proposed that these

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may be viewed as 'bridging' themes, linking the micro or local, with the macro or institutional. It is also proposed that power and knowledge interact with the theoretical notions of structure and agency, in order to influence each individual's conduct and interests in the interaction – both on the side of the provider and the patient.

The tension between structure and agency displayed in the user/provider relationship is seen throughout social theory. The healing encounter may not be a level 'field,' in Bourdieu's terms, as any opportunities for individual agency and transformation are structured in terms of asymmetrical underlying relations, which will more likely favour the reproduction of existing inequalities. In Scambler's view, in looking at health and medicine in society it is not necessary to choose between agency and structure, as the two are transcended in encounters, such as that between physician and patient, which are structured by the interplay of both (2002).

As introduced at the beginning of the chapter, Stimpson and Webb's study of the consultation process focuses on the micro level face to face interaction, and proposes that each party uses tools and strategies, or 'effective self presentation' to try and influence the interaction. They acknowledge that a doctor will employ techniques to maintain their status as the expert, but counter that the negotiation is between both actors, each with a respective agenda. Similarly to Bourdieu, however, they 'do not pretend that the strategies are enacted in an open arena' (1975: 205). They identify limits on the 'possibilities of action' which structure the encounter, and which may be 'less negotiable' than other aspects of the encounter. One of their limits is the patient's perception of what is possible. These perceptions will be influenced by that individuals' presuppositions, which are themselves influenced by any underlying structures, and may likely include a presupposition that their knowledge and status places them in a deferential position to the expert doctor.

As Willis (1977) explores, looking at working class children in the UK, inequality is often articulated and reproduced by disadvantaged people themselves. Concepts of disadvantage and inferior status will be felt and expressed, therefore contributing to the maintenance of such inequality – a lack of 'capacity to aspire,' using Appadurai's more recent phrase (2004). While Willis feels that this can be a type of counter-

cultural affirmation or resistance, it nevertheless results in the reproduction of the status quo, through articulation as their own conceived possibilities – or limits – of action, thereby structuring attitudes and behaviour and degrees of agency. This has clear parallels with the 'weapons of the weak' employed by the sick and by patients in Malawi, as already described, but which may actually worsen their situation, by limiting their access to the benefits of diagnosis and appropriate treatment.

While anthropologists and sociologists accept that knowledge is socially produced and distributed, scientists and medics still use the prior claim to a natural objective reality to maintain the status quo of their authority, based on their knowledge. The pervasiveness of such a claim is seen in the use of language to distinguish between the knowledges of different groups, such as the use of terms such as beliefs and understandings to describe the perceptions that do not conform to the western scientific 'knowledge.' (Good 1994). Social science was slow to challenge this dominant epistemology and, indeed, originally measured itself against this scientific paradigm, as noted in Chapter 3. While social theory has since moved on, questioning the applicability of positivist principles to the social realm – where meanings may be unobservable and reality less predictable than science infers (Baert 1998) – this tension has endured and one area where such a struggle is clearly played out is in the health arena.

This section therefore aims to examine the theoretical opposition between lay and expert knowledge on which disease control and health promotion methods for TB are commonly based, to investigate to what degree this opposition is reflected in reality, and to examine the effects of such constructions at the more macro level. It will question how such knowledge(s) (and theories of knowledge) are produced, perceived and used by – and in the interests of – different groups; who benefits from these constructions; who has authority in their production; and whether there is any opportunity for change. In looking at the privileging of medical over other forms of knowledge, the chapter will illustrate how the social scientific and medical anthropological method continue to struggle for recognition, in trying to represent the unheard voices of non medical identities – and how such methods have been (ab)used in the past to serve particular interest groups in order to maintain, rather than challenge, existing relations (e.g., through traditional health education, where

knowledge equates with behaviour change and the victim is blamed for their lack of redemptive knowledge, while those in possession of such knowledge are reified). Most importantly, it is proposed that this environment has delayed critical analysis of the problems of both TB service organisation and delivery and the multiple constraints that patients and suspects face.

Throughout the fieldwork, issues of knowledge, education and power were persistent themes. While the researcher used the opposition between clinical (formal) knowledge and lay/traditional (informal) knowledge, to frame discussions, the views elicited and observed across groups both made use of such a framework and transcended it, as the following discussion will show.

7.2.1 Faith in ' knowledge'

Perhaps the most common view illustrated by differing respondent groups, and one which supported the more traditional biomedical interpretation, was the immense faith in an unquestioned, objectified category of 'knowledge' – spoken of by both lay and most staff members.

In group discussions, health staff were generally happy to discuss beliefs and understandings in terms of what their patients believed and practised. This was predicated on a somewhat artificial distinction between staff and the lay community, as staff themselves are members of those communities.[208] At times, this boundary dissolved at the initiation of the staff themselves,[209] and within each group, there were often individuals who were happy to speak out and discuss their ambiguous position between 'communities' and 'clinicians.'

This picture was also reflected in individual interviews with staff members, where the differences between cadres and the influence of a strict medical hierarchy became much clearer. Stated attitudes often varied between cadre level, shown in their differing professional concerns and priorities, as well as their reports of patients'

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[208] It proved easier to frame discussions of knowledge and understandings within the 'us/them' paradigm, owing to the tension revealed between 'clinical' and 'lay' knowledge, and the limits that respondents' perceptions of the interviewer, presented - i.e., their desire as staff to present the 'correct' clinical picture to her, as a representative of the TB Programme.

[209] For example, when discussing the TB/HIV issue, where HCWs were candid in discussing their own lack of knowledge and understanding.

behaviour towards them as health care workers. This area will be examined further in following sections looking at the role of education and the staff hierarchy. However, on the whole, and particularly amongst lower cadre staff, attitudes towards 'knowledge' were shared with their patients and public.

In these attitudes, such 'knowledge' was associated with education, training, and modern medical science. It was reified as something to be obtained and something which most ordinary people lacked. It was seen as the key to behaviour change (in terms of health promoting behaviours), with an assumed attribution between the two and was opposed to common lay 'understandings' or beliefs, which were perceived as resistant obstacles to change – *"You know, villagers are villagers. They always stick to their guns."* (LLAMA002). It was viewed as a positive goal, which health workers should assist lay community members in obtaining, through their dispensing of advice and 'health education.' Unlike common lay knowledge, therefore, proper clinical knowledge was attributed with symbolic value. It was also seen as having political value by those at the policy making level.[210]

Amongst lay community members, evidence to support such opinions was provided mainly by men, citing the importance of medical training and diagnostic tests,

"Because a body is a difficult thing. I can say that I am OK, but I don't know anything about my body! That is based on testing, which you are all used to these doctors doing." (LLA008M)

Both Malawian men, and HCWs, tended to demonstrate an almost positivist attitude to health, valuing medical science for its ability to 'know' the problem through empirical observation and testing. Amongst lay women, the need to follow hospital advice or medical instructions was emphasised, and, in the event something went wrong, there was a readiness to blame the patient for not following advice, rather than question the decision or treatment given by the doctor. On the whole, those people

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[210] This was described in Chapter 5, with the NTP Programme Managers' views of how tuberculosis control in Malawi had initially not been viewed as having medical status or credibility, but was 'relegated' to the field of environmental health. One of the PMs remembered how, in earlier days, he had not been interested in working with TB, owing to its poorer status as a public health concern, rather than a clinical area. As he put it, TB was considered a "weaker component" by clinicians, being in the environmental health arena. As the NTP developed, a deliberate strategy to raise its credibility was thus to bring more clinical personnel into the management structure, so that they could negotiate effectively with the Medical Officers in control of health policy and planning in the MOHP and fit within the medical hierarchy that operates throughout Malawian health institutions.

who were educated – often described as 'civilised' or 'enlightened' – were praised for having the knowledge, and thus assumed ability, to do the right thing,

"Most people don't want to go to hospital when they suspect TB. Only very few – and usually these are enlightened people – will go to hospital if they have a problem with TB." (LLA002M)

"Those who come late [to the HC] *it's just because of not knowing... But with those who are civilized enough, they come here earlier and they are treated earlier and they get better so earlier."* (04US)

On the other hand, the 'ignorant' villager was blamed for not doing the right thing. A consistent emphasis was therefore placed on the need to be better informed with appropriate knowledge. Owing to the generally unquestioned attribution between knowledge and behaviour, both lay and staff respondents prioritised a need for better provision of this information and used a lack of education to explain peoples' 'poor' health decisions.

"They do not know what they need to do in order to maintain good health...People in villages, they are lacking civic education to teach how they can live in good health." (LLB004M)

"Health people need to be coming here to encourage us and to give us information as many people don't know. They don't understand." (LLA004F)

This tendency to reify the role of knowledge in influencing peoples' behaviour was seen in both lay and, particularly, HCWs' attitudes to 'health education.' Unlike the more progressive social-ecological approaches to health promotion and behaviour change which are current in academic circles and advocated as 'best' practice, the attitudes of nearly all health workers met, without exception, were of a more traditional, didactic approach to what was termed 'health education.' In a similar way to the manner in which 'knowledge' was objectified as something tangible to be 'got,' health education was spoken of as something tangible, to be 'done' – *by* health workers *to* lay people.

"You know, the knowledge are still wrong. That's why, when going there we also make a programme, we'll give them health education talk concerning each and every disease." (LLAHSA001)
"Where there are field workers this is very easy. You go there and health educate the community, yes." (01RS)

Maintaining an opposition between clinical knowledge and lay or traditional knowledge, HCWs talked dismissively of peoples' mistaken ideas and problematic

beliefs. This attitude was extended to traditional healers as well, particularly by lower cadre workers, who demonstrated much stronger support for this fixed opposition between the 'right' clinical knowledge and the 'wrong' lay knowledge than their senior counterparts. Some statements revealed an unquestioning acceptance of biomedical ideas. Where a low cadre member of staff might have a basic idea of some clinical notions, these would be clung to and promoted as the only way to do things properly,

"There are differences. Because here, when a person comes here, they will be given medicine that is appropriate and in quantities that suit what they're suffering from in their body. But, at the traditional healer's, there is nothing like dosage. So, quantities of medicine given to the patients doesn't really matter, which I find to be dangerous." (LLAWA002)

The most common views put forward by lower cadre workers were that traditional healers were only after money, and did not really offer any worthwhile treatments. This echoed the views of some individual lay community members, who perceived the trade to be mainly a money-spinning operation. More perceptively, one ward attendant spoke of traditional healers' roles in introducing conflict and competition into a community.[211] In his words,

"I cannot speak for others, the other members of staff here, but personally, I think that traditional healers also sow seeds of enmity among people when they say, for example, 'so and so died because so and so put a bad spell on them,' and so on. So, I find that this is not good. They just bring enmity and I do not believe in them". [212] (LLAWA001)

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[211] In his study of the witch in society and history , Sanders (1995), observes that "witchcraft … frequently is associated with interpersonal conflict, and persons often look among people they know for the witch responsible for their ills. This especially is true of societies where a few personal relationships serve most of an individuals' needs and where people are likely simultaneously to be in several different social relationships with one another. Consequently, it is characteristic of small scale societies and of small stable local communities" (ibid:101).

[212] It is debated in the literature whether witchcraft accusations often arise as a result of a social upheaval, or whether they are a part of the process of social change (Sanders 1995). Some posit that witchcraft fulfils a functional role in the maintenance of social stability, through a cathartic reassessment of the usefulness of existing social relations and the reproduction of 'new (but not novel)' social relations – a 'social strain gauge' (Marwick 1970). Others debate whether the changes brought about through witchcraft can always be viewed as positive (i.e., in maintaining social relations) or whether they are inevitably conflict driven and indeed drivers of conflict, in their aggravation of fears and enmity, which likely remain after an initial catharsis (Nadel 1970). Nadel concludes that witchcraft beliefs enable a society to continue functioning, yet without truly resolving any underlying conflicts and contradictions, and indeed fuelling those tensions instead. In Malawi, the enduring power of witchcraft belief, its association with grudges, disputes and jealousy (Peters 2002), and role in furthering the cycle of such frictions would seem to support Nadel's position.

An additional aspect, however, and one which added a further dimension to the common one-dimensional portrayal of the 'ignorant' lay person and the 'knowledgeable' health worker, was that these same lower cadre workers were also the ones, as discussions progressed, to frequently lament their *own* lack of access to health related information and knowledge. While a common view was that *"patients take everyone working at the health centre to have knowledge of the disease* [TB]" (05RS) and that *"because the community sees all of us as doctors, so we should be able to answer common questions"* (04RS), what emerged when discussing HCWs' ability to answer peoples' questions was a very patchy hierarchical picture. As one respondent phrased it *"it is answers according to experience."* Medical assistants and clinicians felt more confident and better informed than those with less training and experience. HSAs – the cadre with responsibility for health promotive activities in the community – commonly stated that their knowledge was often partial, and depended on the difficulty of the questions, and which areas of TB they addressed.

"At times we feel inadequate" (03RS); *"Sometimes the community know more than us"* (03US); *"We are unable to assist the community, because we don't have enough knowledge"* (05RS).

The implications of this were explained, as several groups highlighted how this situation contributed to misunderstandings and incorrect information being passed through communities:

"Because being a doctor, being an HSA, I may not want the community to know I am ignorant of these things. So, instead I will cheat them" (01RS).

The need for more information was illustrated, as one respondent said,

"So that if we go in the field, we tell people the truth, not just telling them what we get from the air" (05RS).

The differences in confidence and knowledge levels between cadres was said to have further effects in terms of the circulation of information. While clinicians were identified as those who received more training and were in a stronger position to respond to queries, they were also *not* the staff members who had greatest contact with the communities. HSAs in particular were identified as the health workers who spent time 'in the field,' working with villagers, yet many of them were untrained or admitted to knowing little of TB. Thus, the traditional opposition between the educated health worker and the ignorant lay person can be seen to break down, when

examined more critically in context, by the same individuals who also subscribed to this opposition themselves.

Sharing the same desire for the elusive cure-all 'knowledge,' most lay respondents also lamented the poor availability of health related information. While this research questions the over-reliance on such information as being the solution to all access worries, it recognises the role of information as one potential complementary strategy amongst many, to improve peoples' ability to access health care. For many respondents however, the intertwined and sometimes indistinguishable roles of education, information and knowledge, were often presupposed as *the* primary influence. This was a view that was consistent with that promoted by health workers.

Not only allopathic doctors, but traditional healers tended to play on their role as 'experts,' guarding the secrets of their trade and maintaining an aura of power and even potential danger if their territory was encroached upon. During fieldwork with traditional healers, 'magic' tools would sometimes be symbolically displayed or manipulated to remind the interviewer that she was dealing with somebody who holds special knowledge and therefore power, which few others have or can comprehend. In interviews, this stock of knowledge was largely protected, in order to maintain this advantageous position. Only one or two healers were willing to talk in detail about particular practices or methods while others would laughingly deflect questions which probed too deeply. One healer however, took obvious pleasure in hinting at the extent of his power when revealing aspects of his practice. Often though, he would dwell on the impressive end result, rather than the means, and, at the conclusion of the meeting, his desired effect was seen in a shaken Malawian interpreter, clearly in awe of such an individual's power.

Even clinicians – in medicine's view, 'converts' to the cause of allopathic practice – would not usually challenge the expertise or powers of the healer. They were acknowledged to have skills and knowledge of a different order, but with those skills came ability and power. While the clinicians felt unable to comprehend such practices, this did not mean that the symbolic capital held by the healer would necessarily be questioned.

"...Because you find that maybe a traditional healer could be <u>here</u>, do something here, but that could affect someone who is in Mzuzu! [500kms away] *So, in a way, this, I mean my training, has been, has made me wonder how these traditional healers work? I mean, though I know that sometimes it's connected with maybe, people think that maybe they fly at night, or whatever. And still, I had that belief, because they don't come into the open and say openly, we do one, two, three... And if you can ask them maybe to take you to South Africa now during the day, they wouldn't do that! But maybe at night, they would take you there."* (LLAMA003)

Interestingly, and as already outlined in the previous section, lower cadre HCWs were less likely to show such accepting attitudes to the researcher. They often explained their oppositional attitudes through an association with education, or the perceived validity of medical over traditional practice with an incompatibility between the two:

"When I was young, my father was a teacher, so when we got sick, we have gone to hospitals, not to traditional healers." (LLBHSA004)
"Well, in my life, from the time I started working in the hospital, I do not use traditional medicine." (LLAWA002)

7.2.2 The role of education

The perceived role of education was a consistent theme in both lay and HCW narratives of power, knowledge and communication. On the whole, a dichotomy was drawn between the educated, trained HCW and the 'ignorant,' uneducated community member. Although such a dichotomy was shown to be flexible, as already described, it was not uncommon to meet with defensive low cadre HCWs, who had had little more training, if any, than their clients, but who were unwilling to reveal this, either to their clients, or, initially, in interview with the researcher. Their tendency was thus to cling to the clinical paradigm and the little pieces of information they had gathered on the job, articulating and promoting these notions until such time as some of them felt prepared to admit gaps, rusty skills and knowledge, or the (total) lack of opportunity for training or access to information – and therefore the reality that they were often barely in a better position than their public.

Training was an issue that raised considerable debate, amongst all groups. The major concern on the part of workers was the *selectivity* of the available training sessions and the influence of the medical hierarchy – already education based – on structuring access to any training opportunities. All respondent groups stated that participation in training sessions was for selected members only, and tended to involve the *same* individuals at higher cadre levels. Given the increased role for HSAs as field workers

in managing decentralized care and health promotion for TB, there was considerable concern about their lack of inclusion in training sessions. The feedback given from nearly all groups was that clinical staff are included, but field staff are forgotten.[213] Those who do receive training were said to rarely cascade information back to other staff.

A very hierarchical perception of the NTP and of information being communicated *down* through it was demonstrated, as staff lamented the lack of attention and monitoring by senior staff. The fact that *only* district level staff ever visited, and that this was rarely monitored, was seen as a fault, and there was a call from different groups for regional and national level staff to take an interest and *"to see if we are implementing all issues that they teach us"* (03RS). As a fairly impassioned plea, one respondent stated,

"You top people must visit us frequently, to see how the jobs are going on. The main problem is, you don't come, you just stay in your offices." (01RS)

Inclusion, quality, frequency and supervision were therefore the main issues of concern to staff members, in their in-service education. Given the vertical structure of the NTP and the flow of information and support from the centre to the periphery (and only in this one direction), ensuring that such information is reaching its targets and 'cascading' from one level to the next should be a priority. Currently, in this fieldwork, respondents felt that the flow from district to health centre level (therefore enabling health centre staff to reach the public) was problematic.

Education was not just an issue of importance in terms of staff training and information levels. A consistent theme was the influence of individual education and background – of both HCW and patient – on their communication. Some attention has already been paid to this topic in the earlier section, where the focus was on the interaction between patient and clinician. Here, communication between the public

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[213] Lower levels, such as ground labourers, ward attendants, patient attendants and the occasional HSA, on the whole reported that they had *never* received any training, and all staff, regardless of position, were worried about being kept informed and up-to-date, particularly in view of recent changes in the NTP. The same attitude to knowledge as an essential, dependable commodity, but one which was out of reach, was therefore demonstrated by staff, in addition to lay people.

and different levels of health staff will be considered, in addition to how education is perceived to influence these encounters.

As a main theme, rural/urban differences were frequently identified. This was to a large degree predicated on assumed knowledge and education levels with the (fairly accurate) presupposition that rural villagers were likely to be less educated than their urban counterparts.[214] Rural patients (especially women, as reported by male clinicians) were described as more 'ignorant,' less likely to understand and follow or remember a doctor's instructions. It thus followed that they would be more likely to follow old traditional ways and be less inclined to change these practices. Conversely, it was often reported that urban dwellers were more likely educated or 'civilised,' and, therefore, were able to relate more to what the doctor told them, and would follow advice more closely. COs and MAs reported feeling more at ease with these urban patients. While they were said to also complain and demand more from the doctor, owing to their educational level and knowledge base, this was praised by clinicians and seen to contribute to a picture of knowledge as equated with empowerment.

This picture, however, was shown to be more complex when examining other cadres' perspectives. This was particularly interesting when considering the cadre of HSAs. As already observed, HSAs have been identified as the nearest source of information and the main source of health advice at community level. One of their main functions is to carry out 'health education' outreach, amongst other health promotion activities. However, unlike their clinical colleagues, HSAs need only to have completed their Junior Certificate of Education[215] and will only have received 6 to 8 weeks training in basic health, nutrition, water and sanitation procedures. This training and educational background was shown to influence an HSA's relationships with their client base.

In contrast to clinicians, who prefer the urban areas *because* clients on the whole are more educated, and therefore more receptive to their advice, most HSAs reported that rural villagers, rather than urban people, were better, 'easier' clients – owing to their lower educational level:

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[214] As shown in the 1997/8 Integrated Household Survey.
[215] Primary school leaving certificate.

"You know, in rural areas, you can teach the villagers <u>*everything*</u> *because they don't have any knowledge of everything. So, if once you visit them, they see you as, what, an educated one, who when you are teaching them, they can't even argue with you. Sure."* (LLAHSA001)

Villagers were said to respect the HSAs, listen to what they had to say, have little prior health related understanding themselves and therefore would view HSAs as a source of valuable knowledge. HSAs were perceived by them to be trained, knowledgeable 'doctors,' rather than as 'only' the preventative health worker that they are. They are accorded status as a 'proper' health worker, yet are also appreciated because they are more in touch with their community and relatable to as community members – rather than as distant health centre clinicians.

On the other hand, urban folk, who may be more educated themselves, were said not to respect the HSAs as much – for the same reasons inverted. HSAs therefore disliked working in urban areas on the whole, because they were challenged by a difficult, more educated public who often dismissed them as lowly workers from whom they had little to learn. Much of the urban population was reported as having their own ideas and as being unwilling to listen, leaving the HSAs feeling disempowered by their lack of sufficient training and knowledge to engage with this population. This scenario was made worse by the urban environment. Unlike in the rural areas, where a community may be instructed to assemble by the traditional chief, the fragmented urban community is less easily mobilized by its local political leaders. People in cities are both more mobile and more preoccupied with daily livelihood activities. This, combined with their apparent prejudices, leaves them less motivated to spend time listening to a partially trained health worker.

HSAs were therefore seen to be highly sensitive to their ambiguous professional status and to the role of education in either cementing, or undermining, their 'value' in other peoples' eyes. This 'discomfort' and lack of confidence at carrying out outreach activities in city locations had the unfortunate result that hardly any HSAs were active in the urban, and poor, areas of Lilongwe. Until this research started in Area 24, no HSA had made contact with the local political leaders, or were seen by the community to have a presence in the area. The 'power' associated with knowledge and education is seen to have very real effects in the health outcomes for the urban

poor. While the traditional dichotomy places knowledge and power in the hands of the health worker, it can be seen that such a dichotomy is challenged in an environment where power is articulated in more discursive forms and relationships, which need to be recognised.

These assumptions which inform the role and responsibilities of an HSA have implications for health policy. Their lack of efficacy in urban areas, owing to the challenging nature of the environment and their own sense of powerlessness and educational inadequacy, has hitherto gone unrecognised and instead, the HSA continues to be given greater responsibilities with an increasing work burden and demands placed on them by all the selective health delivery programmes (malaria, TB, HIV, etc) in addition to the integrated PHC services. For TB alone, but also for integrated health provision, it is important to address the issue of training, education and empowerment for *staff*, as one means of improving their efficacy.

7.2.3 Hierarchy and communication

Related to the attention needed to training and empowerment at all staff levels, is the need to recognise the associated impact of a strict staff hierarchy inflexibly rooted in educational levels. In speaking to medical staff, an appreciation was shown for the need for a well-organised team, and it was generally accepted that such organisation was grounded in the medical hierarchy,

"You would expect someone with a higher qualification to be above you, to be your senior. There's no way you'd give, someone less senior would give orders. The senior should give you orders, that's how things should work." (LLAMA003)

Such a hierarchy is strongly adhered to and largely unquestioned with the feeling that 'that's how things should work.' Challenging the hierarchy was rare and instead it is mainly accepted – even with its inconsistencies.[216] However, in private discussion, COs and MAs expressed dissatisfaction at being in the paramedical cadre, where the inflexible educational entry requirements prevented them from ever gaining the status of a full doctor. A reasonable pass at the Malawi Certificate of Secondary Education (MCSE) was the entry requirement for CO/MA training, yet not enough to qualify for MO training. Once a CO/MA, and even with many years direct clinical and

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[216] While State Registered Nurses are 'technically' more qualified than COs and MAs, having gained a full degree qualification from a constituent college of the University of Malawi, in practice the Officer in Charge of a clinic is always a paramedic CO or MA, rather than a nurse.

management experience, there was no possibility of further qualification or ascending further up the hierarchy, owing to their original educational entry level. Only those with an exceptional MCSE pass would be allowed entry to the original training path for a doctor. Education had thus been both a barrier and an enabler: serving as the criteria for entry, but then also as a ceiling to further advancement.

In the same way that patients and community members have been shown to follow pragmatic decision-making paths, the same can be said of the political level in the use and representation of scientific knowledge and formal education. Given that it suits pragmatic and political purposes, knowledge is objectified in opposition to lay beliefs, e.g., in explaining poor TB notification rates or poor adherence rates. Such an opposition forms the basis of a 'high-jacked' form of health promotion, where knowledge as an objectified commodity is held up as the key to causing behaviour change and as the solution for a range of patient related problems. This sits comfortably with the patient blaming paradigm and is an easier 'solution' than acquiring an in depth understanding of the multiple influences on community, patient and HCW choices and behaviour. Staff all the way down the hierarchy are therefore encouraged to place faith in the role of education/knowledge, which serves the dual purpose of maintaining the knowledge/understandings dichotomy and reproducing an education-based medical hierarchy that offers an acceptable justification for the limits to one's advancement but complements this with benefits of a degree of status and power according to one's position in such a hierarchy. It suits those at the top to maintain this beneficial status quo by reinforcing the opposition between lay and professional understandings, while simultaneously failing to acknowledge the fluidity in practice and the flaws in this opposition. The maintenance of such a status quo also limits opportunities for alternate, or rather complementary, methodological approaches and questions that might reveal such fluidity and thus challenge the prevailing epistemology.

Educational attainment and opportunity is once again seen to be privileged, and reinforced within a traditional medical education system. Such a system is supported by the technocrats and those already at the top of this medical hierarchy in public statements and policy decisions. The Malawi MOHP has appeared remarkably inflexible in refusing to consider adapting such a system to the practical needs of an

understaffed, over stretched health service, which would benefit from opening up further training and qualification opportunities to its paramedical cadre.[217] This resistance and inflexibility can be interpreted as serving an agenda where 'proper' doctors are respected, reified and right, and where the objectification and reification of medical knowledge supports the existing professional medical establishment, and those who direct it.

The impact of such an approach is reflected in the attitudes of lower cadre health workers. Interestingly, higher cadres (COs/MAs in urban) in discussion often seem much more at ease with the two systems – traditional and allopathic, or even lay and medical, between which they see little tension and so do not hold them in such opposition. They themselves accept both as a continuum of care/healing, rather than opposed paradigms and are often comfortable accepting both, depending on circumstance. An example of this was that their own belief in witchcraft was not seen as conflicting with their training and position. However, this cadre still privileged 'knowledge' on the part of the lay community as being one of the keys to positive health promoting behaviours.

In contrast, and as indicated previously, the lower cadres very much objectify medical 'knowledge' and understanding as a desirable commodity, which rural people do not have and urban people have little more. Traditional/lay knowledge is opposed to clinical knowledge and expressed in terms such as *"From time I started working in a hospital, I do not use traditional medicine."* These categories are therefore accepted and used by those with an introduction to formal education and exposure to some training within the clinical sector, and clung to more strongly depending on circumstance and agenda. The response of lower cadre HCWs to the researcher can also not be ignored, in terms of how she was perceived, what it was felt she wanted to hear and the effects of a power imbalance between a foreign, policy level researcher and a community health worker.

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[217] During the fieldwork period, discussions were taking place between government and key donors supporting their health program about ways in which to address the significant gaps in capacity (outlined in Chapter 4). One key donor proposal was to eliminate the 'ceiling' on advancement that paramedic COs and MAs face, unable to complete full Medical Officer training, in addition to introducing some other possible 'fast track' training options for lower level staff. GoM, however, were resolute that such options would not be explored. This debate is continuing at the time of submission of this thesis.

Lay perceptions of medical knowledge and awareness of the staff medical hierarchy evoked some subtly conflicting sentiments. Revealed as a common theme was that the care-seeking public, particularly in rural areas, tended to regard all staff members at a health centre as some kind of 'doctors,' regardless of their actual title or position.[218] It was therefore not uncommon to seize an opportunity to discuss health concerns and questions with a passing health worker, regardless of whether they were talking to a qualified nurse or a ward attendant. In addition however, some awareness of such a staff hierarchy was revealed in that they were reported to in fact be *freer* to talk with those *lower* cadre staff members, as they felt less intimidated and more able to talk openly. This apparent contradiction between regarding all staff as doctors, yet feeling freer with those perceived to be 'lower' in status, could be interpreted as displaying the more relational effects of the power/knowledge imbalance on peoples' behaviour. While keen to access medical knowledge about their condition, yet feeling too intimidated in a clinical consultation to really ask, community members would feel more confident and comfortable talking to those less well educated staff members, but whom they felt had some medical status or training. Medical knowledge was nonetheless respected and reified in both scenarios, but the symbolic and actual power of a clinician's consultation was enough to deter some patients, or lead them to seek better communication elsewhere. Once again, knowledge is seen as both barrier and enabler.

As argued in the introduction, in Malawi the biomedical model is an introduced paradigm that has worked very readily with a pre-existing acceptance of status and hierarchy. This status may be either ascribed/inherited - as for traditional chiefs - or learnt/acquired - as by some traditional healers - but once attained, it is a defining identity and the key to one's social mobility, defining to where one may move and justifying one's ability to do so. In an environment where people are often keen to progress, yet shy of attracting grievances and jealousy by gaining status through inappropriately competitive means,[219] education is a sanctioned means by which to

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[218] In fact, it was observed by one clinical officer that the vast majority of Malawians have never been treated by a proper 'doctor' in their lives and certainly do not distinguish between the paramedics they regularly meet and the doctors who they don't.

[219] As demonstrated in the widespread fear of and reported use of witchcraft and sorcery, to disable those who have done better than others.

advance oneself. It is usefully mediated through a strict and controlled hierarchy, which limits overt or shameless advancement. It serves the needs of those at very top (e.g., policy makers and programme managers), and those at bottom (e.g., WAs and HSAs), in distinguishing themselves from the wider community and having a valid role and 'status.'

Such a system relies on an opposition between informal, local understandings and formal, taught knowledge, as embodied in orthodox TB control principles. This opposition is also used to avoid the presentation and use of ideas and findings, which are construed as non-scientific (e.g., those identified through medical anthropologic or sociologic means). Science and technology thus become used (inappropriately) almost as ideology, to legitimate and justify actions and decisions which may in fact be *non-*technical, but which will be presented as such – to avoid popular engagement and debate. In Scambler's terms, this therefore becomes "politically effective legitimation for the undemocratic exercise of power" (2002:128).

However, in practice, and particularly in terms of peoples' choices and behaviour, such an opposition, while used as a good concept to 'think with,' is largely lost to pragmatic needs in the search for cure or care – wherever that may be found. The disease control paradigm holds 'lay belief' in opposition to it, almost as a bounded untouchable opposed kingdom. It largely fails – or chooses not – to recognize that interaction between the apparently separate bounded worlds of community and clinic influences the perceptions and beliefs held within each. These are fluid, 'living' constructions, as clearly seen in the development of the construct 'TB of the bones,' or peoples' reinforced belief in witchcraft owing to TB's diagnostic failures. Inconsistencies in both lay and HCW responses betray fluidity and pragmatism, when considering what people *actually do* and why. The dominant biomedical approach, however, typically will not reveal these inconsistencies, owing to a limited research agenda that continues to maintain a social/clinical opposition, that is as false as that it ascribes to the Malawian care-seeking context.

7.3 KNOWLEDGE, POWER AND TB CONTROL
While these issues have been teased out into separate themes of knowledge, education, hierarchy and communication, it can be seen in the accompanying

discussion that these elements are intertwined and inseparable, all of them illustrating the discursive effects of power and authority in areas relevant to TB control – even if little acknowledged.

It is seen that the traditional dichotomy of medical knowledge over traditional beliefs, and the privileging of clinical science as a 'stock' of power to be controlled, protected and used as symbolic capital is often played out in peoples' behaviour and articulated discursively in their own reported perceptions and understandings. As in Paul Willis' (1977), Stuart Hampshire's (1999) and Arjun Appadurai's (2004) terms, people articulate their own inequalities, or conceived possibilities of action. It can also be seen that a situation of biomedical domination, maintained and reproduced through a strict medical hierarchy, contributes to the maintenance of a status quo of control, largely in the hands of clinicians and health policy makers.[220] In the case of Malawi NTP staff, this almost religious belief in the hierarchy of medical knowledge is felt by technicians to be in the interests of potential patients, as a measure to preserve the real benefits of medical attention and treatment. Flexibility is seen as weakness, which might render the programme vulnerable to loss of control and more dramatic challenges, such as those proposed in health sector reform.

Conversely, however, such a single disciplinary stance actually ends up obscuring the need for, and likelihood of, any critical reflection, leading to improvement. It may also be interpreted as self-interested protectionism and attachment to the medical agenda, rather than a defence of patient needs. Some would argue that lack of change suits those in authority – as indeed it does in the developed world, where clinicians just as guardedly protect their territory. Protectionism and retreat into technical TB control is rooted in a scientific rationalism that provides legitimation, beyond challenge: "Doctors' trump card in this on-going struggle with policy makers is their hold over life and death. Unless managers and governments wish to become directly responsible for life and death decisions, doctors will continue to retain the upper hand in any contest with the advocates of efficiency and effectiveness." (Hunter in Purdy and Banks 2001: 170)

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[220] Policy makers in the health field are usually clinicians themselves, for very similar reasons of clinical credentials and protecting the 'field.'

It is therefore a sad irony that such a stance may be undertaken with genuine conviction that is in the patient and public interest, yet, in so doing, makes great assumptions about those interests, and neglects or dismisses the range of tools that could be used to learn more about them. This research has illustrated the relational possibilities of power and knowledge, and revealed a complexity of contradictions in practice, which the dominant medical paradigm and its associated research methods have traditionally tended to ignore or failed to recognize: the compromised Health Surveillance Assistants, caught between clinic and community, respected in rural areas and ignored in urban ones; co-existing, the public perception that all workers at a health centre have some medical training or ability and are able to offer good advice, regardless of cadre, or in explicit preference to the intimidating doctor; the significant development of 'TB of the bones' – completely unnoticed by the NTP establishment, but a widely accepted health construct, amongst both lay people and frontline practitioners, and with important implications; the varied and inconsistent care-seeking paths of the poor, balancing their health needs with care costs, and underwritten by asymmetries of power, knowledge and resources.

The fact that such complexity has commonly been excluded from the policy making agenda in planning for health and disease control is rooted in the same opposition between the clinical and the social that is promoted and pervades every level of practice – from that of a Health Surveillance Assistant in Nathenje to that of the National TB Programme in Lilongwe. In another guise, such an opposition is also framed through a dichotomy between the national/institutional and the local/historical, which is infrequently bridged. The findings presented here show these oppositions to be both practically and theoretically unhelpful.

Practically, inefficiency is seen in the limited adaptation of the NTP to a very fluid environment, fostered by a lack of systematic attention to those circumstances, that could enable informed innovative responses, rather than continuing poor and deteriorating TB outcomes.

Theoretically, the recognition of the socially constructed nature of knowledge points to the value of a closer relationship between the medical and anthropological, rather than conflict between them. In any setting, medicine is locally and historically

situated and constructed, as shown in the findings. Social science methods, informed by anthropology, may usefully highlight the areas of interface, which can then inform policy responses – medical and otherwise, better designed to suit the needs of ordinary people. Rather than a one-way channel for medical knowledge to be disseminated to citizens – and indeed frontline health workers – a two-way exchange needs to be enabled, that also channels contextual information to policy makers and providers and credentialises local level voices and experience, thereby levelling the (playing) 'field' and redrawing the 'terms of recognition' (Appadurai 2004).

CHAPTER 8: CONCLUSION

INTRODUCTION

In his introduction to the Bangkok International AIDS conference on July 15th 2004, former South African President Nelson Mandela told the international audience that it was battling a two-headed monster, *"The world has made defeating AIDS a top priority. This is a blessing, but TB remains ignored,"* he said.

This thesis has aimed to give some overdue attention to the massive global problem of TB. It has utilised an in-depth case study of a country bearing a significant and worsening TB burden, yet with a well-functioning 'model' National TB Programme, to investigate and highlight areas of practical and policy weakness, and then to try and understand why such weaknesses have persisted, largely undetected.

In order to do this, a range of predominantly qualitative tools were chosen, to build upon the more routinely used quantitative operational research methods and available statistical data. This was intended to further enhance our understanding of TB's enduring impact in Malawi – an understanding that has previously been limited by the range of questions and tools utilised. Through the use of a social analytic approach, hitherto unidentified obstacles within the system have been detected and, in addition, a key question has been raised as to why such an approach has not been credentialised by the TB community before now, thereby allowing the persistence of such obstacles.

It is proposed that TB control has developed and, until recently, thrived in a biomedical and biologically constructed policy environment for health, where medical knowledge is valued over and above 'common' knowledge. This has enabled attention to focus on the individual behaviour and responses of those patients in clinical care, judged against exacting medical criteria, with little attention to how patients get to care, and what may shape or structure their behaviour and responses throughout the illness experience. Development-oriented solutions of 'empowerment' and health education have even fitted within this same paradigm, with the emphasis placed on everyday people to equip themselves with the information and knowledge to act appropriately and interact with their providers productively. The globally promoted model of disease control for TB rests on these principles, emphasising early

care seeking, efficient history taking and diagnosis, and adherence to treatment, with the expectation on the patient to do the right thing at each of these stages. It is only with the worsening outcome indicators of recent years - despite promulgation of the internationally endorsed DOTS strategy for TB control - that the need to critically examine this dominant model in practice has become clearer.

This research accepts that ordinary people have colluded with modern medics (and indeed traditional healers) to allow the dominance of their 'gaze,' owing both to the symbolic capital of clinical knowledge and also to the very real benefits of treatment. However, where positive outcomes and the benefits of that treatment are declining and, arguably, the strength of that clinical 'gaze' is itself obstructing any critical reflection and change, such a situation merits re-evaluation. In order to do this, the sidelined voices and experiences of ordinary people should be heard, so that practical service responses can be appropriately designed and the terms of access and encounter changed, redistributing 'control' to those who are actually at risk. In this way, access to the clinical 'gaze' will be promoted, but the very nature of that gaze may be altered, with both health policy makers and frontline providers encouraged to look beyond both the sick individual and their clinical lens.

DISCUSSION

In the Malawian context, it is shown that the common construction of indigenous beliefs as 'barriers' to correct care-seeking behaviour furthers a misleading "culturalist' discourse (Seidel and Vidal 1997), that simplistically blames the victim for making uninformed or ill-conceived decisions and reduces the attention paid to the *range* of barriers to peoples' care-seeking for TB symptoms. This research suggests that such an adversarial and simplistic relationship, seen in the opposition of 'correct' medical knowledge and 'incorrect' lay beliefs, should be rejected. Instead there is a need to investigate and record the range of local knowledges in existence, amongst both ordinary people and health care providers, in addition to identifying all influential factors, which may affect a sick individual's care-seeking actions. Some of these are indeed cultural or health-related perceptions and understandings, including social stigma, traditional beliefs or gendered norms of behaviour. Other factors are plainly material, including physical accessibility, distance, transport and (opportunity)

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costs. Still others are organisational, related to responses (or lack thereof) on the part of the health provider or programme.

In terms of peoples' health-related perceptions, this thesis finds that, contrary to prevailing assumptions, some may actually be complementary or used as allies in the fight against TB (e.g., general healthy practices of avoiding smoking and alcohol when suffering from TB). Others may be located in unexpected constituencies, such as those that are in fact promoted and reinforced by the medical establishment, rather than by community members (e.g., HCWs' role in perpetuating the myths of 'no sex, we're on TB treatment' and reinforcing the perception that HIV/TB are one and the same disease). It is thus imperative that the full range of understandings is identified (across all relevant groupings), and that through an appreciation of such diversity, appropriate interventions may be designed, which involve, target and work with relevant populations – whether traditional healers, health care workers or urban and rural lay communities.

In promoting an understanding of the local context that looks beyond the culturalist paradigm, this investigation also explored the multi-factorial barriers that both limit or enable an individual's ability to seek care for their health problems. Despite the considerable material challenges, it has been found that people typically seek care at the allopathic services in the first instance. It is therefore critical to *get this first response right*. Patients are actively *looking for help* and it is usually when the health service has failed them that they turn to traditional practitioners to address their needs and answer their queries (i.e., to find the cause of their illness). The research has found therefore that sick people do not just visit traditional healers owing to their 'beliefs,' but owing to the organisational and systemic barriers, which the current health service, in interaction with people's socio-economic environment, presents. Individuals are agents on a pragmatic care-seeking path and it is more often the *systemic* barriers that fuel a need for socio-cultural alternatives, rather than the reverse (e.g., HCWs' role in disseminating the notion of 'TB of the bones'; the lengthy diagnostic process with its many costs and considerable hurdles even to the keenest care-seeker; the rushed interaction between doctor and patient, inhibited by the 'clinical gaze,' lacking in privacy, and without a verbal diagnosis; the ill-equipped

HSAs, too intimidated to do their jobs in the urban squatter settlements which provide classic conditions for TB to spread).

Globally and nationally, the increase in Smear negative (Sm-) pulmonary TB is also shown to need urgent recognition and response. It was a quietly pervasive theme throughout the findings, seen in the striking phenomenon of 'TB of the bones,' the reports of more people dying and increased treatment failures, the instances where TB suspects are told 'you have no TB, go home.' A focus on Sm- TB in national (i.e., training of HCWs) and in global policy (i.e., free treatment advocated for Sm- patients, not just Sm+ patients) will be necessary to assist and target providers and policy makers, as much as potential patients.

In general, this research supports an increased focus in TB control on *programmers* and *providers*, in addition to the more usual emphasis on patients. For providers, attention must be paid to the healing encounter, as this is where it is hoped clinicians will identify TB suspects and ensure they are started on the appropriate diagnostic and treatment path for TB. It is an essential part of the government health service provision, more directly under the influence of the NTP, and is the interface between patient and provider, upon which many assumptions in TB control have been shown to rest. However, findings demonstrate that, while the emphasis in the allopathic encounter is placed on the patient to be forthcoming, descriptive and detailed in explanation of their problems and care-seeking history, so that the clinician may make an accurate working diagnosis, this is limited by several obstacles.

One is the enormous burden of work under which Malawian government clinicians operate. Their available time with each patient is minimal, their consulting environment is poor, their remuneration and motivation is generally low. Another is the perceived and actual power imbalance between patient and provider, already described, and classically illustrated in Foucault's use of *le regard* or 'the gaze.' This is compounded by the cultural tendency – as demonstrated in traditional healing practice – for patients to remain silent during diagnosis, leaving everything in the hands of the provider and without questioning what is said. This is particularly

exacerbated for poor and less educated women, for whom the power imbalance is often greatest.[221]

In addition, patients' only forms of agency or resistance – their so-called weapons of the weak (Scott 1987) – may arguably and ironically contribute to the maintenance of TB in their communities. Their resistance is shown in withholding information (which might otherwise lead them to start the TB diagnostic path) from clinicians in the healing encounter. It is also shown in seeking care with traditional providers, when they have been failed by the health service, but still seek a cure. If the consultation follows a pattern of poor communication and history taking, or the diagnostic process is halted inconclusively with the clinician's statement that 'there's nothing wrong,' as is often the case with a smear negative sputum result, the patient will be lost from the system. As their illness continues, having failed to find help at a doctor's, they will likely choose to seek care *and explanation* for their continuing problems with a traditional healer, where answers may be found.

The orthodox sociological proposition of a balanced healing encounter is clearly undermined in the Malawian setting, as are the conventional 'remedies' to any failed interaction – typically information provision and the assumed result of an empowered patient. Some theoretical critiques assert that equipping patients with appropriate information is merely furthering the dominance of the medicalisation paradigm, giving credence to the value of clinical knowledge over and above the experience and language of the patients (Lupton 1997). In Malawi, however, the range of other factors clearly constrains the goal of positive interpersonal communication, even before the notion of increased information to empower patients may be tested.

The implications of such findings for TB may thus be apparent, with possible impacts at *each stage* of the diagnostic pathway, from first contact with a practitioner to the receipt of sputum results further down the line. As a result, for those in National Programmes, 'TB control' should not implicitly equate with a Programme's control

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[221] While this research has started the process by drawing attention to the importance of the healing encounter in Malawi and the many factors affecting the communication between patients and provider, it is felt that much scope remains for much more detailed investigations to follow. It is suggested that an important follow up might seek to explore the influence of gender, socio-economic status, educational level and location on both provider attitudes to patients and of patients to providers.

over TB suspects and patients, as seen in the longstanding preoccupation with treatment adherence. Attention must also be paid to getting TB suspects to diagnosis in the first place.

As a disease of poverty, the impacts of that poverty on sick individuals' ability to both access and maintain treatment are considerable, as demonstrated in the list of negative variables presented in both urban and rural poor settings: distance, transport, income lost, etc. However, the current model of TB control is presented as though existing in a social, economic and political vacuum. It thrives on a simplistic model of biomedicine and the individual, and uses such a model to reinforce and reproduce itself (i.e., by threatening that if such control is lost, the TB battle will also be lost). In fact, both biomedicine and the individual are situated in realities that reflect both local specificities and global political economic relations. Those working in TB control could embrace and utilize such connections more effectively than current practice indicates. An acknowledgement of the impact of poverty on TB – in its multiple dimensions – will enable both the design and testing of innovative service delivery interventions and the adoption of an advocacy role on the part of policy makers, in order to try and influence some of the contributors to this fundamental problem (e.g., the use of active case-detection, particularly in poor areas; partnerships with other providers, both formal and informal;[222] holistic health promotion campaigns utilising appropriate media and targeted at the needs of different population groups; multi-sectoral initiatives that address cross-cutting issues of poverty, health and development).

IMPLICATIONS

As this study has shown, a range of material, social, epidemiological and organisational obstacles exist in Malawi, some of which were hitherto unknown, but all of which are impacting the efficacy of conventional TB control. This thesis serves to document and discuss them in-depth, leading to some practical service-delivery recommendations. In addition, however, this research proposes that the previous lack of discussion of such issues has resulted from a dogmatic and uncritical adherence to DOTS that has been reinforced by a dominant medical epistemology in disease

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[222] For instance, private allopathic, traditional healers, drug vendors, etc.

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control. Based on the evidence gathered, it is strongly argued that this prevailing epistemological dominance has actually delayed recognition and discussion of the range of obstacles to TB control, prevented detection of some specific problems, and averted any re-evaluation and response on the part of policy makers and programme deliverers.

Policy making is often regarded uncritically as a rational, staged process or cycle of development, implementation and assessment (Shore and Wright 1997), rather than the more disordered and politicised area that it is, being devised and used by diverse individuals guided by particular influences and ideologies. The question of how a given discourse becomes dominant and ultimately 'policy' is therefore a complex one. This thesis illustrates how DOTS for TB control has utilised the dominant medical discourse to exclude and de-legitimise alternate methods to support TB control. The supposedly 'neutral' language of science is used to frame policy and disguise any interests at stake, through the 'rational' but exclusively expert language of medical science. The closed linear model of policy development is embraced, keeping it in the hands of self-proclaimed policy makers (themselves legitimised by dominant medical discourse):

"Policies work as instruments of governance, as ideological vehicles, and as agents for constructing subjectivities and organising people within systems of power and authority" (ibid: 35).

This thesis attempts to bring those typically excluded from such formal policy-making processes into the discussion, so that subsequent policy is better negotiated, designed and influenced to match the needs and expectations of its supposed beneficiaries. It presents the voices, concerns and experiences of those most at risk from TB – in urban squatter settlements, rural poor villages and at the frontline of health service delivery. However, the process of making 'their' knowledge into public knowledge, such that it *"...enters the public collective realm..."* (Baert, 1998:33), and therefore, has the ability to influence and precipitate change, is not an established one. Indeed, it is one that has been limited by the biomedical model of practice that has historically privileged medical knowledge alone and avoided any systematic social scientific exploration of the contexts in which TB occurs. Conventional constructions of disease have been favoured, which advocate that control of the individual is sufficient to maintain control of the disease.

As findings have shown, in Malawi the problems related to TB have been changing, as have local responses, and therefore, it is argued, so should the prevailing approach to TB control. Presently, there is little recognition amongst the TB community that striving to maintain 'control,' utilizing biomedical means alone, actually precludes gaining an understanding of the context in which one is operating. Such an understanding could in fact be used to promote change and, potentially, *better* 'control,' rather than the mythically feared chaos that might ensue.[223] This would not discount the epidemiological principles on which classic TB control rests, but it would recognise that the approach should no longer be directed by those principles alone, to the exclusion of other available evidence, and other available methodologies. 'Control' should, in effect, be *shared* more equitably with TB suspects and sufferers themselves. This would be through the range of research methods that are used to monitor and inform programmes, and indeed the resulting service responses and institutional mechanisms that would better enable people to access diagnosis and manage any resulting treatment on their own terms and in light of their needs.

As Baert has written (1998), when faced with unanticipated change, new theories are generated. This has been proven at the local level in Malawi, with instances such as the development of 'TB of the bones.' It is, however, yet to be adequately demonstrated at the policy level, and this lack of adaptation has contributed to worsening TB outcomes year on recent year.

For a disease of poverty, a more equitable approach to TB control – shared by providers with their patients, and by clinicians with social scientists – is potentially a unique vehicle for change, if it can seize the opportunity to work with other disease control and poverty issues as part of a global movement for health and development. As such, it needs to advocate for this position, building on the strength of its medical foundations but also utilising innovative and systematic social science research to highlight the inter-related importance of poverty, disease control, health and

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[223] This attitude was clearly reflected in early responses by TB specialists to the potential provision of antiretroviral therapy in Malawi (Harries, Nyangulu et al. 2001), where the adherence of patients to HIV therapy was questioned and the lack of control of such patients was predicted to lead to antiretroviral 'anarchy.'

development on the global stage, but also, to use country specific findings in the adaptation of national DOTS programmes that then bring innovative and improved service delivery to those at the TB frontline – both potential patients and providers.

APPENDIX 1: Map of Malawi

Nathenje market place (1) – actors and crowd

Nathenje Market place (2) – crowd watching
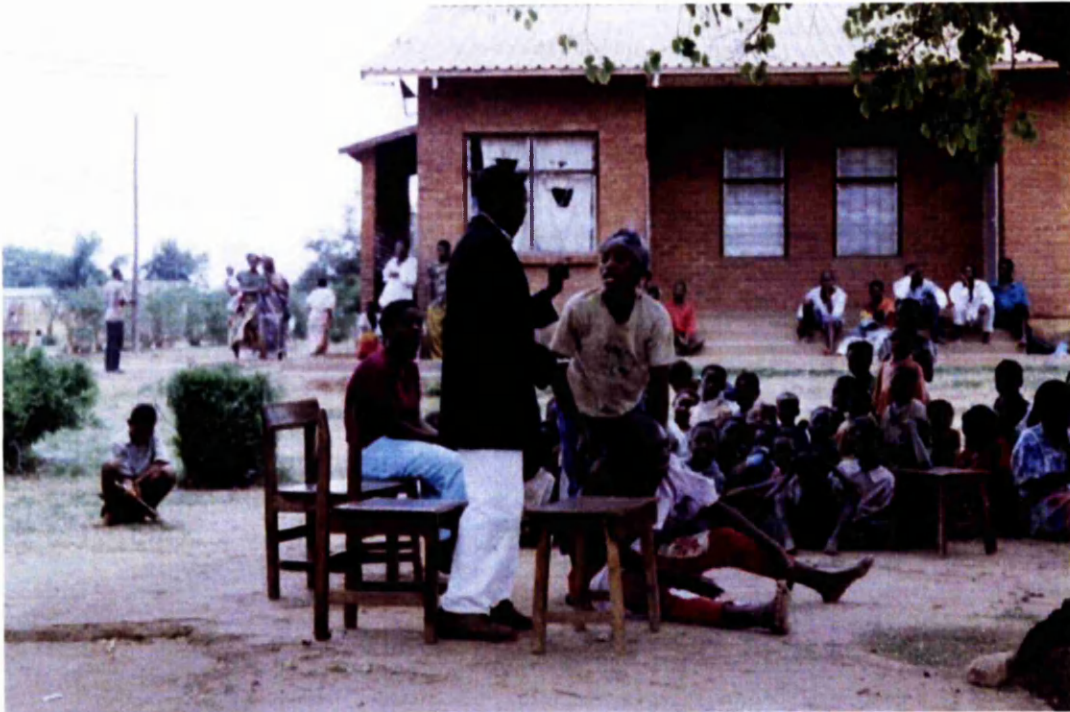
Nathenje health center (3) – actors

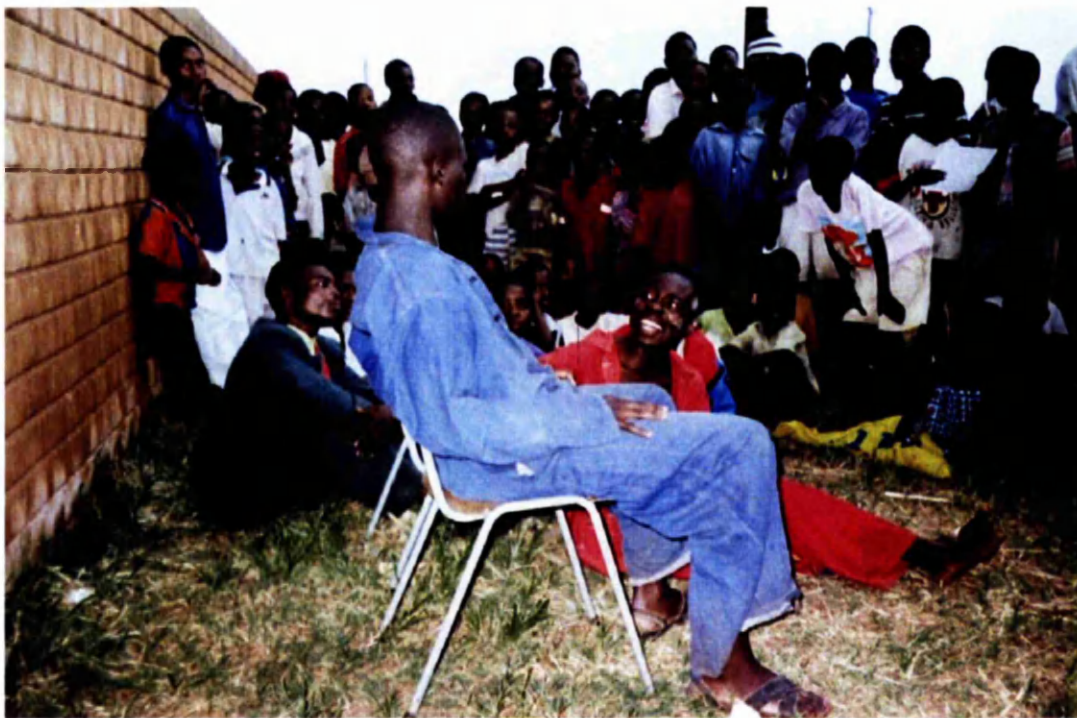Nathenje health centre (4) – crowd watching (mainly mothers)

Ngwenya thoroughfare (1) – play in progesss

Ngwenya throughfare (2) – crowd watches

Ngwenya (3) – crowd starts to gather (despite rain clouds), with chiefs onlooking from chairs

Ngwenya (4) – actors and crowd

APPENDIX 3: KAP Survey Questionnaire

Q. no	QUESTION	Instruction	Codes	Response options
1.	Sex?		SEX	1. Female 2. Male
2.	Age in years? **Zaka zakubadwa?**	*Exclude if < 16 years*	AGE	_ _ yrs
3.	Current marital status? **Muli pa banja?**		MARITAL	1. Single, never married 2. Married/non formal union 3. Divorced/separated 4. Widowed 99. Not known
4.	Ethnic group? **Mtundu wanu ndi chiyani?** **Ndinu a mtundu wanji?**	*Refer to list*	ETHNIC	1. Chewa 2. Nyanja 3. Tumbuka 4. Yao 5. Lomwe 6. Sena 7. Tonga 8. Ngoni 9. Ngonde 10. Other Malawian sp:_____ 11. Asian 12. Foreigner 99. Not known
5.	How far from the BOMA/district centre do you live?		DISTANCE	_ _ _ km
6.	Have you ever heard of TB? **Kodi munamvapo za matenda a TB?**	*If answer is 'no,' jump to no.28*	HEARDTB	1. Yes 2. No
7.	How did you hear about TB? *(From what sources?)* **Munamva bwanji za matenda a (TB)?**	*Respondent can give <u>more than one</u> answer*	HOWHEAR	1. Relative who was a patient 2. Friend who was a patient 3. Informal chat 4. Health talk 5. Radio 6. TV 7. Newspaper or magazine 8. Poster 9. Leaflet 10. Drama

				11. HSA 12. Traditional healer 13. Promotional event 14. Other sp: 99. Not known
8.	Can you tell me the signs and symptoms of TB? **Kodi mungandiuzepo zizindikiro za matenda a TB?**	*Respondent can give more than one answer*	TBSIGNS	1. Persistent cough 2. Persistent cough with sputum (productive cough) 3. Weakness or tiredness 4. Loss of breath 5. Loss of weight 6. Loss of appetite 7. Bloody sputum 8. Sweating at night 9. Fever/'malungo' 10. Other sp:_____ 99. Not known
9.	How is TB transmitted? How does somebody catch TB? **Kodi TB imafala bwanji?**	*Respondent can give more than one answer*	TBCATCH	1. Droplet infection or a TB patient coughing/spitting 2. Overcrowding 3. Poor ventilation 4. Unboiled milk 5. Sexual activity 6. Infected meat 7. Treading barefoot on infected spit 8. Breaking sexual taboos 9. Smoking tobacco 10. Sharing utensils with a TB patient 11. Other sp:_____ 99. Not known
10.	How is a TB diagnosis made at the health facility? **Kodi akuchipatala amadziwa bwanji kuti munthu akudwala TB?**	*Respondent can give more than one answer*	TBDIAG	1. Testing sputum 2. X-ray 3. Clinical examination 4. Other sp:_____ 99. Not known
11.	Can TB be treated? **Kodi TB imachizika?**	*If answer is '2,' jump to no. 13*	TBTREAT	1. Yes 2. No 99. Not known
12.	How can it be treated? **Imachizidwa bwanji?**		HOWTREAT	1. Taking a course of drugs from the health centre 2. Self treating with bought medicine 3. Traditional medicine

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				4. Other sp: 99. Not known
13.	Can TB be cured? **Kodi munthu wodwala TB amachila?**		TBCURE	1. Yes 2. No 99. Not known
14.	Have you heard of HIV/AIDS? **Kodi munamvapo za HIV/Edzi?**	*If answer is '2' jump to no.16*	HIVAIDS	1. Yes 2. No
15.	Do you think someone with TB also has HIV/AIDS? (Do you think that TB and HIV the same disease?) **Kodi wodwala TB ndiye kuti alinso ndi Edzi?**		TBHIV	1. Yes 2. No 3. Probably 4. Not sure 99. Not known
16.	Have you ever had TB yourself? **Kodi munayamba mwadwalapo TB?**	*If answer is '2' jump to no.18*	TBPATIENT	1. Yes 2. No 99. Not known
17.	Did you receive treatment for TB? **Munalandira mankhwala/chithandizo cha TB?**		RECTREAT	1. Yes 2. No 99. Not known
18.	Have you ever known anyone with TB? **Kodi mumadziwapo munthu wina yemwe anadwalapo TB?**	*If response is '2,' jump to no.20*	TBCLOSE	1. Yes 2. No 99. Not known
19.	Who was this person/people? **Kodi munthu ameneyu ndani wanu?**	*Respondent can give more than one answer*	TBWHO	1. Immediate family 2. Relative 3. Friend 4. Colleague 5. Same village 6. Other sp: ————————
20.	At your local health facility, have you seen any information or educational materials about TB? **Kodi munaonapo uthenga uli wonse wa TB kuchipatala chakwanu kuno?**	*If response is '2,' jump to Q23*	SEENMAT	1. Yes 2. No 99. Not known
21.	What materials have you seen? **Uthengawo unalembedwa potani?**	*Respondent can give more than one answer*	WHATMAT	1. Poster 2. Calendar 3. Leaflet 4. Other sp:_____

22.	Did information from these materials help you to understand about TB? **Kodi uthengawo unakuthandizani kuti mumvetse za matenda a TB?**		HELPMAT	1. Yes 2. No 99. Not known
23.	Have you ever heard health staff talk or give advice about TB? **Kodi munamvapo adokotala akuphunzitsa za TB?**		TBADVICE	1. Yes 2. No 99. Not known
24.	Do you think that TB patients receiving treatment should smoke? **Kodi wodwala TB amene akulandira mankhwala akhoza kusuta fodya?**		TBSMOKE	1. Yes 2. No 99. Not known
25.	Do you think that TB patients receiving treatment should drink? **Kodi wodwala TB amene akulandira mankhwala akhoza kumwa mowa?**		TBDRINK	1. Yes 2. No 99. Not known
26.	Do you think that TB patients receiving treatment should have sexual relations? **Kodi wodwala TB amene akulandira mankhwala akhoza kugonana ndi mwamuna kapena mkazi wake?**	*If response is '1' or '99,' jump to question 28.*	TBSEX	1. Yes 2. No 99. Not known
27.	Where or from whom did you hear this? (that TB patients should not have sex) **Kodi munamva kuti za nkhani imeneyi?**	*Respondent can give more than one answer*	SEXADVICE	1. Health centre staff 2. HSA 3. A TB patient 4. Family member 5. Friend 6. In the community 7. Traditional healer 8. Other sp: _____ 99. Not known
28.	What is your relationship to the head of the house hold? **Ndani amene ali mutu wa pabanja panu?**		HOUSHEAD	1. Myself 2. Spouse 3. Son/daughter 4. Grandchild 5. Father/mother 6. Other relation 7. Servant 8. Not related

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29.	Has the head of the household attended school? **Kodi anapitako kusukulu?**	*If response is '2' end here.*	HEADSCH	3. Yes 1. No 99. Not known
30.	What was the highest class that they completed? **Nanga munalekezera pati?**		HEADCLASS	1. Standard 1-4 2. Standard 5-8 3. JCE 4. MSCE 5. Above MSCE sp:_____

Ndathokoza kwambiri!
Thank you very much!

APPENDIX 4 : List of Abbreviations/Acronyms

AFB	Acid Fast Bacillus
AIDS	Acquired Immuno Deficiency Syndrome
ARV	Anti-retroviral therapy
BCG	Bacillus Calmette-Guérin Vaccine
CBO	Community-based organizations
CHAM	Christian Health Association of Malawi
CHSU	Community Health Sciences Unit
CHW	Community Health Worker
CO	Clinical Officer
DFID	Department for International Development, UK
DHMT	District Health Management Team
DHO	District Health Officer
DOTS	Direct Observed Treatment, Short-Course
DOT	Directly observed therapy/treatment
DTO	District Tuberculosis Officer
EA	Enumeration area
EHP	Essential Health Package
EPTB	Extra-pulmonary TB
FGD	Focus group discussion
GDEP	Global DOTS Expansion Plan
GDP	Gross domestic product
GFATM	Global Fund to fight AIDS, TB and Malaria
GNP	Gross national product
GOM	Government of the Republic Malawi
HC	Health centre
HCW	Health care worker
HIV	Human Immunodeficiency Virus
HSA	Health Surveillance Assistant
HSR	Health sector reform
IEC	Information, education, communication
ILO	International Labour Organisation
IMF	International Monetary Fund
IPCC	Inter-personal communication and counselling
IUATLD	International Union Against Tuberculosis and Lung Disease
KAP	Knowledge, attitudes and practices
KNCV	Royal Netherlands Tuberculosis Association
MA	Medical assistant
MCSE	Malawi Certificate of Secondary Education
MDR	Multi-drug resistant (TB)
MDHS	Malawi Demographic and Health Survey
MK	Malawi kwacha (currency)
MO	Medical Officer
MOHP	Ministry of Health and Population of Malawi
MOLG	Ministry of Local Government
NAC	National AIDS Commission
NGO	Non Governmental Organisation
NORAD	Norwegian Agency for Development Cooperation
NTP	National Tuberculosis Control Programme

PHC	Primary health care
PMG	Programme Management Group
PRSP	Poverty Reduction Strategy Paper
PS	Principal Secretary
PSG	Programme Steering Group
PTB	Pulmonary TB
SM+	Smear-positive
SM-	Smear-negative
STI	Sexually Transmitted Infections
SSA	Sub-Saharan Africa
SWAp	Sector wide approach
TA	Traditional authority
TB	Tuberculosis
TH	Traditional healer
TBA	Traditional birth attendant
VCT	Voluntary counseling and testing
WB	World Bank
WHA	World Health Assembly
WHO	World Health Organization

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