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The economic burden of illness for households

A review of cost of illness and coping strategy studies focusing on malaria, tuberculosis and HIV/AIDS

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"A local Bangladeshi synonym for TB is Rajer rog – King's disease – since it is a disease that only Kings can afford to suffer"
(Croft & Croft, 1998: 253).

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Preface

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Contents

1. INTRODUCTION: PURPOSE & SCOPE OF THE PAPER

1. Ill-health and the household costs of illness can undermine livelihoods and contribute to impoverishment, processes that have been brought into sharper focus by the social and economic impact of the HIV/AIDS epidemic (Ainsworth et al., 1998; Barnett & Whiteside, 2001; World Bank, 1997). Concerns about the links between ill-health and impoverishment have placed health at the centre of development agencies' poverty reduction targets and strategies (DFID, 1999; World Bank, 2000) and increased the weight of arguments for substantial health sector investments to improve access for the world's poorest people (WHO 2001). People's ability to access health care at low cost is therefore central to reducing poverty as well as improving health.

2. Household interactions with health services, and the costs that they bear from illness and treatment, are also central to the performance of health care interventions, particularly their coverage and equity implications. The existing quality weaknesses and cost burdens of health care may deter or delay health care utilisation or promote use of less effective health care sources or practices – particularly by the poor (Bloom et al., 2000; Sauerborn et al., 1996a/b). Health services, as a result, are frequently ineffective in reaching the poor, generate less benefit for the poor than the rich, and impose regressive cost burdens (Fabricant et al., 1999). For example, two recent reviews of the relationship between tuberculosis (TB) and poverty (Nhlema, 2003), and malaria and poverty (Worrall et al., 2002), found that poor households more frequently opted for care outside the modern sector than better off households, and that the cost of TB or malaria treatment, as well as distance to health facilities, were significant barriers to access for poor households (Nhlema et al., 2003; Worrall et al., 2002). To improve the poor's access to TB or malaria interventions, both reports point out that policy-makers need to better understand patient barriers to accessing and using treatment which include the economic burdens that both diseases impose on poor households' budgets and their ability to work (Kamolratanakul et al, 1999; Needham & Bowman et al, 2003; Nhlema et al., 2003; Worrall et al., 2002).

3. The aim of this paper is to review and summarise studies that have measured the economic costs and consequences of illness for patients and their families, focusing on malaria, tuberculosis and HIV/AIDS. This was the broad remit of the DCPP terms of reference, which more specifically requested a review of studies that have examined:

- The costs of illness for households, including both direct (expenditure) costs and indirect (wage and production) costs, and focusing particularly on malaria, tuberculosis and HIV/AIDS;
- Household responses to these illness costs (borrowing and asset strategies etc..);
- The impact of illness costs on household livelihoods and processes of impoverishment;
- Plus any evidence or discussion among studies that indicate health service characteristics exacerbate or mitigate illness costs for poor households.

4. Figure 1 summarises the main variables relevant to the analysis of illness costs and their social and economic consequences at the household level. The framework derives from several studies that have investigated the household costs of illness, coping strategies and their consequences for household livelihoods (Sauerborn et al., 1996b; Russell, 1996; Russell 2001; Wilkes, 1997) but the clear format presented here is copied directly from a recent review paper on a similar topic (McIntyre & Thiede, 2003). The

starting point is the presence and perception of illness, in response to which the sick individual and other members of the household make decisions about whether to seek treatment or not, and from which source, within the context of intra-household decision-making processes, resource constraints and resource allocation priorities. Some illnesses and some individuals may be given priority over others, for example more resources may go to treating economically active members of the household.

>> Figure 1: Framework

5. The framework helps to illustrate the main focus of the paper, which is on the costs of illness for households (section 4) and the asset strategies that they mobilise to cope with illness costs (section 5). The implications of these illness costs and asset strategies for household asset portfolios and processes of impoverishment are also reviewed, although evidence on the links between illness and impoverishment is limited and scattered.

6. In the analysis of illness costs in section 4, the paper also attempts to include any evidence or discussion about the links between household illness costs and health service characteristics that exacerbate or mitigate these costs, for example aspects of health service delivery, quality and charging that influence access, treatment preferences and costs for patients.

7. The units of analysis in the cost of illness studies reviewed included cost per illness episode, cost per patient, or the household cost of illness. The household is preferred as a unit of analysis for assessing the economic costs and consequences of illness, because decisions about treatment are based on negotiations within the household (but not necessarily from an equal bargaining position), the costs of illness do not only fall on the sick but on other household members who care for the sick and accompany them to get treatment, and because the costs of illness fall on the household budget which has implications for the resources available to other members (Berman et al., 1994; Sauerborn et al., 1995).

8. In this paper, direct costs of illness refer to all household expenditures linked with seeking and obtaining treatment, including medical and non-medical expenses such as transport or special foods. Indirect costs of illness are defined as the loss of productive labour time due to illness, for both patients and caregivers. The scope of indirect costs included in studies varies (Chima et al., 2003), and can include the time spent seeking treatment by the patient and caregiver and the morbidity time during which the patient or caregiver stop or reduce their productive activities. Some studies go further and measure the cost of mortality in terms of lifetime income foregone. The term cost burden is used in this paper to refer to direct or indirect costs expressed as a percentage of household income.

9. The review of literature focused on four types of study or disease: those that assessed the economic costs of **all illnesses** affecting households; the costs of **malaria**; the costs of **tuberculosis** (TB); and the costs of **HIV/AIDS**. These categories were selected because they are major source of morbidity and mortality in developing countries. They also represent different types of disease, in terms of their severity and duration, which have different economic implications for households: they require a different type and duration of treatment, and so are likely to incur different costs and trigger coping strategies of different intensity and risk to livelihoods and processes of impoverishment.

2. METHODS

10. Systematic searches of the literature were conducted going back as far as 1993 using electronic databases, principally Medline, ISI Web of Science (Social Science Citation Index), Science Direct, Social Science and Ingenta. Several key words and word combinations were used in the search, including: illness, cost, direct, indirect, expenditure, household, coping, malaria, tuberculosis, HIV, AIDS.

11. Colleagues provided copies of relevant unpublished reviews and research reports and use was also made of internet sites likely to provide relevant information and publications, for example:

- International AIDS Economic Network: http://www.iaen.org,
- International Labour Office. HIV/AIDS and the World of Work: http://www.ilo.org/public/english/protection/trav/aids/index.htm.
- United Nations Development Program AIDS and Development Website: http://www.undp.org/hiv/publications/
- UNAIDS: http://www.unaids.org
- USAID Population, Health & Nutrition AIDS web site: http://www.usaid.gov/pop_health/aids/index.html
- World Bank web site on AIDS: http://www.worldbank.org/html/extdr/hivaids/default.htm
- World Health Organization AIDS web site: http://www.who.int/health-topics/hiv.htm
- The HIV/AIDS web site: http://www.aegis.org/

12. The author, with the help of two research assistants, reviewed titles and abstracts to identify studies to be included in the review. As McIntyre and Thiede (2003) observed from their comprehensive review of the literature, many "cost of illness" studies evaluate provider costs, or do not distinguish between the direct costs to households and to government health providers, and often aggregate costs at a country level. Far fewer measure and analyse the costs of illness to patients and their families.

3. METHODOLOGICAL AND COMPARATIVE DIFFICULTIES WITH COST OF ILLNESS STUDIES

13. Comparing the results of studies that have measured the economic costs of illness for individuals and households is fraught with difficulties because they use different definitions of cost, different methodologies to measure and quantify cost, and different units of analysis to analyse and present costs (Chima et al., 2003; McIntyre & Thiede, 2003; Worrall et al., 2002).

14. There is no definitive accounting system for costing illness. As Chima et al. (2003) emphasise in their review of malaria costs, the range of effects and burdens that ill-health imposes is difficult to define and measure so it is difficult to allocate costs to multiple dimensions of illness. For example malaria can cause less obvious health burdens such as impacts on growth and intellectual development, anaemia and low birth weight (Chima et al., 2003). The standard approach, as noted above, is to conceptualise and measure two different cost components: direct and indirect. Less tangible costs of illness such as the suffering, grief or social exclusion arising from illness are rarely included in cost calculations.

15. Direct costs of illness can be difficult to compare across studies because they include different cost items, for example all measure medical costs but some ignore non-medical costs such as transport. Studies have also used different units of analysis, with some measuring individual costs and others household costs (including the patient and caregiver). Different units of analysis also cause comparative difficulties, for example some papers expressed costs per episode, others cost per month or year, and others by per capita household spending or total household spending.

16. Indirect illness costs are even more difficult to compare across studies because there are variations in the scope of indirect costs included and the methodology used to quantify the loss of productive time. First, different studies include different individuals in their measurement of time lost: some only include 'economically active' family members and exclude children or elderly people; others include children's days off school, or if they do work a weight is given to their lost activity days based on estimates of productivity. Second, as noted in paragraph 8, the scope of indirect costs varies, although most include the time spent seeking treatment by the patient and caregiver and the morbidity time during which the patient or caregiver stop or reduce their productive activities. A third comparative difficultly arises from the different methods used to place a monetary value on time lost. The most common is to use an average wage rate but others have used average daily income, or average daily output per adult, or actual output and income lost for each respondent. A conclusion of this review is that studies need to adopt a common methodology to allow more meaningful comparisons.

17. Comparison and interpretation of direct and indirect cost data collected in different settings is also made difficult because these costs are driven by very context specific factors on the demand and supply side, for example: illness-related beliefs and willingness to spend money on treatment at different types of provider; household income and ability to pay for treatment; occupational and activity patterns which influence cash availability at different times of year or the value of activity days lost; service accessibility and availability (are there services on which people can spend money?); service quality and

financing (in settings where user fees are charged, out-of-pocket expenses are likely to be higher than where treatment is free at the point of delivery).

18. Evaluating the economic cost of illness for poor households was made difficult because few studies stratified their cost analysis by socio-economic status. Difficulties in measuring household income or socio-economic status are, presumably, partly to blame for this lack of poverty or equity focus.

19. Related to the above point, cost of illness studies face difficulties in how the data should be presented, in particular whether measures of central tendency best reflect or represent the cost burdens facing the study population. Illness and illness costs are usually distributed very unevenly across households, with a minority incurring very high costs, so measures of central tendency conceal wide variations in cost burdens. The use of mean cost figures, in particular, often exaggerates the cost burdens faced by most households because a minority of high values pull the mean above the median. Median figures may therefore reflect more accurately the costs facing the majority of households, but in many studies only the mean is presented.

4. ILLNESS COSTS AND COST BURDENS

4.1 DIRECT COSTS

Total direct costs and cost burdens

20. Tables 1-4 summarise the direct costs of illness for the four illness categories covered by this paper (all illnesses, malaria, TB, HIV/AIDS). Three problems of interpretation are worth noting at this stage and echo the methodological difficulties outlined in section 3. First, within each table comparison across studies should be made with caution because of the different methodology used across studies, for example some:

- ignored non-medical costs such as transport (see Table 1);
- expressed spending on malaria as monthly per capita household expenditure, others as total household expenditure (see Table 2);
- focused on the direct costs of TB before diagnosis, while others measured TB costs before and after diagnosis (see Table 3);
- only measured costs of health care for AIDS patients and not funeral costs (see Table 4).

21. Second, the figures presented are mean figures and in all cases where data were available the mean was higher than the median cost. For example in Table 4 the mean treatment and funeral expenses for AIDS patients in Tanzania (Mwanza) were US$70.00 and US$44 respectively but the median figures were considerably lower at US$49.00 and US$31.00 (see Table 5 for details).

22. Third, mean cost and cost burdens expressed as a % of annual income conceal wide variations across households and across income groups, with the poor likely to be paying more once an expense is expressed as a proportion of income (see below). An additional problem with annual figures is that they smooth considerable fluctuations in cost burdens over a year. Health expenditures tend to be "lumpy", coming in sudden peaks and concentrating the burden over a period of days or weeks, thus absorbing a very high percentage of income in some weeks or months. For example in the study of TB in Zambia, TB spending was expressed as 99.6% of a month's income rather than 8.3% of annual income (Needham et al., 1998).

<u>All illnesses</u>

23. Among the all illness cost studies the majority indicate that health-related expenditures were between 2.5% and 7.0% of household income, and only two studies estimated the cost burden to be above 10% (Table 1). The affordability or economic impact of these cost burdens for households in each study setting is difficult to interpret, since more detailed information is needed on the opportunity costs or sacrifices faced by households as a result of illness cost burdens. Some analysts assume that a 10% cost burden is likely to be catastrophic for the household economy (Prescott, 1999; Ranson, 2002), but this figure is somewhat arbitrary since it may not be catastrophic for high-income households that can cut back on luxuries, or for resilient households that can mobilise assets and social networks to pay for treatment (Russell, 1996). By contrast poor or vulnerable households facing a lower illness cost burden of 5% may be forced to cut spending on other basic necessities such as food or education. In Sri Lanka, for example, poor urban households dependent on a daily wage struggled to meet basic food and fuel

needs on a daily basis, so that even a small additional expense for health care forced them to borrow money, pawn jewellery or cut food consumption on that day (Russell, 2001).

24. The mean figures in Table 1 conceal variations in cost burden by different types of illness and different sources of treatment (and across income groups - see paragraphs 38 - 43). Two patterns from the all illness cost literature on direct costs by source of treatment were:

- serious illness requiring **hospitalisation** caused high direct illness costs for households (except in the case of Sri Lanka, see paragraph 27);
- for a wide range of illnesses requiring outpatient (OP) treatment, households, including the poorest, made **widespread use of private providers** which increased mean direct cost burdens substantially.

25. In Sierra Leone, for example, a minority of high cost treatment episodes that involved use of private doctors or hospital care accounted for over 50% of all expenditure on treatment among the sample households (Fabricant et al., 1999). The authors calculate that if half of the more expensive cases had been treated at the government primary health care (PHC) level, the mean cost to households would have dropped from 6.9% to 5.6% of income, with a similar relative decrease for the poorest quintile. To reduce household cost burdens, through greater use of government PHC centres, would require improvements to both geographical access and quality of care.

26. Similarly in Sri Lanka, where public health services are delivered free at the point of delivery, the mean direct cost burden of 6.5% was inflated by people's preference to use private doctors and pharmacies for OP treatment for less serious illness. Consultation fees with private doctors and specialists (usually government doctors in private practice hours) made up 40% of all household spending on illness (Russell, 2001). Factors driving people away from public sector PHC / OP facilities included crowds and long waiting times, cursory consultations and poor inter-personal quality of care. In contrast people from all income groups preferred to pay a private doctor for a wide range of less serious illnesses to obtain treatment quickly (thereby saving time and often money), to get a longer consultation with better inter-personal quality of care, and over time to build a trusting relationship with a private doctor of their choice (Russell, 2001).

27. In Sri Lanka, however, direct cost burdens were much lower (less than 2%) for more serious illnesses requiring regular treatment or hospital admission because most people preferred to use pubic providers for these more serious cases. The Sri Lankan case is, in particular, notable for the protection or insurance provided by free hospital IP treatment to all sections of the population (IPS, 2001; Russell, 2001).

28. Cost burdens in other study settings require similar disaggregation and analysis. For example the higher cost burdens in Uganda and Guatemala may reflect local epidemiological factors (for example HIV/AIDS in Uganda), service characteristics (such as user fees charged by public providers in Uganda) or poor geographical access (incurring high transport costs).

Table 1: 'All illness' studies: overview of direct costs

Country	Direct costs	Direct costs as a % of HH income (mean)	Source
Paraguay		**2.5**	Makinen et al., 2000
Guatemala		**16.0**	Makinen et al., 2000
Burkina Faso		**4.4**	Makinen et al., 2000
Burkina Faso		**6.2**	Sauerborn et al., 1996a
Sierra Leone		**6.9**	Fabricant et al., 1999
Uganda		**9.3 / 11.0**	Lucas & Nawagaba, 1999
Nigeria		**7.0**	Onwujekwe et al., 2000
South Africa		**4.9**	Makinen et al., 2000
Sri Lanka		**6.5**	Russell, 2001
Thailand		**3.4**	Makinen et al., 2000
Thailand		**2.6**	Pannarunothai & Mills, 1997

Source: adapted from McIntyre and Thiedes (2003)

Notes: The Makinen et al. studies only include medical expenses and not transport, extra food etc.. Most cost burden calculations are based on extrapolations to be expressed as average annual spending as a % of average annual income. In Uganda and Sri Lanka cost burdens are average monthly spending as a % of average monthly income.

Table 2: Malaria studies: overview of direct costs

Country	Direct costs per capita per month (US$)		Total direct costs per month	Direct costs as a % of HH income (mean)	Source
	Prevent.	Treatment			
Malawi (nationwide)	$0.05	$0.41	$0.46	**2.0**	Ettling et al., 1994
Tanzania (urban)	$0.76				Evans, 1994
Zaire (urban)	$0.97				Zandu et al., 1991
Cameroon (urban)	$1.29	$2.05	$3.34		Louis, 1992
Cameroon (urban	$1.74	$2.67	$4.41		Desfontaine et al., 1989
Cameroon (urban)	$2.10	$3.88	$5.98		Desfontaine et al., 1990
Burkina Faso (rural)	$0.09				Guiguemde et al., 1997
Burkina Faso (urban)	$0.93	$1.18	$2.11		Guiguemde et al., 1994
Ghana (rural)		$0.65	$0.65		Asenso-Okyere & Dzator, 1997
Nigeria (rural)		$1.84	$1.84 per HH	**2.9**	Onwujekwe et al., 2000
Sri Lanka (rural)		$1.66	$1.66 per HH	**2.0**	Attanayake et al., 2000

Source: adapted from Chima et al. (2003)

Notes: All prices are converted to 1999US$ except for Nigeria (1998 prices) and Sri Lanka (1993 prices). All dollar figures are monthly **per capita** household expenditure per month, except for Nigeria and Sri Lanka where the figures are for monthly **household** expenditure. Per capita figures would need to be multiplied by average household size – likely to 5 or more in these settings (the highest being US26 per month in urban Cameroon (Chima et al, 2003). Only three studies estimated spending on malaria as a proportion of income.

Table 3: TB studies: overview of direct costs

Country	Direct HH costs over treatment period (mean)	Direct HH costs as a % of annual HH income	Cost data collection period	Source
Thailand (n=673) urban and rural	$126.0	**8.6**	Pre- & post-diagnosis	Kamolratanakul et al., 1999
India (n=304) urban and rural	$58.6	**13.0**	Pre- & post-diagnosis	Rajeswari et al., 1999
India (n=16) urban	$107.4	**18.4**	Post-diagnosis	Nair et al., 1997
India (n=?) urban	$104.0	**17.8**	Pre- & post-diagnosis	Uplekar et al., 1996a/b
Bangladesh (n=21)	$130.0	**21.7**	Pre-diagnosis	Croft & Croft, 1998
Zambia (n=202)	$46.9	**8.3**	Pre-diagnosis	Needham et al., 1998
Malawi (n=179)	$12.4	**5.0**	Pre-diagnosis	Mann et al., 2002
Tanzania (n=191)	$50.0	**9.3**	Pre- & post-diagnosis	Wyss et al., 2001

Notes: All studies except Mann et al. (2002) were conducted between 1996-7 so all prices are in 1996 or 1997 US dollars. In one Indian study (Nair et al., 1997) all direct costs were not systematically measured, for example transport was excluded and the costs of all visits to doctors after diagnosis were not measured accurately. The costs from another Indian study (Uplekar et al., 1996a/b) were cited in Rajeswari et al., 1999). Comparisons are compromised by the fact half the studies measured spending on TB treatment (medical and non-medical) before and after diagnosis but others measured treatment costs only before or after diagnosis. In half the studies cost burdens were expressed either as a % of annual income (Kamolratanakul et al., 1999; Rajeswari et al., 1999) or as a % of monthly income (Mann et al., 2002; Needham et al., 1998). The latter have been converted to annual burdens by dividing by 12, but it is noteworthy that cost burdens expressed per month were much higher (e.g. **for Zambia TB treatment spending over the period before diagnosis was equivalent to 99% of an average monthly wage**). For the four remaining studies cost burdens are based on this author's (SR) estimates of household income in the study settings. In the Thai study the analysis was stratified by socio-economic group so the mean figure for the whole sample was not available and the figure used is the direct cost of TB for the middle-income (but still poor) group (see Table 7 below).

Table 4: HIV/AIDS studies: overview of direct costs

	Households experiencing:	Direct health costs over terminal period	Direct costs of funeral	Total direct costs	Total direct costs as a % of annual income	Source
Tanzania (Mwanza)	AIDS death n=73	$70.0	$44.3	$114.3	**Towards 100%**	Ngalula et al., 2002
Tanzania (Kagera)	**male** AIDS death	$80.0	$77.00	$157.0	**50% -100%**	World Bank, 1997
Tanzania (Kagera)	**female** AIDS death	$38.0	$54.00	$92.0	**50 - 100%**	World Bank, 1997
Cote d'Ivoire	AIDS patient n=107				**8.4% (just health care spending)**	Bechu, 1997
Thailand	AIDS death n=116	$1,036.6	$1,537.6	$2,574.2	**Over 100%**	Pityanon et al., 1997
South Africa	AIDS patient n=728				**34% (just health care spending)**	Johnson et al., 2002

Notes: dollar values have not yet been converted to a standard year. Costs as a % of income are estimates, based on authors' estimates of income (Ngalula et al., 2002; Pitayanon et al., 1997; Tibaijuka, 1997) or on this author's (SR) estimates of household income from other sources.

Malaria

29. Recent reviews of the costs of malaria (Chima et al., 2003; Malaney, 2003; Worrall et al., 2002) have highlighted the difficulties of cross-study comparisons due to the lack of a common methodology. Drawing from Chima et al. (2003), Table 2 summarises the direct costs of malaria prevention and treatment found across studies, expressed as monthly per capita expenditure (except for the last two studies). These costs are likely to be at least 5 times as high if expressed as household expenditure, for example Chima et al. (2003) note that the figures for Malawi and urban Cameroon would be US$1.88 and US$26.00 per household per month respectively.

30. Only three studies expressed household spending as a proportion of household income and these figures indicate a relatively low cost burden from this single disease over a year, compared to the cost burdens of other diseases such as TB and HIV/AIDS. Nevertheless when combined with the costs of other diseases affecting the household, and the indirect costs caused by malaria morbidity, all the authors of these studies argue that the household costs of malaria are considerable, particularly for the poor (see paragraphs 63-67) and justify more efforts to improve coverage of malaria prevention and treatment interventions among the poor (Asenso-Okyere & Dzator, 1997; Worall et al., 2002).

Tuberculosis

31. Given the long term and serious nature of tuberculosis and latter stage HIV/AIDS it is perhaps not surprising that households incurred much higher direct costs and cost burdens for these two diseases (Table 3 and Table 4). With the exception of the Malawi study, mean household spending on TB ranged from about $50.00 to over US$100 over the treatment period (usually from 6-12 months). Levels of household spending were lower in Sub-Saharan African countries than in Thailand or urban India (Bombay) where per capita incomes are higher (the estimate for Bangladesh is based on a small sample and appears very high).

32. In the livelihood and income-poverty contexts where the TB studies took place, these **cost burdens are very high**, absorbing about 8% - 20% of annual household income, the equivalent of about 100% or more of a household's monthly income in most studies. Given that many of the households in these studies are likely to be poor and struggling to meet basic food and fuel needs on a daily or monthly basis, the considerable direct cost burdens imposed by TB are highly likely to be unaffordable for poor households (see Box 1) and trigger asset and borrowing strategies (see section 5).

Box 1: Poverty I Zambia as a constraint to accessing TB treatment

Father with child suffering from TB:

> "*Here in Zambia the salary of the driver is less than K50,*000 (US$40 per month). *We have to pay for the house (rent), K10,000; the electricity bill…K12,000; and the mealie meal (ground corn) is about K15,000. So that K50,000, in 2 days, is gone. So you have to suffer sometimes: no lunch, no breakfast…*"

Source: Needham & Bowman et al. (2003: 6)

33. Although the long duration and serious nature of TB contributed to the high direct costs of the disease, studies highlighted **health service characteristics that exacerbated TB direct cost burdens** for patients:

- *Centralised public delivery structures for TB diagnosis and treatment*: caused patients to pay for more convenient, local private providers (see below) or forced people have to travel long distances and pay high travel costs to get to the hospital / chest clinic (Kamolratanakul et al, 1999; Needham & Bowman et al, 2003). Decentralisation of diagnostic and treatment facilities may reduce demand for private providers and reduce transport and time costs for patients, but a range of service delivery capacities need to be in place before decentralisation can be implemented effectively (Needham & Bowman et al, 2003);
- *Number of health encounters before diagnosis*: even if poor and vulnerable people overcome the financial and social barriers to seeking treatment for TB, long delays to proper diagnosis were reported, with long "treatment pathways" involving several encounters with different providers in the traditional, private and public sectors (Kamolratanakul et al, 1999; Long et al., 1999; Lonnroth et al., 2001; Nair et al., 1997; Needham & Bowman et al, 2003; Nhlema et al, 2003; Tupasi et al., 2000; Wyss et al., 2001). In Zambia, for example, patients (n=202) reported an average of 6.7 health encounters prior to their diagnosis of TB at the central Chest Clinic, and on average this pre-diagnosis treatment seeking period lasted 63 days (Needham et al., 2003). Reducing the number of health encounters before diagnosis is seen as one strategy to reduce patient direct costs (Needham et al., 2003).
- *Preference for private providers*: when seeking treatment for TB-related symptoms, studies in India, Zambia and Vietnam showed that patients prefer to spend money on herbal remedies and to use private sector providers (traditional and allopathic), increasing direct costs of illness (Rajeswari et al., 1999; Needham & Bowman et al, 2003; Lonnroth et al., 2001). In Zambia, for example, TB-related symptoms were often blamed on witchcraft (curses) and patients paid substantial sums for advice from traditional healers. Patients also purchased ineffective medicines from private pharmacies or paid for consultations with private doctors who failed to diagnose the disease:

  > "*…the person with TB paid the equivalent of 10% of his monthly income for consultation with the traditional healer regarding the symptoms. In other cases, Western medical remedies are fruitlessly tried through self-medication with drugs from a local pharmacy or…private physician. Both private physician and traditional healer consultation were associated significantly with longer* (diagnosis) *delays…*" (Needham et al., 2003)

  As with the all illness studies discussed in paragraph 24-26, TB studies revealed people's reluctance to use the public health system due to poor quality health services, including staff attitudes and lack of trust / confidence in staff and treatment (Johansson et al., 2000; Nair et al., 1997; Needham et al., 1998; Needham et al., 2003). For example in Vietnam, despite a well-organised National TB Control Programme (NTP) with outstanding results, the two most common treatment options early in the illness episode (before diagnosis) were private pharmacies and private doctors, with 50% of TB patients across all income groups going private (Lonnroth et al., 2000). Several factors explained people's preference to opt to pay for a private provider, even when effective TB treatment was available free of charge:

  - Long waiting times at public facilities: speed and convenience of private sector treatment avoided loss of time at work. Although the NTP is "free" to patients the cost of travel and time lost by going public may be higher than the cost of going private;
  - Better inter-personal quality of care at private providers: patients felt that because they were paying they were able to demand and receive better quality care, were more valued as customers and treated better by staff who were better paid and more enthusiastic.
  - The stigma of TB and the desire to keep the condition secret: patients feared being registered as a TB case if they went to the public sector, or being forced into strict treatment regimes (DOTS) that were perceived to be inconvenient and might have repercussions for their privacy.

  The involvement of the private sector in TB treatment is likely to threaten TB control measures (Lonnroth et al., 2001), and better integration of private providers within TB programmes is advocated (Needham et al., 2003).
- *User fee policies*: In Zambia, Thailand and Tanzania user fees at public health facilities contributed to overall TB medical cost burdens (Needham & Bowman et al, 2003; Kamolratanakul et al, 1999; Wyss et al., 2001). In Zambia, although TB diagnosis and treatment are provided free in the centralized Chext Clinic in Lusaka, patients need a referral from a government OP facility to be seen at the Chest Clinic and OP facilities charge fees (Needham & Bowman et al, 2003). In recognition of the financial hardship suffered by TB patients, TB services in Thailand are supposed to be free of charge, but the direct cost data indicated that this policy was not always implemented and that patients were being charged (Kamolratanakul et al, 1999).

HIV/AIDS

34. Several longitudinal surveys have measured household spending on health care for patients suffering from **HIV/AIDS** and the subsequent funeral costs, which in Tanzania (Kagera) and Thailand (Chiang Mai) were even higher than health care costs (Table 4). In Thailand where per capita income is much higher than in Tanzania, households spent more than ten times as much on medical care and the funeral.

35. As early as 1988 Davachi et al (1988) examined the costs of paediatric AIDS cases in Kinshasha and found that the costs of the funeral, coffin and feeding guests at the wake were equivalent to eleven months' salary for an average earner in Kinshasha. The treatment and funeral costs shown in Table 4 are certainly very high in the rural and low cash income contexts where the studies took place, and in most cases the **researchers estimated that the direct costs of HIV/AIDS were catastrophic**, absorbing anything from 50% to 100% or more of annual income. A similar survey in Uganda (Rakai district) reported that households experiencing an HIV-related death made substantial financial outlays for medical treatment and burial, and that two-thirds of these households sold property to cover these direct costs (see section 5) (Menon et al., 1997).

36. The research design in Kagera, Mwanza (Tanzania) and Chiang Mai (Thailand) allowed comparison of the direct costs of AIDS deaths and non-AIDS deaths. All three studies found that medical spending was higher for AIDS deaths than non-AIDS deaths because of the longer duration of illness (Ngalula et al., 2002; Pitayanon et al., 1997; World Bank, 1997), as illustrated by Tables 5 and 6 below. The earlier Tanzania study

(Kagera) also found higher spending on male AIDS deaths compared to female AIDS deaths.

Table 5: The direct costs of AIDS and non-AIDS deaths in Tanzania

	Cause of death					
	HIV/AIDS		Other diseases		Injuries	
Expenditure (US$):	Mean	Median	Mean	Median	Mean	Median
Expenditure on medical care	70	49	41	28	28	0
Expenditure on funeral	44	31	31	22	38	42
Total expenditure	114	71	72	50	66	42

Source: Ngalula et al., 2002; US$1 = TSh 550

Table 6: The direct costs of AIDS and non-AIDS deaths in Thailand

Expenditure US$ (Baht):	HIV/AIDS death (n=116)	Non HIV/AIDS death (n=100)
Medical treatment	$973 (B 24,344)	$883 (B 22,075)
Travel expenses	$63 (B 1,571)	$53 (B 1,332)
Funeral costs	$1538 (B38,440)	$1874 (B 46,850)
Total direct costs	$2574 (B 64,355)	$2810 (B 70,258)

Source: Pitayanon et al., 1997; US$1 = 25 Thai Baht

37. Barnett et al. (2001) have suggested that the surveys in Kagera, Rakai and Chiang Mai may have underestimated the costs and economic impact of HIV/AIDS because the method does not capture the most vulnerable households that may have already broken up due to HIV/AIDS sickness and death, and because the method does not facilitate lengthy encounters and observation. This fact is made apparent if the results of the Kagera study – which portray an appalling situation anyway – are compared with more detailed ethnographic and case study approaches showing a far worse situation for some households and their members (Rugalema, 1999; Williams, 1998).

The poor pay more: direct cost burdens are regressive

38. Evidence shows that the direct costs of health care are regressive, imposing a greater burden (in terms of % of income) on poor families than on better-off families (Fabricant et al., 1999; McIntyre and Thiede, 2003). Although the poor in general spend less on treatment than other income groups (due lack of access, inability to pay, greater use of public services) this spending makes up a higher proportion of monthly or annual income for poor people than for those on higher incomes.

39. With respect to **all illness** costs, studies from India (Mishra et al., 1993), China (Wilkes et al., 1997), Thailand (Pannarunothai & Mills, 1997; Mongkolsmai, 1993), Vietnam (Ensor & San, 1996) and Sierra Leone (Fabricant et al., 1999) have revealed regressive cost burdens across income groups. For example in Vietnam household expenditure on health care was, over the whole sample, 7.1% of household income, but 19.4% for poor households and only 3.9% for 'rich' households (Ensor & San, 1996). In Thailand annual household direct costs of illness were 2.1% of household income for the highest income quintile but a staggering 21.2% for the poorest quintile, potentially catastrophic burdens caused by lower insurance coverage among the poor as well as their lower incomes (Pannarunothai & Mills, 1997). A Universal Coverage policy was

introduced in Thailand during 2001/2 to address this low coverage and reduce cost burdens for the poor.

40. Expanding the coverage of tax- or insurance-based financing systems to protect poor households from out-of-pocket payments for health care is now recognised to be a high priority for governments wishing to expand access and reduce regressive treatment cost burdens (Arhin, 1995; Ranson, 2002; WHO, 1999; World Bank, 2000). In Sri Lanka, for example, the free public health care system was found to protect the poor in two urban communities from high cost burdens associated with chronic illness and hospitalisation: for these services direct costs across income groups were not regressive (Russell, 2001). Sri Lanka is also one of the few examples of a public health system that has achieved a pro-poor benefit incidence in developing countries (IPS, 2001).

41. Only one **malaria** study appears to have examined treatment spending by socio-economic group and found regressive cost burdens. In Malawi, Ettling et al (1994) calculated that annual household expenditure on malaria treatment by very poor households was $19.13 (1994 prices) or 28% of annual household income, but for other households this burden was only 2% of annual income despite similar levels of spending (US$19.94). Such high cost burdens for the poor are likely to trigger asset or borrowing strategies, and a recent review of malaria and poverty has argued that malaria prevention and treatment programmes need to have more of an equity focus and better targeted to the poor (Worrall et al., 2002).

42. Only two **tuberculosis** studies stratified costs and cost burdens by income group (Kamolratanakul et al, 1999; Mann et al., 2002). Although the poor spent less on TB treatment than other income groups these expenditures absorbed a much higher proportion of their income (Table 7). These data suggest that for a serious illness like TB, out-of pocket expenses on medical costs, and notably non-medical costs such as transport and special foods (see below), are well beyond the normal budgets of poor households, and probably beyond the budgets of 'average' or 'non-poor' households if the costs are concentrated over a few months.

Table 7: Incidence of direct cost burdens of TB across income groups

	Mean direct cost (US$)	Mean direct cost as % monthly income	Mean direct cost as % annual income
Thailand (Urban and rural) (Kamolratanakul et al., 1999)			
Income below poverty line (n=153)	84	184	15
Income below average (n=197)	126	103	9
Income above average (n=322)	113	22	2
Malawi (urban) (Mann et al., 2002)			
Poor patients (n=128)	11	172	14
Non-poor patients (n=51)	17	46	4
All patients (n=179)	12	59	5

43. No evidence could be found on the incidence of **HIV/AIDS** costs across income groups, although the evidence already reviewed (particularly for TB) strongly suggests that these burdens are likely to be regressive.

Medical and non-medical direct costs: the 'hidden' costs of illness

44. Levels of expenditure on different medical and non-medical (e.g. transport) items vary according to the health system and access to services in the different study settings, for example whether user fees are charged at government facilities, the extent of insurance coverage and distance to travel.

45. For **all illness** cost studies evidence suggests that the cost of consultations and pharmaceuticals can make up a large proportion of all direct costs, for example in Sri Lanka consultations with private doctors accounted for 40% of all direct costs, irrespective of type of illness, and spending on pharmaceuticals made up a further 33% of direct costs (Russell, 2001). Transport costs held the third largest share of spending in this study (13%).

46. A large proportion of spending on **malaria** also goes towards pharmaceuticals, for example in Ghana they accounted for 62% of direct costs for mild malaria and 70% for severe malaria (Asensi-Okyere & Dzator, 1997). Transport costs for seeking malaria treatment are also significant, particularly for rural populations needing to travel long distances, for example transport accounted for 22% of the direct costs of malaria in Sri Lanka (Attanayake et al., 2000) and 14% in Ghana (Asensi-Okyere & Dzator, 1997). Most notably, however, studies in Sri Lanka (Attanayake et al., 2000; Konradsen et al., 1997) illustrate the importance of non-medical costs for households, in particular special foods to aid recovery from malaria: in one of these studies 46% of household spending on malaria treatment went on special foods (Attanayake et al., 2000). In the Sri Lankan context the high proportion of treatment spending going towards non-medical items reflects the relatively low medical costs incurred by patients due to widespread use of free public facilities.

47. Spending patterns for **tuberculosis** treatment also reveal the importance of non-medical costs such as transport and special foods (Figure 2). In Tanzania and Thailand the costs of medicines, consultations and transport were dominant (Kamolratanakul et al, 1999; Wyss et al., 2001), because of the numerous health encounters before diagnosis and because of the centralised nature of TB provision (see paragraph 33) which meant patients had to travel to a distant hospital facility or central chest clinic for diagnosis and treatment (Kamolratanakul et al, 1999; Needham & Bowman et al, 2003). Transport costs were often doubled because caregivers travelled with the sick patient (Kamolratanakul et al, 1999; Needham et al, 2003; Wyss et al., 2001).

>> Figure 2

48. In Zambia, by contrast, spending on medical items was relatively low (22% of direct costs), to some extent because of a government sponsored medical insurance scheme, while spending on non-medical items such as transport and food was very high (78%) (Needham & Bowman et al, 2003). Table 8 provides a detailed **case study** of **tuberculosis direct costs** and the mean cost burdens they imposed on households' monthly income. Over half the patients (n=202) purchased 'special foods' that are not normally part of their diet (due to the expense) in order to help cure the disease, spending on average $21.00 per month (44% of a month's income) on meat, eggs, vegetables, oranges and orange-flavoured soft drinks (due to the misconception that

they contain orange juice). The authors argue that these non-medical costs (as well as lost income due to illness – see below) are often overlooked by or 'hidden' from policy-makers, just as funeral costs might be for HIV/AIDS victims, but are critical to households and their ability to pay for treatment:

> "*Patient and care-giver transportation expenditures represent 27% of mean monthly income, largely due to the many health care encounters…in care-seeking…Spending on special foods is an even greater cost that has not been recognised in the literature. Within a patient's limited pool of resources, spending on special foods may create shortages of money for the medical consultation and transportation ultimately required in obtaining a diagnosis*" (Needham et al., 1998: 815)

49. McIntyre and Thiede (2003) also highlight another direct but 'hidden' cost that can impose considerable burdens on households: unofficial or 'under-the-counter' fees, which can be substantial in contexts where health workers want or need to supplement their official salaries (Balabanova & McKee, 2002; Killingsworth et al., 1999).

Table 8: Types and level of expenditure for TB – the case of Zambia

Zambia (Needham et al. 1998)	Patient direct cost (n=202)	Caregiver direct cost (n=202)	Total direct cost over treatment period	% of mean monthly income (US$47)
Medical costs				
• Private doctor	$4.12	$0.00	$4.12	9%
• Traditional healer	$1.49	$0.00	$1.49	3%
Government facility				
– Insurance scheme	$0.61	$0.00	$0.61	1%
– Consultation fees (without insurance scheme)	$1.10	$0.00	$1.10	2%
– Diagnostics	$0.60	$0.00	$0.60	1%
– Medicines	$2.08	$0.00	$2.08	4%
• Other medical	$0.12	$0.00	$0.12	0%
Total medical costs	$10.11	$0.00	$10.11	22%
Non-medical costs				
• Transport	$6.89	$5.74	$12.63	27%
• ***"Special food"***	***$17.40***	***$3.22***	*$20.62*	*44%*
• Food	$0.99	$2.09	$3.08	7%
• Other	$0.35	$0.12	$0.48	1%
Total non medical costs	$25.64	$11.17	$36.81	78%
TOTAL	**$35.75**	**$11.17**	**$46.9**	**99.8%**

4.2 INDIRECT AND TOTAL COSTS

Summary of indirect and total cost burdens

50. The indirect costs of lost productive labour time often impose a double cost burden on households at the time of illness: its capacity to earn income is reduced at a time when the household needs additional money.

51. As discussed in section 3, the scope of indirect costs can include the time spent seeking treatment by the patient and caregiver, the morbidity time during which the patient or caregiver stops or reduces their productive activities, and some studies go further and measure the cost of mortality in terms of life time income foregone.

52. The scope of indirect costs could be broadened further to include the economic implications of household coping strategies for the household economy (Chima et al., 2003), for example serious illnesses such as TB or HIV/AIDS can trigger borrowing, asset sales or withdrawal of children from school, responses that have long term income earning implications. These diseases can also lead to social exclusion or marital break down which also generate economic consequences for different household members.

53. This section reviews studies that have examined the loss of productive time for the patient and caregiver caused by morbidity. Coping strategies and their implications are reviewed in section 6.

All illnesses

54. For all illness studies the costs of a range of mild, moderate and serious illnesses were measured. Table 9 summarises the direct and indirect cost findings of three studies that have measured all costs of illness for households. In rural Burkina Faso indirect costs were by far the largest proportion (73%) of total costs, and time lost by healthy caregivers was almost equal to the time lost by the sick. Relatively low direct costs reflect poor service coverage and low incomes, rather than good services at low cost to users.

Table 9: All illness cost studies: summary of direct, indirect and total costs

Country	Direct costs (as a % of HH income)	Indirect costs (as a % of HH income)	Total cost (as a % of HH income)	Source
Burkina Faso (rural)	$4.80 3.7%	$10.56 8.1%	$15.39 (11.8%)	Sauerborn et al., 1995
Nigeria (rural)	$4.44 (7.0%)	$2.36 (3.7%)	$6.80 (10.7%)	Onwujekwe et al., 2000
Sri Lanka (urban)	$7.5 (6.5%)	$5.1 (5.0%)	$12.6 (11.5%)	Russell, 2001

55. In Sri Lanka and Nigeria, by contrast, direct costs were estimated to be higher than indirect costs. In Sri Lanka, as noted in paragraph 26, relatively high direct costs reflect the urban setting and the widespread use of private doctors and pharmacies for PHC / OP services.

56. Perhaps of most interest is the fact all three studies show that mean total illness costs could be interpreted as **'catastrophic'** if the aforementioned cost burden threshold of 10% is used (see paragraph 23). Even in Sri Lanka, where service delivery is free at the point of delivery, direct and indirect costs combined impose a heavy burden on monthly household income. The costs of illness in Sri Lanka raise an **important question for health policy-makers and researchers**: even universal coverage cannot protect households from the full range of costs incurred by households due to illness, particularly indirect costs but also non-medical direct costs such as transport and special foods (see section 4.1). Are there innovative measures which governments, working alongside NGOs and community-based organisations, can develop to help protect households from these 'hidden' costs? No studies were found that had researched this subject.

Malaria

57. The indirect costs of **malaria** are likely to be a key determinant of the disease's overall economic cost because it affects the economically active population and has the potential to frequently incapacitate through recurring episodes over a year. One study in Ghana, for example, found that indirect costs made up 79% of the total cost of seeking treatment per case of malaria, not because of the time taken to travel a modern public provider but because of the very long waiting times at these facilities (Asenso-Okyere & Dzator, 1997).

58. Chima et al. (2003) provide a summary table of different studies in Africa that have measured, firstly, **patient and caregiver days lost** per malaria episode. Nearly all studies from Africa found that sick adults lost 1 to 5 days per malaria episode, depending on severity.

59. Two studies from Sri Lanka found similar levels of disruption to normal activity days. Konradsen et al. (1997) calculated an average of 5.0 person days lost per malaria episode, with the number of episodes over the year ranging from 0 to 5 per individual and from 0 to 11 per household. Most of the days lost due to malaria were concentrated in the rainy season when agricultural activities were greatest (i.e. at time when the opportunity cost of lost time was greatest). Attanayake et al. (2000) report an average loss of 4 activity days per malaria episode: 27% of patients (n=344) were completely incapacitated for 3 days and 20% for 2 days.

60. When children suffered from malaria symptoms caregivers also lost from 1-5 days per episode across African studies (Chima et al.,2003), although most were at the lower end of that range or the activity days were not completely lost. Aikins (1995) cautions that estimation of caregiver time for children is complicated by the need to differentiate time spent on general childcare and extra time spent on caring for a sick child.

61. Average figures for days lost per malaria episode conceal large variations across individuals, for example in most studies only 50% or less of the sample lost economically productive time due to malaria but a minority lost a lot of time. In Malawi 52% of adults reported that malaria had affected their work or study but 32 % of these cases could still work at a reduced rate (Ettling et al., 1994). In Sri Lanka, 39% of malaria patients were economically active (n=133/344) and of these only 59 patients

(only 17% of the whole sample) were affected in terms of lost wages, business revenue or agricultural production.

62. The **monetary value** of days lost due to **malaria** is hard to compare across studies because of the different methodologies used to value lost time (see paragraph 16). The most common is to use an average wage rate (Asenso-Okyere & Dzator, 1997; Cropper et al., 1999; Konradesen et al., 1997). Other studies have used average daily income (Ettling et al., 1994; Guiguemde et al., 1994) or an average daily output per adult (Sauerborn et al., 1991; Shepherd et al., 1991). Attanayake et al. (2000) was the only study to use an output-related approach that measured the actual loss of income attributable to malaria (lost harvest, lost wages) for each respondent.

63. Table 10 summarises the evidence on the average indirect cost of malaria per adult episode, which ranges from US$0.73 in Burkina Faso to up to US$23.00 in Ethiopia. The figures in Table 10 do not provide a good picture of overall income losses and their significance, however, because the number of malaria episodes experienced by household members over a season or year need consideration and income losses need to be expressed as a proportion of income.

64. Several studies have attempted such cost burden calculations (Attanayake et al., 2000; Ettling et al., 1994; Konradsen et al., 1997; Leighton & Foster 1993; Onwujekwe et al., 2000) and the authors conclude that income losses from malaria can be of great economic significance to households and the wider economy. Table 11 summarises these indirect cost burdens that range from 2% - 6% of income: not necessarily catastrophic on their own but potentially catastrophic when combined with other indirect illness costs. In Sri Lanka, for example, Konradsen et al. (1997) calculated that on average a household lost 13 economically active person days per year due to malaria, causing an average annual household income loss of US$15.56 (1997 prices), or 6 % of household income per year, with most of these losses concentrated in the rainy season. These indirect cost burdens were in addition to other indirect costs of illness that were equivalent to US$47.46 per year or 18% of annual income, making a total indirect illness cost burden of 24% of income.

Table 10: Mean indirect cost of malaria per episode

Country	Indirect cost per malaria episode	Source
Ghana (rural)	$7.63	Asenso-Okyere & Dzator, 1997
Malawi (nationwide)	$1.54	Ettling et al., 1994
Burkina Faso (rural)	$4.21	Guiguemde et al., 1997
Burkina Faso (rural)	$0.73	Sauerborn et al., 1991
Ethiopia	$6.00 - $23.00	Cropper et al., 1999
Sri Lanka (1993 prices)	$4.15	Attanayake et al., 2000

Source: adapted from Chima et al. (2003)
Notes: All prices are 1999 US$ except Sri Lanka

Table 11: Indirect cost of malaria as a proportion of income

Country	Unit of analysis	Indirect cost as a % of income	Source
Malawi (nationwide)	Annual cost	2.6%	Ettling et al., 1994
Sri Lanka (rural)	Cost per episode	4.9%	Attanayake et al., 2000
Sri Lanka (rural)	Annual cost	6.0%	Konradsen et al., 1997
Nigeria (rural)	Monthly cost	2.0%	Onwujekwe et al., 2000

65. In Nigeria the mean indirect cost of malaria to households was actually higher than indirect costs caused by other illnesses: malaria cost US$1.28 per month or 2% of monthly household income, while all other illnesses cost US$1.08 or 1.7% of monthly income (Onwujekwe et al., 2000).

66. To summarise, from most studies it appears that the indirect costs of malaria range from about 1-5 days per episode, equivalent to income losses of about US$1.00 to US$8.00 per episode, and when converted to a proportion of income the indirect costs of malaria are equivalent to between 2% to 6% of annual household income. These indirect cost burdens are likely to be much higher for poor households but there was very limited evidence on the indirect cost incidence of malaria across income groups.

67. A few studies have estimated **the total economic costs of malaria** by adding together direct and indirect cost estimates (Asenso-Okyere & Dzator, 1997; Attanayake et al., 2000; Ettling et al., 1994; Leighton & Foster 1993; Onwujekwe et al., 2000). Table 12 summarises these total cost of illness estimates as a proportion of income.

Table 12: Total costs of malaria as a proportion of income

Country	Unit of analysis	Total cost as a % of income	Source
Malawi	Annual cost	7.2%	Ettling et al., 1994
Sri Lanka (rural)	Cost per episode	6.7%	Attanayake et al., 2000
Nigeria (rural)	Monthly cost	4.9%	Onwujekwe et al., 2000
Nigeria	Annual cost	7% - 13%	Leighton & Foster, 1993
Kenya	Annual cost	9% - 18%	Leighton & Foster, 1993

Notes: Leighton & Foster was cited in Chima et al. (2003).

68. The ratio of indirect to direct costs varies depending on the methodology used to estimate indirect costs, and due to the study setting. In Sri Lanka, for example, the availability of free treatment at public providers reduced average household spending on malaria and made indirect costs of morbidity more prominent (Attanayake et al., 2000). In urban Kenya direct and indirect costs made up 86% and 14% of total costs respectively, but for rural small farmers indirect costs from malaria were more prominent making up 62% of total costs (Leighton & Foster, 1993).

69. Very few malaria studies disaggregated indirect or total costs by socio-economic status, but these are likely to be regressive. For malaria only one study disaggregated costs by socio-economic status and found that while the average total cost burden of malaria was 7.2% of household income (Table 12), the total cost burden for very poor households was considerably higher at a potentially catastrophic 32% of annual income (Ettling et al., 1994).

Tuberculosis

70. The indirect costs of productive labour time lost due to **tuberculosis** are likely to be considerable and, as in the case of malaria, a key determinant of the disease's overall economic cost because TB is a long-term disease that can take several months or even years to cure, and a disease that affects the economically active population. In a Zambian study, for example, 44% of patients (n=202) were the main source of income for the household (Needham et al., 2003).

71. In Thailand 20% of patients reported income reductions due to either patients' or caregivers' decreased ability to work (Kamolratanakul et al., 1999). In India the average number of work days lost was 83 days: 48 days before treatment and 35 days during treatment (Rajeswari et al., 1999). In Zambia, before commencing TB treatment 46% of patients and 30% of caregivers were absent from work due to the illness, and 31% of patients had to stop work completely, missing an average of 48 days work (Needham et al., 1998). In Tanzania time lost from work due to TB was estimated to be the equivalent of one person per household (74% of patient working capacity; 29% of caregiver working capacity) over the duration of the illness, which could be from 4 to 12 months (Wyss et al., 2001).

72. The **monetary value** of days lost due to **tuberculosis** is once again hard to compare across studies because of the different methodologies used to value lost time, but Table 13 summarises the evidence available on the direct, indirect and total costs of tuberculosis, and Figure 3 provides a graphic illustration of these costs. The annual indirect costs of TB are relatively low in Thailand and Zambia when compared with direct costs, possibly reflecting low values allocated to lost time or the high direct costs noted earlier associated with multiple health encounters and widespread use of the private sector (see paragraph 33). Nevertheless indirect costs in Zambia are still considerable at $26.7 or 5% of annual income.

73. By contrast in India and Tanzania indirect costs are the main cost burden experienced by households: these costs are exorbitant and highly likely to be economically catastrophic, the equivalent of 26% and 80% of annual income respectively (Table 13). The very high estimate of the indirect cost of TB in Tanzania stems from extrapolations of lost time and wages over several months (Wyss et al., 2001). Three different illness scenarios were developed to extrapolate income losses over the duration of the disease, although the authors note potential inaccuracies with these estimates due to the lack of data available:

- Best case: household loses US$38.00 per month for 4 months = total income loss of US$154 over the course of the illness;
- Middle case: household loses US$53.00 per month for 8 months = total income loss of US$431.00 (see Table 13) over the course of the illness;
- Worst case: household loses US$113.00 per month for 12 months = total income loss of US$1384.00 over the course of the illness.

Table 13: TB studies: summary of indirect and total costs

Country	Direct HH costs (as a % annual HH income)	Indirect HH costs (as a % of annual HH income)	Total costs data collection period	Source
Thailand (n=673) urban and rural	$126.0 (8.6%)	$51.0 (2.3%)	$177.0 (10.9%)	Kamolratanakul et al., 1999
India (n=304) urban and rural	$58.6 (14%)	$112.4 (26%)	$171.0 (40%)	Rajeswari et al., 1999
Zambia (n=202)	$46.9 (8.3%)	$26.7 (4.8%)	$73.6 (13.1%)	Needham et al., 1998
Tanzania (n=191)	$50.0 (9.3%)	$431 (80%)	$481 (89.3%)	Wyss et al., 2001

Notes: All studies were conducted between 1996-7 so all prices are in 1996 or 1997 US dollars. In half the studies indirect cost burdens were expressed either as a % of annual income (Kamolratanakul et al., 1999; Rajeswari et al., 1999) or as a % of monthly income (Mann et al., 2002; Needham et al., 1998). The latter have been converted to annual burdens by dividing by 12, but it is noteworthy that cost burdens expressed per month were much higher (e.g. **for Zambia TB indirect costs over the period before diagnosis were equivalent to 57% of an average monthly wage**). In the Thai study the analysis was stratified by socio-economic group so the mean figure for the whole sample was not available and the figure used is the indirect cost of TB for the middle-income (but still poor) group. For the Tanzania study the middle scenario for direct and indirect losses is used.

>> Figure 3 here

74. Across the four studies shown in Table 13 the total cost of TB as a proportion of household income is considerable, higher than the indirect cost of malaria (see Table 12), and above a "catastrophic" threshold of 10%. These catastrophic costs result from the double burden of direct and indirect costs, which in turn stem from the long duration of illness and, notably, delays to proper diagnosis and treatment.

75. Only two tuberculosis studies stratified the analysis of indirect costs by income group (Kamolratanakul et al, 1999; Mann et al., 2002) and as with direct costs, indirect costs as a proportion of income are higher for poor income groups. For example in Thailand income reductions amounted to 5% of the poorest group's annual income, 2.3% for the middle group and 3.3% for the group with above average incomes.

76. The financial hardship caused by TB, particularly for the poor, is likely to deter many poor people from seeking treatment (Needham et al., 1998; 2003). In Vietnam, for example, focus group discussion participants argued that lost income was a major cost of TB and that poor people needed to work and could not afford to seek treatment for fear of losing their job (Lonnroth, 2001).

77. In recognition of the financial difficulties caused by tuberculosis many countries have adopted a policy of free care for TB patients, but as discussed in paragraph 33, research indicates that patients often seek treatment from a range of private providers before attending a government facility for proper diagnosis, and even when they visit a government facility they may be charged (Kamolratanakul et al., 1999; Needham et al., 2003) or there are hidden non-medical treatment costs mainly for transport and special foods (Needham et al., 1998; 2003; Lonnroth et al., 2001). Government or community-

based support for poor patients to cover the indirect costs of illness and the 'hidden' direct costs of transport and special foods was not evident from any studies.

HIV/AIDS

78. The social and economic ramifications of HIV/AIDS for households and their different members are complex, long term and have wide scope, ranging from the time spent seeking treatment by the patient to the cost of mortality in terms of life time income foregone: the indirect costs of HIV/AIDS mortality in Chiang Mai, for example, were estimated in this way to give an average loss of life time earnings of US$28,700 over 30 years, or US$47,700 for those patients who had had a supplementary job (Pitayanon et al., 1997).

79. This section spends little time on the indirect costs of HIV/AIDS, because:

- the indirect costs of HIV-related opportunistic infections such as TB are likely to impose burdens similar to those discussed under TB (in fact a considerable proportion of the sample population in settings such as Zambia, Tanzania and to a lesser extent Thailand are likely to be HIV-positive patients);
- the indirect costs of HIV/AIDS for patients and caregivers in the latter phases of the disease, when the patient is very sick and requires long term and constant care, will inevitably be severe for the household (Bachmann & Booysen, 2003; Barnett et al., 2001; Hansen et al., 1998; Johnson et al., 2002; Knodel, et al., 2001; Pitayanon et al., 1997; Rugalema, 1998), despite the role of coping strategies in mitigating some of these impacts (World Bank, 1997);
- the indirect costs of mortality, in terms of lost income over an extended period, will inevitably be high (Pitayanon et al., 1997);
- analysis of the indirect costs of a long term terminal illness such as AIDS cannot be undertaken without reference to the coping or 'struggling' strategies used by households to deal with catastrophic direct and indirect cost of AIDS. For example asset sales may have long-term implications for future income and threaten the sustainability of the household economy.

80. In its latter phases HIV/AIDS makes ill and kills children and prime-age adults. From these basic demographic impacts on the household flow many indirect economic and social impacts, the most common and fundamental being:

- Loss of a breadwinner and income earning opportunities;
- Diversion of productive labour to caring.

81. Most evidence from Africa and Asia shows that HIV/AIDS morbidity and mortality causes a large loss of productive labour time and a decrease in household income (Ainsworth et al., 1998; Bachmann & Booysen, 2003; Bechu, 1997; Menon et al., 1997; Ngalula et al., 2002; Rugalema, 1998; World Bank, 1997). For example in Tanzania Rugalema (1998) found that among people living with AIDS men lost an average of 297 days of productive work over an 18-month period and women lost 429 days. In this context women lost more days because in general they work longer hours than men, performing both productive and reproductive activities, and are also more likely to be caregivers within the household (McIntyre & Thiede, 2003). In Thailand 35% of households with an AIDS death (n=116) felt a serious impact on agricultural production, with about half of family production lost, leading to a 48% reduction in family income (Pitayanon et al., 1997).

82. To understand the high indirect costs of HIV/AIDS it is necessary to go beyond time lost due to illness and to examine the evidence on coping strategies and their implications for households assets, income and expenditure patterns and thus household resilience to the economic impact of the disease, or vulnerability and processes of impoverishment that are triggered by the disease.

5. COPING, STRUGGLING AND IMPOVERISHMENT

83. This section briefly reviews evidence on the strategies that individuals and households mobilise to cope with illness costs. Coping strategies have become a frequently used term in the development literature, initially highlighted by work investigating household responses to famine and then to structural adjustment programmes (see for example Davies, 1993; Devereux, 1993; Kanji & Jazdowska, 1993; Moser, 1998; Swift, 1989). Coping strategies can be defined as a set of actions that aim to manage the costs of an event (shock) or process that threatens the welfare of some or all of the household members. Ultimately coping strategies are seeking to sustain the economic viability and sustainability of the household (Sauerborn et al., 1996b).

84. Coping strategies are vitally important for poor households faced with illness cost shocks, since the costs associated with serious illness can absorb a large proportion of the household budget and therefore require the mobilisation of substantial additional resources. Even minor illness costs can exceed the low and insecure daily or weekly budgets of the poor, who often survive on a daily wage that is barely enough to meet minimum food requirements (Russell, 2001). Ability to cope with the extra costs of minor illnesses, let alone more serious ones, is therefore essential for the health and livelihoods of poor households.

85. The concept of coping is now being applied to illness costs and the short- or long-term shocks they impose on the household economy (Goudge & Govender, 2000; McIntyre & Thiede, 2003; Russell, 1996; Sauerborn et al., 1996b). These studies have categorised and listed different types of strategy used to cope with illness costs, and in the earlier literature strategies were categorised into those that prevent costs (non-treatment) and those that manage or cope with costs.

86. Strategies to cope with costs were further divided into:

- *Strategies to cope with the direct costs of illness*: often adopted in sequence by households to minimise the risks to livelihood sustainability (for reviews see Russell (1996), Goudge & Govender (2000) and most recently McIntyre & Thiede (2003): using savings; pawning jewellery; borrowing or making claims from social networks; selling food stores; reducing consumption of non-essentials and then more essential items; diversifying income sources; selling unproductive assets; reducing investments (e.g. withdrawing a child from school); selling productive assets such as livestock, land or machinery.
- *Strategies to cope with the indirect costs of illness*: the above strategies are also used to cope with indirect costs, but a particularly important strategy for coping with the loss of a worker is intra-household labour substitution (Sauerborn et al., 1996b).

87. Studies that ignore coping strategies can lead to misleading conclusions about the costs of illness (Chima et al., 2003). On the one hand, ignoring the effects of borrowing, cuts to food consumption or asset sales may underestimate the total costs of illness to households. On the other hand, ignoring intra-household labour substitution that mitigates or negates any production or wage losses can lead to overestimation of indirect illness costs.

88. This point is pertinent to how coping strategies can be evaluated in terms of their affordability and sustainability. Put simply and as two extremes, do coping strategies:

- lead to high levels of debt, damage asset portfolios and threaten the future sustainability of the household economy and the household's existence as a social unit?
- mitigate the impact of illness costs and sustain the household's economy and existence?

89. Household ability to cope with illness costs, in terms of their access to strategies and the affordability and sustainability of these strategies (McIntyre & Thiede, 2003), is linked to two key factors:

- *Household vulnerability or resilience*: based on household asset portfolios that include human, physical and financial assets, and intangible social resources. The latter are the social networks and local organisations such as funeral societies and savings groups that household members can draw on for information, support and financial help at times of illness. Several studies have revealed the importance of social resources for households faced with illness costs beyond their budgets (Fabricant, 1992; Lucas & Nuwagaba, 1999; Russell, 1996; Russell, 2001; Sauerborn et al., 1996b, World Bank, 1997).
- *The type of illness*: the severity and duration of illness will influence the level and duration of illness costs, thus determining the coping strategies that households adopt and their affordability or sustainability over the medium term. A useful framework of four illness categories that necessitate different types of coping has been developed by McIntyre & Thiede (2003). The more serious and longer term the illness the more likely it is that the household will struggle or fail to cope with the costs, becoming impoverished or even failing to survive as a social unit.

The four illness categories are used below to structure the analysis of coping strategies.

Acute mild or moderate illnesses

90. Common illness shocks that affect most households, particularly those with several young children, are frequently managed through relatively small scale borrowing or use of savings (Russell, 2001). After the illness event households repay loans or replenish their assets. Although these illnesses pose least threat to the sustainability of many households' livelihood, they can still be a significant shock to vulnerable households with few assets. Research in Sri Lanka and Bangladesh shows that poor and vulnerable households with only a few assets left in their portfolios are likely to struggle to meet even these small extra-budgetary expenses (Pryer, 1989; Russell, 2001).

Recurring spells of illness such as **malaria**

91. Evidence from the malaria literature reports widespread use of intra-household labour substitution to cope with indirect costs and reliance on social networks or asset sales to cope with direct costs (Chima et al., 2003). The room for manoeuvre that households possess for labour substitution at times of malaria morbidity will crucially affect whether illness leads to loss of output or income. Chima et al. (2003) suggest that in parts of sub-Saharan Africa the potential for labour substitution within and between families might be quite high, but the empirical evidence on the extent of labour substitution and its impact on output is limited.

Permanent disability or chronic illness, such as **tuberculosis**

92. In developing countries with limited or no welfare safety nets, chronic conditions such as diabetes, hypertension and tuberculosis impose high costs over time if regular treatment is required and if the sick are recurrently incapacitated. The high costs of illness associated with TB were illustrated in the previous section, often going well beyond a poor household's monthly budget and absorbing a large proportion of annual income. The strategies adopted to meet these costs are either likely to be cost prevention strategies (do not seek treatment or abandon treatment) or relatively risky coping strategies to mobilise substantial additional sums of money. This review, however, could not find conclusive evidence on the relationship between TB costs, coping and impoverishment over time, although some of the strategies documented are likely to have serious implications for the households involved.

93. In Thailand, for example, the authors refer to the financial impact of TB for poor households as '*devastating*', with 15% of poor households selling property and 10% taking out loans to meet the direct costs of TB (Kamolratanakul et al, 1999). Several studies reported spending cutbacks on education for children, clothing, and "non-essentials" such as tobacco or alcohol (Kamolratanakul et al, 1999; Luhanga et al., 2001; Rajasweri et al., 1999).

94. In India, 67% of rural patients and 75% of urban patients incurred TB-related debts for the illness episodes studied (Rajeswari et al., 1999). In the same study 11% of schoolchildren of parents with TB (n=276) discontinued their studies and an additional 8% took up employment to support their families. Girls are more likely to be withdrawn from school for these caring and domestic tasks (Mann et al., 2002; Nhlema et al., 2002).

95. In Uganda an evaluation of the implications of TB costs for patients (n=32) and their families (Saunderson, 1994) revealed that 21 out of 22 subsistence farmers had lost production because of their disease, 8 out of 10 workers had stopped working, two wives had been divorced since their illness and several children had been withdrawn from school because of parents' inability to pay school fees.

96. Qualitative research also reported risky coping strategies and greater vulnerability to future shocks as a result of TB, for example in Vietnam focus group discussion respondents expressed how TB expenses had exceeded their available resources. The fact that patients had to spend 2 months in hospital in accordance with national guidelines increased expenses and more importantly led to income losses:

> "*The only alternative* (to hospital) *for them as poor people had been to practise self-medication or to borrow money, the latter resulting in debts that for some had taken years to pay back*" (Johansson et al., 2000: 41).

97. In most studies the overwhelming impression is that the cost burdens of TB can be extremely high for poor households, forcing risky coping strategies that reduce their asset portfolios, increase vulnerability to future shocks and posing questions about the sustainability of 'coping' strategies.

Terminal and steadily deteriorating health, such as **HIV/AIDS**

98. The high and recurring direct and indirect cost burdens of HIV/AIDS force a range of coping strategies that are being documented through a growing body of research (see for example Mutangadura et al., 1999). A recent study on strategies to cope with HIV/AIDS in Harare, Zimbabwe, for example, reports that more than 60% of households borrowed money to cover the direct costs of the disease, about a third had reduced expenditure on basic needs, and between 20-30% had sold assets (Mutyambizi, 2002, cited in McIntyre & Thiede, 2003).

99. Given the catastrophic costs that accompany HIV/AIDS for individuals and households in developing countries, many struggle rather than cope (Rugalema, 2000, cited in McIntyre & Thiede, 2003). The economic or social viability of the household often comes under threat. Studies from various parts of sub-Saharan Africa indicate that HIV/AIDS causes a process of impoverishment that coping strategies cannot mitigate.

100. The types of coping mechanisms identified in the literature (Bachmann & Booysen, 2003; Bechu, 1998; Knodel et al., 2001; Pitayanon et al., 1997; Tibaijuka, 1997; World Bank, 1997) include:

- Those that struggle with the direct costs of illness and smooth consumption levels: using savings and other stores; help from parents, extended family and other community actors; borrowing; sell unproductive then productive assets; cut food consumption; withdraw children from school to cut spending or increase labour supply.
- Those designed to alleviate indirect costs / labour losses: adjust household composition (but more common in Africa than Thailand); diversify income sources; take children from school to work; hire labour; grow different crops; decrease area cultivated; work longer hours.

101. The series of household surveys conducted in the mid-1990s (Ainsworth et al., 1998; World Bank, 1997) were a little more optimistic about household resilience and the sustainability of coping strategies. For example the survey in Cote d'Ivoire indicated a certain degree of household resilience, at least in the medium term, through recovery of consumption levels following an AIDS death (Bechu, 1998), and the prevention of household collapse:

> "*Survey data suggest that when it comes to coping with the economic impact of such a loss, households in general are surprisingly resilient*" (World Bank, 1997).

102. Such tentative conclusions may have been a little optimistic, as the note in paragraph 37 suggests. Table 14 provides a case study to illustrate the serious impact of HIV/AIDS on the household economy, and compares this impact with a non-HIV/AIDS death.

103. AIDS deaths may impose a larger burden than non-AIDS deaths on households because: (a) there is a high chance of multiple cases within the household; (b) stigma generates social exclusion; (c) often many households within a community are affected reducing community resilience and ability to cope.

Table 14: The impact of HIV/AIDS on household livelihoods in Northern Thailand

Household coping strategy	HIV/AIDS death (n=116)	Non-HIV/AIDS death (n=100)
Use savings		
• % households using savings	60	53
• average savings used	US$837	US$664
Consumption expenditure reduced		
• % hhs reducing expenditure	52	50
• % change in hh food consumption	42	25
• % hhs seriously affected	29	30
Sale of assets		
• % hhs selling assets	19	12
Borrowing		
• % hhs that borrowed	11	20
• % borrowing from bank	8	29
• % borrowing from moneylender	23	21
• % borrowing from relatives	46	25
• % borrowing from ROSCAs	23	25
• average amount borrowed	US$2671	US$953
Transfers in		
• % hhs receiving transfers in	15	7
• amount in year	US$319	US$579

Source: Pitayanon et al. (1997)

104. As a consequence of illness costs and coping strategies, common impacts identified in the literature include:

- Reductions in income (Bachmann & Booysen, 2003), of up to 70% in some cases in Thailand (Kongsin & Watts, 2000; Pitayanon et al., 1997);
- Reduced consumption of basic needs including food, although some evidence suggest that this can recover (Bechu, 1997; Kongsin & Watts, 2000; Pitayanon et al., 1997);
- Withdrawal of children from school (Lundberg & Over, 2000);
- Sale of productive assets undermining future economic viability of household: for example in Tanzania 29% of HIV deaths led to property being sold (Ngalula et al., 2002): in Uganda (Menon et al, 1998) two thirds of households experiencing an HIV death sold property to pay for medical treatment. The percentage of households owning durable goods such as a motor vehicle, radio, or bicycle declined over the 3 year panel survey among households that experienced an HIV-related adult death.
- Impoverishment (Kongsin & Watts, 2000) and dissolution of households; the growing problem of orphaned children;
- Emotional trauma / stress.

105. Finally, there is mounting evidence that women bear a heavier burden of the household impact of HIV/AIDS at all stages, from early childhood when they may be allocated less food and withdrawn from school as the household copes with the costs of AIDS, through to stigmatisation on the death of a husband and greater social exclusion, and finally a lonely and impoverished widowhood (Barnett et al., 2001).

6. CONCLUSION

Summary of findings

106. Nearly all the studies reviewed presented evidence on the costs of illness, and some highlighted ways in which health service weaknesses had contributed to high direct and indirect costs for patients, and how costs might be lowered through improvements to service delivery or financing. No studies had been designed to research how different health service provision arrangements affected household costs of illness. Thus there was no clear evidence to show how health services had reduced household costs (for example pre- and post reform, or comparing similar study settings against one another with a comparable methodology).

107. Some studies, however, did indicate the more obvious service characteristics that offered protection against high direct illness costs, for example in Sri Lanka free hospital treatment protected a range of socio-economic groups from high direct cost burdens for chronic illness and hospital admission. In Zambia, an insurance scheme used by TB patients was costly to purchase but reduced medical costs over the duration of the illness. In any setting where poor households can obtain protection against out-of-pocket payments at the time of illness, for example through tax-based financing or voluntary health insurance coverage, direct costs are likely to be lower.

108. **Direct costs of illness** among the all illness cost studies were mainly between 2.5% and 7.0% of household income with two studies estimating the cost burden to be above 10%. The direct costs of malaria as a single disease were lower than for all illnesses, but TB and HIV/AIDS imposed very high direct cost burdens on households. Mean household spending on TB ranged from about $50.00 to over US$100 over the treatment period, which imposed very high cost burdens of between 8% and 20% of annual household income. Given that many of the households in these studies were poor and struggling to meet basic food needs, the considerable direct cost burdens imposed by TB were likely to be unaffordable and trigger asset and borrowing strategies. Latter stage HIV/AIDS treatment and funeral costs were very high with researchers estimating them to be catastrophic, absorbing anything from 50% to 100% or more of annual income. Funeral costs made up a substantial proportion of household expenditure, partly because treatment was not available or at least deemed to be ineffective and patients were cared for at home before they died.

109. Direct costs burdens were regressive. Although the poor spent less on treatment than other income groups due lack of access, inability to pay or greater use of public services, poor households' spending made up a higher proportion of monthly or annual income. Evidence showed that the direct costs of health care for poor households ranged from 15% to 20% of household income. High cost burdens for the poor are likely to trigger asset or borrowing strategies.

110. The review identified high non-medical direct costs. While medical costs for consultations and pharmaceuticals could be significant, particularly in urban contexts where there was a thriving private sector, non-medical costs for transport, special foods and funerals were also considerable. For example in Sri Lanka special foods to aid recovery from malaria accounted for 46% of household spending on the disease, and in Zambia spending on non-medical items such as transport and food made up 78% of

direct costs, with households spending an average of $21.00 per month (44% of a month's income) on special foods.

111. Direct cost burdens tended to be exacerbated by demand and service provision features. Firstly, across studies there was widespread use of private providers which increased mean direct cost burdens substantially. For TB, for example, studies in India, Zambia and Vietnam showed that patients preferred to spend money on herbal remedies and to use private sector providers (traditional and allopathic). Factors encouraging use or private providers for a range of diseases included their "close to client" location and easy access, reducing loss of time and wages that could be incurred at crowded public facilities where long waiting times were commonly experienced. Poor quality of care at public providers encouraged people to use the private sector. In particular people were willing to pay money for better inter-personal quality of care at private providers, which was especially important for serious diseases where patients needed staff sympathy, commitment, listening and trust. Public sector disease control measures for communicable diseases such as TB (registration, DOTS) were also perceived to be inflexible, inconvenient and a threat to privacy (the stigma of TB and the desire to keep the condition secret deterred use of public TB programmes in some instances). Secondly, most studies showed that hospital care generated high direct costs, especially for IP services, due to high user fees and the long distances people had to travel to reach a hospital. Centralised provision of TB testing and treatment services, for example, exacerbated direct and indirect costs of treatment.

112. When presenting and interpreting direct cost data it is worth remembering that a range of access barriers, including financial constraints, prevent the poorest and most vulnerable from seeking treatment at all, causing negligible direct costs but possibly exacerbating indirect costs due to lack of treatment. If access to health services is improved the direct costs for some users will increase, but indirect costs may decrease. This point is worth considering with respect to TB and the HIV/AIDS epidemic, since wider access to better treatment and in particular anti-retroviral therapy will have implications for the balance of direct and indirect costs of illness.

113. **Indirect and total costs of illness** were often as significant or more significant than direct costs, and when combined with direct costs the total costs of illness imposed very high cost burdens on households. Even in Sri Lanka, for example, where public service delivery is free at the point of delivery, the direct and indirect costs of all illnesses combined imposed a total mean cost burden of over 10% on households. The indirect costs of malaria, TB and HIV/AIDS were usually a substantial and dominant cost component due to the nature of these diseases, and studies showed that the total costs of malaria, TB and HIV/AIDS were potentially catastrophic.

114. Household **resilience or vulnerability** to illness costs depended on the severity and duration of illness, as well as household asset portfolios that influenced ability to cope, and the sustainability of coping. Evidence on TB and HIV, for which the costs of illness were highest, indicated that households struggled to cope and adopted strategies that were negative for asset portfolios, potentially leading to impoverishment.

Policy debates

115. Policy research and debates need to address access constraints, the factors that increase costs for poor households, and to support a range of other assets and strategies

that households use to cope with illness costs. Policy debates need to be broadened and to be made more innovative, focusing not only on how to mitigate direct medical costs, but also how to mitigate non-medical direct costs such as transport and special foods, and more importantly the indirect costs of illness and how to support coping strategies.

116. For example the costs of illness in Sri Lanka raise an important question for health policy-makers and researchers: even universal health service coverage cannot protect households from the full range of costs that households incur, particularly indirect costs but also non-medical costs. Are there innovative measures which governments, working alongside NGOs and community-based organisations, can develop to help protect households from these 'hidden' costs?

117. To reduce or mitigate **direct medical costs**, the service delivery weaknesses that increase direct costs to households need to be addressed, for example:

- Expand coverage of tax- or insurance-based financing systems to protect poor households from out-of-pocket payments for health care, since these payments impose significant barriers to access and considerable cost burdens on the poor. Protection against higher hospital costs is particularly important (Arhin, 1995; Ranson, 2002; Russell, 2001; WHO, 1999; World Bank, 2000).
- Improve quality of care at public facilities, focusing on reducing waiting times and better inter-personal quality of care, in order to attract patients from the private to the public sector and reduce direct costs. Building community and patient trust in lower level public facilities is a key challenge.
- Invest in "closer to client" health services (WHO, 2001) to reduce excessive transport and time costs identified in the literature, and also to reduce the direct medical costs incurred at private (but less effective) providers. For example decentralisation within an urban context has been advocated as a reform measure to improve patient access to public TB diagnostic and treatment services and to reduce demand for private services. Decentralisation may reduce patient costs substantially, but a range of service delivery capacities need to be in place before decentralisation can be implemented effectively (Needham & Bowman et al, 2003);
- Because of access barriers of the poor and regressive cost burdens, introduce a greater equity focus or targeting into specific programmes, for example malaria prevention and treatment and TB treatment (Nhlema et al., 2003; Worrall et al., 2002;). Although malaria incidence by socio-economic group within countries does not show any clear poor-rich gradient (Worall et al., 2002), the evidence about the economic consequences of the disease does show that poor people suffer more serious consequences due to lack of access to prevention and treatment and higher cost burdens. There is a need to target anti-malaria campaigns so that the poor gain better access to prevention and treatment at lower cost.

118. The studies reviewed highlighted the considerable economic burden imposed by 'hidden' **non-medical direct costs**, in particular the cost of special foods purchased by families to help deal with malaria or TB. Although the value of nutritious food cannot be doubted, it does not provide a cure and the expense has opportunity costs for poor patients, reducing ability to access and pay for treatment. Policy-makers need to consider ways of reducing these costs, possibly starting with better information about nutrition for diseases such as malaria and TB.

119. Cost of illness studies show quite clearly that health services cannot cover all the costs of illness borne by patients and their families. In addition to non-medical direct costs, notably transport, special foods and funeral expenses for AIDS victims, the review has also highlighted the **potentially catastrophic burden of indirect costs**, and the **important role of household assets** and coping strategies. Such asset strategies in the case of serious illness, however, lead to impoverishment and household dissolution. In the context of the HIV/AIDS epidemic, it is not only households but social relations in the wider community that are being adversely affected, threatening agricultural production and educational levels and reducing households' ability to cope.

120. Policy-makers, informed by new research initiatives, therefore need to support both household assets and coping strategies, and wider community responses, that enable households to cope, particularly with the heavy cost burdens of HIV/AIDS. Government agencies must link with NGOs and community-based organisations that work to support people, not only with the 'hard' matters of savings and assets on which this paper has focused, but also through counselling and caring initiatives. Supporting the future assets of the community – children orphaned by AIDS and withdrawn from school – is a particularly urgent priority for governments.

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Figure 1: Framework of key variables relating to the economic burden of illness for households

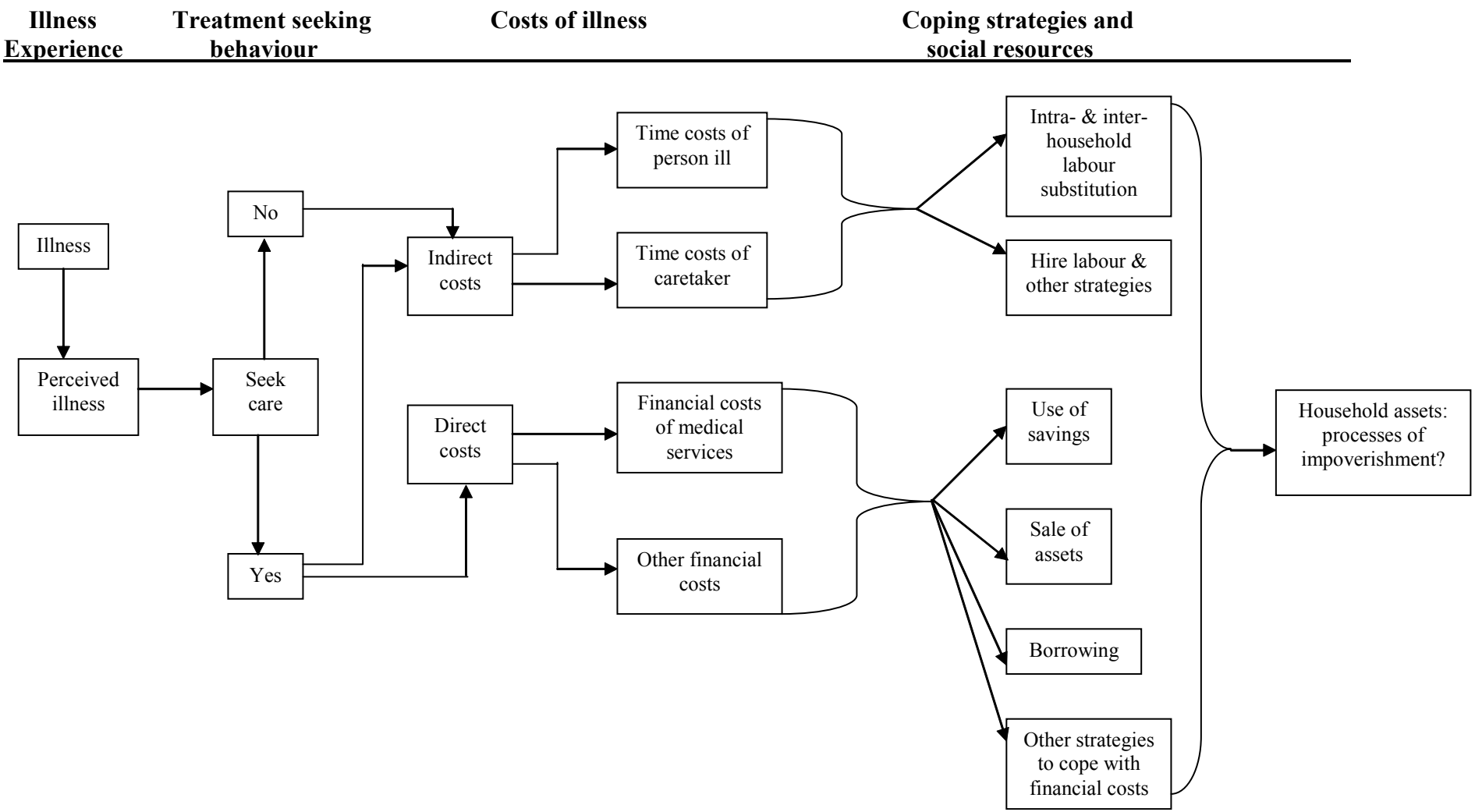
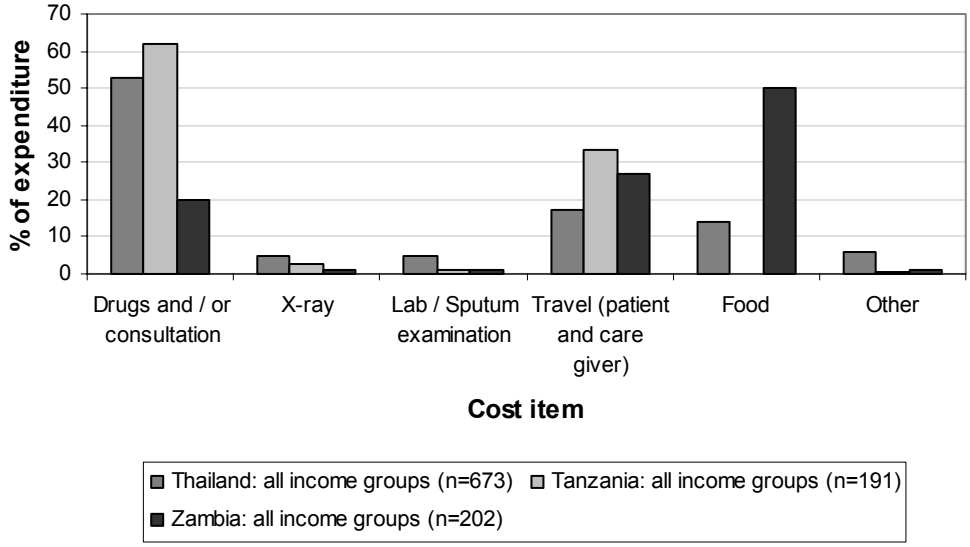


Figure 2: Distribution of household spending on TB treatment across cost items



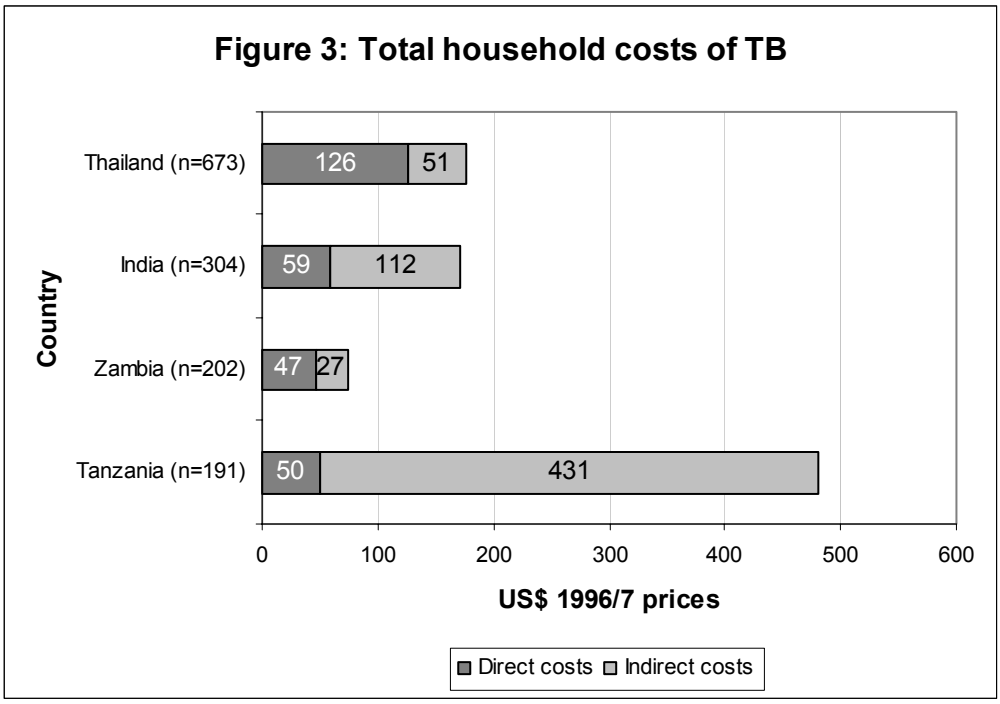


Figure 3: Total household costs of TB
Thailand (n=673)
India (n=304)
Zambia (n=202)
Tanzania (n=191)
126
51
59
112
47
27
50
431
Country
0
100
200
300
400
500
600
US$ 1996/7 prices
Direct costs
Indirect costs