A REVIEW OF STUDIES DEALING WITH ECONOMIC AND SOCIAL CONSEQUENCES OF HIGH MEDICAL EXPENDITURE WITH A SPECIAL FOCUS ON THE MEDICAL POVERTY TRAP

ALPS Systematic Literature Review 3

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1. Introduction

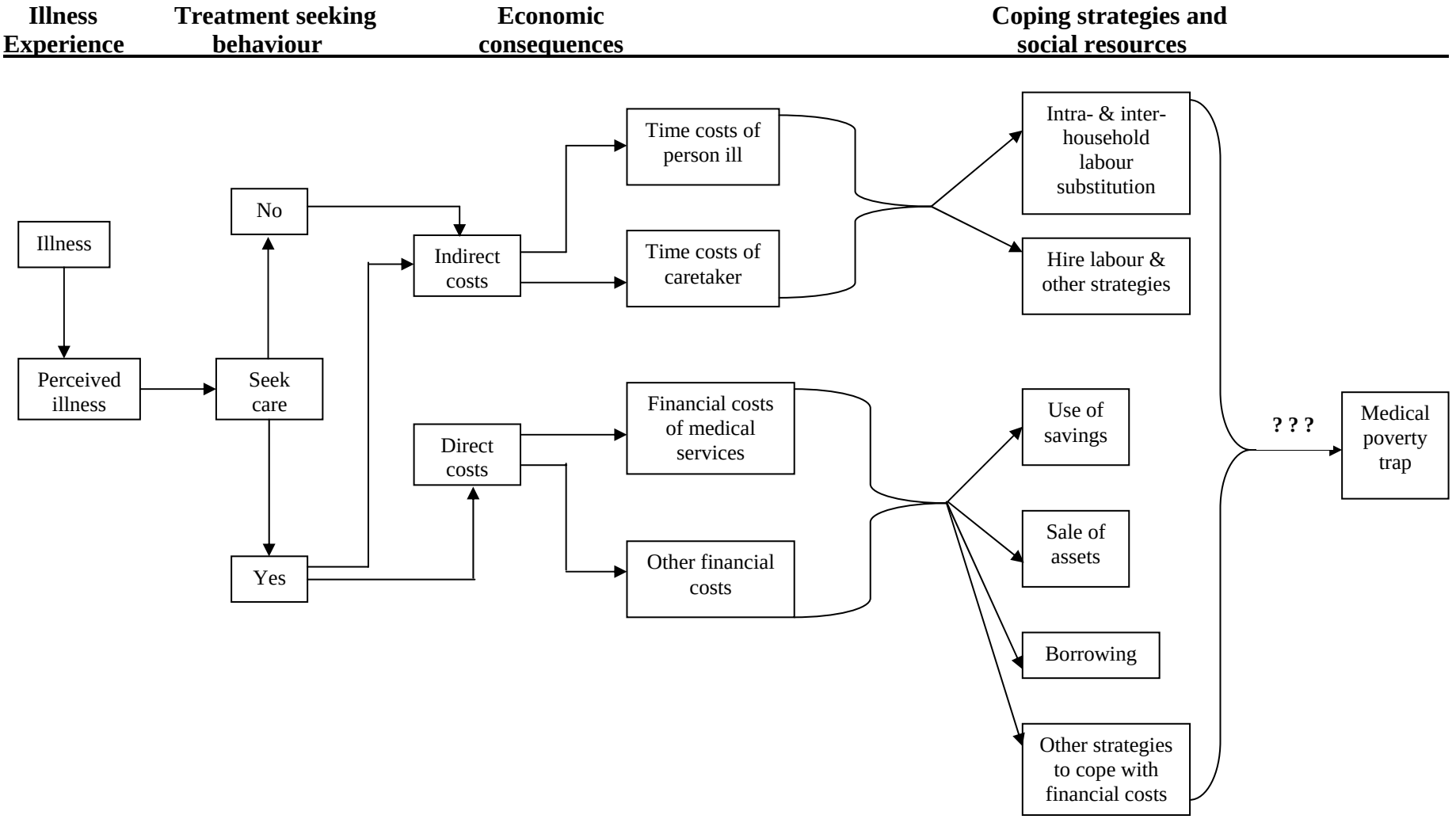
This paper is part of a series of four literature reviews that have been undertaken for the Affordability Ladder Program (ALPS) research program. ALPS is adopting a household level approach to considering issues of access to and affordability of health services, as well as the consequences of illness and health service use, for different households.

This paper focuses on the economic and social consequences of illness for households. Figure 1 below contains a flow-chart presentation of the key issues that need to be considered from the household perspective relating to these consequences. The starting point is the occurrence of illness and whether or not an individual perceives this as ill-health. Once an individual perceives that they are ill, the individual and other members of the household make a decision either to seek treatment (whether this is self-treatment or visiting some form of health care provider) or not to treat the illness. As these issues are covered in the previous review paper, they will not be considered in this paper.

The focus of this review is on the next stages of the illness process. In particular, there is detailed consideration of the economic consequences of illness. There is a range of direct financial costs arising from the treatment seeking process, while indirect costs, in the form of productive time lost, can be incurred whether one seeks care or not. Various strategies can be adopted to cope with both the direct and indirect costs of illness. While many of the coping strategies are internal to the household, the existence of social resource networks enables households to engage in a broader range of coping strategies. The success or failure of households in coping with the economic consequences of illness determines whether they are able to protect their asset base and incomes or whether the household falls into the medical poverty trap.

The paper is structured in terms of the stages outlined in Figure 1. Section 2 briefly outlines the review methods. Section 3 is devoted to the economic consequences of illness, while section 4 reviews household coping strategies and evidence on the medical poverty trap. A special focus on HIV/AIDS is presented in section 5.

Figure 1: Simplified flow-chart of key issues relating to the economic and social consequences of illness



2. Methods

The aim of this review was to identify and critically assess literature relating to the economic and social consequences of illness at the household level and household responses to these potential consequences.

Comprehensive searches of electronic databases were conducted, going as far back as 1966 where such data were available electronically. A range of key words relating to economic and social consequences of illness and household responses were used in these searches (e.g. access, utilisation, cost, coping strategy, poverty ratchet, social resources). These were either combined with generic health-related terms (e.g. illness, ill-health, health care) or specific health problems (e.g. HIV/AIDS, diabetes, malaria). Electronic searches were also conducted for authors known to have undertaken research in this area (e.g. Sauerborn, Russell).

Box 1 summarises the major databases searched and the number of citations identified. This was supplemented by a search of certain internet sites, including:

- Regional Network for Equity in Health in Southern Africa – http://www.equinetafrica.org
- Institute of Development Studies (including ID21 site) – http://www.ids.ac.uk/ids
- World Health Organisation – http://www.who.org
- World Bank – http://www.worldbank.org

Box 1: List of databases searched and number of references identified

Name of electronic database	Number of references
Medline	5,284
ISI Web of Knowledge (including Social Science Citation Index, Science Citation Index, Arts & Humanities Citation Index)	722
Science Direct	1,094
Cinahl	157
Social Sciences Abstracts (SSA)	56
TOTAL	**7,313**

International colleagues were also requested to provide copies of 'grey' literature (e.g. unpublished research reports). A 'snowball' technique was used to follow up key documents cited in publications identified through the electronic searches.

Both authors independently reviewed abstracts of the papers identified through the above techniques to determine whether or not the full text should be reviewed. The inclusion criteria were relatively broadly specified, in that the document should contain information on, or describe appropriate methodologies for obtaining information on:

- Economic consequences of illness (direct and/or indirect costs); and
- Social resources and strategies for coping with illness and its economic and social consequences.

The key exclusion criteria related to studies that did not focus on the individual or household level (e.g. macro-level cost of illness studies).

Of the studies identified through the electronic and other searches, a total of 62 were included in this review. Information was initially abstracted in the form of an annotated bibliography and then analysed to identify key issues and trends. The results of this review are presented in the following sections.

3. Economic consequences of illness and health care use

3.1 Definitions and methodological issues in cost of illness studies

The economic consequences of illness for which health care is sought fall into two broad categories, namely direct and indirect costs. As indicated in Figure 1, if no care is sought, only indirect costs could be incurred. Direct costs have been defined as "the cost of medical, non-medical, and patient- or family-related resources used to prevent, diagnose, treat, or rehabilitate persons with a disease" (Begley et al., 1999: 40). Total direct costs include costs to the health service user, health insurers and government. Given the focus of ALPS on households, direct costs for this review refer to all financial payments made by households in the process of seeking and obtaining care. Indirect costs refer to the costs of time lost to undertaking normal productive activities due to illness, health care seeking activities and premature death. While many studies attempt to determine the impact of these indirect costs on society

as a whole, in this review the emphasis is on the costs of lost productivity to a household.

These costs have been quantified in a range of what are broadly termed 'cost of illness' studies. Many of the 'cost of illness' studies were intended to provide information on the total direct and/or indirect costs of a specific disease in a particular country, that could then be used to advocate to authorities for a larger share of health care resources for that particular disease. In this paper, we are concerned about the costs to individual households of illness and hence, many of the cost of illness studies do not provide appropriate information. Unfortunately most of the studies that provide only aggregate, as opposed to household, level data relate to the cost of illness in high-income countries, while most of the studies focussing on household level issues relate to low- and middle-income countries. Thus, very little useful information could be found on the cost of illness to households in high-income countries.

It is important to stress at the outset that the focus is on households rather than on the individual who is ill. As noted by Sauerborn and colleagues: "While illness occurs in individuals, its costs do not fall on ill individuals alone. …It was the household … that made decisions regarding health care choice and the allocation of time and financial resources to treatment. Sickness of one member affects the time use of healthy members and influences household decisions regarding the allocation of financial resources." (Sauerborn et al., 1996a: 298).

Direct costs

Direct costs of health care include the costs of health care goods and services, such as payments for consultations (whether official or unofficial), diagnostic tests and drugs. However, these are not the only costs that have to be borne by a patient and their family. The cost of transport to a health facility for the patient, and frequently for an accompanying family member, can be substantial. There are other costs that are sometimes overlooked such as food for a hospitalised patient when no or inadequate food is provided by the hospital, and accommodation costs for a family member accompanying a patient who is hospitalised in a facility far from their home. Another direct cost of illness, that is often given insufficient attention but is of increasing

significance, particularly in countries facing a serious AIDS epidemic, is the cost of funerals (Tibaijuka, 1997).

Unfortunately, many of the 'cost-of-illness' studies do not distinguish between costs that are borne by the household and costs that are covered by government health departments, health insurance schemes and other health care financing intermediaries. In addition, many of the estimates from these studies are only presented in aggregate terms as the economic impact in a country rather than the average cost to individual households. Thus, there are a limited number of studies that have concentrated on household costs of illness and treatment seeking.

Indirect costs

While direct costs only focus on financial consequences, the inclusion of indirect costs allows for a more comprehensive review of all economic consequences. Indirect costs include productive time losses to the person who is ill and to other household members. Those who are ill may incur lost productivity costs when they seek care (time travelling to and from the facility and time waiting to be examined, for a diagnostic test to be performed or for medicines to be dispensed), or when they are so ill that they cannot work. Other household members may also incur lost productivity costs when they accompany a sick person in seeking care or when they engage in home-based care-giving.

Once again, the majority of the 'cost of illness' studies have estimated the total cost to the economy of a particular illness rather than costs that are born by the household. Often, total productivity loss is estimated as the number of days off work due to ill-health, and sometimes the years of productive life lost due to premature death, multiplied by the average wage rate (Chima et al., 2003). A similar approach is used to calculate productivity losses due to care-giving activities. A concern about this approach is that it does not account for time loss consequences to those who are not regarded as economically active (e.g. unemployed or elderly household members). This serves to further undervalue individuals that already tend to be marginalised.

There are a number of challenges in quantifying the costs of productive time lost at the household level. For example, how does one quantify the cost of time lost in

subsistence farming and non-remunerated household activities? Most frequently, the cost of employing another person to undertake these activities, i.e. the market value of this service, is used as the basis for estimation (Rothermich & Pathak, 1999; van Roijen et al., 1995). However, this may lead to an overestimation of the cost of productive time lost, particularly if there is intra-household labour substitution (i.e. another household member undertakes the work of the person who is ill). Even where this occurs, there are still economic consequences as that household member cannot undertake their normal activities. It may be a child that stops attending school to work in place of a sick parent, which may have implications for their level of educational achievement and future work prospects, particularly if adult family members are frequently ill. A wife may work in the fields while her husband is ill, and as a result be unable to undertake household chores, some of which could have implications for the health of other household members (e.g. fetching clean water, cooking nutritious food). If there is no intra-household labour substitution and no employment of someone else to undertake these activities, the household may lose wage income or other income (e.g. from the sale of crafts) during the period of illness. Alternatively, crop production may not be as successful as usual in the case of subsistence agricultural activities. These issues highlight the difficulty of accurately estimating the actual burden of indirect costs of illness for households.

Sources of data on direct and indirect costs

In order to accurately and comprehensively calculate direct and indirect costs for households, information has to be obtained directly from the household itself. Most frequently, this is done using a household survey questionnaire with detailed questions on the actual medical and non-medical financial costs incurred during a recent illness (using a recall period of one month or less), as well as information on the time devoted to obtaining care and days of sick leave. Average wage data for that geographic area are then used to estimate the indirect costs. Questions may also be included on the time other household members devote to caring for the sick individual.

Recently, an alternative approach has been recommended for the collection of such data, namely requesting a household to maintain a cost diary for the duration of an illness (Goosens et al., 2000). All medical and non-medical financial costs incurred

by the household can be recorded in this diary. In addition, information on time lost to productive activities, and actual loss of wages, can be recorded. It is argued that "while questionnaires usually rely on momentary recall, diaries provide information prospectively over a period of time, resulting in a minimum recall error … and therefore generally in better and more complete reporting of the data" (Goosens et al., 2000: 689).

The following sections present empirical evidence on the extent of direct, indirect and total costs of illness to households. We have focused on presenting information from those studies that allowed for this cost data to be expressed as a percentage of household income. It should be noted that some studies present data for monthly illness costs and income while others present the same data for a one year period and are thus not directly comparable. However, illness costs as a percentage of income should be similar whether presented on a monthly or annual basis ***if*** there are no major seasonal variations in illness patterns and income generating potential.

3.2 Empirical evidence on the direct costs of illness and treatment

Extent of total direct costs

Direct cost estimates vary widely across countries and according to the methodology of the study (e.g. many studies only focus on the direct costs of health care goods and services and ignore transport and other costs). However, the majority of studies suggest that health care expenditure tend to be less than 10 percent of household income on average (see Table 1). Some regard 10% of household income being consumed by health care expenditure as the cut-off point for catastrophic expenditure levels (Prescott, 1999; Ranson, 2002).

Table 1: Overview of direct costs from recent studies

Country and source	Health care expenditure as % of household income
Paraguay (Makinen et al., 2000)	2.5
Thailand (Makinen et al., 2000)	3.4
Burkina Faso (Makinen et al., 2000)	4.4
South Africa (Makinen et al., 2000)	4.9
Guatemala (Makinen et al., 2000)	16.0
Burkina Faso (Sauerborn et al., 1996a)	6.2
Uganda – two rural districts (Lucas & Nuwagaba, 1999)	9.3-11
Sri Lanka (Russell, 2001)	6.5

Notes: The Makinen *et al.* studies only include direct costs of health care goods and services while the other studies all include a broader range of direct costs (e.g. transport, extra food) All of the results, except for the Uganda and Sri Lanka studies, are expressed as estimated total household health care expenditure in a year as a % of annual household income. The Uganda and Sri Lanka studies are expressed as average household expenditure on health care and other health care related expenses in the preceding month as a % of average monthly household income.

Clearly, the percentage of household income devoted to health care expenditure varies across individual households and according to the type of illness or health care event. Hospitalisation is recognised as potentially imposing catastrophic costs on individual households. Maternity care can also impose considerable costs on households. A study in Bangladesh, where there is only a nominal registration fee for maternity care but high direct costs for medicines, transport and food etc., found that while the majority of households (52%) spent less than 50% of their monthly household income on the direct costs of delivery, 21% spent 50-100% of their income and a further 27% spent 1 to 8 times their monthly income (Nahar & Costello, 1998). In countries where substantial hospital fees are charged for maternity care, the birth of a baby can result in significant financial consequences for households.

The direct costs of long-term fatal illness, particularly AIDS, have the most devastating effects on households. A study in Tanzania has estimated that the direct costs of treatment for a person living with AIDS during a six month period is about 64% of per capita household income for the same period (Tibaijuka, 1997).

Distribution between different types of direct costs

It is useful to explore what components contribute most to the overall burden of direct costs. Once again, the distribution of direct costs is highly variable according to the

health system of each country (e.g. whether or not user fees are charged, geographic accessibility of facilities, whether there is substantial insurance cover or whether out-of-pocket expenditure dominates, etc.). It is therefore difficult to generalise results of such context specific findings.

The empirical evidence does suggest that the cost of drugs often contribute a sizeable share of direct costs. For example, drugs accounted for 62% of direct costs for mild malaria and 70% for severe malaria in Ghana (Asenso-Okyere & Dzator, 1997). Similarly, drugs contributed 63% of the costs of treating lymphatic filariasis in India (Babu et al., 2002). In the case of a normal delivery in Bangladesh, drugs accounted for 39% of direct costs and 55% for caesarean section deliveries (Nahar & Costello, 1998). As an average of all health care direct costs, irrespective of type of illness, drugs accounted for 33% in Sri Lanka (Russell, 2001).

It has also been found that transport costs, either for the patient or for both the patient and an accompanying person, are not insignificant. Transport costs accounted for 14% of the direct costs of malaria in Ghana (Asenso-Okyere & Dzator, 1997), 22% for malaria in Sri Lanka (Attanayake et al., 2000), 20% for maternity care in Bangladesh (Nahar & Costello, 1998), and 14% for overall health care in Sri Lanka (Russell, 2001).

Costs that are often not taken into account, such as costs of nutritious food for a sick family member and the costs of accommodation and food for an accompanying household member, can also be considerable. For example, these 'other' direct costs were found to be as high as 18% in India for chronic lymphatic filariasis (Babu et al., 2002), 27% and 24% respectively for normal and caesarean section deliveries in Bangladesh (Nahar & Costello, 1998) and 46% for malaria treatment in Sri Lanka (Attanayake et al., 2000).

Another direct cost that could increasingly impose a substantial burden on households is that of unofficial fees. However, very few studies have attempted to quantify the extent of unofficial, informal or 'under-the-counter' fees. While Russell (2001) found that informal fees were virtually non-existent in Sri Lanka, a recent study in Bulgaria specifically focused on this issue and found that they can be substantial. Nearly a

quarter of interviewees had made informal payments, the majority in the form of gifts but some in the form of cash. The median value of gifts was equivalent to 1.5% of average monthly salary or 7% of the minimum monthly salary while the cash payments were equivalent to 4.4% and 21% respectively (Balabanova & McKee, 2002). Another study in Bangladesh found that on average per patient, unofficial payments at public health facilities were 12 times more than official fee payments. Although high income patients pay the highest level of unofficial fees in absolute terms, for the lowest income group unofficial fees amounted to nearly 72% of average monthly income, while these payments were only 43% and 32% of average monthly income for the middle and high income groups respectively (Killingsworth et al., 1999). As public funding of health services decline and the real salaries of health workers fall, the household burden of paying informal fees is likely to grow.

This section has highlighted that it is important not only to quantify the cost of official consultation fees when considering the direct costs of seeking care, but also to document the cost of drugs, unofficial fees, transport, different than normal food for the sick person and other frequently ignored financial costs.

Evidence on the direct costs of treatment for different socio-economic groups

There is considerable and consistent evidence that the direct costs of health care impose a far greater burden on poor families than on high-income households. For example, a study in Thailand found that annual household direct costs were equivalent to 21.2% of annual household income in the lowest income quintile, but only 2.1% for highest income quintile (Pannarunothai & Mills, 1997). In this study, the greater relative burden on poor households is not only attributable to the lower income levels, but also to the lower insurance coverage in the lowest income quintile households (33%) compared with the highest income quintile (62%).

A study of hospitalisation costs in China found even greater differentials, with the costs per hospital admission accounting for 59% of net annual household income for poorest, 18% for the middle-income group and 8% for highest income group (Wilkes et al., 1997).

3.3 Empirical evidence of the indirect economic consequences of illness

Indirect costs are less frequently quantified in cost of illness studies than direct costs, partly due to the methodological challenges of obtaining accurate indirect cost estimates. The majority of studies that have quantified both cost categories suggest that indirect costs of illness are in fact greater than the direct costs (Koopmanschap & Rutten, 1994). The ratios of indirect to direct costs from some recent studies are summarised in Table 2.

Table 2: Overview of relationship between indirect and direct costs from recent studies

Country, disease and source	Ratio of indirect to direct costs
Rwanda, Malaria (Ettling & Shepard, 1991)	3.6
Sri Lanka, Malaria (Attanayake et al., 2000)	3.2
Burkina Faso, all illness (Sauerborn et al., 1996a)	2.5
Ghana, Malaria (Asenso-Okyere & Dzator, 1997)	2.1
Sri Lanka, all illness (Russell, 2001)	0.8
Nigeria, Malaria (Onwujekwe et al., 2000)	0.7
Nigeria, all non-malaria illnesses (Onwujekwe et al., 2000)	0.4

While some of the studies may have overestimated indirect costs (see earlier discussion on methodological challenges), some studies have been very cautious in only estimating income loss and costs of paying replacement labour etc. that were actually incurred by individual households. One such study, although finding that indirect costs were lower than direct costs, found that indirect costs are not insignificant and were equivalent to 5% of monthly household income (Russell, 2001).

Indirect costs differ considerably, both in absolute terms and relative to direct costs, between different types of illness. Certain chronic illnesses can impose a considerable burden on households. A study in India found that chronic lymphatic filariasis patients lose up to 19% of productive workdays per year (Babu et al., 2002). Lost productive time costs are not only experienced by those who are ill, but also by other household members. The burden on other household members can be particularly severe in long-term terminal illness such as AIDS (Hansen et al., 1998). A number of researchers have noted that the time costs of healthy household members are often as large as the time costs of those who are ill (Sauerborn et al., 1996a).

From a gender perspective, the time lost to productive activities is often greater when women are sick. For example, a study of people living with AIDS found that whereas men lost an average of 2,376 working hours (or 297 days) over a period of 18 months, women lost 3,432 hours (or 429 days) of productive time (Rugalema, 1998). This is due largely to the relatively long hours that women work, particularly when household maintenance activities are included. One study documented the differential working days for men and women in Burkina Faso. In the season with limited agricultural activity, women have 5.7 hours of productive work per day on average compared with 3.8 for men, while there is a lower differential between women and men (6.8 and 6.6 hours per day respectively) during the season of agricultural activity (Sauerborn et al., 1996b). Women, being the primary household caregivers, are also more likely to face loss of productive time when caring for ill household members.

Unfortunately, no empirical evidence could be found on the indirect costs of illness for those who do not seek care. This is an area that would be important to investigate in future studies.

In summary, indirect costs are frequently ignored in studies on the consequences of ill-health for households. There is considerable evidence that these costs are not insignificant, and are in the case of some illnesses greater than the direct costs. As such, they should be adequately documented in any study concerned with the economic consequences of illness.

3.4 Overall economic consequences

When one combines the direct and indirect costs of illness, the total economic effect of illness on households is frequently above 10% of household income. For example, the total household costs of malaria per year were as much as 18% of annual income in Kenya and 13% in Nigeria (Leighton & Foster, 1993), and nearly 19% of annual income in a newly settled part of the Amazon region in Brazil (Sawyer, 1993). Total costs for all forms of illness totalled 11.5% of monthly household income in Sri Lanka (Russell, 2001), and about 11% of average monthly income in Nigeria (Onwujekwe et al., 2000).

As with direct costs alone, there is consistent evidence that total economic costs impose a heavier burden for the poorest households. While the average total costs of malaria were 7.2% of annual household income in Malawi, they were equivalent to 32% of household income in the lowest income households, even though the absolute value of these costs for the poorest households of $25 per annum was lower than the average of $40 (Ettling et al., 1994). A more recent study also highlighted the skewed distribution of illness costs between households, particularly between different socio-economic groups. While total illness costs were 11.5% of monthly income on average, 65% of households faced a total cost burden of 5% of income or less, while 5% of households had an illness cost burden exceeding 40% of income. For the lowest income quartile of households, nearly a quarter had an illness cost burden exceeding 10% of income, whereas only 18% of the highest income quartile were in a similar position (Russell, 2001).

3.5 Key issues on economic consequences of illness

The preceding sub-sections have highlighted the importance of attempting to comprehensively quantify both the direct and indirect costs of illness. If one focuses narrowly on the financial costs of health care goods and services, a considerable proportion of the economic burden of illness on households will not be documented. There is consistent empirical evidence that illness costs consume a greater share of household income in poorer households than in higher income households. It is these vulnerable households that require particular attention in evaluating strategies for coping with these costs and assessing the likelihood of falling into the medical poverty trap (covered in the rest of this paper) and for policy interventions to protect their livelihoods (covered in the fourth paper in this series).

4. Coping, struggling and the medical poverty trap

4.1 Coping with costs of illness and the role of social networks

As the previous section shows, households are confronted with a variety of direct and indirect costs of illness. The structure of health care and social security systems in the

specific country setting, the type and duration of the individual health problem, the socio-economic status and the closely linked ability to pay, and the social resources available for the patient determine the relative individual burden of various illness-related costs. Shouldering this burden takes different forms. One way of distinguishing these forms is to focus on the time perspective of individual or household responses to health care costs. This section presents the lessons from a broad range of literature describing how individuals cope with the social and economic costs of disease.

Drawing on the extensive literature on household responses to food shortages during famines in the 1980s, short and medium term responses to accruing financial or time cost burdens resulting from disease or injury have been termed coping strategies (Davies, 1993; Devereux, 1993; Sauerborn et al., 1996a). Coping strategies are responses to crises, adapted within the prevailing system of rules. Therefore, the definition does not include strategies that adapt rule systems to meet livelihood needs (Mutyambizi, 2002). Sauerborn and colleagues emphasise that "the negative effect coping strategies seek to avert is the breakdown of the household as an economic and social entity" (Sauerborn et al., 1996a: 292).

As Goudge and Govender (2000) point out in their literature review on household ability to cope with resource demands of ill health and health care utilisation, Sauerborn, Adams and Hien (1996) were among the first authors to apply the concept of coping strategies to costs associated with ill health.

Households use a range of strategies to cope with the direct and indirect costs of illness. As will be highlighted later, the distinction between coping strategies for direct and indirect costs is not a clear one; when a strategy to cope with the indirect costs of illness results in a drain on financial resources, this will lead to adopting the same coping strategies as are used for direct costs of illness. The most frequently used strategies are reviewed below, followed by a consideration of the factors that influence household's choice between alternative coping strategies.

Immediate responses to direct costs – using cash, mobilising savings and changing consumption patterns

Many studies from low- and middle-income countries testify that only a small percentage of households are capable of meeting the financial costs of illness by using cash or savings (Kabir et al., 2000; Sauerborn et al., 1996a; Wilkes et al., 1997). A slightly different picture is reflected in a study from Sri Lanka, where a minority of households indicated that they did not have sufficient available cash to pay for care: 37% for chronic care, 33% for acute care and 47% for inpatient care (Russell, 2001). Results from a study in Zimbabwe show that less than ten percent of households confronted with high direct costs for medical treatment use savings to cope with the economic burden, indicating a low incidence of household savings; moreover, the confrontation with treatment costs often leads to households reducing their general consumption (Mutyambizi, 2002). For poor households this generally means a reduction in food intake (Rugalema, 1998; Tibaijuka, 1997). A study in Bangladesh and the Philippines calculates that an illness of the household head on average leads to a 5.4% drop in calorie consumption (Foster, 1994).

Sale of household assets

The sale of assets as a means of increasing household liquidity is a strategy that ranks differently in the coping strategy hierarchy between and within countries, depending on the socio-economic and cultural context. Many studies particularly highlight differences between a country's rural and urban areas. For example, a study done in Ghana reports that the value of assets sold in order to cover costs of illness was higher in urban than in rural areas; in urban areas assets sold include clothing, televisions, automobile parts, jewellery, shoes, typewriters and miscellaneous trading items, whereas in rural areas households mainly sold food items (Mock et al., 2001). While selling assets is placed among the more common strategies in rural Burkina Faso, where livestock actually serves as an "ambulatory savings bank" (Sauerborn et al., 1996a: 294), it is neither common in rural China (Wilkes et al., 1997), nor in urban Bangladesh where the sale of assets are regarded as a last resort (Kabir et al., 2000). Clearly use of this strategy depends on the availability of assets and the fact that different assets exhibit different characteristics with regard to their saleability and their importance to the socio-economic stability of the household. Especially when assets are sold that form an integral resource of a household's livelihood, like land or

livestock in a rural setting, a vicious cycle of increased vulnerability may be launched (Tibaijuka, 1997; Topouzis & Hemrich, 1994).

Securing a loan

The literature suggests that borrowing is the most common response in order to cope with medical costs. For example, research on households' responses to costs associated with maternity care in Bangladesh shows that of those who had insufficient funds to pay for services, the major coping strategy was to borrow from relatives or friends (61%), or to borrow from a money lender (18%) (Nahar & Costello, 1998). A survey in Tanzania among individuals who had used health services in the previous month indicated that 40% had borrowed money to pay for this service use (Abel-Smith & Rawal, 1992). Another study found that between 25% and 49% of respondents in surveys in Kenya, Uganda, Nigeria, Guinea and Burundi had borrowed money to pay for health services (McPake et al., 1993).

The effect of loans on household livelihoods can be severe and is influenced by the character of the loan-giver and the business terms of the loan. A study in Ghana found that 41% of households that had a member who had been severely injured had borrowed money to cope with the economic consequences of this health problem and that the majority of these households were "still in debt" up to a year after the injury had occurred (Mock et al., 2001). An interesting small-scale study of 24 households in rural China, which reports a relatively high percentage of borrowing in order to cope with high direct medical costs, presents follow-up research three years after the medical expenses occurred. Ten out of 14 households had not been able to repay their debt in full. Interestingly enough, repayments whether full or in part were financed by selling animals or using remittances from household members working outside the village (Wilkes et al., 1997).

Other strategies for dealing with direct costs

Households may also attempt to diversify their income by engaging in activities that are different to their normal work, such as weaving mats, sewing etc., to try and generate quick cash income. Some household members may also be forced to sell their labour to generate cash, although this is usually regarded as a last resort (Sauerborn et al., 1996a).

Strategies for coping with indirect costs

There is also a range of strategies employed in order to counterbalance indirect costs of illness. Tasks are re-allocated among household members (intra-household labour substitution), and in some cases external labour is hired or advantage is taken of free community labour if available. In rural settings, some households shift to less labour-intensive crops or change the capital-labour mix of production. Again, the choices are subject to availability in the specific context.

Intra-household labour substitution is the most frequently adopted strategy for dealing with the indirect consequences of ill-health. There may be drastic social consequences of intra-household labour substitution, particularly when children are expected to take on the work activities of a sick parent. The medium- and long-term economic and social effects of taking children out of school or postponing school registration, requires further research. However, it has been reported that in sub-Saharan Africa girls are more likely to be taken out of school than boys, imposing a setback to the chances of young women to receive an adequate education (Mutangadura et al., 1999).

However, this strategy may not be able to address the full indirect consequences of ill-health. A household survey focusing on the burden of malaria in Sri Lanka shows that even while about 19% of economically active patients' work was performed by other household members, a quarter of the economically active malaria patients had to hire labour to undertake their normal activities while ill (Attanayake et al., 2000). Households are then confronted with a similar set of choices in order to cope with this financial burden as they are when confronted with direct medical costs.

Evidence of the most common coping strategies

There are few studies that provide empirical evidence on the distribution between coping strategies in different countries or for different illnesses. Those studies that have ranked coping strategies according to their frequency unfortunately do not relate the results to households' availability of choices. Thus, although limited empirical evidence is presented below, it should be interpreted with caution and should not be regarded as generalisable outside the specific country context.

A recent study on strategies to cope with costs of HIV/AIDS in two communities in Harare, Zimbabwe, reports that more than 60% of households borrowed money in order to cover the direct medical costs associated with the disease, about a third of respondents reduced their expenditure on basic needs, between 20 and 30% sold assets and less than 10% used their savings (Mutyambizi, 2002). A study in Rwanda found that 72% of households were not able to finance health care costs associated with HIV/AIDS on their own and that 66% of people received financial assistance from various sources (such as family, friends, church or employer), not mentioning to what extent returns were expected, whereas 18% borrowed money and 5% sold assets (Schneider et al., 2001). The authors of this study point out that social networks have "become the support system for 90% of the patients living with HIV who cannot afford health services on their own" (p. 8).

While, there is insufficient evidence from the literature to derive a pattern of responses to costs of illness that would allow for general conclusions on strategy preferences of households, it is evident that relational networks are of considerable importance.

Relational net as a determinant of access to strategies

The set of options for responding to direct or indirect costs of illness is greatly shaped by the relational net both within the household and between the household and its environment. Social resources and networks play a role both for the availability of loans at interest rates that are acceptable to the household and for the availability of labour support. While the first means is more commonly utilised to cover direct medical costs and the second describes a strategy to keep up a functioning household economy, the conditions of acceptance of both coping strategies are determined by the degree of stress, i.e. the level of urgency, under which the household has to act. A desparate household, for example, accepts loans at ruinous interest rates (Kabir et al., 2000).

An overview of the importance of intra-household relations for the choice and effectiveness of coping strategies has been provided by Goudge and Govender (2000). The social resources relevant for a household's ability to cope with the costs of illness

comprise inter-household relations and social networks, community organisations and sources of credit (Russell, 2001).

Several studies describe the importance of family ties, including the 'extended family', for households confronted with high costs of illness. Where strong family ties or close relations with neighbours exist, support includes direct financial support, intra-family loans and temporary labour supply. In many instances the common core of economic activity, the household, is expanded to include the extended family, and sometimes the broader community, which then assists with economic support, such as low-interest cash loans (Ayé et al., 2002; Kabir et al., 2000; Lucas & Nuwagaba, 1999; Mock et al., 2001; Munthali, 1998; Nahar & Costello, 1998; Russell, 2001). One study even reports an informal system of borrowing medicine within the neighbourhood (Jayawardene, 1993).

Reciprocity as a key mechanism in social networks is generally reported to extend beyond bilateral relationships. Expectations of returns extend to third parties and well into the future. Gifts among extended kin in order to cover direct health care costs have only rarely been reported and are mainly received by relatively wealthy households (Sauerborn et al., 1996a). While fee waivers are not a common phenomenon, there may be an element of reciprocity involved. Although sometimes free care is provided to the extremely poor (Wilkes et al., 1997), health care provided free of charge to the "wealthy" and influential has also been reported (Sauerborn et al., 1996a), which can be interpreted as an expectation of some future return whatever form it may take.

Community organisations which have relevance in coping with the consequences of illness include rural co-operatives, savings clubs, collective community funds that may require regular contributions and/or adequate security (Lucas & Nuwagaba, 1999; Ranson, 2002; Schneider et al., 2001) and small labour groups that form a reserve from their daily earnings (Pryer, 1989).

Factors determining access to strategies

Whereas the overall catalogue of strategy choices looks rather similar across different study areas and country settings, the actual prevalence of strategies applied depends

on the respective access to choices. As becomes clear from the literature, households' choice of coping strategies are influenced by socio-economic background, household composition, cultural setting and the kind of costs households are facing.

Access to strategies is determined by factors relating either to household characteristics ('internal factors') or to the socio-economic environment ('external factors'). These factors can be grouped in three dimensions, which represent logical steps within the concept of access: the availability, the acceptability and the affordability of a strategy.

The availability of a strategy may limit the set of feasible strategies. If, as described for the case of a county in rural China, existing assets are considered rather illiquid, the sale of assets is not an element of the readily available set of choices. If potential money lenders consider a household too poor or possess too little information on the characteristics of the household in need they may not be willing to lend to them (Kabir et al., 2000). If the negative economic impact of the disease on the household is considered too serious or long-lasting by would-be creditors, they will be reluctant to engage with the affected household (Rugalema, 1998). Obviously, the subjective availability of options can sometimes be restricted by information constraints.

The acceptability of available options is the next dimension of access to coping strategies. Acceptability, while naturally also controlled by cultural variables, is strongly needs-driven and therefore dependent on the degree of hardship. Only when reversible mechanisms of loss management are exhausted and self-insuring assets disposed, will a household accept disposal of productive assets as an option (Mutangadura et al., 1999). Only when households have been pushed into calamity, is begging practiced as a survival strategy (Sauerborn et al., 1996a).

The affordability of a coping strategy represents the third dimension of access. If a certain form of loss management is both available to the household and accepted, but not affordable, say, because borrowing at exorbitant interest rates or further reducing consumption just lead to destitution, this form of loss management cannot be accessed as a coping strategy. There is evidence that households take account of the longer-term consequences of different strategies. They demonstrate an "awareness of a

future beyond the current crisis when assets [may] be needed for [different] purposes" (Devereux, 1993: 55).

If several strategies can be accessed, the choice is influenced by the type of disease or disability that underlies the cost burden, i.e. the 'tracer condition'. This decision is basically one of household economics taking into account the time dimension. Again, the sustainability of household livelihoods forms the core of the household's choice.

Illness characteristics and the "sustainability" of strategies

It is useful to suggest four categories of tracer conditions that do not just determine the choice of coping strategies, but also their sustainability:

1. short-term or non-recurring illnesses,
2. (seasonally) recurring illnesses,
3. permanent disability and chronic disease,
4. terminal or steadily deteriorating ill health.

The first category seems to pose least risk to sustainability of the household economy. One-off economic setbacks to a household can often be successfully managed without permanent damage to livelihoods. This is different, however, when the one-off health event takes the form of a 'catastrophic health shock', the impacts of which have been thoroughly analysed by Prescott (1999) using Indonesia's National Socioeconomic Survey. The crucial indicator of the risk of a financial catastrophe for the household is the price-income ratio.

Recurring spells of illness with associated direct and indirect costs pose a different kind of threat. As becomes clear from the studies dealing with household responses to the economic burden of malaria, in many instances certain strategies seem to have become routine in communities that are regularly confronted with the problem, especially when it comes to dealing with the need to substitute labour in order to minimise the indirect costs of illness.

A different framework applies when it comes to permanent disability and chronic disease. The strategies for actually being able to cope with the economic burden of disability are particularly constrained for a number of reasons. Firstly, disabled

people on average find themselves at the lower end of the income scale both in the developing and the developed world. The disabled tend to receive less education, have lower socio-economic status and are more often unemployed than non-disabled people (Yach, 2001). Secondly, they are frequently marginalised, not as well integrated in communities and are often subject to negative social attitudes and to stigmatisation and neglect (Neufeldt & Mathieson, 1995). Literature on the impacts on the economic livelihoods of the disabled has been comprehensively reviewed in a survey commissioned by the World Bank (Elwan, 1999). While the narrow definition of coping hardly applies to responses to persisting conditions, there is a strong need not to neglect responses to recurring medical costs for the permanently disabled.

Although social protection for the disabled has been institutionalised in high-income countries, the disabled are on average economically worse off than the healthy. The correlation, however, is a lot more pronounced in the developing world (DFID, 2000). Besides malnutrition and infectious and non-infectious diseases, war and violence rank among the main causes of disability in developing countries. The enormous household and social costs of land mines combined with the impact on people's livelihoods is just one example of how not only are households' ability to cope reduced, but also how social structures alter with households containing disabled members falling into a particularly disadvantaged position (Andersson et al., 1995).

The fourth category of tracer conditions is formed by diseases which are terminal and usually go along with a steadily declining health status. These conditions typically go hand in hand with recurring direct costs of treatment. One of the outstanding examples is HIV/AIDS. Whereas HIV/AIDS can largely be considered a treatable chronic disease, comparable to diabetes, as a result of the availability of modern medical technology, its terminal character has a dominant impact on livelihoods in the developing world where it poses one of the major health threats. HIV/AIDS, the economic impact of which is discussed in more detail later, causes both high recurring medical costs for treatment of the disease itself, (home-based) care and the treatment of opportunistic infections (Hansen et al., 1998; Tibaijuka, 1997), but also income losses in the widest sense both on the side of the ill person and on the side of other income earners who have to care for the ill individual (FAO, 1997; McGrath & Ankrah, 1993; Mutyambizi, 2002; Rugalema, 1998). The term "coping strategy" in

connection with HIV/AIDS may be misleading. Although a broad range of household responses to the economic burden of HIV/AIDS has been expounded and comprehensively reviewed (Mutangadura et al., 1999), it has been argued that they do not represent 'coping strategies' since that would imply households are managing well or at least persevering. Yet in many cases household responses lead to dissolution of the household, and the potential for households to regroup as viable social economic entities under the burden of HIV/AIDS can be doubted; therefore household responses to HIV/AIDS could be described as 'struggling' more than 'coping' (Rugalema, 2000).

The exercise to assign coping strategies to these categories of health events has not been undertaken in the literature explicitly. Yet the review of studies in the field shows that there is a clear relation between the coping behaviour and both the absolute economic dimension of the impact as well as the disease burden over time. Table 3 tries to link disease categories to possible coping strategies that are opportune as long as the sustainability criterion is fulfilled. We can speak of an opportune coping strategy as long as a household's livelihood is not jeopardised. There are other arguments outside this context, such as equity considerations, that speak strongly for the establishment of mechanisms beyond rudimentary coping strategies. Sustainability is basically assured if costs stay below the income or revenue at the respective levels of aggregation – across those involved and over time. We will show that this is an important criterion within the analysis of the medical poverty trap.

Table 3: Sustainability of 'strategies'

	Acute or non-recurring ('minor') illness	**(Seasonally) recurrent illnesses**	**Permanent disability / chronic disease**	**Terminal illness/ steadily deteriorating health**
Examples from literature	Kabir et al. (2000) Russell (2001)	Jayawardene (1993) Onwujekwe et al. (2000)	Chale et al. (1992)	Hansen et al. (1998)
Characteristics of (potentially sustainable) coping strategy	Mobilisation of cash, savings; short-term loans	Adaptation to periodic costs; development of occupational/ income-generating patterns	Permanent support system (involving social resources, such as community prepayment scheme)	
Crucial indicator for sustainability	Price-income ratio	Periodic cost-income ratio	Total operational cost-revenue ratio	

The discussion of coping strategies under different tracer conditions leads to an important conclusion. It is not feasible to generalise a pattern of strategies to cope with the economic impact of illness that is applicable across different types of diseases and in different country contexts. Even if it is possible to subsume a range of coping strategies observed for different scenarios under common headlines, strategies adopted depend to a high degree on the specific circumstances of the case. Between different categories of tracer conditions the same conclusion is valid as for the comparison of responses to drought with responses to HIV/AIDS – "the assumption that households adopt patterns of coping strategies that can be generalised across disasters is, at best, tenuous" (Rugalema, 2000: 542).

4.2 "Poverty dynamics"

Poverty, health and the medical poverty trap

Poverty has been widely discussed as both a cause and a consequence of ill health and disability. Yet studies that have tried to operationalise poverty in order to describe interrelations between poverty and health and the existing dynamics are rare. This is astonishing, especially since a lot of methodological progress can be observed in the literature on socio-economic inequality and health and taking into account that poverty and inequality can be considered simply different aspects of the same phenomenon (Lewis & Ulph, 1988). The most probable reason is that while the quantitative tools of inequality measurement appear generalisable over different country backgrounds, a poverty concept that adapts well to different study contexts can hardly be established. Poverty refers to a situation involving a lack of income and assets, and therefore low levels of consumption and welfare. There are circumstances in which a relative concept of poverty, defined in terms of standards and norms of a given society at a given time, seems appropriate. There are also scenarios in which the concept of absolute poverty, determined by a fixed minimum level of consumption, seems adequate (Rosenberg & Wilson, 2000). The latter seems especially apt in a low- and middle income country context where the poverty line can be fixed at a level below which a sufficient diet and provision of basic needs is not feasible. The application of a relative concept of poverty may be more fitting in the analysis of developed countries.

Participatory methods have been increasingly used as a contextual method in poverty analysis over the last decade. These methods allow for an understanding of social, cultural, economic and political specifics of the study context and, for that reason, seem especially adequate for an investigation of the interplay of ill-health and poverty with regard to certain tracer conditions and with regard to complex study context where causalities are not readily accessible. The concept and methodology of participatory poverty assessments has recently been critically reviewed by Ruggeri-Laderchi (2001).

In high-income countries, income data are readily available and serve as a rather good proxy for socio-economic status. The analysis of household surveys discloses links between poverty and health (Benzeval & Judge, 2001; Thiede & Traub, 1997). In high-income countries, the causal path from a household's relative income towards health is more pronounced than the path from health towards a household's socio-economic position. Yet there are indications that ill health increases the risk of households dropping below the poverty line over time even in high-income countries such as Germany, despite the existence of a social welfare net (Thiede & Traub, 1997). Even if ill health may only be one contributing factor, indirect costs of illness and disability may take on a dimension that cannot be counterbalanced by the social security system, although households may have some flexibility in making use of the various branches of social security, such as delaying or postponing retirement decisions (Jimenez-Martin et al., 1999). The problem of accessibility of certain support services may play an important role in this context. The social and economic consequences resulting from illness-related costs in high-income countries have not been sufficiently investigated and form an important area for further research. The results will be of great value for health and social policy not only in high-income countries. In a world in which social systems from high-income countries are easily copied or adopted by other countries for various reasons, evidence of this nature should not be overlooked.

The investigation of the dynamics of the interplay between poverty and health becomes particularly important in countries that do not possess a close-meshed welfare net. Authors have described the phenomenon of a "medical poverty trap" (Whitehead et al., 2001) in which medical costs increase the poverty of those who are

already poor. Kabir and his colleagues found that among the urban poor in Bangladesh, illness is identified as "the most likely constraint on a household's ability to improve its status" (Kabir et al., 2000: 720).

There is also evidence of a "ratchet effect" (Chambers, 1989) that prevents people below the poverty line who face costs of illness from moving out of poverty. The effect seems not to be just a temporary phenomenon: A study from Bangladesh demonstrates how ill health can be an initiating factor to the further entrenchment of poverty over two generations (Pryer, 1989). The medical poverty trap has not been systematically examined but stark evidence from the reviewed literature on household coping strategies supports the hypothesis.

The medical poverty trap describes both the fact that chances of a household below the poverty line ever moving out of poverty diminish once confronted with illness-related costs, and the fact that a vicious cycle of poverty and ill-health easily sets in once a vulnerable household slides below the poverty line as a result of illness. Vulnerability has been described as being closely linked with net assets (Chambers, 1989). Vulnerability plays a key role in the analysis of the medical poverty trap as it involves the propensity for asset diminution (tangible and social). In order to avoid the poverty trap a household must be able to access a set of assets that it can transform into—among other outcomes that are intangible—a consumption level above the poverty line and an asset base that allows the continuation of these transformations in the future (Bebbington, 1999). The objective of coping strategies for the household should therefore be to re-establish its economic and social viability after the crisis (Curtis, 1995).

Coping strategies and poverty dynamics

Coping strategies seem to play a crucial role in the dynamics around the poverty line. As these strategies relate to a particular crisis, they are essentially short-term in nature and are generally not sustainable. Some authors therefore distinguish between coping strategies and adaptation processes (Davies, 1993). Strategies that are not based on the concept of risk-pooling among a group of individuals, such as community prepayment schemes, involve either a direct reduction of household wealth, a reduction of (food) consumption or an accumulation of (financial) obligations, usually

a combination of these outcomes. Consequently, the household's situation after coping must be compared, in terms of its economic robustness, with the situation before the onset of the disease.

Qualitative studies in vulnerable environments report people's perception that households are frequently driven into poverty by illness. Some studies indicate that even direct treatment costs are out of reach for a significant fraction of the population. A case study of household coping strategies in two Ugandan rural districts estimates that as many as 20% of people with serious health problems cannot afford treatment at either private or government facilities (Lucas & Nuwagaba, 1999). The vicious cycle between poverty and disability has been reviewed by Yeo (2001). It is bolstered by limited access to education and employment, to land and shelter, to health care, healthy food and sanitation. This leads to the acceptance of hazardous working conditions, to unhygienic, overcrowded living conditions and to malnutrition. Hence, the risk of illness, accident and impairment for the poor is higher than for the non-poor. Illness then leads to further exclusion, income loss and poverty. Very poor households find that some of the strategies of coping with costs of illness adopted by others are not accessible for them. Since they cannot provide security, the poorest often face unfavourable terms for taking up loans in order to pay for medical treatment (Kabir et al., 2000). As they are often marginalised, the very poor also do not have access to social resources such as informal insurance schemes (Pryer, 1989). If illness hits those below a certain level of poverty, the likelihood of upward mobility fades away, the medical poverty trap snaps shut.

The risk of poverty as a result of (unsustainable) coping seems high. Studies describe a downward spiral that may well drive vulnerable households below the poverty line. The sale of productive assets that form a basis for a rural household's livelihood, such as land and livestock, as a response to medical costs, impacts on subsequent incomes. As this strategy is usually not the household's first choice, the asset-selling household is generally indebted already. No further investments into the economic base, such as buying fertiliser, are possible. Agricultural yields decline and a cycle of further impoverishment is set off (Wilkes et al., 1997). Households are often not able to restructure their asset portfolio over time. Impoverishment as a result of medical costs leads to malnutrition which then again predetermines a decline in health status and

declining ability to engage in income-generating work (FAO, 1997). Tragically enough, reduced food consumption or sacrificing nutritional status ranks among the more common coping strategies (Rugalema, 1998; Tibaijuka, 1997). A Tanzanian study of the economic welfare of household's confronted with costs of illness shows that "coping" pushed 9 out of 10 households into a lower income bracket (Tibaijuka, 1997). A different Tanzanian study revealed that more household resources (cash, asset sales, reduction in consumption) were used to pay for treatment and nutritional needs of an ill male household member than for an ill female household member; very few assets were sold to pay for the medical treatment of women and they were rarely sent to medical centres for treatment (Rugalema, 1998). It may be useful in future studies to explore whether patriarchal households enter the medical poverty trap faster.

It is a logical consequence of strategies affecting the economic position of the household – either by reducing assets or even the household's income base or by accruing financial obligations or accumulating debt – that the vulnerability or inclination towards poverty is increased. Whenever illness prevails or is further fuelled by scarcity of resources, the downward process accelerates.

Only when the economic position of the household is stable enough to mitigate a temporary decline (and economic stress related to the disease is only temporary), asset or income reducing coping strategies can be considered viable. The set of coping strategies that least affects households' livelihoods is one based on social resources. Risk-pooling and/or reciprocity-based approaches tend not to impact on households' vulnerability. These, however, are not widespread and, as pointed out before, usually do not cover the worst-off who are most vulnerable.

5. "Struggling" with the economic consequences of HIV/AIDS in sub-Saharan Africa

HIV/AIDS embodies a catastrophe for many households and communities, especially in the countries of sub-Saharan Africa which are marked with the highest HIV/AIDS prevalence world-wide. The epidemic affects the vulnerable groups of the population

most. The negative effects of HIV/AIDS-induced illness on livelihoods and income of households in sub-Saharan Africa have been studied extensively. The direct and indirect costs of illness are immense, related to household incomes and cannot be shouldered by most. As a result of the deficiencies of medical care systems in African countries, medical costs and caring must be taken on by the (extended) family. Medical costs include cost of drugs, treatment and caring. HIV/AIDS is a terminal disease, involving a continuously declining health status, particularly in the African context of extremely limited access to anti-retrovirals. Households have adopted a wide variety of strategies of coping with the disease. Since in many instances, however, long-term viability of a household cannot be regained and the illness of an adult within the household results in household dissolution, the term 'coping strategy' does not seem adequate in this context. Consequently, Rugalema (2000) describes the households' endeavours as mere 'struggling'. Even death itself brings about an additional burden. The adverse economic impact of funeral costs on households is strong and leads to additional sales of property by the family in many cases (Ngalula et al., 2002). In some rural settings funeral costs are even higher than medical expenses (FAO, 1997). Certainly, the indirect costs of death at community level are at quite a high level. Attending funerals and – as customary in a number of settings – respecting the mourning period as well as providing moral support to victims and families diverts working days from economic activities (Tibaijuka, 1997).

Both direct and indirect costs related with HIV/AIDS have been studied in various country contexts (Hansen et al., 1998; Munthali, 1998; Mutyambizi, 2002; Rugalema, 1998; Tibaijuka, 1997). Some characteristics on the direct-cost side include high costs for drugs and treatment (partly resulting from opportunistic infections), high costs of care, especially when home-based care is an option (Hansen et al., 1998), and high funeral costs. Indirect costs, typical to HIV/AIDS, that go beyond the indirect costs of other severe diseases include the burdens of sigmatisation, as assistance from extended family and the community is severed.

Studies from various regions in sub-Saharan Africa all reflect a similar socio-economic downward spiral. In rural areas, loss of labour due to illness leads to decreasing land use and sinking agricultural production at community level. At household level loss of labour directly results in lower income. The affected

household is confronted with higher non-food expenses, namely for health care. The household's ability to produce and accumulate food decreases. This brings about increasing dependency ratios, poorer nutrition and health for all household members, increasing expenditure of resources in terms of time and money on health, more food shortages, increasing household vulnerability and so on (FAO, 1997).

Households confronted with the disease have responded according to similar patterns in different environments. These can be divided into three categories according to the strategies' objectives, namely to

- improve food security
- raise and supplement income, and
- alleviate loss of labour (Mutangadura et al., 1999).

Food can be secured by substituting cheaper commodities or with "wild food", reducing consumption or sending children away to live with relatives. Households try to raise income by borrowing and selling assets. Non-productive assets are sold before productive assets, and sometimes agricultural produce is sold even if this enhances malnutrition (Tibaijuka, 1997). They make efforts at involving as many household members as possible in income-generating activities (intra-household labour substitution) and replacing lost labour with the help of resources from other households within informal networks (inter-household labour substitution). Income generating activities include all forms of casual labour, and in very poor settings also child work and sex work (Munthali, 1998; Mutangadura et al., 1999). To compensate for the loss of labour, a common coping strategy is removing children from school (Rugalema, 1998). Further, additional labour is hired, especially for agricultural production. This, again, is dependent on the availability of cash to pay the workers. Topouzis and Hemrich (1994) report cases in which household agricultural production had been changed to less labour-intensive crops and cases of declining cultivated areas in response to illness-related labour shortages. Many affected households furthermore try to partly counterbalance the loss of labour by working longer hours (Topouzis & Hemrich, 1994). In general, it is nothing more than an academic exercise to try and systematise coping strategies in response to HIV/AIDS according to phases

or degrees of effectiveness. It has been observed that essentially households struggle to survive by whatever opportunity comes their way (Mutyambizi, 2002).

Household-based coping strategies do not generally achieve the protection of the household's viability. The loss of productive assets for an HIV/AIDS-stricken household is usually too big. The direct negative impact of the illness that leads to the loss of breadwinners in the household, which orphans many school-age children and leaves the elderly and those in need of care without attendance and support, is just fuelled by the economic consequences of struggling with direct and indirect medical costs.

The problem of children orphaned by AIDS poses long-term economic and social effects as many of these victims of the disease struggle to cope with its indirect costs. As a result, many of the AIDS orphans are not enrolled in school. Study results from Zambia show that 32 percent of AIDS orphans in urban areas do not attend school, as compared with 25 percent of non-orphaned children (UNAIDS, 1999).

All household-based coping strategies bear negative effects on household assets. The specific characteristics of the pandemic mean that there is no chance for the affected households' asset portfolios to recover. The social dimension of the medical poverty trap has become obvious in those countries which are affected by the disease. What results is the breaking up of households and community structures, decreasing agricultural production, a decline in education and complete destitution at a micro-level, jeopardises the social, economic and political fibre of societies at a macro-level (Bollinger & Stover, 1999; Bollinger et al., 1999).

Among community responses to the economic burden of HIV/AIDS, certain structures based on social assets have developed that signify adaptation processes at a collective level. These are strictly-speaking not coping strategies. Hence they provide the potential to secure livelihoods at community level (Mutangadura et al., 1999):

- Social support groups take the form of voluntary assistance groups for times of special needs (sickness and funerals) or special occasions (e.g. marriage ceremonies). These are generally small in scope.

- Indigenous savings associations emerge as rotating savings and credit associations or “conventional” savings clubs.
- Self-help groups have the advantage of being able to also provide adequate psychosocial support to households affected by HIV/AIDS.
- Child and orphan support organisations and income-generating projects (IGPs) have been strongly supported by NGOs. They are formal community-based organisations but have not evolved as community responses.
- Community home-based care programmes include medical and nursing care as well as economic, social and emotional support. These programmes are usually highly expensive and thus far communities only play a minor role in the organisation (Gilks et al., 1998; Hansen et al., 1998).

Community based responses appear to provide more viable responses to the economic and social burdens of the HIV/AIDS pandemic. Their efficiency and sustainability as well as their socio-economic and cultural impacts need to be carefully studied in order to generate workable policy responses (see ALPS Review 4). The case of HIV/AIDS highlights mechanisms and dynamics of the medical poverty gap. It illustrates well the degree to which household-based coping strategies jeopardise household livelihoods and demonstrates that social resources as reflected by community responses are more likely to prevent affected households from sliding into a medical poverty trap. There appears to be a strong need, however, to develop community capacities and strengthen community responses.

6. Conclusions

A wide range of evidence shows that the costs households are facing as a result of illness differ in dimension and kind with a number of factors: predominantly, the socio-economic, cultural and geographical backgrounds of households, the type of disease and the health system structure. Research on economic and social consequences of disease and households’ responses has mainly been conducted in low- and middle-income countries. Studies reveal how illness perception and treatment seeking behaviour are influenced by different demand-side and supply-side

variables relating to treatment access. They also disclose conditions that influence the relative importance of direct and indirect costs. Strategies used by households to counterbalance inability to perform a social role – be this productive work or a certain role in the household – have been regarded as strategies to cope with indirect costs. When evaluating the results it is crucial to note that most of these strategies incur the same kind of economic burden as the so-called direct costs. In many circumstances, the economic impact of indirect costs by far outweighs the effect of direct costs. Therefore a focus on direct costs of treatment is too narrow. In order to assess the total economic burden of illness and to evaluate possible social and economic consequences with a focus on the medical poverty trap, critical attention needs to be paid to the indirect costs such as work or education time lost.

It has been discussed how households form their choice of how to respond to crises imposed by illness, however small the set of choices may be. A similar overall set of strategy choices across study areas is utilised differently according to households' access to strategies. Based on the literature the review distinguishes availability, acceptability and affordability of strategies as three dimensions of access to coping strategies. The factors influencing these dimensions relate to household characteristics and the socio-economic environment; a set of internal and external factors determine which strategy is feasible and which is not.

The review points out a number of studies that have reported on the incidence of responses to costs of illness. The observed figures provide an overview of the frequency of strategies utilised; yet they do not tell us anything about strategy preferences, as the choice sets available to individuals are not outlined at all. Consequently, there is a need to investigate household responses in relation to the absolute economic impact of disease-related costs and the disease burden over time.

It is obvious that household responses to the burden of illness shape poverty dynamics significantly. Unfortunately, poverty has hardly been conceptualised in the studies dealing with the economic burden of illness. Yet studies on the economic impact of illness on households support the hypothesis of a medical poverty trap. Future research needs to trace poverty dynamics as a result of health events over time.

Some generalisations have been possible and provide insights on the non-sustainability of household-based coping strategies. Only when households can fall back upon a broad asset portfolio, will strategies for coping with not increase their vulnerability. It has been argued that only household or community responses based on social resources can provide a certain level of protection to household livelihoods in crises brought about by illness. This is of importance when considering appropriate health policy interventions to address the economic and social consequences of ill-health.

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