
*What do we mean by ‘major illness’? The need for
new approaches to research on the impact of ill-
health on poverty¹*

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Abstract

It is widely recognised that ill-health is one of the most serious challenges that many individuals, households and families have to face. But there is limited knowledge of the complex *processes* involved in suffering from and coping with multiple and diverse health-related challenges. Provision of support to those suffering ill-health has focused on acute illnesses which are often implicitly assumed to follow the pattern: get sick, consult with a provider, receive diagnosis, obtain treatment and recover. It has similarly become commonplace for economists to associate serious illness with ‘catastrophic health expenditure’. These presumptions have led to support mechanisms being seen primarily in terms of providing assistance in meeting the cost of in-patient treatment.

Such approaches fail to address the multiple and complex pathways which link ill-health and well-being. Individuals suffering from dengue fever, tuberculosis, emphysema, diabetes, lymphatic filariasis or AIDS might all be classified as having a ‘serious illness’. However, in terms of risk to life, level of disability and distress, duration of illness, prognosis, stigmatisation, availability and cost of treatment, and a range of other factors, their situations may differ radically. The impact of an illness is also highly dependent on the demographic and socio-economic characteristics of the individual falling ill, the household of which they are a member and the extended family and social networks to which they belong.

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Research in Cambodia, China and Laos has focused on households affected by a 'major illness', defined broadly in terms of risk to household livelihoods. It was based on an innovative approach involving in-depth, one-year retrospective studies. Its purpose was to investigate the *processes* set in motion as different types of households coped with different types of health problem.

Introduction

POVERTY AND ILL-HEALTH

It is widely recognised that ill-health is one of the most serious challenges that many individuals, households and families have to face. Apart from the pain and distress suffered by the affected person and those who care for them, serious illness can have a wide range of deleterious impacts and is generally accepted to be a common cause of household impoverishment (Gertler and Gruber 2002; Wagstaff and Van Doorslaer 2003). There is also evidence that health shocks² are seen by the poor themselves as one of their greatest concerns: "*loss of income coupled with cost of treatment and the transformation of a wage-earner into a dependent-make injury and illness common triggers of impoverishment*" (Narayan *et al.* 2000). A recent series of participatory studies in Kenya, Uganda, India and Peru found "that healthcare is overwhelmingly the single-most important reason for households descending into poverty" (Khrisna 2006). However, while there is a considerable literature on economic impacts and associated 'coping strategies' in relation to ill-health in general (e.g. Sauerborn, Adams and Hien 1996) and for some specific diseases (Russell 2004), there is limited detailed knowledge as to the *process* whereby different types of households are affected by and cope with the great variety of serious health-related challenges they may encounter.

Many studies, often because of the limitations of available data sources, have simply not addressed the multiple and complex pathways which link ill-health and well-being. These pathways can be seen as reflecting

² The word 'shock' has become part of the core language of the Social Protection literature (e.g. World Bank 2001, Chapter 8). As indicated below, it is the view of the authors that this language often fails to appropriately address the diversity of the effects of ill-health and injury on individuals and households.

the combined effects of a multiplicity of factors including:

- The variable nature of health problems. To take just a few examples, individuals suffering from dengue fever, TB, emphysema, diabetes, lymphatic filariasis or AIDS might all be classified as having a 'serious illness'. However, in terms of the risk to life, level of disability and distress, duration of illness, prognosis, physical availability and cost of treatment, and a range of other factors, their situations may differ radically.
- The demographic and socio-economic characteristics of the individual falling ill, the household of which they are a member and the extended family and social networks to which they belong. For example, loss of an adult worker following an accident may be disastrous for a small, isolated household but a minor problem where other family members are able and willing to absorb any additional workload. In many countries the outcome of a serious illness in a poor rural household may depend primarily on the availability of support from relative rich, urban-based relatives.
- Local and national employment opportunities, that for example may allow those disabled by long-term illness to find alternative sources of income generation.
- The effectiveness of formal or informal mechanisms (at national local or community level) intended to assist distressed households.
- The functioning of the health system and, in particular, the availability of safe, effective, affordable and trusted care.

It has recently become commonplace for health economists³ to use the term 'catastrophic health expenditure' when referring to situations in which household expenditures on healthcare exceed a given proportion of 'disposable income', typically estimated as total consumption expenditure less spending required to meet basic subsistence needs (Xu *et al.* 2003). It is argued here that such indicators, while of considerable interest, should by no means be seen as adequately reflecting the range of issues which need to be addressed in either understanding the links between ill-health and poverty or

³ Note that the medical community and health insurers use the term 'catastrophic illness', the former basing their classification on the specific diagnosis, the required intervention and the characteristics of the patient, and the latter on the absolute cost of treatment.

in designing social support mechanisms. To make an obvious point, it is difficult to understand why the word 'catastrophic' should be applied in cases where individuals with substantial wealth elect to spend part a large sum on healthcare - for example to replace painful hip joints, but not to cases where a poorer individual has to cope with similar disabilities because they cannot afford such treatment. Of particular concern is a tendency for policy-makers who adopt the catastrophic expenditure language to make the implicit assumption that illness-related poverty is primarily a consequence of such expenditures and that they relate almost exclusively to inpatient treatment costs.

In practice, detailed household studies show a variety of mechanisms through which health shocks and poverty interact (Russell and Gilson 2006; Knaul *et al.* 2006). Serious acute events may indeed require costly hospital care. However, chronic illnesses and even comparatively less serious recurrent acute health problems (common in households with large numbers of young children) can also place a major strain on household financial resources. Long-term conditions that completely or partially disable the sufferer and may follow a gradual course of increasing economic and possibly physical dependency on other household members are especially burdensome. Heart disease, AIDS, Lymphatic Filariasis and some cancers are examples of this kind of challenge. Injuries resulting in the loss of sight or limbs may entail limited health expenditures but have serious consequences in terms of paid employment or the viability of household enterprises. A variety of conditions, for example vitiligo, incontinence and even some STIs, may have limited immediate consequences in terms of physical health, income or expenditures but potentially extremely serious social implications in terms of loss of status, isolation, rejection and persecution. If we endorse the now almost universally accepted paradigm that poverty is a multifaceted phenomenon, covering not only financial but many other dimensions of deprivation (e.g. OECD/DAC 2001; World Bank 2001), individuals afflicted in these ways might reasonably be described as experiencing illness-induced poverty. Moreover, in many cases social exclusion will lead to severe constraints on employment opportunities, resulting in long-run economic decline. These very different types of shock call for very different responses.

As indicated above, a focus on health expenditures also crucially ignores the fact that many of the poor, and possibly most of the very poorest, spend very little - even as a percentage of total expenditure - on health care,

simply because they are unable or unwilling to access qualified providers given other demands on their extremely limited resources. As a recent study in Chad highlights, “households ignore health problems - absorbing them into the experience of everyday life ... When illnesses appear as crises it is often because ... easily treatable problems spiral out of control.” (Leonard 2005). Of course, immiserating expenditure on health care is an important issue, but it should not preclude a focus on the potentially immiserating effects of not accessing health care when needed, especially as it is the poorest households who are more likely to experience the latter.

For example, when a key worker is incapacitated, household labour supply is reduced and demand increased, as care of the sick individual places additional burdens on other members, especially women. Any consequent reduction in household production would be exacerbated by expenditure on health care, if such care were available and accessible. In a poor household such expenditure will often necessitate reduced food consumption (World Bank 2001), possibly impacting on labour productivity. Over time it may lead to a run down of savings; forced borrowing at high rates of interest; and/or sale of physical assets, possibly further reducing income flows if this includes land, livestock or production tools and equipment. At each stage of an illness, household members have to make difficult judgements as to the costs and benefits of alternative health care seeking strategies - including the strategy of not seeking care.

Research on health shocks and interventions designed to support households in coping with them has to address two other complicating factors. These relate to the wide range of perceptions, attitudes and beliefs which different populations attach to health issues. First, in some developing countries much expenditure on health care, perhaps especially by the poor, is wasted, at least in clinical terms, on inappropriate, ineffective, unnecessary or even dangerous treatments, often prescribed by providers with no formal qualifications (Fabricant, Kamara and Mills 1999; Mills, Rasheed and Tollman 2006). Assisting households to purchase such treatments would generally be seen as counterproductive, though given the power of the placebo effect (Ernst and Herxheimer 1996) and the multiple factors which determine attitudes to different sources of healthcare knowledge (Gilson 2005; Russell 2005), the general population and the medical profession may well disagree as to which treatments should be so regarded. Many governments and agencies have found the concept of consumer-lead,

demand-side financing attractive (Ensor 2003), partly on the grounds that it 'empowers' those consumers to demand better services from providers. However, assuming that this removes the requirement for effective supply-side interventions to influence and ultimately regulate the behaviour of providers would be a very high-risk strategy in many countries, given the information asymmetry between those claiming possession of health expertise and their clients (Hammer and Berman 1995).

Second, and more contentiously, it is possible to argue that interventions which tend to make treatment attainable but only at substantial cost need very careful consideration. For example, many of the serious funding problems currently confronting health care systems in developed and transition countries relate to the availability of expensive, and sometimes only moderately effective, treatments which may prolong the life of elderly patients (Westerhout and Pellikan 2005). In countries where health care costs are primarily met from current income or limited savings, should interventions be introduced which make it possible for the poor to purchase effective treatments for their aged relatives with serious illness but only if they - and their children - make major, and possibly permanently damaging, sacrifices? Similar, and in many respects even more difficult, issues arise in relation to the treatment of AIDS. How can households or extended families refuse their members long term treatment with ARVs, even if the possibly heavily subsidised cost remains high enough to gradually drive them into destitution? A very heavy 'burden of choice' may be placed on households already living under constant stress by such well-intentioned initiatives.

LIMITATIONS OF EXISTING SUPPORT SYSTEMS

The complex nature of health shocks and the limited current understanding of their impact mechanisms can be a source of frustration for those attempting to design effective interventions. However, disregard of that complexity and the fact that "*Fighting iatrogenic poverty calls for more than just establishing some kind of social health insurance*" (Meessen *et al.* 2003), carries high risks. The insufficiently considered application of potentially useful concepts such as catastrophic health expenditure has encouraged the implementation of somewhat simplistic strategies which fail to address the needs of large numbers of the poor and especially the very poor. As indicated above, discussion around the provision of support for those suffering ill-

health has tended to focus on acute illness episodes with a trajectory which might be crudely characterised as: get sick, consult with a provider, receive diagnosis, obtain treatment, recover. Support has been seen in terms of providing assistance to meet the cost of consultation and treatment, typically via a combination of: narrowly targeted and often disease-specific exemptions for selected population groups; establishment of (possibly subsidised) 'critical illness' insurance schemes for the majority; and a variety of safety net arrangements for the poorest. The focus on treatment costs for serious acute illness episodes is understandable in terms of the operation of support schemes. For example, many are designed solely to provide financial assistance in meeting hospital inpatient care costs (STEP Programme 2005). From the point of view of scheme management this has considerable advantages: illnesses resulting in inpatient episodes are a tiny proportion of the total, which limits the number of transactions undertaken by the scheme; each episode can be considered as an isolated event taking place over a fixed period; and there will typically be detailed documentation on diagnosis, treatment, outcome and costs, allowing rigorous financial monitoring of expenditures and at least the possibility of effectively regulating the quality of services provided.

However convenient from an administrative perspective, it seems evident that such an approach neglects whole areas of serious health-related needs - physical, psychological and social. It is possible that this narrow focus is warranted, given realistic levels of funding and the need therefore to both prioritise and to ensure financial probity and clinical standards. However, such a case must be argued, not simply assumed. Given that substantial public resources are typically invested in the establishment of support schemes with the professed objective of reducing the impact of ill-health on targeted populations, it seems reasonable to assess the full range and severity of such impacts before deciding how those resources would be best allocated. It is argued here that such assessments have rarely been undertaken. This was the starting point for the project described below.

The 'Poverty and Illness' (POVILL) project

The aim of the POVILL project was to understand the potentially complex impacts of ill-health on household livelihoods for a reasonably large number⁴ of affected households in selected study areas in three countries, Cambodia, China and Laos. At an early stage in the design it was agreed that these households should be selected using a strict probability sampling approach such that it was possible to make valid statistical inferences to the overall study area populations. This was seen as highly desirable in terms of influencing policy makers in each country who are involved in the design of social support mechanisms intended to assist households in coping with illness. Note that it precluded a number of alternative and less resource costly methods of identifying relevant households such as sampling from facility or support scheme records (as many individuals with major illness fail to seek care from a qualified provider), purposive selection based on the judgement of local officials or community based exercises. POVILL was specifically intended to identify an *unbiased* sample of households affected by major health problems.

The study focused on households affected by a 'major illness', which was conceived very broadly as indicating health problems which had the potential to seriously damage household livelihood strategies, increasing the risk of impoverishment. The primary causal pathways to impoverishment were seen as: increased expenditures on inpatient and/or outpatient care; and/or limitations on household productive and reproductive⁵ activities, linked to illness-induced changes in household labour demand and supply. Note that the study was concerned with the *potential* impact of health problems on individual and household well-being because one main objective was to identify those factors - relating to the characteristics of the illness, affected individual, household, healthcare system, support

⁴ Roughly speaking, sufficient to permit the defensible use of statistical analysis.

⁵ This use of the word *reproductive* derives from the literature on social reproduction and refers to the functions of households in the following areas: 1. capacity to produce and rear children, 2. day-to-day maintenance of households through food processing and cooking, care of children and other dependents, cleaning etc., 3. maintenance of household viability inter-generationally through securing necessary economic inputs and social relations (adapted from Young 1981).

mechanisms, etc - which tended to determine the magnitude of the impact experienced.

RESEARCH METHODOLOGY

Existing knowledge about illness-poverty linkages is mostly derived from questionnaire surveys that collect information on health service utilisation and expenditure, typically on the basis of a two-week or one-month recall for acute illness-episodes and a one year recall for inpatient treatments. The findings of such surveys have been very useful in drawing attention to key issues, but provide very limited information as to how specific types of illness, affecting specific members, impact various types of household - differentiated for example in terms of size, demographic composition, asset ownership, access to social support networks, etc. In particular, it is extremely difficult using cross-sectional surveys, even if a 'before-and-after' strategy is adopted (i.e. running two surveys separated by a suitable time period), to adequately capture the step-by-step *process* whereby households cope, or fail to cope, with the immediate, short-term and longer-term consequences of ill-health. Knowledge of such processes seems a pre-requisite for the design of schemes designed to support household coping strategies.

Ideally, such information might be gathered by directly monitoring affected households, as evidenced by the substantial body of work based on anthropological case studies of households containing members with specific illnesses, especially HIV/AIDS (Seeley 1995; Thomas 2006). However, these seem to be necessarily limited in terms of the number of households that can be studied (given the level of expertise required), and the extent to which they can be seen as representative of the general population. Longitudinal sample surveys have been used successfully to monitor health care seeking behaviour (Tipping and Segall 1996; Lucas and Nuwagaba 1999). However, these also have limitations. They tend to be based on the completion of relatively simple data sheets by local community members and it may be unrealistic to expect that such people can be trained to record the complex processes described above. In addition, such surveys have mainly been used to collect data predominantly relating to minor illness episodes in a limited number of small communities over a relatively short time period. Even where population health status is poor, major illness events are much less common, which would imply either that surveyed populations would have to be substantially larger or that monitoring would have to take place over a

much longer time period if a reasonably large sample were required. Scaling up in this way may be very difficult given that “organizational logistics and running costs, and the demand for a level of local expertise and participation” are identified as disadvantages of the approach (Tipping and Segall 1996). Long term monitoring of major illness would probably be feasible where a large population was already under long term surveillance (in sentinel sites, demographic surveillance sites, etc.), though in this instance serious ethical issues would be raised (i.e under what circumstance should those undertaking the monitoring intervene and in what ways?).

Given the known limitations of other available methods, the research strategy for POVILL was based on an innovative approach involving in-depth, one-year retrospective studies of household affected by major illness using teams of social scientists. A limited number of geographical case studies, based on purposively selected counties in China and health districts in Cambodia and Lao PDR were undertaken. In each of these areas households affected by major illness were identified and studied using a two stage approach:

- A rapid and reasonably large-scale household questionnaire survey was undertaken using cluster sampling of households within the selected study areas. This aimed to identify households substantially affected by different categories of serious health problems and to estimate the proportions of such households in the population.
- The sampled households were analysed and classified into a number of strata based on the information provided by the questionnaire survey (the choice of stratification variables is indicated below). In-depth studies, typically requiring 1-2 person days, of a probability sample of the households in purposively selected strata were then undertaken by a team of social scientists.

One issue discussed at length during the design phase was whether to include a matching control group in order to assess the relative experiences of households which had/had not experienced a major illness. Such an approach had obvious attractions but was eventually discarded. This was partly on the basis of resource allocation. The desire to capture the diversity of illness experiences described above would clearly have been constrained to a greater or lesser extent if detailed studies on a comparator group had been undertaken. There also seemed limited benefit from a policy perspective in

determining that households which had suffered a major illness, defined above as one with the potential to have severe adverse effects on household livelihood strategies, had fared less well than those which had not. The converse finding would have been extremely interesting but would also have contradicted a considerable volume of existing research evidence, as discussed above, and was considered unlikely.

THE RAPID SURVEY

The rapid survey was undertaken in purposively selected study areas: two operational districts in Cambodia; two counties in each of two Chinese provinces; and two districts in each of three provinces in Laos. In each area, a multistage cluster sampling procedure was adopted to select village communities, each consisting of around 100 households. All households in these communities were enumerated, giving total samples of some 6,000 households in Cambodia, 12,000 in China and 3,000 in Laos. The sample sizes were based on evidence from existing surveys that in any given year around 5% of households might be affected by the type of major illnesses addressed by the project⁶. Thus it was intended to conduct in-depth exercises with around 300 households in Cambodia, 600 in China and 150 in Laos.

The primary purpose of the rapid survey was to identify households for the in-depth exercise. However, it was also intended to provide estimates of: (a) the proportions of households substantially affected (in terms of expenditures, income loss, additional care/labour burdens, increased debts, reduced assets, etc.) by specific categories of ill-health in the selected poor rural areas in each of the three countries; (b) the proportions reporting access to and use of formal or informal support mechanisms, with a particular focus on schemes specifically designed to support households suffering from health shocks. The survey questionnaire was administered to all the households in each village community by mobile teams of four trained enumerators. A generic version is available on request from the authors. Final versions varied somewhat from country to country, depending on local circumstances.

⁶ It is recognised that this was a subjective and somewhat arbitrary estimate, obviously dependent on the severity of health-related impact that would be used to identify a 'major illness'.

The selection criteria for households to be included in the in-depth study varied between countries, depending on local circumstances and policy concerns. In line with the aims of the research, the underlying principle was that the households selected should have experienced a health shock that had the potential to severely affect their livelihood options. Note that this allowed the inclusion both of households that had been severely damaged and households that coped reasonably well - possibly with the aid of support schemes - allowing interesting comparisons between these two groups. In each country, selection had to be based on the application of specified rules to the data obtained from the initial rapid survey, maintaining the statistical validity of estimation procedures. For example, in Cambodia disease-specific groups were selected, based on a limited number of serious diseases which were known to be highly prevalent and have very diverse characteristics in terms of their likely impact on affected individuals and households. In China, three mutually exclusive groups of households were selected on the basis of health expenditures and loss of labour time, irrespective of their specific health problems. Here the defining criteria were: (a) inpatient expenditure $> x$; (b) inpatient expenditure $\leq x$ and outpatient expenditures $> y$; and (c) inpatient expenditure $\leq x$, outpatient expenditure $\leq y$ and loss of productive labour time $> z$. The values x , y and z were determined by considering the levels of each variable that would be generally seen as posing a serious problem for the poor rural households in the areas studied. A random sample of households in each group was taken for the in-depth study. In Lao, final decisions on selection criteria are still under discussion.

THE IN-DEPTH STUDIES

The in-depth exercises collected both quantitative and qualitative data. One specific aim was to derive reasonably reliable estimates of a range of quantitative variables including incomes, expenditures on health care, financial support received, duration of illness or disability, etc. It was anticipated that the use of experienced researchers at this stage, and the time allocated to each household, should mean that such data was considerably more reliable and consistent than would be obtained from most surveys, which are typically undertaken by relatively junior enumerators working under tight time constraints. The qualitative components were intended to allow the researchers to gain an understanding of the overall process by which households had been impacted by ill-health and the coping strategies

adopted to mitigate that impact. It was also seen as a basis for researchers to assess and interpret the quantitative data, improve its quality (for example by using additional questions if it became clear that responses had been inappropriate) and generally allow more rigorous and thoughtful analysis and interpretation of findings.

Each in-depth exercise was typically carried out by a team consisting of two or more members, including at least one male and one female researcher, both with substantial field experience. Fieldwork was mainly based on extended interviews, usually undertaken over a one day period, with adult members of the selected households. These interviews used a combination of structured forms, to enter basic comparative data (generic version available on request from the authors), and a range of semi-structured instruments. Discussions were sometimes recorded using a dictaphone if household members did not object. Because the study instruments were employed by experienced researchers, they were encouraged to use them in a flexible manner and to explore issues as they arose.

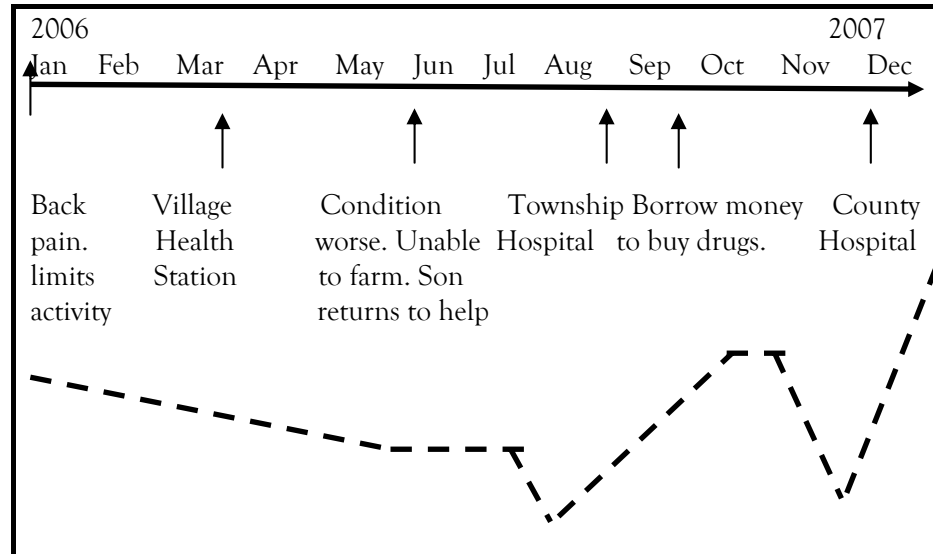
To allow a detailed assessment of the multidimensional poverty status/vulnerability of each household, basic data were collected on: level of education and participation in production activities for each member; estimated household incomes by source and expenditure flows by type; access to credit; participation in social and community activities; and household 'livelihood asset' ownership (covering physical, financial, human and social capital assets). A particular emphasis was placed on understanding the 'history' of relevant health problems, both from a health-seeking perspective and in terms of the consequences for different household members. Topics covered included: the physical impairment suffered by affected member(s), focusing on constraints on productive, domestic and social activities; healthcare seeking behaviour, including the cost and effectiveness of treatment; the various coping strategies adopted by household members at different times; financial and other types of support provided from both formal and informal sources; and the role played by livelihood assets and other contextual factors. By investigating the *process* which was set in motion by the onset of health problems, the aim was to understand why some households had been driven into extreme poverty while others maintained or occasionally even improved their standard of living. It was hoped that this would allow identification of the key points in

that process at which external assistance might have been proved most beneficial..

An 'illness narrative' (Groleau *et al.* 2006) - which sought to document the history of each health problem addressed was used to provide the underlying framework for other aspects of the study. For example, one key area of interest was to assess the financial assets of the household at the time when the illness started and monitor how these changed as the illness progressed, possibly with increased expenditures on health care and/or decreased income generation. Similar issues arose in relation to the varying work loads of different family members in response to changing demands for additional household care or ability of the sick person to undertake normal activities. The first stage in the interview was therefore to establish the sequence of 'events' from the onset of the illness to the present date.

The interviewer would first obtain a general outline of the sequence of events, asking simple questions such as "when did you first become aware of the problem?" (if it started during the year) or "how was your health at the start of the year?" (if it started before the beginning of the year) and "what happened next?". A timeline was to be drawn (on paper or on the ground) such that the respondent(s) had a visual display which they could amend as the interview proceeded. A simplified illustrative example is shown as Figure 1. The dashed line represents the overall health of the affected person as assessed by the respondents.

Figure 1. Illustrative one year time-line.



The next stage was to check that all significant events had been recorded, using an event list based on that shown in table 1. Questions might be of the form: “were there any other times when you sought advice or treatment from a health provider?”, “did you use any other medicine or receive other treatments apart from those you mentioned?”, “how did you raise the money to pay for that treatment?”, “did anyone help you at that time?”, and so forth. The primary aim was to understand the *sequence* of events - not their precise timing. Indications that one event happened ‘soon after’ another or ‘several months later’ were seen as perfectly adequate for analysis and interpretation. Similarly, the aim when gathering quantitative data was to obtain a reasonably accurate estimate, not to seek undue precision. Once the time line had been established, the interviewers attempted to obtain a fuller understanding of each event on the line. The task for the researchers was not to ask a set list of questions but to discuss events in turn and ensure that they had assembled key items of data on each, using the structured recording forms. Note that some of this information would have been obtained in establishing the time line and that information on one event might have been provided when discussing another.

Table 1. Time Line Events and Attributes

<p><i>Change in health status:</i></p> <ul style="list-style-type: none">• Symptoms and severity (specific symptoms / pain, mobility, etc.)• Limitations on production, household, or 'basic living' tasks (duration, constraints) <p><i>Self-treatment:</i></p> <ul style="list-style-type: none">• Type of treatment• Drugs taken• Source of treatment/drugs• Cost of treatment/drugs <p><i>Out-patient consultations:</i></p> <ul style="list-style-type: none">• Type of provider• Distance travelled to provider• Did they identify the problem (diagnosis)• What treatment was prescribed• Was the treatment followed• Expenses involved: travel/fees/drugs/gifts/other• How was money raised• Satisfaction with provider <p><i>In-patient episodes</i></p> <ul style="list-style-type: none">• Type of provider• Distance travelled to provider• Did they identify the problem (diagnosis)• Length of stay• Reason for discharge• Expenses involved: travel/fees/drugs/gifts/other• How was money raised• Satisfaction with provider <p><i>Seeking and/or obtaining assistance from anyone outside the household</i></p> <ul style="list-style-type: none">• Individual(s) or institution approached• Type of help sought• Type of help obtained (labour, goods, cash, exemption from charges, etc.)• Details of help obtained (labour time, quantity of goods, cash amount received, services exempted, etc.)• Satisfaction with help obtained <p><i>Asset sales and borrowing:</i></p> <ul style="list-style-type: none">• Assets sold• Money borrowed• Source of loan• Amount of loan <p><i>Other memorable good and bad events</i></p>
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Discussion

The reliance on household survey data relating to the short-term recall of illness episodes and longer-term recall of hospitalisation evident in much of the literature on the impact of ill-health and health care seeking behaviour, has clearly not arisen by chance or oversight. It is in large part a consequence of the relative ease of gathering at least basic data on such events using traditional questionnaire surveys. Though there is considerable debate as to the relative advantages of one to four week recall periods for illness episodes (e.g. Keller *et al.* 1997), it is at least plausible that such timescales allow reasonably reliable responses to be obtained for questions relating to symptoms, onset and length of illness, care seeking behaviour, health care expenditures, etc. Similarly, it is usually assumed, perhaps with less certainty, that entering hospital is a sufficiently rare and memorable occurrence that respondents will be able to provide information on, for example, length of stay, diagnosis, treatment and cost of care, which are sufficiently accurate to justify detailed analysis and interpretation.

It has been argued above that in spite of the attractions of such traditional surveys, there is an urgent need from both academic and policy perspectives to go beyond the kind of information that they can deliver. Continuing to estimate the incidence of predominantly minor, acute, symptomatic illnesses such as fevers, coughs, episodes of diarrhoea, etc., or the proportion of such episodes which result in a visit to a facility described by the respondent as a pharmacy, clinic, health centre or hospital, is simply not sufficient to address existing serious knowledge gaps relating to the impact of ill-health on households or to guide policies intended to mitigate the effects of such impacts. Household survey data on those hospitalised may be of greater interest, if the sample size is sufficiently large to allow detailed disaggregation of what is typically a very small proportion of sampled individuals. However, a focus on inpatient treatment, many aspects of which can often be much more reliably researched by means of facility-based surveys⁷, typically fails to address the needs of the poor and poorest

⁷ There is a tendency in some countries to use data from large-scale household surveys as a substitute for conducting serious facility assessment exercises, which should include inpatient surveys. These have the great advantage of being able to combine facility records with respondent information. This approach is also used in the research project described here.

individuals, who are least likely to access such treatment, and those who suffer from chronic conditions. This latter failure has become of increasingly concern as more and more evidence has emerged on the extent of chronic illness, even in poor populations, and the serious consequences for both affected individuals and other household and family members (WHO 2006).

The alternative approach described in this paper was developed partly from frustration with existing sources. It was seen by those involved as one potential way to address at least some of the concerns raised above. It lays no strong claim to originality, except possibly in terms of the application of recent methodological innovations in other areas to research on poverty and health. The emphasis on the need to consider dynamic processes, to acknowledge the diversity and complexity inherent in many of these processes and the requirement to adopt an interdisciplinary approach, integrating a wide range of quantitative and qualitative methods, reflects much current thinking in the general literature on poverty analysis (Addison, Hulme and Kanbur 2007). The use of visual time lines to promote discussion of illness events and elicit quantitative information relating to those events is closely aligned to recent work using 'life trajectory' diagrams (Baulch and Davis 2007; Davis 2006). The strategy of using an initial large-scale survey to identify a target population for in-depth studies can be seen as a natural extension of the commonly adopted practice of using group-specific modules to gather data on nutrition, disability, etc. in national household survey questionnaires (e.g. NSSO 2003).

The overall value of the approach will of course have to be assessed in the light of research experience. However, as with any innovative methodology, the development process has already raised a number of potential limitations and concerns which will need to be addressed in any future applications. For example, the assumption that the design of the initial large-scale filtering survey would be relatively straightforward - with enumerators asking a comparatively short list of questions to determine if a surveyed household was a potential candidate for the in-depth study - has had to be abandoned. In many respects this reflects the range of health-related conditions and the diversity of impacts experienced by households which originally motivated the research. A series of value judgements had to be made as to how selection of target households should be undertaken. Should we only be concerned with households that had been seriously adversely affected by ill-health or was it just as important to include those

that had adopted successful coping strategies, possibly with the assistance of government or other support schemes? Should the death of a household member automatically qualify that household for inclusion? How should the long-term physical disability of a household member be considered: in what respects was the situation of, say, an individual born with a limb deformity, essentially different from another suffering from crippling arthritis, if both conditions similarly affected their ability to cope with productive labour or household tasks? How could the impact of ill-health on household wellbeing be assessed if the household had also suffered from other serious shocks, for example crop failure or loss of employment?

One unresolved issue raised in the design phase was the extent to which we were making the most effective use of local knowledge. Given that we were specifically focusing on the variability of circumstances confronted by households experiencing serious illness, should we not seek to tap into the fund of detailed contextual knowledge possessed by local health workers and health system managers, or even local government officials and community based organisations, on the basis that they would be able to guide us through the key health-related concerns voiced by their constituents and associated coping strategies of greatest relevance. The design team did include a number of senior health and other government officials from each country but they could obviously not be expected to have the detailed local knowledge that might be available to their community-based colleagues. It was pointed out that there could be risks in placing too great a reliance on this source. For example, in many areas the health sector tended to be highly male-dominated and it was possible that what might be key health concerns or preferred coping strategies for women would be downplayed or simply not well understood. Potential social or political biases, for example in relation to minority groups, would also have to be considered. In the case of health conditions which were to some degree stigmatised, local agencies might tend, consciously or unconsciously to underestimate their prevalence. Partly under time pressures and partly because of the complexities of integrating this knowledge base, there was no serious attempt to systematically follow this approach, other than through ad-hoc discussions with local key informants. However, it is an interesting methodological avenue that should be further explored.

One major concern of those designing the field work was the extent to which the attempt to conduct in-depth studies on a scale much larger than

usual would result in novel and often daunting challenges for those social scientists undertaking the household investigations. As opposed to the tasks normally associated with large scale surveys, these individuals were tasked not to act as enumerators completing a questionnaire but rather to use their research skills in an independent and creative fashion to gather and record a wide diversity of detailed quantitative and qualitative information on a relatively large sample of households. A number of the techniques and methods required might be familiar but they would previously been associated with much smaller-scale household case study exercises. Moreover, researchers were to be encouraged to interact with multiple household members and adapt the methodology to the specific household context that ill-health had created, for example varying the sequence of topics addressed to allow for the particular preoccupations of various household members. It was recognised that meeting these requirements while maintaining the relaxed, conversational approach on which the effectiveness of the methodology crucially depends, would require the allocation of substantial researcher time to each household investigation.

The in-depth researchers would also have to take on the difficult task of convincing household members, who in many cases would have been through, or be going through, an extremely distressing experience, to discuss that experience at length. It was recognised that cumulative exposure to such distress might also have a considerable impact on the researchers themselves, particularly as there would inevitably be cases where respondents expressed the hope that taking part in the study would lead to practical support, whatever initial statements were made to the contrary. It was therefore seen as essential to provide extended periods of rest for researchers between groups of interviews in order to maintain their morale. Overall, it is seen as extremely important to the success of the methodology that the burden on the field researchers be strictly limited, allowing them to operate as far as practicable in a relaxed and unhurried manner. The adoption of excessive targets in terms of household interviews per individual or unreasonable demands for information on each case would risk severe damage to the quality of their work and hence to the primary objectives of the research.

Finally, the development of the methodology has led to discussions of a much more general issue which will only be partially addressed in the current project. This relates to a familiar but still intractable concern, the extent to which the traditional household unit should remain the primary

focus for data collection and analysis. This issue has been frequently raised but rarely addressed in relation to large scale surveys. The general attitude seems to be that while the limitations of the household focus must be recognised, they are not sufficiently serious to warrant the radical revision of research methodology required if it were to be abandoned (O’Laughlin 1999). It may be that such a position was perfectly reasonable. However, in recent times it has become evident that in many countries, including those which are included in the current research, the nature of rural households has radically changed, to the extent that it is often extremely difficult to argue that they can be described as more or less autonomous economic units for research purposes.

For example, many of those described as ‘household members’ are living away from home as ‘temporary’ migrant workers but typically play a major role in both income and expenditure aspects of the household economy. They will often fund investments that determine future production and independently purchase goods and services intended to benefit all members of that household, whether resident or not. In some case they may provide accommodation, care and financial support to other ‘household members’ that allows them to access urban health care facilities. Treating their involvement in the household economy simply in terms of their ‘transfer payments’ seems wholly inadequate. For example, in the context considered here, the impact of the serious illness of such a migrant worker may have even more damaging implications for a rural household than the similar illness of a resident member. This raises very difficult problems in terms of practical research strategies. Even with the detailed in-depth interviews proposed, it does not seem realistic to suggest gathering detailed and reliable information on many aspects of an identified major illness - progression of the illness, treatments, costs, etc. - where it involves a household member who is living elsewhere. Work on designing the current project has clearly identified this as a serious problem and some modifications to the research instruments and procedures have been undertaken to take account of it. However, much more thought will be required to determine a truly satisfactory solution.

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