Coping with the costs of illness in slum households in Bangladesh. An empirical analysis of the relationship between income distribution and household behaviour
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CONCLUDING REMARKS: LESSONS FOR HEALTH SYSTEMS RESEARCH

Our study has demonstrated that comprehensive community-based research on health care seeking issues is required to study household coping with the costs of illness. These issues include the household socio-economic and illness profiles, and, patterns of costs of illness and of the utilisation of all health care options, including non-use, in the population. We indicated that the duration of these community-based studies should be long enough to capture the full extent of these costs on the household behaviour and economy.

The combination of qualitative research and quantitative research methods turned out to be indispensable. While the cognitive study produced valuable information in its own right on popular disease classification, the health care options a study population perceives to be available, and the reasons and constraints operating in health care choice-making, this data were indispensable to properly prepare the longitudinal survey. This preparation included the design of the questionnaires for the longitudinal survey, the preparation of the guidelines for the interviewers, and the introduction of the interviewers in the subject of health care seeking in the slums in Dhaka-City. As far as the (direct and indirect) costs of illness were concerned, we primarily used specific background information from the international literature to construct our analytical framework, and, with the latter, to design appropriate questions for the longitudinal survey (and for the case studies). Because of the complexity of the issues (both qualitative and quantitative) involved in the investigation of the costs of illness and coping with these costs, we choose not to include them in the cognitive study that preceded the longitudinal survey. This complexity also refrained us from incorporating in our study the psychic and social costs of illness, and how slum households cope with such costs.

A special word is required on the relationship between national health surveys and studies like ours. Few national surveys currently attempt to investigate aspects of household coping with costs of illness, particularly the indirect costs. National surveys typically have sample sizes of between 2,000 and 3,000 households, which usually include only a few hundred slum households. Assuming, for instance, a sample size of 2,400 households, a proportion of 25% of the total population living in urban areas (such as is believed to be the case in Bangladesh), and 30% of this urban population living in slums, we obtain a sub-sample from the slum population of 180 households, which are usually spread over the main cities of the country. Therefore, in view of the complexity and the magnitude of the indirect costs of illness

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8 In the present document, we did not present the findings of the cognitive study, nor of the case studies, conducted after the completion of the longitudinal survey.

9 It is to be noted that we used direct questioning to investigate direct costs of illness and how these costs were covered (see Questions 9 and 10 respectively in the Illness and First Health care resource questionnaire, and in the Subsequent Health care resource questionnaire in Annexes 4.2 and 4.3). For studying the indirect costs, direct questioning was also used (see under Question 8 in the same questionnaires for travel and waiting times; and Questions 10 of the Household Baseline survey (Annex 4.4) and of the Socio-economic and Demographic Update Form for loss of income). As mentioned in section 9.1 of Chapter 9, a deductive method was used for the investigation of coping with loss of income, namely the identification and analysis of changes in the household income and occupation pattern in relation to the nature of the loss of income (cause and duration of reduced earning capacity).
compared to the direct costs, research on indirect costs and household coping with these costs should be included in or added to the national household surveys in a systematic manner. Considering the complex and multi-faceted nature of these costs and household coping with these costs, particularly in (vulnerable) sub-groups of the population, and the less appropriate research methodology adopted by national health surveys to study these issues, we would rather opt for systematic additional studies than for inclusion in national health surveys.

In order to link the findings of our study (on a specific sub-population, and a specific topic) with the broader context of health systems research and development, we suggest the following agenda for complementary research:

1) Studies on **health care seeking and coping with the costs of illness in other sub-groups of the population.**
   The comparison of the findings of these studies with those of our study would allow for investigating intra-urban and urban-rural disparities in costs of illness for the patient and his/her family and on related household coping, but also in the broader issues of ill-health and health care seeking which may be associated with the way in which households cope.

2) Studies on the **provision of health care.**
   These studies include investigations into the organisation of health care delivery, including the types and characteristics of the health care options and providers, and the levels of health care delivery. They should further focus on gaps and overlaps in population coverage with health services, and on distribution of responsibilities not only on a geographical basis, but also within a socio-economic and cultural context, as well as on the type of service mix provided. For instance, many projects nowadays focus their attention on mothers and children (age and gender-based) and to reproductive health (often mainly family planning) and child health, usually delivered as an ‘essential service package’ at community-level and/or referral level. As such services leave important sub-sections of the population without care (for instance the income-earners), or consider health care delivery strategies only as a sum of categorical health interventions, proper research into the above topics is urgently needed with the aim of how to convert such services into the integrated community-based Health Centres of the health care system described in the policy implications of the present study.

3) Studies on **health care financing and expenditure.**
   These studies consist of documenting issues relating to health care expenditure and how it is currently financed at the national (macro-) level through the available sources of financing, including the proportions of national revenue spent on different types of health care activities and levels of health care delivery. There is also need to study health care financing and expenditure at the intermediate level, particularly when policies of devolution and decentralisation are implemented. Third-level studies should then focus on micro-financing issues, such as the expenditure pattern of different types and levels of health services within a Health District, and how they are (or could be) financed by individuals, households and the community, and by other sources of financing. Finally, a specific component is research on the modes of payment by individuals, households and the community in relation to the mechanisms of health care provision and management.

4) **Action-research on the functioning of health services within a health care system.**
   Research projects should be set up as demonstration projects of the rational organisation of a health care system, incorporating community-based health services and referral-level general hospitals. These projects should thus reflect the implementation of health services within the framework of a Health District. It should be noted that action-research is fundamentally different from operations research. The latter essentially ‘examines the supply-side of health programmes with the aim to obtain a better understanding of operations in these programmes and with this to
improve the delivery of services' (Mookherji S., 1994). In this context, health programmes are separate interventions on different aspects of health care, such as family planning or control of diarrhoea. In contrast, action-research in health care considers health care as a 'critical social issue' (Susman G., Evered R., 1978). It aims at contributing to the practical concerns of people about health care in a comprehensive way by developing their self-help competencies. An essential characteristic of action-research is that, from the start, it involves many partners, including policy-makers, the local population, and the researchers themselves (from different disciplines). It is implemented in a cyclical process of problem (re)identification, empirical decisions on the best action, implementation of this action and its continuous evaluation, and feed-back of the evaluation findings in the re-identification of the problem.

5) Action-research is also required to investigate how to decrease the burden of ill-health on the household income-earning capacity and economy through initiatives in income-generating activities and health care financing schemes.

It should be stressed here that the research agenda described from 1) to 5) is not detailed in a sequential manner. Indeed, action-research, when properly designed for a Health District, may well capture the essential of research topics mentioned under 1) to 5).

6) Finally, specific policy-oriented research is required to analyse to what extent the findings of all the previously mentioned types of studies have been instrumental in influencing the process of relevant policy formulation, implementation and evaluation. This research should be incorporated in the broader framework of analysis of any existing health policy or feed into the development of a new one. It should not only address what the findings of studies, such as the ones presented here, can contribute to the health policy process, but also how it can be implemented, and, not the least who may possibly support or reject the changes suggested (Walt G., Gilson L., 1994). In order to enhance the chances of diffusion of findings into the policy process, policy-makers should be involved in the preparatory design process of the research, particularly of the action-research. Ideally, such research is commissioned by the concerned health authorities (Davis P., Howden-Chapman Ph., 1996).