Chapter - 1

Introduction

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This is a study about National Burden of Disease (NBD) studies. Following the publication of the Global Burden of Disease (GBD) results (World Bank, 1993; Murray and Lopez, 1994, 1996, WHO, 1999), both individuals and organisations committed to health policy are hoping to gain insights from comprehensive assessment of disease burden at national and sub-national levels. The World Health Organisation (WHO) has launched a Global Program on Evidence and Information for Health Policy. A few national burden of disease estimates have been made[1]. Funding agencies and International Financial Institutions tend to commission NBD studies with an expectation that the ensuing results from them would inform their deliberations about health sector reform, planning, and development by countries seeking to reform or develop their health sector. Given the current aspirations for evidence- based policy formulation, an important question that surfaces is: what is the appropriate investment in a NBD study for local data collection? This is one of the two primary motivations for this study. Burden of disease is now sought to be quantified by summary measures of population health, that combine information on mortality and morbidity. Assignment of weights to different health states is a key step that allows for combination of mortality and morbidity. Nature of the health state valuations both at the individual and community level have a bearing on the measurement of disability weights and its use in burden of disease estimates. Unfortunately, burden of disease estimates have hitherto used disability weights obtained from convenience samples. It will be helpful to understand the nature of valuations by individuals of different health states. Understanding the distribution of values assigned by members of a community to the same health state facilitates uncertainty analysis as also the interpretation of burden of disease estimates. A further methodological challenge is to measure health state values in a partially literate community. This is the second motivation for this study.

The term national burden of disease (NBD) study is used in a generic sense to mean local burden of disease estimation for national and sub-national entities. Diversity in size of countries in the world means that the population in

[1]For example, Mexico, Mauritius, and Australia.

sub-national entities like a state in India or a province in China can equal or exceed the total population in some countries. The problems and potential uses of burden of disease estimates for such sub-national entities would be similar to situations in other countries. The term NBD is used because it has gained currency of usage to connote a comprehensive assessment of disease burden for national and sub-national entities.

The work is presented in nine chapters. In this introductory chapter, I first review the literature available on aids to priority setting in the health sector, and then try to identify the different motivations for the development of synthetic measures[2] of population health status. In the following section, I review various efforts till date that have attempted to quantify health and illness. Significant attempts in the past and current formulations of synthetic measures are high lighted. The Global Burden of Disease (GBD) study, which provides an important background to this study, is then described. Finally I outline the research questions and conclude the introduction with a discussion about possible ramifications of this study. I use the situation in Andhra Pradesh (AP) state in India to build up my arguments and illustrate experiences with a NBD study. Chapter Two describes data sources and the methodology employed to arrive at the general demographic estimates required for a NBD study. General demographic estimates consisting of mortality as well as population statistics for AP are presented. The subsequent chapter deals with the cause of death in AP. The importance of cause of death statistics for NBD estimates is briefly discussed, followed by description of data sources, methodology and cause of death estimates for the NBD study. Chapter Four presents the general approach to estimating descriptive epidemiology of diseases for computation of disease burden. The following chapter takes up tuberculosis as an example and illustrates steps for estimation of it's descriptive epidemiology using locally available data on tuberculosis in India and Andhra Pradesh. Ideally one would have liked to generate such descriptive epidemiological estimates for all diseases. Unfortunately constraints of time and resources were not conducive to the achievements of substantial progress in this direction. So I have used the India epidemiological estimates from the GBD96 study (Murray and Lopez, 1996) as inputs for estimation of disease burden in AP, with a hope that these two chapters will help stimulate further work in the country and improve the data base for estimation of locally anchored epidemiological estimates for most diseases. Chapter Six describes the methodology of the health state valuation study done in Andhra Pradesh. It reviews the literature on health status measurement and describes the methodology of the studies in Andhra Pradesh, including analysis

[2]By a synthetic measure of health status, I mean a formulation that combines mortality and morbidity components. An alternative terminology would be summary measures of population health status, which I use synonymously with synthetic measures.

in order to assess reliability and validity of the measurements. In Chapter Seven I present results from the community survey of health state valuation, and sum up the findings from the health state valuation study. Chapter Eight examines the age weighting and discounting schemes incorporated into the DALY measure and illustrates how NBD teams can deliberate about available decision options and connect the same to local preferences about age. The last chapter, i.e. Chapter Nine, presents results from the burden of disease estimates for AP with different levels of anchorage to local data. Differences in the burden of disease results from various estimates are examined in the light of research questions raised in Chapter One. Chapter Nine concludes with a presentation and analysis of AP burden of disease estimates and highlights the importance of some findings for the health policy of the state.

Setting priorities in health sector:

Real operations of a health system, on a day to day basis, treat certain problems, meet certain requirements and bypass some others. Priorities are set explicitly or implicitly[3]. It is important to recognize that health sector priorities are ultimately set through social and political processes. Linkages between health policy and social political process have been fairly well documented (see for example; Walt 1994; Mckeown et al 1994; Carr-Hill 1991). Analytical approaches to priority - setting operate within the socio - political environment. They modify the socio- political environment by changing peoples information set. On the other hand socio political interests may engender development of specific analytical approaches. Although expressions like "priority - setting techniques" and its minor variants are used in health policy literature they actually refer to technical and analytic aids to priority - setting. This semantic distinction is important, since a good deal of criticism of specific aids to priority - setting arise from an apprehension that they are formulaic. The expression "health priority setting" is used here to mean analytic aids to priority - setting in the health sector.

Analytical aids to priority setting consist of processes and criteria (Goold 1996). Priority setting criteria refer to the variables considered relevant for the ordering of alternative choice for instance, age, sex, capacity to benefit from treatment etc. Priority - setting processes refer to the procedures followed to arrive at certain criteria, and application of these chosen criteria to specific data. Both procedural justice and the shared criterion of fairness appear to be

[3]Priorities may not be set at all and things may be allowed to drift, either due to bureaucratic habit or political corruption. The social political remedy for such a situation is to ask for explicitly set priorities and seek action conforming to those priorities. While this problem is more fundamental, the starting point for this work is that decision makers do recognise the need for priority setting and are willing for change.

important for health priority setting. Analytical aids to priority setting can either be qualitative or quantitative. While this study is about quantitative aids to policy analysis, usefulness of qualitative information, such as case studies, should also be kept in perspective (Filstead 1981).

At the macro level, two distinct forms of health priority setting can be distinguished, namely: (a) systemic and (b) benefit package definition or rationing. Systemic priority - setting is about health sector wide policies. For example, allocation of financial and managerial resources between public health oriented interventions and clinical services; speciality profile of outputs from education and training institutions, technology assessment, regulatory policies to discourage undesirable activities, and incentive regimes to encourage desirable services. Although systemic priorities would encourage certain services (say the ones considered cost-effective) and discourage expensive services, there may still be scope for a few persons to receive the expensive services. In other words systemic priorities act on the overall volume of services rather than on specific cases. Rationing is implicit in a systemic priority setting, although its application to individuals may vary. Explicit rationing by definition of benefit packages may be based on the same set of ethical principles and allocative criteria, but apply at an operational level.

Aids to priority setting in the health sector:

To understand both the process as well as data requirements for health priority setting it will be useful to review actual priority - setting exercises in the recent past. I have reviewed four such efforts undertaken during the 1980s and early 1990s. Two of these are country - specific (US and UK) and two were undertaken by international agencies. These are: (a) domestic health policy consultation for US undertaken by the Carter Center, (b) interdisciplinary committee on health promotion constituted by a group of four health care organizations in the UK, (c) UNDP - sponsored monograph on establishing health priorities, and (d) the World Bank's World Development Report 1993 on investing in health. All these efforts were directed towards determination of systemic priorities. A large body of literature focusing on rationing and benefit package definition exists (see for example Malek 1994). A well known example of priority setting exercise for rationing of health care is the Oregon experiment (Strosberg et al. 1992). They are not reviewed here for two reasons, namely: (a) the present work is concerned with the perspective of the developing country and (b) the four efforts for systemic priority setting specifically reviewed here provide enough understanding of the role of quantifying of disease burden, which is the focus of this study, for priority setting.

Table - 1.1 US "Closing the gap" project - common data format.

Health outcome	Statistic
Mortality	Deaths, Crude death rate, age standardized death rate, age specific mortality rates, years of potential life lost before the age of 65.
Morbidity	Incidence rate, annual period prevalence, days of hospital care, hospitalizations, physician visits, days lost from work or major activity.
Complications	Blindness, paralysis, amputation.
Quality of life	Individual (disability, missed education opportunity, training, employment), Family (transportation to health facility etc.) Social (greater dependency etc.).
Direct costs	Short stay hospital care, physician and other professional care, pharmaceuticals, special equipment and long term institutional care.

Soon after its establishment in 1981, the Carter Center in the United States of America (US) appointed a health policy task force to identify domestic problems in the health field. This task force identified reduction in the size of disease burden, preventable or treatable with current technology as a priority. In effect this was a full - scale health sector priorities review. The emphasis was on generic risk factors (also referred to as precursors in the study report) for several health problems. The study was named as "Closing the gap". Methodological details and results of this consultation have been published (Foege, Amler and White 1985; Amler and Dull 1987). Major health problems in the US were identified in September 1983 by an expert panel using five criteria, namely: (a) point prevalence and temporal trends, (b) severity of health impact and cost, (c) sensitivity to intervention using current scientific or operational knowledge, (d) feasibility of such interventions, and (e) generic applicability of such interventions to other health problems. Identified problem areas included: alcohol dependency, arthritis, cancer, cardiovascular diseases, dental diseases, depression, diabetes mellitus, digestive diseases, drug dependence, infectious and parasitic diseases, respiratory diseases, unintended pregnancy and infant mortality, unintended injury and violence. Definition of these problem areas are so broad that real prioritization must depend on additional criteria and data sources used to study each of them. Each problem area was assigned to a consultant, and an expert panel from different specialties, both of whom followed a common data format (Table-1.1) to quantify illness and its component

attributable to specific risk factors. Four out of the five groups of data relate to quantification of disease burden.

In 1985 a group consisting of four health care organizations[4] in the United Kingdom (UK) sponsored a research fellowship in health promotion and appointed an interdisciplinary committee to guide the project (Smith and Jacobson 1988). The main focus of this committee was to identify priorities for health promotion efforts. This committee listed three overall health goals and six criteria to identify health sector priorities. The three goals were: attainment of (a) longevity, (b) a good quality of life, and (c) equal opportunities for health. The six priority setting criteria were: (a) need for action and strength of supporting evidence, (b) feasibility or effectiveness of action and strength of evidence supporting it, (c) public support and acceptability, (d) professional support, (e) political support, and (f) economic benefits. To identify needs for action, the committee explicitly analyzed mortality patterns by broad age groups. Priorities for reduction of mortality and improvement of quality of life were identified using the mortality analysis and group consensus. Top causes of current or emerging disease burden implicitly identified by the committee include: circulatory diseases, cancers, sexually transmitted diseases, road safety, mental health, congenital abnormalities, prematurity and low birth weight, vaccine preventable diseases and dental diseases in childhood.

Some time before 1988, the United Nations Development Program (UNDP) commissioned Julia Walsh to prepare a monograph on establishing health priorities in the developing world (Walsh 1988). Walsh reviewed literature, discussed with scientists and program officers in the World Health Organization (WHO), the United Nations Children's Fund (UNICEF), UNDP, World Bank, non profit funding agencies and members of the faculty drawn from a few academic institutions. These consultations suggest an effort to structure the monograph contents around the prevailing consensus about priorities in health sector, even though no formal consensus method was used. In the monograph Walsh first takes stock of the burden of illness, relying mainly on causes of death. About 20 disease categories were identified as leading causes of illness and death in the world. She then listed available interventions, their cost and efficacy, and discussed factors affecting effectiveness. Although the monograph does not give details about the manner in which estimates of mortality and intervention efficacy were gathered, it does bring out the sequence of analytical steps required for identifying priorities in health service provision and research.

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[4]The Health Education Council named The Health Education Authority from April 1987, King Edward's Hospital Fund for London, The London School of Hygiene and Tropical Medicine and The Scottish Health Education Group.

The World Bank's World Development Report (WDR) 1993 was devoted to the importance of investments in health and priorities within the health sector (World Bank 1993). This report made use of two background studies, namely (a) the global burden of disease (GBD) study (WDR 1993 Appendix -B) and (b) the health sector priorities review (Jamison et al. 1993). The GBD study quantified global burden of premature mortality and disability caused by about 100 diseases. Diseases cumulatively accounting for more than 90 percent of premature deaths were included in the list. A new measure of population health status, the disability-adjusted life year (DALY), was used. The health sector priorities review made use of the DALY as a common denominator to account for output from different health interventions. Each of the 25 specific diseases or disease clusters were taken up by multidisciplinary teams who studied the cost-effectiveness of available interventions.

Certain methodological characteristics appear common to all priority - setting exercises in public health, namely: (a) some form of quantification of disease burden, (b) feasibility and cost-effectiveness of interventions, and (c) reliance on consensus among experts. The role of disease burden estimates in priority - setting needs elaboration. Evidently a disease burden estimate is only one component of a priority - setting exercise. Faced with disease burden estimates, people quickly recognise the main causes of illness and develop a motivation to reduce them. This motivation to apprehend the main causes of disease burden inevitably leads one to search for appropriate technologies and their cost-effectiveness. Considerations of technical, practical feasibility and cost-effectiveness of interventions play a crucial role in the minds of policy makers (along with social political and ethical considerations) in determining which causes of disease burden are targeted by health care delivery system and which are the subjects of further research. Thus, the primary role of a disease burden estimate is to set the agenda by creating an environment of concern and motivating policy makers. In addition, disease burden estimates provide benchmarks for future evaluation of the effect of health care interventions. Specific disease burden estimates are useful for analysing the cost-effectiveness of interventions and health resource allocation modeling.

Limitations of disease burden information for priority - setting should also be recognised. It is sometimes believed that an understanding of the composition of disease burden and an identification of the main causes of illness are all that is required for priority - setting. People tend to uncritically assume that priorities are set by merely attacking the main causes of illness. This is partly true in so far as some form of "attack" on main causes of illness is imperative. For example, the main causes of illness should be important subjects for research. In the case of health services, disease burden information may help attract attention to the problem. However, feasibility and cost effectiveness

are additional considerations to set priorities for organisation and delivery of health care services. Health care priority - setting is distinct from research priority setting. Health priority setting includes both, but may be used, in context, to mean priorities in service provision. Mooney and Creese (1993) have discussed the role of disease burden estimates in priority setting. While Prost and Jancloes (1993) discuss the role of epidemiology in public health priority setting. Note that disease burden estimates mostly consist of descriptive epidemiological information. Descriptive epidemiology provided traditional disease burden profiles consisting of cause specific mortality and disease-prevalence. Family of summary measures of health status like the quality adjusted life year (QALY) do incorporate some value judgments by way of disability severity or health state preference weights etc. (Shiell 1997). Even then, QALY measures are more sensitive to descriptive epidemiological estimates (Murray and Lopez 1996). So discussions about role of epidemiological estimates in priority setting would apply to summary measures of disease burden estimates as well.

Motivation for development of synthetic measures of health status:

The formal study of population health status and its potential for improvement require appropriate measures of health status. Three concurrent trends in public health appear to have contributed to development of various health status measures. These are: (a) changes in the concept of health, (b) the epidemiologic and demographic transition, and (c) concerns about rising costs of health care. I briefly review these trends as also the development of health status measures in response to each one of them.

The quantification of health status or its complement the disease burden is inextricably linked with the concept of health. For example, if we restrict the definition of health to survival alone, a single dimension of measurement based on mortality is adequate to represent the health status of a community. Mortality - based measures, namely life expectancy, infant mortality rate (IMR), crude and age - specific death rates are the most durable of all statistics used in public health. Expanding the definition of health to include absence of any kind of illness episodes, would require an additional dimension to count all illness episodes. Many household health surveys[5] report a simple count of illness episodes per person per time period. Chiang (1965) proposed a composite

[5]For example: the Survey of Sickness from 1943 to 1952 in UK (Logan and Brook 1957); National Sample Survey (NSS) 42nd round in India on health - related maters.

index of health based on mortality, illness episodes and average duration of illness episodes. Lumping all kinds of illness episodes into one category has its limitations. All episodes, irrespective of severity of illness, risk being homegenised and treated the same. Critical analysis of different contributing factors like causative organisms, risk factors etc. would not be possible. Consequently, an elaborate classification of illnesses into specific disease entities has developed, to account for the growing awareness of various disease processes. The International Classification of diseases and causes of death (ICD), periodically revised by the WHO, provides a standard reference list of all diseases and guidelines for coding of causes of deaths of which the concept of which the 10th revision (ICD10) is the latest (WHO, 1993). The burden of illness due to each disease under this concept of health based on "absence of specific disease" is measured by cause - specific death rate (mortality dimension) and prevalence or incidence of the diseases. For example, the WHO study group on measurement of levels of health listed prevalence surveys in many countries (WHO 1957).

Changes in the concept of health could result from a process of enlightenment, and / or be a response to emergent problems. But mere enlightenment is usually not enough to introduce and implement real changes in the way we do things (design and implementation of health status measurement tools, in this case). Changes in magnitude is another important consideration. The practical difficulty of dealing with emergent problems usually impels the search for solutions. Complementary changes in related concepts (for example, the concept of health in this case) facilitates action and helps in development of solutions. The epidemiological transition (Omran 1971, 1983) from high to low mortality conditions and the demographic transition due to controlled fertility impelled the development of new measures of health status. These transitions produce characteristic changes in disease profile and age composition, namely: (a) reduced incidence or prevalence of infectious diseases, (b) increased prevalence of non - communicable and degenerative diseases, and (c) increase in proportion of elderly and geriatric population. Each of these changes has its impact on the measurement of health status. Sanders (1964) observed that improved health care may, by promoting survival of the old and of the disease- prone young, result in an increase in the prevalence of chronic disease. Hence traditional indices of health service performance such as IMR and standardised death rates may show improvement despite rising morbidity. For example, decline in general mortality including tuberculosis deaths in the US improved the relative ranking of other causes of death including ischaemic heart disease. Although tuberculosis continued to be a problem, its importance, previously recognized on the basis of number of deaths, appeared to wane. Dempsey (1947) pointed out that mortality rates do not tell the full story of

tuberculosis burden. Most people with tuberculosis are afflicted at a younger age group. In other words those dying of tuberculosis lose many more life years as compared to those who die of ischaemic heart disease as the latter usually occur only late in life. To remedy the measurement problem, Sanders used a time-based measure of premature mortality, i.e., potential years of life lost. The essence of her argument was to attach higher importance to death of young adults in comparison to the death of elderly persons.

The impact of the higher prevalence of non-communicable diseases on health status measurement is exemplified by arthritis and cancers. Arthritis is a typical non-degenerative disease that does not kill but affects the quality of life. Non-conventional outcome measures for rheumatoid arthritis patients were developed by the American Rheumatism Association (ARA functional scale) during the late 1940s (Stenbrocker et al 1949; Deyo 1992). Although the ARA functional scale is now superseded by more reliable and valid measures (McDowell and Newell 1996), this is an example of early efforts to use non-conventional health status measures to meet the specific requirements of a non-communicable disease. Similarly Karnofsky and Burchenal (1949) developed a scale for the clinical evaluation of chemotherapeutic agents in cancer patients. Increase in the size of elderly population in the post - transition period required more geriatric care. To measure geriatric patient outcomes Katz and others developed an index of activities of daily living (ADL) in 1957 (McDowell and Newell 1996, Rosser 1983, Katz et al 1963).

Concerns about rising costs have been made manifest through three clearly distinguishable policy instruments, namely: (a) health technology assessment, (b) planning and program evaluation, and (c) health resource allocation. Evaluation of new therapeutic alternatives consisting of new drugs or procedures started including cost-effectiveness as a criterion. Although some treatments were clearly preferred by patients, it was difficult to establish their cost-effectiveness using a traditional outcome measure of survival. The inability to rationally justify superiority of clearly preferred treatments motivated the search for suitable outcome measures to capture the benefits of a better quality of life in addition to better prospects of survival. For example, in case of angina, it was observed that coronary artery bypass surgery (CABG) was quite popular with patients and doctors but did not increase survival time of angina patients. The survival-based measure suggested that CABG was no more efficient than medical management of angina, implying that there would not be any justification for the costlier operation. But doctors observed that many patients were clearly better off after CABG. They enjoyed a better quality of life. Hence the coronary artery surgery study (CASS 1983) used quality of life measures to conduct a comparitive study between medically and surgically treated patients.

In the US, the RAND corporation's success with program planning and budgeting in the Defense Department promoted a policy climate favoring planning in every sphere of public policy. For the health sector, this manifested itself in a law passed in 1966 by the US Congress (PL89-749), which required comprehensive planning for health services, manpower and facilities. A response to this emphasis on planning was the work of Fanshel and Bush (1970) to develop a comprehensive health status index, that could be used as an output measure for planning and evaluation. Subsequently the same team used changes in quality-adjusted life expectancy as the measure to evaluate the New York phenyl ketonuria (PKU) screening program (Bush et al 1973). Similar enthusiasm about the usefulness of planning was prevalent in Europe as well. Pole (1973) has described the impact of program planning and budgeting requirement of all government departments in UK on the development of health status measurement. Early studies on health status measurement from a resource allocation perspective include relative valuation of health states by Berg (1973), Torrance (1976), and Sackett and Torrance (1978).

Quantifying health and illness in populations:

Health status can be assessed either with the help of a profile or a single index. Health status profiles would consist of many indicators each representing a different dimension of health status. Table-1.1 is an example of a population health status profile used by contributors to the "Closing the gap" exercise mentioned earlier. An index of health status is a synthetic measure incorporating within its ambit, different dimensions which perforce receive some relative weightage through the combining formula. There are advantages and limitations attached to both types of assessment. For example, Stourman and Falk (1936) opined that combining indicators to produce a single index might result in a loss of information relevant to individual problems. On the other hand, scalar indexes enable computation of cost effectiveness ratios across interventions targetting different diseases and provide some guidance for resource allocation.

Different motivations and circumstances requiring quantification of health outcomes, some of which were mentioned above, have contributed to (a) many measures of non-fatal health outcomes, and (b) a general class of synthetic measures of health status. All synthetic measures combine in some way fatal and non-fatal health outcomes. Developments about various health status

measures have been documented periodically through conferences[6] and review articles (Chen and Bryant 1975; Rosser 1983; Patrick and Bergner 1990). Recently a good number of monographs on health status and outcomes assessment have appeared (Walker and Rosser 1992; McDowel and Newell 1987, 1996; Spilker 1996; Murray and Lopez 1996). I will restrict myself to the class of synthetic measures of population health. Of many indicators used or suggested in the past, three are indispensable in understanding population health status measurement as it stands today. These are: (a) Fanshel and Bush's (1970) health status index (HSI); (b) Sullivan's health expectancy (1971); and (c) Chiang and Cohen's (1973) index of health status (H). I will briefly describe each of these and then discuss various indicators of population health status currently in vogue.

Fanshel and Bush (1970) proposed that the multidimensional experience, related to health, of living at any point of time (i.e., a health state) should be transformed into a single dimension of functional (or its complement: dysfunctional) status for purposes of health status measurement.

They defined a set of ordered health-related functional states and then arrived at a set of weights assigned to each functional state (Table-1.2). These weights represent the health status index (HSI) corresponding to the respective health state. The authors proposed various approaches to ascertainment of social preference weights for different

Table-1.2 Ordered functional states defined by Fanshel and Bush (1970)

S_i	State	Weight
S_A	Well-being	1
S_B	Dissatisfaction	0.9961
S_C	Discomfort	0.9844
S_D	Minor disabled	0.9687
S_E	Major disabled	0.9375
S_F	Disabled	0.875
S_G	Confined	0.75
S_H	Bedridden	0.5
S_I	Isolated	0.33
S_J	Comma	0
S_K	Death	0

[6]The ones I have read about are: (a) Conference on health status indexes conducted by Health Services Research at Tucson Arizona, October 1-4, 1972 (Berg 1973); (b) a series of three workshops held at the University of York in 1979-81 held by the British Social Science Research Council and the European Science Foundation (Culyer 1983); (c) a series of conferences on advances in health assessment, sponsored by the Kaiser family foundation and other agencies, held respectively in 1986 (Lohr and Ware 1987), 1988 (Lohr 1989) and in 1991 (Lohr 1992) (d) series of workshops organised by the REVES on calculation of health expectancies (Robine et al. 1993).

health states. They recognized that the issue regarding assignment of weights to different health states is important and needed detailed study. The weights chosen by them were first arrived at by assuming that each health state in the middle of the ordered list was twice better than the one below it, and some adhoc adjustment according to their judgment. One way to view these weights would be to think of them as ten classes of disability (eight, if we count the classes between perfect health and death). Having defined the health status index, which is conceptualized as a point in time measure, the authors proposed a function time unit called disability free year (DFY) as the measure of program output.

Chiang and Cohen (1973) revised the simplistic illness episode-based measure proposed by Chiang (1965) and conceived of an index of health (H). They continued, however, with the one year period prevalence approach taken by Chiang earlier (1965). Since the natural history of disease varies a lot by age, proper description of population health status would require a profile of H by age and sex groups. To construct the index (H) they started by thinking of the health continuum divisible into a set of ordered categories or states of health (S_i) and called it the health spectrum. The health spectrum extends from optimum health at the top to death at the bottom. The health status of a population in any calendar year (H_t) was defined by them as: $H_t = \sum_{i=1}^{s} w_i e_i$, where w_i = weight assigned to health state S_i, e_i = expected duration spent in health state S_i, and s = lowest health state. If everyone is perfectly healthy, the index assumes a value of 1. Actual values of the index would be in the open interval (0,1). For actual estimation, Chiang and Cohen envisaged that the prevalence of health states at the beginning of a year could be measured and other parameters estimated with the help of a stochastic model using transition probabilities from one health state to another.

Sullivan (1971) proposed two types of life expectancy indices in addition to the standard life expectancy: disability free life expectancy and bed disability free life expectancy. The health expectancy indicator, currently espoused by the network on health expectancies (REVES: described later), is conceptually similar.

At present, one has discerned four synthetic measures of health status literature available. These are: (a) the quality adjusted life year (QALY), (b) health expectancy indicators (HEIs), (c) disability adjusted life year (DALY), and (d) healthy year equivalent (HYE). Each of these concepts is briefly explained below.

QALY[7] is a family of time-based measure of life with adjustments for health related quality of life (HRQOL). The numeraire of this measure is the concept of a year of perfectly healthy life, or as Fanshel and Bush (1970) called it, the well year. Thus the state of perfect health is assigned a weight of one. Death is assigned a weight of zero. Other health states characterized by existence of diseases, morbidities, and / or reduction in functional status are assigned weights in the interval (0,1), although negative weights for states considered worse than death have also been considered. To compute the health outcome of a disease or an intervention targeting some disease, weights assigned to different health states resulting from the disease till the end of some potential life expectancy are added up. Formally QALYs enjoyed by an individual over a period of time, say L is: $QALY = \int_0^L w(t)\, dt$, where $w(t)$ is the health state weight at time t. For practical purposes one works with discrete periods of time in which case the formula can be written as $QALY = \sum_{t=0}^{L} w_t$, where the total duration L is split up into discrete time periods and the last time period is designated L. In order to compute QALYs lost due to various diseases, the formula would be: $QALY_{lost} = L - \int_0^L w(t)dt$. The sum total of QALYs enjoyed by each individual yields.

By way of illustration, let us consider the following examples: Kaplan (1994 p130): "Consider a hypothetical patient with AIDs. On the day he was assessed he coughed, wheezed or was short of breath. He had no limitations in mobility, because he drove his car to the clinic. However, he was in bed or in a chair most of the day and performed no major social role. The preference weights associated with the observable state suggests that peers evaluate the state to be about 0.6 on a 0 to 1.0 scale. If the person remains in this state for an entire year, he looses 0.4 well years. If this situation was maintained over the course of a decade the person would lose the equivalent of four well years of life."

[7]The term QALY appears to have been popularised by Weinstein and Stason (1976, 1977). Weinstein and Stason referred to the work of Bush and others (1973) on health status index and the work of Torrance (1973) on utility maximisation model for health program evaluation. Close variants of this term were already in use by developers of health status index (HSI) which is a forerunner of the Quality of Well Being (QWB) scale, in use now (McDowell and Newell 1996). For example "well year" was used by Fanshel and Bush (1970), and quality adjusted life expectancy was used by (Bush, Chen and Patrick 1973). Kaplan (1988 p216) mentions that the term QALY was adopted by the US congressional office of technology assessment in 1979 and gained further recognition after that. Zeckhauser and Shepard (1976) appear to have been instrumental in introducing this term in the active vocabulary of economics as can be inferred from the remarks made by Fabian (1994).

Kaplan (1988 p208) : "A disease that reduces the quality of life by one half will take away 0.5 well years over the course of one year. If it affects two people it will take away one well year over a period of one year."

Fixing L at one year we get a period prevalence - based estimate of QALYs. Usually the motive is either to estimate disease burden or calculate cost per unit effectiveness (i.e., cost per QALY). The effectiveness of an intervention can be calculated by letting L= *life expectancy at the time of intervention*. Thus if a program starts at time $t=0$ QALYs gained may be computed as: $QALY_{gained} = \int_0^L (w_1(t) - w_0(t))dt$, where $w_1(t)$ is weight assigned to health states under the concerned program and $w_0(t)$ represents health state weights without the intervention. QALY has invariably been used in the above format, to measure the marginal effect of an intervention on quality of life. One instance is the cost-effectiveness of the PKU program in New York (Bush, Chen and Patrick 1973). Its application has been further extended to a larger number of interventions. For example, the league tables of intervention cost per QALY gain were prepared by the Oregon Health Services Commission, USA, for definition of benefit packages (Strosber, 1992). A regional health authority in UK attempted to use cost per QALY as a basis of allocating incremental funds for speciality development (Allen, Lee and Lawson, 1989). QALY has not been used, so far, to quantify aggregate disease burden at national or regional levels. Thus QALYs, according to its common usage, are to be viewed as a derivative of health expectancy or gap measures of population health status.

A key step in operationalisation of QALY involves the assignment of weights to various health states. Much of the debate about QALY focuses on the theoretical basis and practical methods used to derive weights for various health states. Differences in the assignment of weights to various health states distinguishes members of the QALY family. This is not unique to QALYs. All synthetic measures of health status must assign weights to different health states in some way or other. Since the concept of QALY first appeared from work related to assignment of weights to health states, it is appropriate to introduce it here. I will discuss these issues in chapter Four on review of literature and methodology of the health state valuation study. In addition to problems about reliability, validity, and ethical correctness of health state weights, the theoretical and ethical soundness of QALYs as a basis of cost-effectiveness analysis and health priority setting has been critiqued (Allen and others, 1989, Carr-Hill, 1991). Many of these critiques would apply to all synthetic measures of health status.

Table-1.3 Family of health expectancy indicators (HEI)

HEI	Description
Disease - free life expectancy	Average number of years a person is expected to live free of disease if current patterns of mortality and morbidity continue. Here all disability states are implicitly weighted as zero along with death.
Impairment (IFLE), disability (DFLE) or handicap (HFLE) free life expectancy	Average number of years a person is expected to live free of impairment, disability or handicap respectively, given current patterns of mortality and morbidity.
Healthy life expectancy (HLE)	This is based on population data of perceived health status. Also referred to as life expectancy in good health.
Health adjusted life expectancy (HALE)	Weighted expectation of life summed over a complete set of health states. Weights for health states range from 0 for death to 1 for perfect health as in case of QALYs. This is a fully synthetic measure comparable to QALYs or DALYs.

[1] Source: Compiled from Harry van de Water P.A.; Perenboom Rom J.M., and Boshuizen Hendriek C. Policy relevance of the health expectancy indicator: an inventory in European Union countries. Health Policy. 1996; 36:117-129, Table-1.

A family of health expectancy indicators (HEIs) has grown, building upon the concept proposed by Sullivan (1971) mentioned earlier. The international network on health expectancy (NHE, more popularly known by its French acronym, REVES) has been active in standardizing and encouraging the use of various HEIs for the measurement of health status (Robine et al 1992; Harry et al 1996). HEIs (Table - 1.3) are built around the WHO's international classification of impairments, disabilities and handicaps (ICIDH: WHO, 1980). Impairment is defined as any disturbance to the body's mental or physical structure of functioning. Disability is defined as any restriction or lack of ability to perform an activity in the manner or within the range considered normal. Handicap is defined as a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents fulfillment of a role that is normal for that individual. In other words, a handicap is the person - specific impact of impairment and / or disability. The ICIDH concepts of disability and handicap are sometimes referred to by different terms, especially in the United States. For example, the US Committee on a National Agenda for the Prevention of

Disabilities used the term functional limitation to mean ICIDH disability and used disability to mean ICIDH handicap (Pope and Tarlove 1991). Here, the terms disability and handicap are used as in the sense propounded by ICIDH. Of all HEIs, the health-adjusted life expectancy (HALE) is fully synthetic and corresponds to QALY or DALY in terms of coverage of health states. HALE uses graded weights for different health states. Assignment of weights to different health states is done using approaches followed for QALY. Disease, disability or handicap - free life expectancy for certain diseases, disabilities or handicaps, as the case may be, have been calculated in many industrialised countries. But the application of health adjusted life expectancy (HALE) remains to be done (Harry et al. 1996).

The DALY measure was developed for the WDR 1993 on investing in health (World Bank 1993). Murray (1994, 1996) has described technical and theoretical bases of the DALY measure. It is a measure of health gap from a chosen standard life expectancy in perfect health. Disability associated with the state of perfect health or complete well - being is assigned a weight of 0 and disability due to death is assigned a weight of 1. Disability weight used in computation of DALY is the complement of health state weights used in QALY. Thus all debates about assignment of weights to intermediate health states would be applicable to DALYs as well. The DALY measure restricts the information set for health status weights to age, sex and disability. It excludes handicap. An incidence approach is usually taken for computation of DALY to match the incidence nature of mortality data and to force internal consistency of other epidemiologic parameters. In addition, prevalence DALYs and disability-adjusted life expectancy (DALE) are estimated to allow for sensitivity analysis. Annual incidence of DALY is computed from demographic data like age cause - specific mortality statistics as also descriptive epidemiological knowledge about the age of onset, incidence and duration of different disease. Members of the DALY family are distinguished by the choice of age weighting and discounting parameters. The incorporation of age weighting and discounting in the DALY measure has been criticised. Murray (1996) argued as to why age weighting and discounting may be consistent with societal beliefs and has supported the same with some evidence. The formulation presented by Murray (1996) allows computation of DALYs without age weighting and discounting. In this way, age weighting and discounting become a matter of choice of parameters for specific applications. Since the debate on age weighting and discounting are both unlikely to be resolved in the near future, the formulation that allows for computations with and without age weighting and discounting are both useful by allowing for sensitivity analysis. A more practical distinguishing feature of DALY is its usage as a summary measure of population health status. Global, and regional estimates of disease burden have already been made (World Bank, 1993; Murray and Lopez, 1994, 1996, WHO, 1999).

The healthy year equivalent (HYE) has been proposed by Mehrez and Gafni (1989) and elaborated or defended in subsequent articles (Mehrez and Gafni 1990, 1991; Birch and Gafni 1992; Gafni, Birch and Mehrez 1993). The distinction between HYE and QALY lies in conceptualization of the valuand (Buckingham, 1993). For QALY, a static measure of health status (for example, functional status) is first arrived at. A weight is then assigned to this static health state. QALY is then computed by multiplying the health state weight with its expected duration. The prospective QALY endowment for a person at any age is the sum of the product of anticipated health states and the respective duration up until the end of life expectancy at that age. Mehrez and Gafni start by assuming that QALY seeks to measure people's preferences for health states, and opine that rational preferences would be defined for the full life prospect at any point of time rather than for discrete units of function time or static health states. Hence they propose that the appropriate valuand is the full life prospect at any age rather than the static health state as is assumed for QALY. To meet this shortcoming of QALYs they propose to measure people's preference for the full life prospect at any age and with different health conditions by a two - step procedure. In the first step respondents are asked a standard gamble question to find the indifference probability between completely healthy life and the life in poor health. In the second stage the indifferent gamble arrived at from the first stage is valued using time tradeoff questions. For example, what reduced number of healthy years is equivalent to the uncertain prospect contained in the indifferent gamble from the first state. Note that HYE differs from QALY only in conceptualization and derivation of weights for health states. Most critics (Buckingham 1993, Culyer and Wagstaff 1993) believe that HYE is same as QALY at best, and implementation of the two stage valuation procedure is likely to introduce errors in the worst -case scenario.

The Global Burden of Disease study:

The first global burden of disease (GBD) estimates were made by a team led by Christopher Murray at Harvard University. The study was sponsored by the World Bank in collaboration with WHO to provide disease burden estimates for the WDR 1993 (World Bank 1993). The DALY measure was constructed during the course of this study[8]. This study undertook the daunting task of estimation from a vast array of data and, more importantly, from a significant

[8]In Appendix 1.1 I reproduce the DALY formula as presented by Murray in 1994 and then in 1996. I have furnished detailed steps of integration of various components of the DALY construct leading to the formula as presented by Murray (1994, 1996). These details are provided for ready reference and didactic purposes.

lack of data. Further revisions of the GBD have since been published (Murray and Lopez 1994, 1996). The general willingness to embark on estimation despite enormous data deficiencies, the tenacity to improvise methodological solutions for indirect estimation of epidemiological parameters, the development and use of internal consistency checking tools[9] to seek more plausible estimates, and above all an emphasis on the overall picture rather than on single disease entity or solitary interventions may be cited as noteworthy methodological developments.

The burden of disease method (BDM) provides a lot of scope for health policy analysis. Comprehensive study of disease burden with an internally consistent apportionment of observed mortality and disease prevalence should help decouple epidemiological assessment from advocacy. The synthetic DALY measure facilitates debates about importance of non-fatal health outcomes vis a vis premature mortality. A single measure of health outcomes enables comparison of cost-effectiveness of all interventions within the health sector. Publication of GBD results in the WDR 1993 (World Bank 1993), the WHO (Murray and Lopez 1994), and subsequently by the Harvard School of Public Health (Murray and Lopez, 1996), has given the BDM a good deal of visibility and generated enthusiasm in many parts of the world. However the complexity of the DALY measure coupled with inadequate understanding of how the massive data requirements for its computation are met (given the enormous lack of cause of death statistics and epidemiological information) provoked considerable disbelief[10]. How could these estimates be generated in the absence of relevant data?

Theoretical arguments for the DALY construct, like time preference, have their roots in economics. The estimation of cost-effectiveness estimation, an important argument in support of the DALY construct, requires inputs from economists. The computation of DALYs requires both direct and indirect estimation of general demographic status, cause of death, and descriptive epidemiology of a large number of diseases. This not only calls for a collaboration between experts from various disciplines, but also necessitates a prerequisite of sound multidisciplinary skills combining a knowledge of, say, economics, demography and epidemiology, at the very least. Unfortunately support for training of people from developing countries, for such tasks, is lacking. Skills

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[9]For example, DISMOD. DISMOD is a software modeling relationship of incidence, prevalence, duration and cause- specific mortality of a disease. See Murray and Lopez, 1996 p 204-209.

[10]I make this comment on the basis of my own observations and interactions with participants at the burden of disease workshops , students and fellows at the Harvard School of Public Health among other fora.

about estimation of disease burden are taken for granted. But that is not the case. Scarcity of skills in burden of disease methodology is one of many reasons it remains mystified and inaccessible for purposes of policy formulation[11].

Flexibility in data requirements for national and regional burden of disease estimation is another cause for concern. An enormous amount of information, including mortality, causes of death, incidence, prevalence or duration of about 100 diseases and 125 sequela, is the ideal requirement for the accurate estimation of disease burden in a region. The GBD estimation process met this challenge in three ways, namely (a) a concerted effort to collect as much data as was possible to gather, (b) improvisation of indirect estimation tools to bridge the remaining gaps, and (c) use of internal consistency tools like DISMOD. Some of the indirect estimation techniques used in the GBD study have been found to be robust enough for wider application. One example is the estimation of cause of death by three broad groups from general mortality level. Even here the model will hold good if the interrelationship of injury epidemics with other causes of death are as well behaved as the communicable and non communicable diseases have been in the past. Many of the indirect techniques have been improvised to handle specific situations. In the initial publications of GBD results (World Bank 1993, Murray and Lopez 1994), most of these improvisations were not published. Murray and Lopez (1996) have since provided a more detailed account of various approaches to detailed cause of death estimations from less reliable data. However, indirect estimation and consistency tools are useful only if some data are available. What if no data is available or as is usually the case, or enough is not known in order for these indirect estimation tools to be useful? Some time before undertaking the GBD study, Murray (1990) had reviewed major international health initiatives during 1970s and 1980s. He identified three main constraints to utility and scientific validity of priority - setting techniques as: (a) the empirical information base; (b) normative choices including (i) design of health indicator, (ii) categorization and problem definition and (iii) social time preference; and (c) local patterns of illness and local availability of resources. The GBD study has made normative choices, and a health indicator has been designed for this purpose. Massive efforts have

[11]This is my personal experience and belief strengthened by experiences in various burden of disease training workshops, and interactions with National Burden of Disease team members. People appear to have difficulty in dealing with incomplete data and the use of internal consistency tools to estimate statistics from them. The overwhelming computational load poses another difficulty. For example, the country presentations in the session on burden of disease in Forum-3 meeting of the Global Forum for Health Research at Geneva in June 1999, brought out the difficulty in gathering large volumes of data and the daunting task of handling a large number of spreadsheets. Several discussions were about dealing with inadequate data and computational load. I happened to chair this session and hence have personal knowledge.

been made to put together available empirical information at global and regional levels. But more information, which simply does not exist now, has to be generated. Local patterns of illness need to be estimated. Further developments in disease burden estimation need to be propelled in this direction.

Efforts to conduct a national burden of disease (NBD) estimation tend to start with a lot of enthusiasm but also confronts various challenges. Local NBD team members set out to collect mortality data, cause of death and epidemiological information. They can at best, secure a few mortality estimates and perhaps cause of death estimates. Even for these, data may be available by very broad cause groups. This is when the task of improvising with indirect estimation is embarked upon. After application of some general and relatively clear indirect estimation techniques, there would still remain causes of death or disease entities for which no clear cut clue is available. Many epidemiologists would then fall back upon numbers already estimated for the concerned region in the GBD to which the particular country belongs.

A major contribution of the burden of disease method, as noted by Murray (1996), is to harness the culture, in the field of applied demography, of embarking on an estimate in the face of data deficiencies rather than shy away from it as most epidemiologists are likely to do. It is important to recognize the difference in subject matter of demographers and epidemiologists that contributes to a difference in their attitude to indirect estimation. Any indirect estimation process would revolve around a few anchors that link the underlying model to reality. Demographers have traditionally used indirect estimation for general mortality levels and to a limited extent for very broad causes of death. Population census or some survey data on, say, children ever born, is usually available to demographers. A NBD study usually requires detailed estimate, for causes of death, incidence and prevalence of about 100 diseases. For any NBD to be useful, these anchors must be clearly defined and their prerequisites satisfied. A minimum data requirement that includes and defines the vital anchors required for credibility of local NBD estimates is yet to be worked out. In other words a set of NBD estimates can still be produced irrespective of how much data on mortality, causes of death and disease epidemiology is available. Consequently the black box of decision maker's relative values (Murray, 1994) is largely replaced by the black box of NBD estimates rather than being opened up and subjected to public scrutiny.

Such intermediate phases in the development of a new methodology are inevitable. I believe that a synthetic measure of premature mortality and non-fatal health outcomes, as also integrated sector wide assessments like NBD are useful and essential for more informed policy formulation. I note these difficulties here to take stock of current problems and to describe how I tried to

address some of them in course of the present study. Thus one of my objectives through estimating burden of disease in Andhra Pradesh is to focus on methodological issues of practical importance, and to seek operational linkages between existing skills in the area of demography, disease specific epidemiology and burden of disease estimation.

Research questions:

On the one hand, information about local burden of disease can be obtained from the corresponding regional estimate in the GBD study. For example, one could look at the GBD estimates for India to learn about the pattern of disease burden in Andhra Pradesh. The first step in anchoring the regional estimate to local data would be to use local age and sex composition, since population figures are relatively easily available. Let us call this the minimally anchored local burden of disease estimate. On the other hand , primary data could be collected to arrive at most accurate estimates of all parameters required for the estimation of disease burden. In other words, every epidemiological and social choice parameter is directly measured for the country or state in question. Let us call this the best anchored local burden of disease estimate. This, in turn will require a fully developed vital registration, certification of cause of death and epidemiological system. It may neither be feasible to achieve the required institutional changes right away nor prudent to invest in resources and wait for institutional developments to materialise. At a more practical level, intermediate levels of anchorage may be optimal. Let us suppose there are patterns of anchorage to local data that we can call reasonable and another set of anchorages which we can call adequate, such that reasonable is better than minimal, adequate is better than reasonable and best is better than adequate. To standardize the meaning of reasonable and adequate anchorages, it would be necessary to clearly define the minimal criteria corresponding to each of these terms.

One of the primary concerns of this study is to measure and explain how different levels of local anchorage modify results of a national burden of disease study. To assess differences between results, it is imperative to identify characteristics of the output in question. These characteristics must be relevant to the purpose for which burden of disease results are utilized. Two important uses of burden of disease estimates are (a) information for priority setting and (b) cross-sectional or inter - temporal comparison of disease burden.

Most priority - setting exercises, cross - sectional or inter - temporal comparisons appear to process and use disease burden information in one or more of the following ways:

1. Rank ordering causes of disability,
2. Magnitude of disease burden,
3. Mortality - morbidity relationship, and
4. Age and sex distribution of disease burden.

Some form of rank ordering of causes is always involved in the processing of disease burden information. Lists of the main causes of ill health or its variants are quite commonly used to draw attention to important health problems. For example, Murray and Lopez (1996) highlight the top ten causes of disease burden in presenting results of the GBD study. Rank ordering is implicit for the inclusion of diseases in an analytic basket. Priority - setting exercises usually limit attention to a manageable number of diseases in the analytic basket. For example, the "Closing the gap" project described earlier identified major health problems for further analysis. Inclusion of specific disease entities in this analytic basket of "major health problems" must have involved some notion of rank order of all prevalent disease entities in the US.

The magnitude of disease burden is usually processed in conjunction with some normative information about a tolerable level of disease burden. Norms may arise from knowledge of distribution of disease burden or an understanding about attainable levels of health status. In addition, the magnitude of burden due to various causes helps prioritize between interventions with similar cost-effectiveness ratios. The magnitude of disease burden is commonly compared across population groups, geographical regions or at different points in time for the same population.

Mortality - morbidity composition of disease burden is being used of late to highlight the importance of non-communicable and degenerative diseases in the post - epidemiologic transition period. For example, changes in disability - free life expectancy have been used to emphasize the important fact that, in many situations, gains in life expectancy accompanied by stationary disability free - life expectancy means increasing prevalence of disability. In the GBD study the same point is sought to be made using mortality component (YLL) : morbidity component (YLD) ratios.

Age and / or sex are fairly powerful clustering criteria for targeting health care interventions. For example, child health, school health and maternal health programs target specific age or sex groups. Changes in distribution of disease burden by such groupings will naturally influence the importance attached to respective groups in any priority setting exercise. Hence it will be interesting to see how different levels of local data input changes distribution of disease burden by age and sex.

Summary measures of population health status use health state weights to combine morbidity experience of the population with its mortality. It is assumed that individuals have a well - defined value assigned for each health state. However, this hypothesis has not been empirically tested. The nature of health state valuation function has important implications for reliability and validity of health state value measurement studies. If each individual possess a well - formed single valued function of health state values for the entire range of health states, all differences in test and retest valuations can be attributed to measurement error. If, on the other hand, the true health state value is a multivalued function, our interpretations of conventional measures of reliability will change. Another issue is, whose valuation of health states should be used? It is generally agreed that the valuation should ideally be measured at the community level. Here again, it tends to be assumed that the community has a widely shared valuation attached to all health states. But in actual practice a community might not have the same degree of crystallisation of valuations for all health states. The valuations may be more diffused for some health states, and crystallised for some others. Take for example, the case of quadriplegia. All members of a community may assign to it a health state weight close to that of death. This would be an example of well - crystallised valuation by the community. On the other hand, members of the community may differ freely about the weight assigned to, say, infertility. The valuation for infertility may be more diffused. These differences in distribution of valuations within the community will have important implications for interpretation of burden of disease estimates based on single valued disability weights, and in parametrisation of uncertainty analysis of disease burden estimates.

Murray and Lopez (1996 p288) have observed that rank order of diseases and injuries was insensitive to an alternate set of disability weights. But the relative size of disability to mortality components of disease burden changed. Using a set of disability weights sensitive to minor and trivial illnesses and small deviations from perfect health state, decreased the disability adjusted life expectancy. Allen and others (1989) felt that ordinal ranking of cost per QALY for different interventions would not change with appreciable changes in the corresponding index of health status. They observed that life - saving procedures would always tend to score better than palliative or pain - relieving measures which in turn would show lower cost to effectiveness ratio than expensive continuing therapy.

However, there are other compelling reasons to attach importance to the assignment of disability weights. Firstly, the robustness of disease burden estimates or cost-effectiveness ratios to alternate set of disability weights is a feature of the current epidemiological state. As mortality continues to decline and the prevalence of degenerative diseases further increases, the importance

of disability weight for these results will correspondingly increase. Secondly, alternate sets of health state weights will certainly affect composition of the disability component of disease burden. This may, in certain circumstances, be an important input to policy analysis. For example, let us suppose that mortality in a country has declined to a level close to our understanding of the biological potential of longevity. Then it would make sense to analyse the composition of disability as such, to prioritise between interventions seeking to improve health related quality of life.

Finally, the whole purpose of seeking out summary measures of health status would be defeated if adequate attention is not paid to component subjects of synthesis. Moreover, most health - related quality of life measurements have taken place in the industrialised and economically developed countries. An important concern has been if the health state weights are robust across various cultural settings. Health - related quality of life is now sought to be defined by restricting to domains of functioning that are universally most essential to one's ability to pursue valued life goals (Schumaker and Naughton, 1995). Thus local measurement of disability weights is important from two perspectives, namely (a) sensitivity of national disease burden estimates to locally measured disability weights as opposed to use of global disability weights and (b) understanding health status weights across cultures. It is pertinent to note that disability weights used in computation of DALYs are the complement of health state weights or quality adjustment weights. Estimating one weight yields the other by simple arithmetic manipulation (disability weight = 1 - quality adjustment weight). These terms are used here interchangeably.

To sum up, the specific research questions sought to be addressed by this study are:

1. What is the appropriate investment in a NBD study for local data collection?
2. How does one measure health state valuations in developing countries with partially literate communities?
3. What is the nature of health state valuation function in the mass psyche?
4. What is the distribution of valuations for different health states?
5. Does the distribution of valuations of health states allow us to assign a single valued disability weight to each health state?

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