

# Assessing the burden of sexual and reproductive ill-health: questions regarding the use of disability-adjusted life years

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The use of the disability-adjusted life year (DALY) as the unit in which to calculate the burden of disease associated with reproductive ill-health has given rise to considerable debate. Criticisms include the failure to address the problem of missing and inadequate epidemiological data, inability to deal adequately with co-morbidities, and lack of transparency in the process of ascribing disability weights to sexual and reproductive health conditions. Many of these criticisms could be addressed within the current DALY framework and a number of suggestions to do so are made. These suggestions include: (1) developing an international research strategy to determine the incidence and prevalence of reproductive ill-health and diseases, including the risk of long-term complications; (2) undertaking a research strategy using case studies, population-based surveillance data and longitudinal studies to identify, evaluate and utilize more of the existing national data sources on sexual and reproductive health; (3) comprehensively mapping the natural history of sexual and reproductive health conditions — in males and in females — and their sequelae, whether physical or psychological; (4) developing valuation instruments that are adaptable for both chronic and acute health states, that reflect a range of severity for each health state and can be modified to reflect prognosis; (5) undertaking a full review of the DALY methodology to determine what changes may be made to reduce sources of methodological and gender bias. Despite the many criticisms of the DALY as a measurement unit, it represents a major conceptual advance since it permits the combination of life expectancy and levels of dysfunction into a single measure. Measuring reproductive ill-health by counting deaths alone is inadequate for a proper understanding of the dimensions of the problem because of the young age of many of the deaths associated with reproductive ill-health and the large component of years lived with disability from many of the associated conditions.

**Keywords:** reproductive medicine; cost of illness; health status indicators; quality of life; disability evaluation; sexually transmitted diseases; maternal mortality; longitudinal studies.

*Voir page 664 le résumé en français. En la página 665 figura un resumen en español.*

## Introduction

The concept of sexual and reproductive health was first fully articulated at the 1994 International Conference on Population and Development (1). It arose out of two mutually opposed impulses. Demographers and family planning experts were mainly concerned with issues of population growth, structure and change and their impact on social and economic development. Advocates of women's health and rights were focused more on gender imbalances and the health needs of people. The discussion between these two positions led to the concept of sexual and reproductive health, a paradigm that reflects a conceptual linking of the discourse on human rights with that on health. It is a

concept bounded by a positive vision of good health, well-being, equity, and social justice, and not by a specific disease, pathology or set of organs.

It is generally acknowledged that sexual and reproductive health must address key disease entities — sexually transmitted diseases (STDs), human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS), maternal mortality. It is also argued that there is a need to pay attention to positive, life-enhancing aspects such as “a safe and satisfying sex life” and “the enhancement of life and personal relations”. The language of reproductive health advocates is expressed in a style that includes terms such as “comprehensiveness”, “integration”, “a full range of services across the life cycle”. This definition is all encompassing and vast and it remains unclear to what extent sexual and reproductive health is something that can be measured in any meaningful way and, if not, how will it be possible to translate the political imperatives into action for programmes. Is it conceivable to try to ascertain the burden of disease due to reproductive ill-health in the absence of any conceptual clarity on what it covers?

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Defining sexual and reproductive health in terms of health and well-being, rather than in terms of the avoidance of death and disease, poses challenges for making measurements. A similar challenge has taxed the ingenuity of many researchers ever since the WHO concept of health as “a state of complete physical, mental and social well-being” was first developed. In 1957 WHO convened a study group on measurement of health status to examine the options for bringing this positive concept of health into operation and such work has continued intermittently ever since (2). A recent review of measurement efforts concludes that further conceptual and methodological research will be needed to describe and monitor sexual and reproductive health and well-being (3). In the meantime, attempts to measure health status usually focus on measuring ill-health or the presence of disease, disability and mortality.

At the same time as the new concept of sexual and reproductive health was being articulated, the Global Burden of Disease (GBD) study was initiated by the World Bank in collaboration with WHO to quantify the burden of disease and injury. The GBD study assessed the relative magnitude of diseases and injuries in global and regional populations, as well as the effects attributable to some major risk factors and socioeconomic determinants, although the latter analysis was relatively weak. This information was required for a variety of purposes, including the identification of major health problems and their relative magnitude, recognition of disease patterns, prioritization of health problems for research investments, and for decision-making in the allocation of health resources across different health interventions (4). A metric that would capture both fatal and non-fatal health outcomes, separately and in combination, was needed. The measurement unit used for this exercise was the disability-adjusted life year (DALY) (5).

The DALY was explicitly founded on the measurement of disease rather than the measurement of health status or health gains due to particular interventions. The introduction to the third volume of the Global Burden of Disease and Injury series noted “given the current state of health measurement, most analyses must ultimately fall back on measures of mortality, morbidity and disability. Analyses of outcomes, determinants, resources and even intervention effectiveness in reproductive health require clear and unambiguous specificity to facilitate meaningful measurement” (6). There is discussion over the extent to which the DALY methodology adequately measures losses of healthy life due to reproductive health conditions. It has been argued that it cannot adequately capture the holistic aspects of reproductive health. However, in the absence of a viable alternative, reproductive health activists can be accused of failing to base their advocacy on sound evidence. This paper puts forward some suggestions for modifying DALYs that could help to bridge this divide.

## What is a DALY?

The DALY is a time-based, composite indicator of burden of disease that adds losses of healthy life due to morbidity and associated disability to losses due to premature death (7). The starting point for calculating DALYs is the classification of diseases, injuries and their sequelae into 107 causes of death and 483 disabling sequelae, on the basis of the ninth revision of the International Classification of Diseases (ICD-9) (8). To determine the number of years of life lost due to premature mortality, deaths are assigned a disease category and grouped by age, sex and demographic region, based on death records where available and ‘expert judgement’ where not (9). Numbers of potential healthy years of life lost are estimated on the basis of the differences between the actual ages at death and an ideal standard life expectancy (10). In the 1993 burden of disease exercise, a standard life expectancy of 82.5 years at birth was used for women and 80.0 for men for all countries, irrespective of current life expectancy calculations. A difference of 2.5 years between males and females was selected to represent the ‘potential true biological difference’. In future burden of disease exercises, it is likely that a standard life expectancy will be used for both sexes on the grounds of equality.

For disability, the incidence of cases by age, sex and demographic region are derived from various data sources or on ‘expert opinion’ where more reliable data are not available. The number of years lived with disability (11) are obtained by multiplying the expected duration of the disability (to remission or to death) by a disability weight that is supposed to reflect the average severity of the disease compared to full health and death. In the 1993 exercise, seven disability classes were defined, and a weighting agreed upon by experts, between perfect health (zero) and death (one), represented the severity of each disablement (12). Severity weights were then assigned to each of the 483 disabling sequelae using an expert panel, which derived weights using person trade-off methods (13). When making assessments, the panel was asked to evaluate ‘the average individual with the condition described taking into account the average social response or milieu’. This approach to weighting conditions works better for chronic disabling conditions which are relatively stable over time (deafness, blindness, paraplegia) than for acute and intermittent conditions (migraine) or those with a rapidly evolving prognosis (certain cancers).

The initial calculation of the unweighted DALYs lost due to a particular disease in a specific population group is given by:

$$\begin{aligned} \text{Time (years) lost due to premature death} &= \text{expected} \\ &\quad \text{standard lifetime minus age at death} \\ &\quad \text{plus} \\ \text{Time lived with a ‘disability’} &= \text{duration of disability} \\ &\quad \text{multiplied by severity weighting} \end{aligned}$$

The 1993 global burden of disease exercise included a further two steps (14). Firstly, weights were attached to DALYs lost at different ages, a year of young adult life being valued higher than that of young children or the elderly. Next a yearly discount rate of 3% was used, so that future years of healthy life were valued at progressively lower levels. The arguments for and against discounting are summarized elsewhere (15).

## Using the DALY to measure reproductive ill-health

There is little question that the use of the DALY methodology to estimate the global burden of disease in the 1993 *World Development Report* represented a substantial improvement on earlier quantification attempts, and brought reproductive health more prominently on to the global health and development agenda. Reproductive ill-health was found to contribute 5–15% of the global burden of disease, even by the most restrictive of definitions (6). The main contributors to the burden were deaths and disability related to pregnancy and childbirth, sexually transmitted diseases including AIDS, and reproductive tract cancers. Moreover, ten-year projections over the period 1990–2000 suggested that the disease burden due to reproductive ill-health was unlikely to diminish rapidly.

Reproductive ill-health accounted for 22% of the global disease burden among women of reproductive age (15–44 years), compared with 3% for men. In sub-Saharan Africa reproductive ill-health was particularly significant, and accounted for approximately 40% of total DALYs lost in reproductive age for women and 9% in men of reproductive age (Table 1). Maternal conditions dominated the burden of reproductive ill-health, particularly in areas where this burden was highest, for example sub-Saharan Africa and India. It should be noted that these calculations do not take into account the most recent available data on the burden of disease due to HIV.

## Data inputs for calculating DALYs

How were the DALYs for reproductive ill-health generated? To answer this question it is necessary to describe in some detail the methodology used for deriving reproductive health DALYs. Essentially, the following defined steps are required:

- to list the causes of reproductive health deaths and disabilities as described in the International Classification of Diseases (ICD);
- to identify the major sequelae of each cause of death and disability;
- to develop regional and global estimates of mortality and incidence and/or prevalence of each condition;
- to describe age of onset of each condition and duration until death or remission;

- to ascribe an average disability weight for each disabling sequelae identified.

Each step represents a challenge from the point of view of reproductive ill-health. This paper suggests some ways in which the process might be modified to improve the estimates of the burden of reproductive ill-health. Much of the discussion presented here arose out of the deliberations of two informal international consultations on DALYs and reproductive health convened by WHO in April 1998 and January 2000 (16, 17) (see Acknowledgements for list of participants).

## Which conditions should be included?

Taking ICD-9 as the starting point, which diseases were included in the 1993 burden of disease exercise and which should be included in any future calculations? The 1993 estimates included the major STDs, namely syphilis, gonorrhoea, and chlamydia in adults and in children as a result of perinatal transmission; HIV/AIDS infections in adults and in children; reproductive tract cancers including cancers of the cervix, breast, uterus, ovaries, penis and testes; and maternal deaths and disabilities resulting from the five major direct obstetric complications, namely, haemorrhage, sepsis, hypertensive disorders of pregnancy, obstructed labour, and abortion. The final list of diseases and sequelae included in the 1990 Global Burden of Disease (GBD) estimates is shown in Table 2.

## Defining the boundaries of sexual and reproductive health

While this appears to be an exhaustive list (Table 2), it looks less than comprehensive in terms of the definition of reproductive health that was adopted at the International Conference on Population and Development. Several additional conditions clearly belong within reproductive health and should be included in any future exercise. These include, for example, gynaecological morbidity due to STDs such as herpes, and reproductive tract infections that are not sexually transmitted, such as candida and bacterial vaginosis. Menstrual disorders might appear trivial yet they affect a large number of women. Infertility was included only as a disabling outcome of sexually transmitted diseases, or postpartum/post-abortion sepsis rather than as a non-fatal health outcome in its own right. Although female genital mutilation is a cause of pain and suffering in large parts of the world, it was not taken into account in the first GBD exercise since it is not listed in ICD-9. Psychological disabilities related to sexuality and reproduction, were excluded. Puerperal psychosis and postpartum depression are not infrequent among women following childbirth. Concerns about sexual performance, premature ejaculation and inability to

Table 1. Total DALYs lost due to reproductive ill-health in women and men of reproductive age as a percentage of total DALYs lost in the 15–44-year age group, 1990

	Total DALYs lost (%)									
	STDs excluding HIV		HIV		Maternal conditions	Reproductive tract cancers		Total		
	female	male	female	male	female	female	male	female	male	
Established market economies	2.36	0.10	0.99	4.08	2.09	3.18	0.02	8.62	4.20	
Former socialist economies	3.52	0.30	0.03	0.09	6.25	2.83	0.03	12.63	0.41	
Sub-Saharan Africa	6.31	1.79	8.38	6.29	24.45	0.54	0.02	39.69	8.54	
India	6.58	2.49	0.20	0.43	19.19	1.42	0.01	27.40	2.93	
China	0.21	0.05	0.00	0.01	6.91	0.99	0.01	8.12	0.06	
Other Asia & Pacific Islands	7.00	2.05	0.14	0.24	14.55	1.66	0.01	23.36	2.30	
Middle Eastern Crescent	1.47	0.32	0.03	0.18	18.70	0.97	0.02	21.17	0.51	
Latin America and Caribbean	3.97	0.60	1.06	3.63	9.64	2.14	0.02	16.80	4.25	
World	4.23	1.09	1.78	2.02	14.47	1.42	0.01	21.90	3.12	

Source: Ref. 7.

maintain an erection, are among the commonest reported psychosexual disorders in men (18).

Although the 1990 GBD focused attention on the burden of ill-health related to pregnancy and childbearing, some major conditions were excluded. Using ICD-9 as the starting point for the analysis leads to the exclusion of maternal tetanus and HIV during pregnancy under the maternal mortality and disability rubric. Moreover, disabilities related to indirect obstetric complications were not included, even though they have been estimated to cause 20% or more of all maternal deaths. A much more significant omission, in terms of the overall burden of disease, is that of stillbirths. The DALY calculations do not attribute any healthy years of life until the moment of a live birth. Stillbirths are not counted, therefore, as adverse outcomes either for the mother or for perinatal health. The conditions excluded in the 1990 exercise, and which should be considered for inclusion under reproductive health in the GBD 2000, are shown in Table 3.

Even with the inclusion of these additional conditions, it could be argued that key elements of sexual and reproductive health are missing. Where, for example, would the pain and suffering associated with forced sex, rape or sexual abuse be covered? A more detailed and explicit description of the conditions that rightly belong in the broad reproductive health agenda is needed. One way of achieving this would be to detail comprehensively the natural history of sexual and reproductive health conditions — in males and in females — and their sequelae, whether they be physical or psychological. A detailed delineation of the stages and sequences of key conditions and associated fatal and non-fatal outcomes would greatly facilitate the generation of

the epidemiological data required to construct DALYs (incidence, age of onset, duration, case-fatality, remission) and help to ensure that the full range of conditions is taken into account, along with etiology, sequelae and prognosis in the presence or absence of treatment.

## What is known about mortality?

The next step is to establish estimates of mortality. In the 1990 exercise, different methods were used to estimate mortality in the eight regions listed in Table 1. Data were derived from health service records, disease registries, vital registration systems, health surveys, epidemiological transition modelling and estimates by disease experts. However, the lack of sound epidemiological data on mortality resulted in over-reliance on 'expert judgement' in the attribution of ill-defined causes of death leading, almost inevitably, to underestimates and biases in the DALY calculations. In many countries, particularly developing ones, ambiguous categories such as 'symptoms and ill-defined causes' represent a substantial proportion of the epidemiological mortality data, rendering the accurate allocation of ICD-9 codes problematic (18). Various assumptions were made and imputation strategies used to deal with this problem, some of which may have introduced substantial bias. For example, in the GBD study, ill-defined causes were arbitrarily assigned to communicable diseases if they occurred in children below the age of 5 and to noncommunicable diseases if they occurred in older age groups. As a result many deaths due to AIDS and other STDs were probably assigned to the noncommunicable disease category.

During the preparation of the global estimates, it became clear that the sum total of cause-specific mortality would exceed the total deaths estimated for the world. As a result, cause-specific mortality estimates were proportionally reduced so that the sum of individual cause-specific estimates agreed with estimates of total mortality (19). For this reason, the mortality data figures in the 1993 *World Development Report* and subsequently in the Global Burden of Disease volumes were often at variance with mortality estimates used by specific programmes (6, 7). The validity of this decision remains open to question. For example, comprehensive studies of maternal mortality consistently find underreporting and misclassification of maternal deaths, in particular for maternal deaths due to indirect causes. The DALY methodology is poor at dealing with deaths due to multiple causes.

### What is known about disability?

There is also concern about the availability and quality of the epidemiological data on incidence and prevalence of disability. The DALY is essentially an incidence-based metric but because incidence is often not available, Murray & Lopez have developed a computer model called DISMOD which permits whatever information is available on incidence, prevalence, case fatality, mortality, and remission to be checked for internal consistency. Data on incidence are more likely to be available for conditions subject to surveillance such as tuberculosis, certain cancers, and HIV.

In the area of sexual and reproductive health, while data on prevalence are generally easier to obtain than on incidence, in practice it has proved difficult to generate reliable empirical data. Results from population-based reproductive morbidity surveys have been questioned for the validity of self-reported illness (20). For the most part, community prevalence surveys will be subject to error unless clinical or laboratory diagnostic procedures are used to check the validity of self-report. Some researchers now advocate using facility sources of data despite the inherent problems of bias due to differential utilization patterns. Efforts are under way to assess and improve the quality and interpretation of facility-based data (21). There is a need to raise the rates of case detection and diagnosis of reproductive morbidities, by developing new and standardized criteria and techniques. Although some morbidities, such as genital tract cancers, can be detected by clinical examination and laboratory diagnosis, many remain asymptomatic and are unlikely to be identified only by questions directed to respondents. Many conditions, particularly in women, only become apparent with the onset of extensive complications. STDs and uterine prolapse are good examples of this problem. However, other conditions, such as dyspareunia, can only be identified by direct questioning.

Table 2. Reproductive diseases and their sequelae included in the Global Burden of Disease study, 1990

Condition		Major sequelae
STDs excluding HIV	Syphilis	Congenital syphilis Low birth weight Primary Secondary Tertiary (cardiovascular) Tertiary (gummas) Tertiary (neurologic)
	Chlamydia	Ophthalmia neonatorum Low birth weight Corneal scar (blindness) Corneal scar (low vision) Cervicitis Neonatal pneumonia Pelvic inflammatory disease Ectopic pregnancy Tubo-ovarian abscess Chronic pelvic pain Infertility Symptomatic urethritis Epididymitis Stricture
	Gonorrhoea	Ophthalmia neonatorum Low birth weight Corneal scar (blindness) Corneal scar (low vision) Cervicitis Pelvic inflammatory disease Ectopic pregnancy Tubo-ovarian abscess Chronic pelvic pain Infertility Symptomatic urethritis Epididymitis Stricture
HIV	HIV infection	AIDS
Maternal conditions	Maternal haemorrhage	Sheehan's syndrome Severe anaemia
	Maternal sepsis Hypertensive disorders Obstructed labour	Infertility Neurological sequelae Stress incontinence Recto-vaginal fistula Prolapse
	Abortion	Infertility
Reproductive cancers	Breast cancer Cervical cancer Uterine cancer Ovarian cancer Prostate cancer	

### Describing sexual and reproductive health states

A key step in the calculation of DALYs is the valuation or weighting of different health states. Valuation tries to answer the question: how can health states arising from different disease entities or

Table 3. Areas of reproductive ill-health neglected in the GBD study, 1990

Condition	Examples
Indirect obstetric conditions	Malaria Anaemia Hepatitis Diabetes Epilepsy Cardiovascular disease Tuberculosis Hypertension
Gynaecologic morbidity	Herpes, genital warts, human papilloma virus Bacterial vaginosis Trichomonas Candida Endometriosis Fibroids Ovarian benign tumours Vaginismus, dyspareunia Menstrual disorders
Female genital mutilation Rape and sexual abuse Contraceptive morbidity Psychological morbidity	Puerperal psychosis Postpartum depression
Infertility (not simply as a sequelae)	
Conditions of the male sexual and reproductive organs Morbidities attributable to HIV Stillbirths	Erectile dysfunction Prostate cancer

pathologies be compared? Answering this question raises an immediate conceptual issue, namely, what is it that we are trying to value when comparing time spent in different health states with years of life lost due to premature mortality? The challenge is to bring the definition of reproductive health into operation and identify indicators that:

- reflect the multidimensional nature of the concept of sexual and reproductive health;
- measure the full range of health states, including levels of physical and mental well-being, positive as well as negative aspects of sexual and reproductive health, undesirable symptoms, disability, and social and economic handicap or other participation restrictions within a particular context;
- offer ways to compare and interpret key features of sexual and reproductive health across populations and contexts (3).

One approach consists of developing a qualitative description or vignette describing the experience of the health state for an individual in defined circumstances (Box 1).

Alternatively, classification systems based on a series of domains can be used (Box 2). An example of

Box 1. An example of a specific health state vignette

"A woman of about your age. Recently she was treated for breast cancer which involved surgery to remove her breast and underarm glands. She takes a daily tablet as continuing treatment. She now finds herself in physical health as good as before with the exception of occasional discomfort around her chest wall and stiffness in her shoulder as a result of the treatment. The nature of the surgery means that she must now take extra care with her appearance, especially with the clothes she can wear. Mentally, her state of health has also returned to its former level. She is not unduly anxious about her diagnosis of cancer."

*Example presented by Ritu Sadana at the WHO informal consultation in January 2000 (17).*

the latter is the EQ5D, a descriptive system with specific domains — mobility, self-care, usual activities, pain/discomfort, anxiety/depression — each of which can be categorized on a scale from one to three: one representing "no problem" and three "major problems" (22). The Short Form 36 Health Survey (SF-36), a commonly used health survey instrument, includes eight domains: physical functioning; physical roles; emotional roles; social functioning; mental health; general health perceptions; bodily pain; and vitality. Within each domain, a series of questions contributes to the domain score. For example, the physical functioning domain includes ten items assessing whether the person has limitations engaging in vigorous activities such as running, lifting heavy objects, or participating in strenuous sports on the positive end of the scale, to limitations in bathing or dressing, on the negative end of the scale (23). Such measures are increasingly being used in industrialized countries to assess the experience of illness, events or conditions. Further research is needed on their usefulness in developing country settings and specifically in relation to sexual and reproductive health.

Based on the International Classification of Impairments, Disability and Handicaps (ICIDH) (24), WHO's Global Programme on Evidence for Health Policy (GPE) has selected the following domains for a pilot study to measure health status in developing as well as developed country settings: mobility; self-care; usual activities; pain/discomfort;

Box 2. An example of a classification system based on a series of qualitative, specific domains

- Surgical treatment: lump removed
- Good physical condition: occasional swelling in arm and occasional tender breast, avoid cuts to arm
- Good mental state: relieved to keep breast, not anxious about cancer diagnosis or cancer returning or early death, sexual relations and social contacts as before.

*Example presented by Ritu Sadana at the WHO informal consultation in January 2000 (17).*

anxiety/depression; cognition; sensory; energy/vitality; shame/embarrassment; participation (or overall handicap in a given environment and socioeconomic context). It seems likely that additional domains will be needed to describe the full range of sexual and reproductive health states, particularly to address concerns about the way they have an impact on handicap, participation or other aspects of the socioeconomic context. The inclusion of the domain shame/embarrassment into the WHO pilot studies mentioned above goes some way towards addressing this concern but perhaps not far enough. The issue of stigma could be considered as a separate domain, along with the ability to function as a sexual being or sexuality. Consideration should be given to the inclusion of fear as an additional domain (fear of sexual abuse or violence).

### Whose disability weights?

The process used to elicit disability weights for sexual and reproductive health conditions has come under considerable scrutiny. Whose perspective should be reflected in the preference weights? Specifically, is it appropriate and valid to use standard disability weights developed through 'expert' consensus? Studies have shown that different responses are given by different types of respondents: the general public, health care providers, individuals living in particular health states or family members of these individuals (7). The general pattern is that health care providers tend to rate health states worse than the general public, who in turn rate them worse than those living in the particular health state. In the 1993 GBD study, twelve health professionals (60% male/40% female) from around the world were asked to evaluate the disability for 'the average individual with the condition described taking into account the average social response or milieu' using the person trade-off methodology. Individuals were asked to choose between curing a certain number of individuals in one health state versus another number in a different health state. The methodology elicits the point at which the individual is indifferent between the two choices being offered. At this point the outcomes are equivalent and a weight is derived (15). Proponents of the DALY have argued that the person trade-off methodology that underlies the DALY weights ensured the methodology could be applied in a consistent manner. However, it can only be used by people with a relatively high degree of literacy who accept the idea of trade-off. It is therefore, by definition, an exclusive process driven by academic rather than experiential knowledge.

The protocol used in the GBD study describes the process used to elicit preference weights for only 22 of the indicator conditions (25). The remaining conditions were distributed across the seven classes of disability through a group consensus process.

A further concern is the explicit disavowal by the DALY methodology of community valuation

and preferences, which makes no allowance for any differences in disability severity related to social, cultural or economic contexts. This is likely to affect the relevance and acceptability of the weights for particular countries or population groups.

The 1993 GBD exercise used identical disability weighting for both men and women; no differential impact was acknowledged for the same conditions. For example, a skin disease such as vitiligo can leave women without the chance of getting married, or an infertile woman may find herself divorced against her will. In addition, no explicit consideration was given to the gender differences in access to health services for alleviating the burden of the condition. Men and women may well make different assessment of their values and preferences, such as men tend to value 'function', including an ability to work, while women tend to want to emphasize 'caring', such as concerns with family welfare and appearance. For example, the ranking of diseases causing infertility could be very different from these two perspectives.

The DALY as used in the GBD does not adequately capture the difference between a temporary loss of function compared to a permanent one. The weighting exercise involves eliciting the preferences of individuals over different health states by imagining what it would be like to remain in each health state with no change in the condition for a ten-year period. This approach explicitly excludes any consideration of disease progression and prognosis. For example, the incapacity of not being able to walk naturally for a short time period due to a broken leg or not being able to walk naturally for the rest of your life due to an amputated leg would be valued differently by people. Similarly, the temporary loss of function that results from a curable sexually transmitted disease will be perceived very differently from the permanent damage of an incurable one such as genital warts or HIV infection.

Some concerns cannot be addressed within the current approaches to disability weighting. For example, how is it possible to adequately describe, and give appropriate valuation to, conditions which do not necessarily in themselves cause a lot of suffering but which carry high inherent risks, such as asymptomatic HIV infection, and breast cancer after surgery and/or treatment? A separate though related issue relates to co-morbidities and to sequences of events such as repeated unwanted pregnancies.

Perhaps the most serious limitation of the weighting exercise as conducted for GBD 1990 was the reliance on "expert" opinion. This has been justified on the grounds that the methodologies used for eliciting disability weights, such as person or time trade-off, are intellectually challenging and difficult to use other than with highly educated respondents. Simpler approaches, such as visual analogue scales, are simpler to use and intuitively easy to grasp but have been criticized on methodological grounds (3). Further research among diverse population groups and cultures is needed to assess the extent to which simple

weighting scales can be satisfactorily implemented. And there are strong ethical arguments in favour of carrying valuation exercises in a range of settings and circumstances, with the involvement of community-based health advocates not only health “experts”.

## What DALYs do not measure

Apart from questions relating to the technical inputs required for calculating DALYs, a number of outstanding questions remain about the underlying assumptions and value judgements. What the GBD actually measures is the ‘burden’ of disease, defined in terms of ill-health reflected by functional limitations and premature mortality (26). It takes account of disability rather than handicap, as defined by the ICIDH (24). Thus the disability focuses on restriction of activities rather than disadvantages.

Furthermore, DALYs normally exclude socio-economic, cultural and environmental factors which could impact on the overall ‘burden’, as well as the ability of people to cope. This is probably more relevant for women than men. For example, class 5 ‘severe disability’ is defined as ‘needs assistance with instrumental activities of daily living, such as meal preparation, shopping and housework’ and it has the same meaning irrespective of the sex or social situation of the ill persons. Many conditions involve discomfort, pain, suffering, stigma, or social and economic consequences for reproductive health that are not well captured by the DALY. Obstetric fistula, infertility and vitiligo are examples of diseases that can have severe consequences that are not well captured by notions of disability used in calculating DALYs. Another related concern is that concepts of disability may differ in different cultures and DALYs do not allow for weighting for disability severity in relation to social, cultural or economic contexts.

By focusing on the performance of the individual suffering from the condition, the burdens which fall on households and communities, such as in maternal deaths, are not included. This approach is particularly problematic for diseases and conditions that, by their nature, closely involve other people, as is the case for reproductive health. For example, a man’s infertility may have important implications for his wife’s economic and social well-being.

In addition, the DALY calculations are based on single, non-additive causes of death and disability. This implies that an individual with more than one disability, each of which has its own disability weight, might end up with a sum of disability weights greater than 1, that is greater than death itself.

## Potential next steps

This paper has identified a number of issues that need to be addressed to better measure the burden of disease associated with sexual and reproductive ill-health using the DALY. Suggestions for improve-

ment have focused on two key aspects of the DALY calculation: the underlying epidemiology, and the description and valuation of health states.

Three different approaches could be utilized to improve the availability and quality of epidemiological data. The first would be a series of country case studies bringing together and analysing all the available information on reproductive health. The secondary analysis of existing national data combined with expert consensus and sensitivity analysis should lead to improved regional estimates, particularly in terms of estimates of the burden associated with treated and untreated sequelae of major conditions.

The second approach would involve a standardized and common approach to analysing existing demographic and epidemiological data collected in different populations by longitudinal studies. A number of population surveillance projects already exist in Africa and Asia, for example, Novrongo in Ghana and Matlab in Bangladesh, and they are currently collecting a vast range of information, much of it directly related to reproductive health. In sub-Saharan Africa alone, the INDEPTH network (the International Network of field sites with continuous Demographic Evaluation of Populations and their Health in Developing Countries) links 29 sites in 14 countries with a total of 1.1 million individuals under surveillance (27). Making better use of these sources of data represents a major international opportunity that could fill some of the gaps about the extent and nature of the risks for sexual and reproductive ill-health.

The third approach would be to establish and fund a number of longitudinal studies specifically designed to detect the incidence of reproductive ill-health and the risk of subsequent complications. Such studies could follow a standardized protocol developed by an international panel of experts, with research funds contributed by many donors and implemented under the auspices of an international collaborative scientific effort, possibly under the auspices of the World Health Organization. This approach has been very successfully used in the study of such areas as cardiovascular diseases and diabetes.

To improve the description and valuation of health states relevant to sexual and reproductive health there is a need to develop a cross-national research agenda, to select and test multidimensional indicators of reproductive health and well-being. A key element of this research agenda would include identifying and describing the full range of sexual and reproductive health conditions and specifying the staging sequences and associated disabling sequelae. Subsequently, it would be necessary to assess alternative ways of describing sexual and reproductive health states using combinations of health state labelling and qualitative descriptions and/or classification based on a series of domains. The domains should include, in addition to standard domains such as mobility, those that are of special relevance to sexual and reproductive health such as stigma, shame and sexual functioning. At the same time, there is a



need to develop and test more inclusive processes for ascribing disability weights that can be used in a range of settings and among different population groups.

## Conclusions

Despite the many criticisms of the DALY as a measurement unit, the fact remains that it represents a major conceptual advance since it permits the combination of life expectancy and quality of life into a single measure. Measuring reproductive ill-health by counting deaths alone is inadequate for a proper understanding of the dimensions of the problem because of the young age of many of the deaths associated with reproductive ill-health and the large component of years lived with disability from many of the associated conditions. Some of the concerns about whether the methodology actually captures the total burden can be addressed with relatively straightforward adaptations. Some key changes needed for reproductive ill-health to be better represented in the next GBD include the following.

- Reproductive health needs a definition that is both inclusive and measurable. This will imply greater focus, initially at least, on diseases and pathologies, rather than on the more positive dimensions of sexual and reproductive health. This is not ideal, but it is inevitable given our current inability to measure adequately positive health states.
- There is a need for a full delineation of the natural history of sexual and reproductive health conditions and all associated fatal and non-fatal health outcomes. Addressing this gap is a prerequisite for identifying and describing the full range of conditions, etiology, sequelae, and prognosis in the presence and absence of treatment.
- An international and systematic effort is required to set up a series of country case studies in sexual and reproductive health to identify, evaluate and utilize more of the existing national data sources. The information would undergo secondary analysis and be scrutinized by means of expert panels, to arrive at a set of best estimates.
- New international efforts are required to exploit the valuable population-based data that already exist in reproductive health surveillance systems and in longitudinal studies, particularly those in developing countries. This would involve the use of standardized protocols to obtain and disseminate comparable results.
- A long-term, international research strategy is needed to determine the incidence of reproductive ill-health and diseases, including the risk of complications. This could involve a network of longitudinal studies, particularly in developing countries, as has already been done for child health and survival.
- Work is needed to develop descriptive vignettes and to identify appropriate domains through which sexual and reproductive health states can be described.
- Valuation instruments are needed that are adaptable for both chronic and acute health states, that can take adequate account of repeated acute (of a short duration) conditions, and that can be modified to reflect prognosis. A range of severity for each health state should be included in future valuation exercises.
- International research is needed to identify and test valuation tools that would be appropriate in diverse settings and circumstances.
- If the main basis for the DALY methodology is accepted, a full review is necessary to determine what changes can be made to improve the estimates and to reduce sources of methodological and gender bias.

There is an urgent need to establish a strong, official international network of reproductive health research centres, with specialized expertise and data banks, through which much of this research agenda could be conducted. Much greater efforts are needed to identify and compile the results of such studies, as well as other routinely collected information, and to make them widely available to a broader audience. Also more coordinated efforts are required to collect, publish and disseminate the results and conclusions. As part of the preparation for GBD 2000, a global network could be established to link centres of expertise and to establish an international panel responsible for preparing the next steps. Obvious collaboration would be with the Global Forum on Health Research, Council on Health Research for Development (COHRED), Public Health Alliance, and Cochrane initiative.

If DALYs are to be used to guide decision-making and assess country performance, additional efforts and resources should be given to ensuring that the DALY metric captures reproductive ill-health to the fullest extent possible. Some technical gaps can be filled by improving the basic epidemiological data and improving the valuation exercises to develop disability weights for specified health states. This should involve simplifying the valuation process, reducing the role of experts and thus bringing a sense of local involvement and democratization to the effort. But all this will be worth while only if the results are useful for health policy and planning.

Doubts will still remain about the value of the methodology for identifying national priorities or allocating resources to reproductive health when what is being measured is the burden of disease or reproductive ill-health. The fundamental problem lies in taking disease as the starting point rather than the notion of incremental health gains that potentially accrue to specified interventions. For example, it remains unclear to what extent using burden of disease averted can be used to justify family planning interventions that have a beneficial impact on the health of women and children above and beyond the avoidance of death and disability due to unwanted or mistimed pregnancy. The suggestion has been made that rather than starting with "disease" as the

cornerstone of the system, it would be more appropriate to start with “interventions” (28). This would help focus research efforts in the direction of assessing the effectiveness of interventions in specific settings, an issue about which there remains considerable ignorance. Such information, coupled with data on costs, would provide essential guidance for priority setting at national and local levels. ■

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### Résumé

#### Evaluation de la charge de morbidité des affections sexuelles et génésiques : questions relatives à l'utilisation des années de vie ajustées sur l'incapacité

Le recours aux années de vie ajustées sur l'incapacité (DALY) pour apprécier la charge de morbidité constitue une importante avancée théorique puisqu'elle permet d'associer en une seule mesure l'espérance de vie et divers degrés de dysfonctionnement. C'est particulièrement important dans le domaine de la santé sexuelle et génésique parce qu'il ne suffit pas de compter les décès pour bien comprendre les dimensions du problème.

Les DALY constituent un indicateur temporel et composite de la charge de morbidité qui ajoute les années de vie en bonne santé perdues en raison d'une morbidité et de l'incapacité qui lui est associée, aux années de vie perdues en raison d'un décès prématuré. Il faut connaître deux éléments essentiels pour construire les DALY : les données relatives à l'incidence et/ou à la prévalence des pathologies ; et il faut savoir comment comparer ces états de santé les uns avec les autres, c'est-à-dire disposer d'une série de coefficients de pondération des incapacités pour chaque pathologie.

Dans la pratique, il est très difficile de réunir ces éléments en ce qui concerne la santé sexuelle et génésique. Le concept même de santé génésique se définit à partir d'une vision positive de la bonne santé, du bien-être, de l'égalité et de la justice sociale, plutôt que par une maladie, des signes anatomopathologiques ou une série d'organes précis. Il reste une certaine ambiguïté concernant ses limites précises. La santé sexuelle et génésique, c'est à la fois des entités morbides importantes – maladies sexuellement transmissibles (MST), virus de l'immunodéficience humaine (VIH), mortalité maternelle – mais aussi l'attention portée à des aspects positifs, valorisants de la vie tels qu'une « vie sexuelle satisfaisante en toute sécurité ». Etant donné la globalité de cette vision, peut-on mesurer convenablement la santé sexuelle et génésique et, si ce n'est pas le cas, comment va-t-on pouvoir traduire les impératifs politiques en actions concrètes dans les programmes ? Dans le présent article, on évalue dans quelle mesure les

DALY peuvent être améliorées pour répondre aux problèmes que pose cette mesure.

En 1993, les DALY estimées incluaient les principales MST, à savoir la syphilis, la gonococcie, les infections à chlamydia, le VIH/SIDA, les cancers de l'appareil reproducteur, ainsi que les décès et incapacités maternels dus à cinq grandes complications obstétricales directes. Un certain nombre d'affections supplémentaires devraient être incluses à l'avenir dans toute évaluation mondiale de la charge de morbidité. Ce sont : l'herpès, les candidoses, les vaginoses bactériennes, les complications obstétricales indirectes, les morts-nés, les troubles du cycle, l'infécondité, les mutilations sexuelles féminines, la psychose puerpérale et la dépression du post-partum, les troubles psychosexuels de l'homme et les conséquences indésirables pour la santé du viol et des abus sexuels.

On a besoin d'une description plus détaillée et plus explicite des affections qui appartiennent de droit à la sphère élargie de la santé génésique. Pour y parvenir, on pourrait par exemple établir l'histoire naturelle complète des affections sexuelles et génésiques – chez l'homme comme chez la femme – et recenser leurs séquelles, qu'elles soient physiques ou psychologiques. Le fait de préciser dans le détail les stades et les séquences des principales affections et les issues défavorables ou non qui leur sont associées faciliterait grandement l'obtention des données épidémiologiques nécessaires pour construire les DALY (incidence, âge d'apparition, durée, létalité, rémission) et permettrait de s'assurer que toutes les affections sont bien prises en compte, avec leur étiologie, leurs séquelles et leur pronostic, en présence ou en l'absence d'un traitement.

Pour pouvoir mieux estimer la charge de morbidité due aux affections sexuelles et génésiques, il faut améliorer aussi bien les études épidémiologiques que les exercices d'évaluation. On pourrait améliorer le nombre et la qualité des données épidémiologiques en rappo-

chant les études de cas et en entreprenant une analyse secondaire des séries de données nationales existantes. Il faut une approche normalisée et commune pour analyser les données démographiques et épidémiologiques existantes recueillies dans différentes populations à l'occasion d'études longitudinales.

Pour améliorer la description et l'évaluation d'états de santé se rapportant à la santé sexuelle et génésique, un programme de recherche transnational est nécessaire afin de choisir et de tester des indicateurs multidimensionnels de la santé génésique et du bien-être. Il faut pouvoir décrire autrement les états de santé

sexuelle et génésique, en associant la dénomination de ces états et des descriptions qualitatives ou une classification basée sur toute une série de facteurs, parmi lesquels il faudrait inclure, outre les facteurs classiques telle la mobilité, ceux qui s'appliquent tout particulièrement à la santé sexuelle et génésique, à savoir la stigmatisation, la honte et les aspects liés à la fonction sexuelle proprement dite. Par ailleurs, il faut élaborer et tester des modalités plus diversifiées pour affecter des coefficients de pondération des incapacités utilisables dans toutes sortes de situations et dans différents groupes de population.

## Resumen

### Evaluación de la carga de mala salud sexual y reproductiva: cuestiones relacionadas con el uso de los años de vida ajustados en función de la discapacidad

El uso de los años de vida ajustados en función de la discapacidad (AVAD) como reflejo de las distintas dimensiones de la carga de morbilidad representa un importante avance conceptual, ya que permite combinar la esperanza de vida y los niveles de disfunción en una sola medida. Esto reviste especial importancia en el terreno de la salud sexual y reproductiva, ya que la mera contabilidad de las defunciones no permite comprender claramente las dimensiones del problema.

Los AVAD son un indicador temporal compuesto de la carga de morbilidad que añade las pérdidas de vida sana por morbilidad y por la discapacidad asociada a las pérdidas por muerte prematura. Se necesitan dos datos fundamentales para calcular los AVAD: la incidencia y/o prevalencia de las enfermedades, e información sobre la comparabilidad de esos estados de salud, esto es, una serie de coeficientes de ponderación de la discapacidad para cada enfermedad.

En la práctica, obtener esa información sobre la salud sexual y reproductiva representa un enorme desafío. El concepto de salud reproductiva se define por una visión positiva de la buena salud, el bienestar, la equidad y la justicia social, y no tanto por referencia a una enfermedad, patología o conjunto de órganos específicos. Sigue habiendo cierta ambigüedad en cuanto a sus límites precisos. El grado de salud sexual y reproductiva depende de algunas enfermedades clave, como son las enfermedades de transmisión sexual o la infección por el virus de la inmunodeficiencia humana (VIH), así como de la mortalidad materna, pero también hay que prestar atención a aspectos positivos relacionados con la calidad de vida, como «una vida sexual segura y satisfactoria». Considerando la amplitud de esa perspectiva, ¿es posible medir la salud sexual y reproductiva de alguna manera que tenga sentido, y, en caso contrario, cómo se podrá pasar de la política a la acción programática? En este artículo se evalúa hasta qué punto puede mejorarse el concepto de AVAD a fin de responder a esos retos de medición.

Las estimaciones de 1993 sobre los AVAD incluían las principales ETS – sífilis, blenorragia, clamidiasis, VIH/SIDA–, los cánceres del aparato reproductor, y las defunciones y discapacidades maternas por las cinco complicaciones obstétricas directas principales. En

futuras evaluaciones de la carga mundial de morbilidad deberían incluirse varias enfermedades más, entre ellas las siguientes: herpes, candidiasis, vaginitis bacteriana, complicaciones obstétricas indirectas, muertes prenatales, trastornos menstruales, infertilidad, mutilación genital femenina, psicosis puerperal y depresión posparto, trastornos psicosexuales del hombre, y efectos perjudiciales para la salud resultantes de violaciones y abusos sexuales.

Hace falta una descripción más detallada y explícita de las enfermedades que efectivamente encajan en el programa general de salud reproductiva. Una alternativa para ello consistiría en analizar con detalle la historia natural de los problemas de salud sexual y reproductiva, en hombres y mujeres, y de sus secuelas, tanto físicas como psicológicas. Una descripción detallada de las fases y secuencias de enfermedades clave y de los resultados mortales y no mortales asociados facilitaría sobremanera la obtención de los datos epidemiológicos requeridos para calcular los AVAD (incidencia, edad de aparición, duración, letalidad, remisión) y contribuiría a asegurar que se tuvieran en cuenta todas las dolencias, junto con su etiología, sus secuelas y su pronóstico con y sin tratamiento.

Para poder refinar el cálculo de la carga de morbilidad sexual y reproductiva, es preciso introducir mejoras en los métodos epidemiológicos y de cálculo. Se podrían conseguir más y mejores datos epidemiológicos reuniendo estudios de casos en los países y emprendiendo análisis secundarios de los conjuntos de datos nacionales existentes. Es necesario emplear un enfoque normalizado y común para analizar los datos demográficos y epidemiológicos que han aportado ya los estudios longitudinales de distintas poblaciones.

A fin de mejorar la descripción y la valoración del estado de la salud sexual y reproductiva, debe emprenderse un proyecto de investigaciones transnacionales destinado a seleccionar y probar diversos indicadores multidimensionales de la salud y el bienestar reproductivos. Se necesitan descripciones alternativas de la salud sexual y reproductiva, que combinen la catalogación de los estados de salud y descripciones cualitativas o clasificaciones basadas en una serie de dominios. Entre esos dominios deberían figurar, además

de dominios tradicionales como la movilidad, los especialmente pertinentes para la salud sexual y reproductiva, como la estigmatización, el sentimiento de vergüenza y el funcionamiento sexual. Al mismo

tiempo, es necesario desarrollar y probar más procesos incluyentes de ponderación de las discapacidades que puedan utilizarse en diversos entornos y entre distintos grupos de población.

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