International comparisons of health status are usually limited to mortality because of the lack of widely accepted and uniformly measured morbidity or disability indicators. Morbidity comparisons could include the rates of reportable diseases (e.g., acquired immune deficiency syndrome (AIDS)), the incidence of diseases for which there are registries (e.g., birth defects, cancer), and the prevalence of disabilities reported in national surveys. This chapter reviews available morbidity comparisons and current efforts to develop internationally useful measures of disability, quality-of-life, and healthy life expectancy.

MORBIDITY, DISABILITY AND QUALITY-OF-LIFE INDICATORS

As life expectancy in developed countries has increased, interest in health indicators has shifted from mortality measures to indicators of the consequences of living with chronic illnesses and, to the extent that it can be measured, the maintenance of good health. The World Health Organization (WHO) defines health as “a state of complete physical, mental and social well being and not merely the absence of disease and illness” (252).1 Although health is defined in a positive sense, most available indicators measure the negative complement of health (198). Three types of indicators can be used to describe health or its absence:

1The World Organization of National Colleges, Academies, and Academic Associations of General Practitioners/Family Physicians (WONCA) has recommended that the word “optimal” be substituted for “complete” in the WHO definition, because few people can achieve complete health as it has been defined (9).
Morbidity indicators are reports of diseases or conditions that can potentially impair, disable, or handicap (e.g., the prevalence of arthritis, or heart disease).

Impairment, disability, and handicap indicators, as defined by WHO, measure the consequences of diseases and injuries and their implications for the lives of individuals (box 6-A) (24,161,181,255).

Health-related quality-of-life indicators measure subjective judgments about states of health or disease (19,115,116,134). An example of a quality-of-life indicator is self-perceived health.2

Morbidity Indicators

REPORTABLE DISEASES

Only three diseases—plague, cholera, and yellow fever—require official notification under WHO’s International Health Regulations, but most developed countries have their own disease surveillance systems. In the United States, for example, physicians report to State or local health officials, who in turn make weekly reports to the U.S. Centers for Disease Control and Prevention, when patients have any of 49 notifiable conditions (e.g., AIDS, hepatitis, rabies, and measles) (211). In the United States, notification is not mandatory, and the thoroughness of the reporting...
varies with the seriousness of the condition. Salmonellosis and mumps are, for example, less likely to be reported than are plague and rabies. Reporting is also influenced by the availability of diagnostic facilities, infectious disease control policies, and the vigilance of State and local authorities involved in surveillance activities.

AIDS data are available from all developed countries’ disease surveillance programs. As of mid-1993, cumulative rates of the incidence of AIDS were substantially higher in the United States than in comparison countries (Table 6-1). Spain had the second highest rate (465 cases per million), but it was less than half the U.S. rate (1,268 cases per million). Japan’s rate is remarkably low, at only four cases per million.

Risk factors responsible for AIDS transmission in the comparison countries vary substantially. Homosexual or bisexual activity has been responsible for most of the cases in the United States, intravenous drug use has caused most of the cases in Italy and Spain, and contaminated blood products have been responsible for most of the cases in Japan (98,237,274).

**CHRONIC DISEASE**

Incidence, prevalence, and mortality rates cannot adequately measure the extent and effect of chronic conditions. Chronic diseases are often variable in their onset, progress gradually, and persist for months or years. International differences in chronic disease statistics may be misleading, if the disease entails any long asymptomatic period and is detected at different rates during various stages. A country with an aggressive cancer screening program, for example, might report a higher incidence of breast cancer than a country without such a program would report. To make international comparisons, cancer survival must be evaluated according to what stage the cancer had reached at the time of diagnosis. To evaluate the consequences of disease or disability, measures are needed that could distinguish between, for example, a diabetic individual with no complications and a diabetic patient with heart, eye, and kidney diseases.

**Disability Indicators**

The World Health Organization has developed a conceptual model describing the disability process and has published the *International Classification of Impairments, Disabilities, and Handicaps (ICIDH)* to facilitate measuring the consequences of diseases and injuries (box 6-A).

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**Table 6-1—Cumulative AIDS Incidence Through Mid-1993, United States and Selected Countries**

<table>
<thead>
<tr>
<th>Country</th>
<th>AIDS cases through mid-1993</th>
<th>Cumulative AIDS incidence (per million)</th>
</tr>
</thead>
<tbody>
<tr>
<td>United States</td>
<td>315,390</td>
<td>1,267.8</td>
</tr>
<tr>
<td>Australia</td>
<td>3,697</td>
<td>219.9</td>
</tr>
<tr>
<td>Canada</td>
<td>8,232</td>
<td>309.5</td>
</tr>
<tr>
<td>France</td>
<td>24,226</td>
<td>427.7</td>
</tr>
<tr>
<td>Germany</td>
<td>9,697</td>
<td>123.3</td>
</tr>
<tr>
<td>Italy</td>
<td>16,860</td>
<td>293.1</td>
</tr>
<tr>
<td>Japan</td>
<td>543</td>
<td>4.4</td>
</tr>
<tr>
<td>Netherlands</td>
<td>2,575</td>
<td>171.0</td>
</tr>
<tr>
<td>New Zealand</td>
<td>360</td>
<td>106.2</td>
</tr>
<tr>
<td>Norway</td>
<td>319</td>
<td>75.4</td>
</tr>
<tr>
<td>Spain</td>
<td>18,347</td>
<td>464.7</td>
</tr>
<tr>
<td>Sweden</td>
<td>817</td>
<td>96.1</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>7,341</td>
<td>128.3</td>
</tr>
</tbody>
</table>

*based on data from the former Federal Republic of Germany.


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*Cumulative AIDS incidence is the total number of AIDS cases reported to date (as of mid-1993), divided by the current estimate of the mid-year population.*
An important U.S. civil rights law, the Americans with Disabilities Act (ADA) (Public Law 101-336), defines disability broadly as "a physical or mental impairment that substantially limits one or more major life activities, " a record of such an impairment, or being regarded as having such an impairment (61). This definition outlines generally who is covered by the ADA, but the final determination is made on a case-by-case basis (242).

According to an alternative conceptual model proposed by S. Nagi, the term handicap is dropped and a distinction is made between functional limitations, which entail problems in performing simple actions and disabilities that entail problems in performing complex activities. The WHO framework was criticized, and the Nagi framework was adopted (but modified) in Disability in America, an influential U.S. report published by the Institute of Medicine (IOM). The IOM and others have questioned the use of the term handicap because people with disabling conditions in some countries perceive it as negative (85,1 13).

The U.S. Department of Health and Human Services’ Public Health Service Task Force on Improving Medical Criteria for Disability Determination recommended a strategy to improve the scientific basis for determining disabilities and developed a research agenda regarding medical criteria for such determinations (201).

The North American WHO Collaborating Center for Health Related Classifications will participate in revising the ICIDH and will coordinate its use in the United States and Canada (74).

National statistics on disability are generally available from several sources, such as censuses, surveys, and registration systems (e.g., administrative records from health or disability programs). According to a 1990 survey of data collection policies in 14 countries, almost all countries gather, as part of their population-based surveys, information on the prevalence or incidence of chronic conditions, temporary and/or long-term disability, and long-term incapacity to work (44). But because countries differ in how they conceptualize disability, the content of disability-related questions on surveys varies so widely that international comparisons cannot be made (box 6-B). Furthermore, available surveys sometimes include different populations; some include institutionalized populations whereas others do not (14a).

There are numerous sources of data on disability in the United States, but even here the content of disability surveys varies widely (124). U.S. estimates of the prevalence of work-disability range from 9 to 17 percent based on

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7 The U.S. Department of Health and Human Services’ Public Health Service Task Force on Improving Medical Criteria for Disability Determination recommended a strategy to improve the scientific basis for determining disabilities and developed a research agenda regarding medical criteria for such determinations (201).

8 The extent of self-reporting of medical conditions can vary with the format of the survey question. For example, the proportion of British General Household Survey respondents reporting health problems rose from about one-quarter to almost three-quarters when the survey format changed from being open-ended to including a checklist of medical conditions (13). Such variations support other evidence suggesting that the prevalence of chronic diseases by diagnosis may not be reliably assessed through self-reports on national health interview surveys (89).

9 The United States has compiled national statistics on disability from over 55 countries (187a). Although disability-related statistics are often available from national censuses or population surveys, they are generally not comparable. Three factors hamper efforts to make international comparisons of disability: disagreement on what disability means and on which states of health should be measured; differences in how disability surveys are conducted; and the need to interpret disability statistics in a cultural and social context.

General disagreement on what disability means has hampered attempts to standardize morbidity and disability measures. The WHO classification system has been adopted in Europe but, until recently has not been widely accepted in the United States. Critics of the WHO framework state that the concepts of impairment, disability, and handicap are ambiguous and result in problems of classification (24,25 .85). Some of the problems identified in the ICIDH will likely be resolved when the WHO clarification system is revised in 1993 (181). A U.S. task force on disability criteria recommended that the United States adopt the ICIDH framework and participate in the ongoing revision of the ICIDH (201).

There are numerous sources of data on disability in the United States, but even here the content of disability surveys varies widely (124). U.S. estimates of the prevalence of work-disability range from 9 to 17 percent based on

10 The U.S. National Center for Health Statistics is planning a supplement on disability as part of its National Health Interview Survey in 1994-95 (169).
population-based surveys because of differences in the purposes, context, and content of the surveys (124).

A WHO working group has recommended standardizing questions about disability to promote comparability of disability statistics (44,272). Although having countries change the content and wording of their population-based surveys to promote international comparability might be desirable, such changes would diminish each country’s ability to monitor its internal trends because its new data would not be comparable with its old data. Consequently, the changes might be resisted.

But even if disability-related questions on national surveys were standardized, difficulties would remain in making international comparisons. Disability is commonly measured in terms of “bed days,” “restricted activity days,” or “work-loss days. Restricted activity days might be measured, for example, in terms of responses to the question “Did you have to cut down on any

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**Box 6-B—Examples of Differences in Disability-Related Questions Included in Population-Based Surveys**

Prevalence (or incidence) of chronic conditions
United States (National Health Interview Survey)—Respondents are asked whether during the past 12 months anyone in the family has had any of a list of medical conditions.
Great Britain (General Household Survey)—Respondents are asked whether they have any long-standing illness, disability, or infirmity. If so, they are asked whether it limits their activities in any way and to name what is the matter with them.

Temporary disability
United States (National Health Interview Survey)—Temporary disability is measured in terms of bed-days, work-loss days, school-loss days and other restricted activity days.
Denmark (Danish Health and Morbidity Survey)—Respondents report the number of days in the past 2 weeks that an illness, injury, or complaint has made it difficult or impossible to carry out ordinary daily activities (e.g., domestic work or work outside the home, spare time activities, etc.).

Long-term disability
United States (National Health Interview Survey)—Persons under 70 years of age are asked questions about their ability to perform the usual role functions for their age (i.e., working, keeping house, going to school, or normal play, as well as any limitations in other activities). Person 60 years of age or older and anyone reporting any other role limitation are asked if they need the help of another person with personal care needs, or handling routine needs?
The Netherlands (National Health Interview Survey)—Respondents are asked a series of questions regarding functional abilities (e.g., “Can you carry an object of 5 kilos for 10 meters, for example a full shopping bag?” and “Can you walk 400 meters without resting?”).

Long-term incapacity to work
United States (National Health Interview Survey)—Respondents ages 18 to 69 are asked, “Does any impairment or health problem keep you from working at a job or business?” and “Are you limited in the kind or amount of work you could do because of any impairments or health problems?”
Japan (The Comprehensive Survey of Living Conditions of the People on Health and Welfare)—respondents are asked, “Do you have any kind of restriction on doing the following activities. . . working of any kind?”

**SOURCES.** S. M. Evers, “Health For All Indicators in Health Interview Surveys,” *Health Policy* 23:205–218, 1993; R. Wilson, Director, Office of Epidemiology and Health Promotion, National Center for Health Statistics, Centers for Disease Control and Prevention, Public Health Service, U.S. Department of Health and Human Services, Hyattsville, MD, personal communication, July 1993.
Difficulties in health status, variations in the environment, distinctions in how disability was defined or measured, or survey error could account for these international disparities (106).

Quality-of-Life Indicators

With attention increasingly focused on prevention and treatment for chronic illness, outcome measures that describe the effects of treatment in terms of both mortality and morbidity, and also incorporate public values associated with various outcomes, are potentially useful. Such interventions as heart transplants might increase life expectancy but seriously compromise physical independence, mobility, social activity, and other factors that contribute to the quality of life. Certain indexes try to capture, sometimes in a single measure, dimensions of health that affect its quality. Quality-of-life indicators are based on health-state preferences, which are measures of satisfaction or desirability that people associate with the presence of symptoms and functional limitations that can affect quality of life (50, 51, 52, 53). Health-related quality-of-life measures are increasingly being considered for program evaluation, population monitoring, clinical research, and policy analysis (134). Box 6-C shows a selection of instruments for assessing functional status. Some of these measurements are weighted for quality-of-life factors. WHO’s Quality-of-Life project is developing a survey instrument to assess how patients in developing and developed countries perceive the quality of their lives (33).

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11 Only half of the individuals reporting that they were wheelchair-bound said that they were limited in their ability to work, according to a 1978 survey by the U.S. Social Security Administration (124).

12 An estimated 21 percent of the U.S. population aged 15 and older were estimated to have functional limitations in 1984, according to the Survey of Income and Program Participation (106).

13 The Canadian Health and Activity Limitation Survey estimated that in 1987 approximately 15 percent of the adult population (age 15 and older and including those residing in institutions) had a functional or activity limitation (106).

14 According to a British survey, about 14 percent of adults aged 16 or older were estimated to have a functional limitation in 1986 (106).

15 Both the Canadian and British surveys used a more extensive list of functional limitations than the U.S. survey (106).

16 Some persons with disabilities find certain quality-of-life approaches offensive, because they imply that a year of life with a disability is less valuable than a year without a disability (74).
Healthy Life Expectancy

Information on mortality and morbidity in a population can be integrated to yield measures of life expectancy adjusted for the prevalence of impairment, disability, or handicap. WHO has recommended that these healthy life expectancy indicators be used to monitor the health of populations (256). Healthy life expectancy differs from life expectancy by referring to the number of years someone of a particular age can, on average, expect to live in a healthy state, in view of prevailing age-specific rates of mortality and morbidity (15). Evidence of widespread acceptance of the indicator is its incorporation into the health objectives of various nations. One goal of the United States, for example, is to increase the years of healthy life from an estimated 62 years in 1980 to 65 years by the year 2000 (200). WHO's fourth European regional target toward “Health for All” calls for a 10 percent increase in healthy life expectancy by the year 2000 (267).

A country’s life tables can be adjusted by using information from population-based surveys to estimate what portion of the residents’ life expectancy is free from various types of impairments, disabilities, or handicaps (figure 6-1). An
international network of researchers called REVES\(^{17}\) is developing techniques and proposing standards to be used to calculate healthy life expectancy (113,150,151). These standards would be helpful because although national estimates of disability-free life expectancy exist for more than 30 countries (150),\(^{18}\) the estimates rely on different methods and disability data and cannot be compared (17). Some measures, for example, include a quality-of-life adjustment. The World Bank has

\(^{17}\) The full name of the network on health expectancy and the disability process is Réseau Espérance de Vie en Santé. From 1989 to 1992, the network has convened six international meetings and has published papers, bibliographies, and a world yearbook on statistical calculations of healthy life expectancy (113).

\(^{18}\) Developing countries for which estimates are available include Canada, Denmark, England and Wales, France, Germany (the former Federal Republic of Germany), Italy, the Netherlands, Spain, Sweden, Switzerland, and the United States (113,180).
calculated ‘disability-adjusted life years,’ which include a weighting scheme reflecting relative severity and burden of disabling conditions. These weights were determined by a group of experts (251). The U.S. measurement of years of healthy life also includes a quality-of-life adjustment (200). However, some have suggested that disability weights should not yet be used because there is no consensus on how to measure quality of life, and such adjustments obscure the ability to monitor changes in a population’s health status over time (151).

Most researchers agree on the need for longitudinal surveys to identify the incidence, duration, and possible recovery from impairments and disabilities. The United States has one of the few national longitudinal data sets, the Longitudinal Study of Aging (LSOA). Other countries are beginning to mount such surveys, which will allow international comparisons (153a).

SELF-PERCEIVED HEALTH

Population-based health surveys often include questions on self-perceived health, but the responses to such questions may reflect social perceptions that are culturally bound, making them difficult to interpret and compare (68). Furthermore, international comparisons are often difficult to make, because the wording of survey questions and responses varies by country (20).

A standard question on self-perceived health was included in a 1987 12-country study, “Europeans and Their Health.” A full 79 percent of Irelands’ residents rated their general state of health as “good” or “very good” compared with 60 percent of residents of Italy (table 6-2) (28).22

The U.S. National Health Interview Survey records responses to a question on self-perceived health similar to the question used in the European survey, but the response categories differ somewhat. In the United States, most residents (90 percent) reported themselves to be in “good,” “very good,” or “excellent” health in 1987 (214). This is higher than reports of “very good” or “good” health in Europe in 1987, but the difference in the response categories makes comparisons difficult.

SELF-PERCEIVED STRESS

Perceptions of personal levels of stress are sometimes intended to be a measure of mental well-being. According to population-based surveys in the United States and Canada,24 a greater proportion of adults (aged 18 and older) reported “very stressful” lives in 1985 in the United States (18 percent of males and 23 percent of females) than in Canada (10 percent of males and 8 percent of females). In 1990 the report’s findings were similar (20 percent versus 13 percent of males and 27 percent versus 12 percent of females) (162).

SUMMARY

There is no general consensus regarding disability measures, but they are important for determining whether gains in life expectancy have come at the expense of quality of life. The WHO

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19 The LSOA includes data on disability, institutionalization, and mortality for a sample of U.S. respondents, aged 70 or older, who were originally interviewed in 1984 and then reinterviewed in 1986 and 1988 (152a).

20 WHO has recommended a standard self-perceived health question for survey use (269).

21 The question on self-perceived health on the survey was “How would you describe your state of health in general now? Would you say it is very good, good, reasonable, rather poor, very poor or you don’t know?” (28).

22 A standardized questionnaire related to cancer and its prevention was used as part of the survey. Face-to-face interviews were conducted within the homes of a representative sample of residents aged 15 and older within 12 countries. A total of 11,651 subjects were included in the study (28).

23 In the U.S. Survey, the question is “Would you say your health in general is ‘excellent,’ ‘very good,’ ‘good,’ or ‘fair or poor’ (214).

24 The 1985 and 1990 Health Promotion Surveys in Canada and the National Health Interview Survey Health Promotion and Disease Prevention Supplements included comparable questions on self-perceived stress. In the United States, respondents were asked how much stress they had experienced in the 2 weeks preceding the interview. In Canada, respondents were asked to assess the level of stress in their lives (162).
International Classification of Impairments, Disabilities and Handicaps has been accepted by many nations and used for clinical and health services research, health services planning, and population health monitoring (181,250,255). The ICIDH framework has been criticized, but many of the problems are likely to be resolved in the planned revision of the classification scheme. In view of differences in how health services are delivered, internationally comparable data on disability probably will come from population-based surveys and not from administrative records. Achieving consensus on a disability classification would be a first step toward comparability of information about disability on such surveys. At present, both the content and methods of surveys differ so widely that disability comparisons cannot be made.

Despite international disagreement over what disability means, there is general agreement that years of life without disability should be the focus of public health efforts. An indicator that shows great promise in monitoring health is a measure of healthy life expectancy, which is the number of years someone of a particular age can, on average, expect to live without various impairments, disabilities, or handicaps. Although the different countries have not yet agreed on how to measure healthy life expectancy, many of them have included it as an indicator in their health goals, and efforts are underway to measure and monitor it. An international group of researchers (called REVES) is working toward standardizing this measure.