

The role of statistics on health status in the context of measuring Quality of Life

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Abstract

International initiatives are currently underway to develop improved measures of health status within an overall framework of health statistics. These efforts identify functioning as the key dimension by which the health of a population can be summarized. Functioning is also the aspect of health that is most closely related to quality of life. Functioning and disability represent the impact of pathologies at the cellular, organ and body system level on the person's ability to participate fully in society. The social, political and physical environment in which a person lives can modify the effect of functional limitations in core domains with the effect of maximizing participation in society. While complex, these relationships are central to improving quality of life. However, these key indicators of health have proven among the most difficult to measure in valid, reliable and comparable ways. The Washington Group on Disability Statistics and the Budapest Initiative on the Measurement of Health State are developing and testing question sets that can be included in national statistical data collection efforts. The information generated can be used as core measures of health and health related quality of life. This presentation will provide a brief overview of the work of these two groups and explore the role of functioning in measuring quality of life.

Key Words: functioning, quality of life, health status

1. Introduction

International initiatives to develop improved measures of health within an overall framework of health statistics have identified functioning as the key dimension by which the health of a population can be summarized. Functioning is also the aspect of health that is most closely related to quality of life. Functioning and disability represent the impact of pathologies at the cellular, organ and body system level on a person's ability to participate fully in society. The social, political and physical environment in which a person lives can modify the effect of functional limitations with the effect of maximizing participation in society. While complex, these relationships are central to improving quality of life. These factors involved have also proven to be among the most difficult to measure in valid, reliable and comparable ways. As a first set towards solving these measurement challenges, the Washington Group on Disability Statistics and the Budapest Initiative on the Measurement of Health State are developing and testing question sets that can be included in national statistical data collection efforts. The information generated can be used as core measures of health and to address health related quality of life.

2. Definitions of health and the measurement of quality of life

Health, defined in the broadest sense, encompasses or can be associated with most aspects of physical, mental, and social wellbeing. Such a broad conceptual foundation makes measurement difficult and often results in confusion about which aspects of health are of interest. Mortality has long been relied on as the sole or central measure of health. While mortality and life expectancy are important components of health, focusing solely on mortality falls far short of describing the health of a population. Dividing years lived into those that are lived in varying states which range from 'perfect or optimal health' to 'poor or bad' health provides richer information by which to characterize the health and health related quality of life of populations. How to define this continuum from good to poor health or quality of life presents a challenge given the complexity of the concept of health itself. Health is sometimes equated with disease states or to the clinical measures and biomarkers associated with them. Health can also be equated with biological, genetic, environment and behavioral risk factors or protective factors that can affect pathology and disease state. Common data sources for this medical model of health are laboratory and radiological tests, physical exams, performance testing and medical records. The 'medical' model focuses on what is going wrong within the body and ignores the more social aspects of health. While social factors can affect the development and progression of disease, health itself can be seen as a social phenomenon where our medical concept of health has little or no intrinsic worth but is sought because 'good' health allows one to do the things one wants to, i.e., to participate fully in society. This suggests that we should develop measures of health that address this participation aspect of the concept and include such measures in our statistical systems. The information generated would allow governments to monitor the health of the population in a way that is more relevant to the population; to institute policies and programs that would maximize this aspect of health (social participation); and to evaluate whether those programs are effective.

3. Functioning as a measure of health

Functional status provides a bridge between on the one hand the medical and pathological aspects of health and on the other the social aspects as it provides information on the extent to which impairments and disabling conditions affect social participation. Functioning itself is a complex concept involving multiple domains and levels of severity. While complex, functional status provides a way to summarize the impact of the medical/pathological aspects of health and to link this summary to a quality of life outcome. Functional status also provides a framework for incorporating the effect of environment, where environment is defined most broadly to include the availability of health care and associated services, assistive devices, physical structures, social attitudes and legal requirements. In addition to having a role in causing pathology, the environment acts to exacerbate or ameliorate the effect of pathology.

Functioning measures can be organized by the nature of the task (functional domain) and the nature of the relationship with the environment. Functional domains can be ordered on a continuum from simple (or core) to complex and be measured with or without environmental accommodations. The ability to measure functioning independent of the environment becomes more difficult as the complexity of the task increases. Core domains encompass basic activities such as walking and sensory functioning (vision and hearing), upper body, cognitive and psychological functioning. Measurement of functional limitations for these core domains can be made 'within the skin', that is without the impact of environmental factors that can ameliorate the effect of pathology on performance in these domains. For example, the ability to walk can be measured without the use of assistive devices, such as a cane or walker, even if these are usually used. Functioning in these domains can also be

measured taking the effect of environmental accommodations into account. The impact of some accommodations is to modify the actual nature of the domain; for example when the use of wheel chair changes *walking* into *getting around*. Some types of environmental accommodations are made ‘within the skin’, such as surgery to replace a hip. Different measurement strategies are needed to capture these accommodations to monitor their impact on functioning.

The core functional domains are the building blocks by which other tasks are accomplished. *Self-care* activities can be thought of as the ‘simplest’ of the complex activities and *working* as one of the more complex. Because it is harder to disentangle the impact of the environment in accomplishing complex tasks, most data collection assumes performance in the individual’s current environment. While it is conceptually possible to untangle the effects of unaccommodated and accommodated functioning on core domains and the effect of environmental barriers and facilitators on functioning in complex domains, doing so requires the collection of a large amount of data involving substantial methodological challenges.

4. Functioning as a measure of health related quality of life

Health and health related quality of life are associated but different concepts. Neither concept has clear, agreed upon definitions. As noted above, some definitions of health are so broad so as to encompass all aspects of life. At the other end of the spectrum, some definitions of health related quality of life are equivalent to physical health. Equating the two not only causes conceptual confusion but eliminates one important outcome measure of policy concern. Functioning, when measured within core domains and without accommodation, is a summary measure of health that focuses not on specific pathologies but on the impact of these pathologies on core domains. When functioning is measured within complex domains with accommodation defined broadly, it is a measure of overall quality of life. When the causes of the limited participation in society are anchored in the health domain, the measures are of health related quality of life. The outcome measure goes beyond ‘health’ moving the focus to social participation – the ability to get an education, be employed, earn income and participate in social, cultural and civic activities.

Using functioning as an indicator of health related quality of life has advantages from a statistical agency and from a policy perspective. A major role of a health statistical agency is to monitor key indicators of health and health care over time and across population subgroups to inform policy. This requires detailed as well as easy to understand summary or composite measures. Measures of functioning are currently included among core measures collected by health statistical agencies so will be available on an ongoing basis for policy use. As noted in the UN Convention on the Rights of Persons with Disabilities, a primary policy objective of governments is to minimize participation restrictions due to limitations in functioning originating ‘within the skin’. Statistical data on functioning collected by statistical agencies can be used to measure the level of and changes in health related participation along with the level of changes in functioning ‘within the skin’ and with accommodation. These trends can then be related to program and policy interventions.

5. International comparable measure of functioning

The Washington Group on Disability Statistics (WG) was organized in 2001 following the United Nations International Seminar on Measurement of Disability to address the need for statistical and methodological initiatives at an international level to facilitate the measurement of disability and the comparison of data on disability cross-nationally. All National Statistical Offices are eligible for membership in the WG. Currently, 77 National Statistical Offices are represented, as well as 7 international organizations, 6 organizations that represent persons with disabilities (DPOs), the UNSD, and 3 other UN affiliates. The Secretariat for the WG is located at the National Center for Health Statistics (NCHS), USA. The main objective of the WG is the promotion and coordination of international cooperation in the area of health statistics by focusing on disability measures suitable for censuses and national surveys.

The Budapest Initiative (BI), established in 2005 under the Work Programme of the Conference on European Statisticians, is a collaboration of, among others, the World Health Organization (WHO), United Nations Economic Commission for Europe (UNECE), and Eurostat. Its main purpose is the development of an

internationally accepted standard set of questions for assessing general health state in the context of population interview surveys.

Both groups focus on the measurement of functioning. The WG has a somewhat broader mission as it is concerned with all aspects of the disablement process including the impact of the environment. It also draws members from all countries. The BI focus is on health state as defined as ‘within the skin’ measures of functioning. Membership is primarily from countries in the Economic Commission for Europe. However, there has been considerable overlap in the membership of the two groups. To avoid duplication of effort and inconsistency in products the two groups have essentially merged under the rubric of the WG.

The WG first developed a short set of questions for use in Censuses and in national surveys. The question set was designed to identify the subpopulation that is at a greater risk than the general population of experiencing restrictions in social participation, for example in employment, education or civic life. Risk is increased as a result of difficulties experienced in basic functional domains or actions such as seeing, hearing, walking, cognition, self-care and communication. The ‘at risk’ population captured by the short set of questions will include persons with difficulties or limitations in basic actions who may or may not also experience restrictions in participation. Actual participation levels will depend on the availability of assistive devices, a supportive environment and other resources and these will vary within the group identified as being at increased risk (i.e., disabled). Using these questions in conjunction with other questions on a Census, it is possible to compare the actual level of participation of the subpopulation at higher risk with those not experiencing similar functional difficulties. Observed differences in levels or degree of participation reflect the need for societal accommodation to equalize opportunities for full societal inclusion. This approach to disability definition and measurement is a central tenet of the UN Convention on the Rights of Persons with Disabilities.

The final short question set is:

The next questions ask about difficulties you may have doing certain activities because of a **HEALTH PROBLEM**.

1. Do you have difficulty seeing, even if wearing glasses?¹
2. Do you have difficulty hearing, even if using a hearing aid?¹
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty (with self-care such as) washing all over or dressing?
6. Using your usual (customary) language, do you have difficulty communicating, (for example understanding or being understood by others)?

Each question has four response categories: (1) No, no difficulty, (2) Yes, some difficulty, (3) Yes, a lot of difficulty and (4) Cannot do it at all. The severity scale is used in the response categories in order to capture the full spectrum of functioning from mild to severe.

Given the limitations of the Census format, it is not possible to include all aspects of functioning or all basic actions in the question set. However, the selected domains encompass core aspects of functioning and will identify a large proportion of the population at risk of experiencing restrictions or disadvantages in the major life areas of education, employment, and family, social and civic life. Upon completion of this short set of questions the WG then began to develop an extended set of questions that expanded beyond the core domains and also obtained more information on each domain. This work was merged with the work of the BI.

The BI focused its measurement efforts on health state. Health state is only one of a large number of classes of indicators that would be necessary to provide a full statistical picture of population health. Health state does not

¹ The inclusion of assistive devices was considered for two domains only, seeing and hearing, as limitations in these domains can often be overcome with the use of glasses or hearing aids.

include determinants of health. This exclusion is essential from an analytical point of view and allows the strength of association between a determinant of health and health state to be assessed empirically. Correspondingly, health state is clearly distinguished from overall well-being and quality of life. While there is no doubt that health state is a major factor determining well-being, it is not the only one. It is also important to distinguish health state from physiological markers like blood pressure and cholesterol levels, and from clinically or bio-medically defined disease. Health state is essentially a rigorously structured but vernacular or plain language description of an individual's functional health status.

The BI defines health state in terms of functioning in a core set of health domains, with the following core functional health domains endorsed for this purpose:

- Vision
- Hearing
- Mobility
- Cognition
- Affect (Anxiety and Depression)
- Pain
- Fatigue

Two additional domains have been identified as important functional aspects of health state. These domains are optional for inclusion with the final module:

- Communication
- Upper Body

The parsimonious question set developed by the BI had to be suitable for use in population interview surveys, maintain a consistent meaning in different social contexts, and be able to demonstrate a reasonable degree of heterogeneity within the population being surveyed.

The functional domains met criteria related to relevance and feasibility as well as certain measurement characteristics. Relevance required each of the domains and their associated survey questions to be immediately seen as plausible and reasonable by ordinary individuals, to span the main aspects of health experienced by the population, to be seen as significant aspects of individuals' health and to draw on selected key ideas of the International Classification of Functioning, Disability and Health (ICF). Feasibility refers to a question set that is suitable for use in health interview surveys, has a consistent meaning in different social contexts, manifests a reasonable degree of heterogeneity within the population, and minimizes the number of domains on which questions need to be asked.

The domains also had to meet several measurement requirements. Domains should exhibit statistical independence which means that in most populations of interest, the levels of health on one domain are unlikely to be correlated with levels of health on another. While achieving complete statistical independence is not a feasible goal, the goal remains to minimize dependence and to focus on a set of domains that provides the most information on the population's health. Structural independence between domains is also important and is distinct from statistical independence; it applies when an individual's level on one domain in no way pre-determines his or her level on any other domain. Levels of functioning in each domain should also be graded in severity in an ordered fashion; and functioning should be measured within, on or near the skin. The latter criterion means that the domain refers to something that is intrinsic to the individual (equivalent to "capacity" in the International Classification of Functioning, Disability and Health). In other words, it is independent (to the extent possible) of external factors such as the physical or social environment. While aids like eyeglasses or pain medication can be considered to be essentially "within the skin", wheelchairs and wheelchair accessible public transport are not. This criterion generally implies two of the core ICF concepts – specifically the focus on "functioning and disability" and not "contextual factors", and the focus on more elemental "activity" and not the more complex and typically socially mediated "participation". This criterion also greatly enhances the prospects for another

criterion, cross-cultural comparability. Finally, functioning should be measured in a way that does not preclude preference measurement and the construction of summary measures of health.

The WG and BI questions sets have been extensively tested, both cognitively and through field testing, in many countries across the world.

6. Conclusions

The question set developed by the WG and BI can be used to obtain internationally comparable measures of functional status and, along with other information obtained on national surveys conducted by statistical agencies, can be used to address issues of health related quality of life.

References

Details of the WG organization, history and accomplishments are available online at:
http://www.cdc.gov/nchs/washington_group.htm