Health and Quality of Life Outcomes



Open Access Review

The Centers for Disease Control and Prevention's Healthy Days Measures - Population tracking of perceived physical and mental health over time

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Published: 02 September 2003

This article is available from: http://www.hqlo.com/content/1/1/37

Received: 28 July 2003 Accepted: 02 September 2003 Health and Quality of Life Outcomes 2003, 1:37

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Abstract

To promote the health and quality of life of United States residents, the U.S. Department of Health and Human Services' Centers for Disease Control and Prevention (CDC) - with 54 state and territorial health agencies - has supported population surveillance of health-related quality of life (HRQOL). HRQOL was defined as "perceived physical and mental health over time." Commonlyused measures of health status and activity limitation were identified and a set of "Healthy Days" HRQOL measures was developed and validated. A core set of these measures (the CDC HRQOL-4) asks about self-rated general health and the number of recent days when a person was physically unhealthy, mentally unhealthy, or limited in usual activities. A summary measure combines physically and mentally unhealthy days. From 1993 to 2001, more than 1.2 million adults responded to the CDC HRQOL-4 in each state-based Behavioral Risk Factor Surveillance System (BRFSS) telephone interview. More than one fifth of all BRFSS respondents also responded to a set of related questions - including five items that assess the presence, main cause and duration of a current activity limitation, and the need for activity-related personal and routine care; as well as five items that ask about recent days of pain, depression, anxiety, sleeplessness, and vitality.

The Healthy Days surveillance data are particularly useful for finding unmet health needs, identifying disparities among demographic and socioeconomic subpopulations, characterizing the symptom burden of disabilities and chronic diseases, and tracking population patterns and trends. The full set of 14 Healthy Days Measures (the CDC HRQOL-14) has shown good measurement properties in several populations, languages, and settings. The brief standard CDC HRQOL-4 is now often used in surveys, surveillance systems, prevention research, and population health report cards.

Background and Development of the Measures Why assess Health-Related Quality of Life in populations?

With the epidemiologic transition in the leading causes of death from infectious disease and acute illness to chronic disease and degenerative illness, health-related quality of life (HRQOL) is now recognized as an important meas-

urement in public health as well as in clinical research and some other health-related disciplines [1-3]. HRQOL measures capture the key concepts of health identified by the World Health Organization (WHO) in 1948, "a state of complete physical, mental, and social well-being - not merely the absence of disease or infirmity." A population

health approach addresses the physical and mental health of large numbers of people, involves a definable population, and incorporates social determinants of health along with individual determinants. Continuous monitoring of population HRQOL gives public health agencies current health data they need to assess, protect, and promote population health. Tracking population HRQOL over time also helps identify health disparities, evaluate progress on achieving broad health goals, and inform healthy public policy. These applications complement those of clinical research and practice, where HRQOL assessment measures patient-centered outcomes from medical, surgical, and behavioral interventions.

What are the Healthy Days Measures?

The Healthy Days Measures are a brief set of survey-based questions designed to assess HRQOL – defined as "perceived physical and mental health over time" [4,5]. They include a core set of four questions:

- 1. Would you say that in general your health is; Excellent, Very good, Good, Fair or Poor?
- 2. Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?
- 3. Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?
- 4. During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?

An "unhealthy days" summary measure based on the second and third questions estimates the overall number of recent days when physical or mental health was not good. The complement of this summary measure is "healthy days", the number of days estimated to be healthy. Other, more specific HRQOL and functional status measures include five questions about the existence, main cause and duration of any current activity limitation and the need for help with activity-related personal and routine care, and five symptom-related Healthy Days questions about the number of recent days of pain, depression, anxiety, sleeplessness, and vitality. Together these core and more specific measures are referred to as the Healthy Days Measures or the CDC HRQOL-14 (see measures at: http://www.cdc.gov/hrqol/methods.htm).

How were the Healthy Days Measures developed?

In 1988, an aging studies unit was established as part of the CDC's Division of Adult and Community Health in its National Center for Chronic Disease Prevention and Health Promotion. An early priority of the unit was to develop and validate HRQOL measures for older adult populations. This effort gained additional impetus from the then new CDC mission statement: "To promote health and quality of life by preventing and controlling disease, injury, and disability." With help from experts in HRQOL measurement and population health surveillance, the CDC developed their HRQOL-14 measures [4,5].

Developing a brief, yet valid, set of measures was a key design goal. Another key goal was to identify (via expert consensus) the most important underlying concepts measured by lengthier, validated, generic HRQOL measures such as the Medical Outcomes Survey Short Form 36 (SF-36) and the Quality of Well-Being Scale (QWB), as well as the concept of years of healthy life (YHL) embedded in national 10-year health promotion goals. Other important design goals were compatibility with the WHO concept of health, especially the intent to explicitly include the concept of perceived mental health, and the inclusion of continuous measures and a specific reference time period (the previous 30 days) to provide statistical options and compatibility with key economic concepts, such as cost utility and human capital. The initial program emphasis was on demonstrating the feasibility of these measures in state-level population health surveillance via the Behavioral Risk Factor Surveillance System (BRFSS).

How were the Healthy Days Measures validated?

In the mid-1990s, the CDC aging studies program and two other interested CDC public health programs (i.e., Disability Prevention Program, Office of Women's Health) supported several studies to determine the validity of the Healthy Days Measures in various populations [5,6]. Analyses of responses from the U.S. noninstitutionalized adult population indicated that the CDC HRQOL-14 measures had good construct validity [4,7]. Studies in Hamilton, Ontario, Canada [8]; Sweden [9]; and Puerto Rico [10] have also established the construct validity of the CDC HRQOL-4 for use in general noninstitutionalized adult populations.

In a general statewide population (with a sample enriched for persons who self-reported common chronic physical health conditions or who were assessed as having probable depression based on a 3-item screening measure derived from a validated depression instrument), the single global measures in the CDC HRQOL-14 had acceptable criterion validity with multiple-item SF-36 scales in a manner consistent with expectations [11]. The CDC

HRQOL-14 also could validly distinguish between known disease groups. In community residents and institutionalized persons with known disabilities, the CDC HRQOL-14 also had acceptable criterion validity with the SF-36 [12]. One study found the measure of activity limitation days to be a valid global indicator of disability in general adult populations [13]. And in a direct comparison with several rheumatic condition-specific health status and psychological measures, the CDC HRQOL-4 measures validly distinguished groups of patients with fibromyalgia, osteoarthritis, and rheumatoid arthritis [14]. In older Canadian patients, a self-administered version of the CDC HRQOL-4 measures had good construct and concurrent validity based on reported health conditions, physical exams, and other measures [15].

The CDC HRQOL-4 measures had acceptable test-retest reliability and strong internal validity in a representative telephone sample of Missouri adults, but they were less reliable among older adults [16]. And in a large prospective study, each of the CDC HRQOL-4 measures predicted 1-month and 12-month mortality, hospitalization, and non-hospital utilization of health care [17].

In cognitive studies, elderly persons and those trying to respond with a counting strategy (recalling specific days) rather than an estimation strategy (guessing the approximate number of days) had more difficulty responding to the HRQOL measures[18]. In a Norwegian-language mixed-mode (telephone versus mailed survey) study of a national sample of working-age adults, mode effects were found for the measures on mental health, depression, and anxiety with worse health reported for the mail mode [19]. One unpublished English-language study of mode effects - part of a broader HRQOL methods study among a population of persons with known disabilities [12] found that in-person subjects reported less current and recent activity limitation than did telephone respondents (E Andresen, personal communication, 2003). In another study, persons with disabilities disagreed with their proxies' responses on several of the more subjective CDC HRQOL-14 measures [20].

The use of the CDC HRQOL-14 by itself in clinical settings has not yet been adequately studied. The CDC HRQOL-4, however, can be a useful complement to longer generic clinical measures of HRQOL, such as the SF-36 or the SF-12 (version 2), and its low respondent burden and population comparability are substantial advantages in some clinical settings and circumstances [14,15].

Administration of the Measures What areas of health do they measure?

The CDC HRQOL-4 core questions include one health status measure (self-rated health) and three HRQOL

measures (recent physical health, recent mental health, and recent activity limitation). The CDC HRQOL-14 questions include the CDC HRQOL-4 core measures, five activity limitation questions, and five additional Healthy Days HRQOL questions that measure recent symptoms of pain, depression, anxiety, sleeplessness, and vitality. The activity limitation questions measure the presence of any self-reported current limitation and, if present, its main cause and duration, as well as whether the help of another person is needed to perform basic activities of daily living (ADLs) or other routine instrumental activities of daily living (IADLs). Like the self-rated health measure, these latter measures do not individually fit the CDC definition of HRQOL, because they lack a time dimension - a key component of this definition. However, they are included in the CDC HRQOL-14, in part, because they are typically strongly correlated with the Healthy Days Measures and this helps to establish the construct validity of all of the measures in each population where they are used [5].

How are the Healthy Days Measures administered?

To date the Healthy Days Measures have most commonly been used as part of telephone surveys in the BRFSS, a continuous state-based surveillance system in all 50 states, the District of Columbia, Puerto Rico, the Virgin Islands, and Guam [21]. The BRFSS obtains information on health status, health risk behaviors, clinical preventive health practices, and health care access from a representative sample of non-institutionalized adults, aged 18 years or older in each state or other jurisdiction. The CDC HRQOL-4 measures are typically asked as the first four questions of the survey each month of the year. This format allows the study of seasonal patterns as well as of the population effects of major climatic and social events.

In 2000, the U.S. National Health and Nutrition Examination Survey (NHANES) began asking the core Healthy Days Measures of all examinees aged 12 years and older, thereby providing additional national surveillance, validation, and research opportunities. Numerous other national, state/provincial, and community surveys have also administered the Healthy Days Measures and have published their findings on the Internet or in the scientific literature.

Most survey subjects for the Healthy Days Measures have been adults aged 18 years and older, although adolescents aged 12–17 years have been asked the CDC HRQOL-4 questions in one set of school-based surveys [22]. The questions have most often been administered in telephone format, but some surveys have used in-person interviews or subject-administered questionnaires via mail or in health care settings (see examples on the CDC HRQOL Web site at http://www.cdc.gov/hrqol/).

How long does it take to complete the Healthy Days Measures?

Based on average times recorded by two survey groups, the CDC HRQOL-4 measures take about 1.0 minutes to administer via telephone or computer-assisted personal interview. It takes about 0.2 minutes less for those who report no physically or mentally unhealthy days, because they are not asked the recent activity limitation days question. The five additional Healthy Days "symptoms" questions take another 1.0 minutes. Although the set of five activity limitation questions take another 1.3 minutes to complete, persons without a current activity limitation (about 80% of noninstitutionalized U.S. adults) are asked only the first one of these questions, which takes about 0.2 minutes to answer.

Scoring and Analysis How are the Healthy Days Measures scored?

Unlike other health profiles, the CDC HRQOL-14 does not use a summary score or subscale scores based on psychometrically derived or preference-based weights. Because most of the CDC HRQOL-14 measures were designed to be individual global indicators of HRQOL and activity limitation, such scores were avoided to keep the measures transparent to policy makers. The only scoring used is with a summary "unhealthy days" index, computed by adding a respondent's physically and mentally unhealthy days, with a maximum of 30 for one person. For surveillance purposes and most other applications, the underlying assumption that physically and mentally unhealthy days overlap minimally is preferred to the assumptions of more overlap that are part of other methods [5].

A complementary form of the "unhealthy days" index is the "healthy days" index, calculated by subtracting a respondent's unhealthy days from 30 days. This index estimates the minimum number of recent days when a respondent had good or better health and provides a positive measure of HRQOL that some communities prefer to use. Dividing this index by 30 days (after making additional adjustments for potential overlap of physically and mentally unhealthy days) provides a series of health weights for particular demographic segments that can potentially be used to calculate health expectancy or quality-adjusted life-year (QALY) measures for a population (Moriarty DG, Zack MM, Gizlice Z, Klementiev AA. The use of Healthy Days Measures in health expectancy estimates. Unpublished presentation at the International Network on Health Expectancy (REVES) in Guadalajara, Mexico, 5-7 May 2003 - http://www.prw.le.ac.uk/reves/).

For comparing populations and examining patterns and trends, population means are generally used for the "days" measures. For some analyses, derived measures

based on a cut point are used; for example, "frequent mental distress (FMD)" is defined as 14 or more mentally unhealthy days reported by a respondent [23]. Such derived measures are used to identify population subsets that experience more persistent HRQOL deficits. Additional discussion of scoring is available in the Methods and Measures section of the CDC HRQOL Web site http://www.cdc.gov/hrqol/.

What population HRQOL data are available?

Annual prevalence estimates (means with 95% confidence intervals) for the recent number of days when adults were physically unhealthy, mentally unhealthy, had an activity limitation, or were unhealthy overall (physically or mentally) are available on the CDC HRQOL Web site for each state and nationwide from 1993 through 2001. The percentage of adults with fair or poor health and of adults with 14 or more days on the three core Healthy Days Measures are also included.

Electronic copies of anonymous BRFSS survey data – including CDC HRQOL-4 data for all states (and expanded CDC HRQOL-14 data for some states) – are in the public domain. Data files and documentation for each year can be downloaded from the BRFSS Web site at http://www.cdc.gov/brfss/. CDC HRQOL-4 data from NHANES are expected to be available in the public domain in the latter part of 2004.

Is there automated administration or scoring software?

Sample SAS, SPSS, and SUDAAN syntax for computing the Healthy Days summary measure is available in the Methods and Measures section of the CDC HRQOL Web site, http://www.cdc.gov/hrqol/.

How are the Healthy Days Measures scores interpreted?

Typically, Healthy Days data are aggregated at the population level using means and percentages to interpret the public health significance of group differences over time and between and among subgroups. Comparisons usually include tables or graphs that show group differences in HRQOL. The Journal of the American Medical Association provides a brief fact sheet designed to help clinicians discuss HRQOL issues with their patients, which includes a mention of the Healthy Days Measures [24].

Are the Healthy Days Measures responsive to change?

The "number of days in the past 30 days" response format of the Healthy Days Measures makes them particularly well suited to respond to short-term changes in HRQOL. On a population level, the aggregated core Healthy Days data are responsive to (i) trends (see prevalence data on the CDC HRQOL Web site at http://www.cdc.gov/hrqol/), (ii) seasonal patterns [25], and (iii) the effect of a major disaster (unpublished analysis by authors). Very limited

information from longitudinal studies and only a little pre- and post-intervention data is currently available to evaluate the responsiveness to change of these measures at the level of the individual person, although several such studies are in progress. In an older low-income population of African American men, changes in the physically unhealthy days measure at follow-up were associated with reported changes in medical utilization [26]. Cognitive studies suggest that the measures are responsive to change, because respondents typically attribute their estimates of impaired days to specific episodes of symptoms, injuries, or illnesses [18].

What is a meaningful change for the Healthy Days Measures scores?

By design, a change of one day in any of the Healthy Days Measures is a meaningful change from the perspective of an individual respondent. Implicitly, a change of 2 days is twice as meaningful as a 1-day change (i.e., each number is evaluated by its absolute size). This cardinal property of the Healthy Days Measures is a substantial advantage in interpreting changes in group scores. In addition, any statistically significant difference in population Healthy Days Measures can be interpreted as a meaningful change, but how substantial the change may be more easily comprehended by calculating the total days of change on a population level. For example, a mean improvement of 0.01 recent healthy days in a sample that represents a population of one million persons represents a 30-day gain of $1,000,000 \times 0.01 = 10,000$ more healthy days for that population.

Because the Healthy Days Measures were designed to assess different levels of HRQOL, a 1-day change in one measure is not necessarily as personally or socially meaningful as a 1-day change in another measure. For example, the measure of activity limitation days is designed to measure HRQOL at comparatively low levels of health, while the vitality measure ("very healthy and full of energy") is designed to measure HRQOL at a higher level of health [4,5]. The measures of physically and mentally unhealthy days (and their summary measure) were each designed to assess HRQOL at an intermediate level of health, somewhere between the activity limitation and vitality days measures. Mentally unhealthy days were designed to have parity with physically unhealthy days on the assumption that it made no difference in HRQOL whether physical or mental causes were the reason for an unhealthy day.

Applications of the Measures In which populations have the Healthy Days Measures been used?

The Healthy Days Measures have been used extensively with noninstitutionalized adults. They have also been

used in institutional settings among persons with known disabilities [12] and adolescents [22]. Other study or survey populations have included low-income elders enrolled in a prescription assistance program [17], older patients [15], arthritis patients [14], persons with severe hearing impairments [27], HIV/AIDS survivors [5], persons with bleeding disorders (CDC study in progress), and American Indians [28].

Have the Healthy Days Measures been used in assessments of individual patients?

The use of Healthy Days Measures alone or in tandem with a disease-specific measure in clinical settings or in assessing individual patients has not yet been adequately studied, although in a few published studies the measures have been found to valuable [14,17]. The Foundation for Accountability (FACCT), a nonprofit organization that recommends standard health outcome measures, has developed and tested various standard generic and disease-specific measures that include one or more of the Healthy Days Measures. The generic FACCT measures include ones for general health, caregiver, and end-of-life applications, and the FACCT|ONE disease-specific measures include ones for diabetes, heart care, and asthma available at (FACCT Quality Measures www.facct.org/facct/site/facct/facct/Measures).

The CDC HRQOL-4 can complement longer generic clinical measures of HRQOL, such as the SF-36 or the SF-12 (version 2) in settings where comparability with public domain values are useful, such as in the disease-specific FACCT|ONE measures and in the National Committee for Quality Assurance (NCQA) 2003 Medicare Health Outcome Survey (HOS) (available at http://www.cms.hhs.gov/surveys/hos/download/HOS 2003 Survey.pdf).

What are the applications of the Healthy Days Measures?

The Healthy Days Measures are identified in Healthy People 2010 (the widely used 10-year U.S. agenda for health promotion and disease prevention) as one means of tracking its overall progress [29]. Other federal, state, and local health programs have used these measures and data in such areas as population health assessment and planning [8,9,30–32]; identifying unmet health needs and disparities [33–39]; and assessing the burden of chronic health conditions, such as disability [7,13,40], arthritis [14,41,42], epilepsy [43], obesity [44,45], asthma [46], depression [47], stroke [48], diabetes [49,50], and violence [22,51].

The measures and data are also being used in several national and state-based health performance measures or "report cards", including the Department of Health and Human Services' "Women's Health USA 2002" at http://

mchb.hrsa.gov/data/women.htm, the National Women's Law Center's "Making the Grade on Women's Health: A National and State-by-State Report Card" at http://www.nwlc.org/display.cfm?section=health, the United Health Foundation "State Health Rankings" at http://www.unitedhealthfoundation.org/shr2002/, and the Kaiser Family Foundation's "State Health Facts Online" at http://www.statehealthfacts.kff.org/.

Healthy Days Measures have also been recommended or adopted for use by various U.S. standard-setting groups, including the FACCT, NCQA, and the U.S. Council of State and Territorial Epidemiologists. More recently, the Healthy Days data have been used by some state health departments in summary measures of health to derive the health weights for state health expectancy estimates [52]. See the CDC HRQOL Website for links and references to other applications at http://www.cdc.gov/hrqol/).

What are the main benefits of the Healthy Days Measures?

The Healthy Days Measures have continuous, cardinal, and bounded (range = 0 to 30) mathematical properties that permit a wide range of options in the choice of statistical analysis methods. The core CDC HRQOL-4 measures are the briefest validated set of generic HRQOL measures; are based on a clear and explicit definition of HRQOL; and have a transparent summary measure that is understandable and generally accepted by policymakers in health and related disciplines. The measures provide a cost-effective and less burdensome alternative or complement to longer HRQOL measures. The large public domain resource of CDC HRQOL-4 surveillance data provides comparable population reference data that can be useful in interpreting seasonal, geographic, and temporal patterns - including those of an economic and social nature [53,54]. Finally, due to their validity and brevity and to the availability of extensive population data, the CDC HROOL-4 measures have shown the potential to become a standard in public health, thereby allowing cross-comparisons with other studies that include these measures.

Getting and Using the Measures Which translations are available?

The CDC HRQOL-14 measures were developed originally for use in the U.S. English-speaking population. The concepts assessed by the Healthy Days Measures are believed to be universal, however, and are therefore capable of being adapted for use in other cultures and languages [55]. To reach adults with limited English proficiency, several states have translated their BRFSS surveys into other languages, including Spanish, Vietnamese, Chinese (Mandarin and Cantonese dialects), Korean, Khmer (Cambodian), Haitian Creole, Portuguese, and Tagalog. The most frequently used translation, Spanish, is used with most

BRFSS respondents in Puerto Rico and in several U.S. states with a sizable percentage of Spanish-speaking adults. Additionally, individual researchers have translated some or all of the measures into Norwegian, Dutch, Punjabi, Romanian, and Swedish. Having small sample sizes to date from most U.S. ethnic groups has limited the ability to conduct validity studies of the translated measures.

Can others use the Healthy Days Measures?

Permission is not needed to use the Healthy Days Measures (CDC HRQOL-4 or HRQOL-14), nor is there any charge for using them. The measures have been developed and validated by the CDC and its partners to encourage their widespread use in the public domain. For maximum comparability with existing published research and public domain data, however, users are asked to retain the same wording unless there is a compelling reason for doing otherwise.

Who may I contact to obtain a copy of Healthy Days Measures?

Copies of the measures in English and Spanish are available in the Methods and Measures section of the CDC HRQOL Web site at http://www.cdc.gov/hrqol/. English and Spanish copies of these and other disability, health behavior, and demographic questions used in the BRFSS are available in the Questionnaires section of the BRFSS Web site at http://www.cdc.gov/brfss/.

How can we obtain more information about the Healthy Days Measures?

An overview of the origins and accomplishments of the CDC HRQOL program can be found on the CDC Web site at http://www.cdc.gov/hrqol/. The Web site describes national and state HRQOL surveillance and research activities based on the Healthy Days Measures and provides links to key national and international HRQOL resources. Electronic copies of the CDC HRQOL-14 questions in English and Spanish, MMWR articles, and the program's 40-page technical report "Measuring Healthy Days: Population Assessment of Health-Related Quality of Life" are also available on this Web site [5]. Internet links to several examples of how Healthy Days data have been used by states and communities are included.

For additional information, contact: Healthy Days Measures (MS K-51), Division of Adult and Community Health, National Center for Chronic Disease, Prevention and Health Promotion, Centers for Disease Control and Prevention, 4770 Buford Hwy NE, Atlanta, GA 30341, (770) 488–5464.

How can we obtain scientific support during our study?

Information about key literature references, reports, and training materials can be obtained from the CDC HRQOL program staff (address above). Depending on the relevance of the planned research to the research interests of each program, a limited amount of technical assistance might also be available from this office or from various national, state, and local programs and organizations who use these measures or data.

Future Directions and Conclusions

To extend the policy and research value of the CDC HRQOL-14 measures and data, efforts will be made to clarify key issues associated with the integration of clinical, economic, and population perspectives on HRQOL. Potential applications and adaptations of the Healthy Days Measures in other settings and populations – such as hospitals, assisted living facilities, prisons, skilled nursing facilities, children, and immigrants – will be investigated. Methodological issues of memory and cognition; crossmeasure comparison and scaling; mode, order, and interviewer effects; response-shift adaptations to health and life changes; responsiveness to change; cross-cultural validity; and the dynamic nature of physical and social environmental influences on population HRQOL will also be investigated.

The Healthy Days Measures (CDC HRQOL-4 and CDC HRQOL-14) are valid and useful measures of perceived physical and mental health in diverse groups and in several countries. The CDC HRQOL-4 is a brief standard set that is easily added to health surveys and studies to provide comparability with ongoing population HRQOL surveillance.

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