
Measuring Health-Related Quality of Life for Public Health Surveillance

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Synopsis

In public health research and practice, quality of life is increasingly acknowledged as a valid and appropriate indicator of service need and intervention outcomes. Health-related quality of life measures, including objective and subjective assessments of health, are particularly useful for evaluating efforts in the prevention of disabling chronic diseases. Such data can inform health policy, planning, and practice. Mechanisms for routinely monitoring quality of life of populations at the State and local levels are currently lacking, however.

This article discusses the rationale for and concepts measured by four quality of life questions developed for the 1993 Behavioral Risk Factor Surveillance System, a State-based telephone surveillance system.

To encourage quality of life surveillance by States, the Centers for Disease Control and Prevention's National Center for Chronic Disease Prevention and Health Promotion held two related workshops, one in December 1991 and the other in June 1992. The workshops convened experts in quality of life and functional status measurement and resulted in the formulation of items for the Behavioral Risk Factor Surveillance System on self-perceived health, recent physical and mental health, and recent limitation in usual activities.

The criteria, including feasibility and generalizability, considered by the Centers for Disease Control and Prevention and the workshop participants in the selection and development of these items are discussed. A model that conceptualizes the relationship of quality of life domains measured by the four survey items is presented and validated with preliminary data from the 1993 Behavioral Risk Factor Surveillance System. Finally, how States can use these measures to track progress towards the Year 2000 goal of improving quality of life is discussed.

THE NATION'S GOAL—to increase the span of healthy life for Americans—put forward in “Healthy People 2000” includes not only prevention of premature death, disability, and disease, but also enhancement of the quality of life (1).

The term “quality of life” is popularly understood to encompass a wide range of personal and social concepts, some of which (such as employment, crime, education, and leisure) are not normally addressed by public health professionals. Within the public health context, the term corresponds with the 1947 World Health Organization's definition of health that includes optimal physical, mental, and social functioning (2,3). Thus, health-related quality of life (HR-

QOL) is multidimensional and is composed of, at a minimum, physical functioning, psychological well-being, social and role functioning, and health perceptions (4,5).

HRQOL increasingly has been acknowledged as a valid health indicator with the realization that biomedically oriented measures of a population's well-being, such as mortality and morbidity rates, provide only a partial picture of public health needs and prevention outcomes. Consistent with the scope of public health, HRQOL measures are needed that adequately reflect the prevalence of dysfunction and disability associated with chronic as well as infectious diseases, injuries, and other health problems

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(6,7). HRQOL data collected from the general population can serve to identify and estimate the level of needs of target groups for interventions and to provide a basis for evaluating the cost-benefits and cost-effectiveness of health care programs (2,8,9).

Some HRQOL data are collected annually through the National Health Interview Survey conducted by the National Center for Health Statistics (NCHS) of the Centers for Disease Control and Prevention (CDC). Items on physical and mental health impairments, functional status, and self-perceived health are included in this and other national surveys, such as the National Health and Nutrition Examination Survey. Mechanisms for collecting HRQOL data routinely at the State and local levels, however, have yet to be developed, despite the utility of this information for public health practice and policy formulation (10). The necessity for surveillance of HRQOL at several administrative levels was emphasized in the Institute of Medicine's 1991 report, "Disability in America" (11):

Surveillance methods do not permit us to track the series of changes in health status, functional capacity, and quality of life that people with chronic disease are likely to experience. National and State systems of surveillance of disabling conditions should be refined so that functional limitation and disability resulting from chronic diseases and mental disorders can be measured, and changes in the prevalence of these conditions can be monitored over time.

Regional and local surveillance of HRQOL has been successfully accomplished in the Netherlands, for example, as part of the Healthy Cities Project, and surveillance was initiated in Canada during the 1990 Ontario Health Survey (12-13). In the United States, regional and local HRQOL surveillance would allow

States to monitor their progress toward achieving the Year 2000 goal of enhancing HRQOL.

State and Local HRQOL Surveillance

To stimulate the development of surveillance mechanisms for tracking HRQOL or health status data at the State and local levels and to encourage the use of these data for public health planning, CDC's National Center for Chronic Disease Prevention and Health Promotion convened experts in quality of life measurement, surveillance methods, and State and local public health policy in December 1991. They developed a working definition for HRQOL and identified feasible methods for HRQOL surveillance at the State and community levels. At a second consultation in June 1992, concepts, measures, and mechanisms were refined. The background and content of these expert discussions are detailed in reports of the proceedings (14,15).

These consultations resulted in recommendations for questions to be included in the 1993 Behavioral Risk Factor Surveillance System (BRFSS), which uses telephone surveys to monitor health risk behaviors among adults. In 1993, a total of 102,263 respondents in 49 States participated in the surveys. They were asked about personal behaviors such as weight control, alcohol consumption, and smoking that result in the most significant health and safety problems (16). A fixed set of core questions is asked each year, and a rotating core of questions is asked during specified years. The survey data provide State-level prevalence information that can be used by national, State, and, sometimes, local agencies to direct public health program priorities. The BRFSS was identified by both HRQOL working groups as a viable existing surveillance mechanism for gathering State-based HRQOL data. The consultants also believed that the high visibility of this survey would expeditiously promote interest in quality of life as a public health outcome.

Item Development and Rationale

In discussing the development of HRQOL indicators for the BRFSS, the working groups considered a wide range of issues of feasibility and generalizability, including the following:

- *Public health policy focus*—HRQOL measures must be applicable to all segments of the population and to all public health programs so that they have value for resource allocation decisions.
- *Public and expert perspectives*—HRQOL measures

must make sense to the public (since individual lives are to be maintained or improved) and to experts (who must understand qualitative concepts and know how to measure them).

- *Objectivity versus subjectivity*—For scientific credibility, HRQOL measures must include observable, quantifiable phenomena (functional impairments, for example), as well as subjective, qualitative information (such as perceived health status).
- *Sensitivity to population variability*—HRQOL measures should be sensitive enough to detect valid differences among individuals and subpopulations.
- *Generic versus condition-specific measures*—Although specialized HRQOL instruments must be designed for population subgroups (such as persons with diabetes or quadriplegia), the initial emphasis should be on the development of generic measures.
- *Cultural specificity*—Efforts should be made to ensure that generic HRQOL domains and their relative importance reflect the concepts and values of all population subgroups.
- *Personal versus societal*—Many persons, when asked to describe quality of life, identify community features as aspects of quality of life, but these areas (like public safety and recreation) have sometimes fallen outside of the purview of public health. Rather, the initial focus has been on individual aspects (anxiety and physical activity, for example), but HRQOL experts recognize the importance of community-based measures.
- *Time orientation*—Because a person's actual and perceived health can change over a few hours, a sufficiently long reference period is needed for measuring HRQOL.
- *Reliability and validity*—HRQOL criteria must identify widely accepted health characteristics that can be accurately and consistently measured.
- *Practicality*—HRQOL must be measurable by using limited community resources.

The working groups recommended global HRQOL questions, as well as questions about physical, cognitive, emotional, and social functioning and performance of activities of daily living. Many commonly used HRQOL instruments, such as the Medical Outcomes Study 36-Item Short-Form Health Survey and the Quality of Well-Being Scale, were believed to be too long or complex for widespread use, and instead, single questions were synthesized for key conceptual domains. Four items were then chosen for use in the 1993 BRFSS (see box).

In addition, an expanded set of questions that will include several other suggested HRQOL domains is being developed by CDC's Center for Chronic

Questions on Health-Related Quality of Life 1993 Behavioral Risk Factor Surveillance System

1. *Self-Perceived Health*

Would you say that in general your health is:

- Excellent
- Very good
- Good
- Fair, or
- Poor?

2. *Recent Physical Health*

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?

_____ days

3. *Recent Mental Health*

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?

_____ days

4. *Recent Activity Limitation*

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?

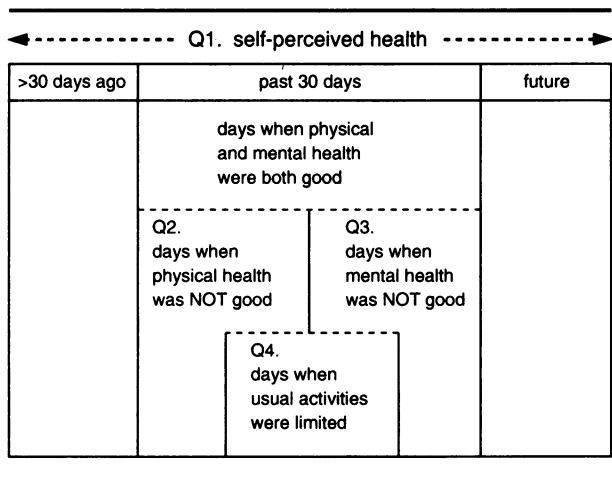
_____ days

Disease Prevention and Health Promotion for optional use by States. An NCHS-developed BRFSS module, which uses questions comparable to those in the National Health Interview Survey is currently available for collecting data on role limitations (15). This NCHS module has been developed specifically to meet data needs for measuring progress toward increasing the healthy lifespan, the first goal in "Healthy People 2000."

The HRQOL items for the 1993 BRFSS measure self-perceived health, recent physical health, recent mental health, and recent activity limitation. Self-perceived health, a commonly used subjective indicator of health status, is strongly associated with a person's objective physical and mental health status (17-19) and is an independent predictor of mortality (20,21); these relationships also persist across age and cultural groups (22-24).

In addition, self-perceived health is a good proxy indicator for chronic disease conditions that have a heavy burden of symptoms and result in a poor prognosis (21), and it has been shown to be sensitive to co-morbidity, or the presence of multiple disease

Conceptual relationship of health-related quality of life questions



conditions (25). Poor self-perceived health has also been correlated with health risk behaviors, including heavy alcohol consumption, smoking, and sedentary lifestyle (26–29), and it is associated with demographic and social factors such as sex, socioeconomic status, and lack of access to health care (30–32).

The questions concerning recent physical and mental health are complementary items that measure the respondent’s perceived level of physical and psychological dysfunction experienced during the previous 30 days. Separate questions about physical and mental health are justified because general health status indicators confound the two and fail to distinguish periods when a person may be experiencing excellent physical health but poor mental health (33). Findings from the Medical Outcomes Study, for example, confirmed the validity of scales measuring independent physical and mental health constructs and their ability to distinguish between patients with clinically identified physical or psychiatric conditions (34). Likewise, the National Co-Morbidity Study, a nationally representative study of mental health, validated that respondents perceive mental health as distinct from physical health and that respondents who report poor mental health often have diagnosable mental disorders, according to a 1993 personal communication from Ronald Kessler of the University of Michigan Institute of Social Research.

The National Institute of Mental Health’s Epidemiologic Catchment Area (ECA) study has also indicated the utility of measuring both concepts; findings demonstrate that mental and not physical health problems constitute the main reasons for early withdrawal of older workers from the labor force (33). Other evidence indicates that the state of both physical and mental health contributes to cognitive

decline among older adults and suggests that interventions need to address both aspects of health (35). Mental health status also influences mortality (36), and mental health symptoms are a partially independent predictor of health services use (37).

The recent state of physical and mental health clarifies the nature of the disability reported by the fourth HRQOL measure, recent activity limitation. This question measures a person’s perceived functional incapacity over the previous month because of either somatic or psychological problems. This measure, which is similar to other commonly used disability constructs (such as the school-loss days, work-loss days, bed-disability days, and other restricted activity days measured in the NHIS), encompasses interference with activities and functions from acute or chronic health problems. The validity of self-reported disability is considered good; disruption in normal functioning is generally self-perceived as significant (38), and self-reported disability days are associated with objective measures of health dysfunction (39). Respondents who have permanently altered their usual activities and recovery expectations because of long-term disabling conditions, however, may not identify any recent functional limitations from such conditions.

The recent activity limitation measure indicates the current level of incapacity of the population, which can be useful for policy setting and planning purposes and for assessing the economic losses associated with dysfunction. Smoking, excessive alcohol consumption, overweight, inadequate seatbelt use, and elevated cholesterol, which are measured by the BRFSS, are among the best predictors of increased disability (40–42). These health risk data can be used to highlight the State-specific burden of associated disability and to suggest the potential cost benefits of interventions targeted at health risk behaviors (43).

Conceptual Model for the BRFSS QOL Items

The model in the chart shows how the four HRQOL questions are conceptually related. According to the model, respondents’ answers to the self-perceived health question partially reflect their overall assessment of their health during the recent past, with some consideration of what their health has been and is likely to be in the future (44). Self-perceived health reflects recent physical health, may also reflect recent mental health (45), and may include some concern over anticipated future physical health. Most people equate “health in general” with “physical health,” although some people have a broader definition of health. Qualitative studies have shown, for example,

Table 1. Recent physical health (days grouped) by self-perceived health status, preliminary data for 2,927 persons in the 1993 Behavioral Risk Factor Surveillance System

Number of days "not good"	Excellent-very good		Good		Fair-poor		Total	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent
None	1,186	65.1	498	27.3	138	7.6	1,822	100
1-2	245	66.6	97	26.4	26	7.0	368	100
3-7	177	48.2	135	36.8	55	15.0	367	100
8 or more	69	18.6	74	20.0	227	61.4	370	100
Total	1,677		804		446		2,927	

NOTE: Chi-square = 748.6, degrees of freedom = 6, $P < 0.0001$.

Table 2. Recent mental health (days grouped) by self-perceived health status, preliminary data for 2,936 persons in the 1993 Behavioral Risk Factor Surveillance System

Number of days "not good"	Excellent-very good		Good		Fair-poor		Total	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent
None	1,204	61.0	519	26.3	249	12.6	1,972	100
1-2	181	65.1	69	24.8	28	10.1	278	100
3-7	186	55.4	97	28.9	53	15.8	336	100
8 or more	107	30.6	118	33.7	125	35.7	350	100
Total	1,678		803		455		2,936	

NOTE: Chi-square = 166.8, degrees of freedom = 6, $P < 0.0001$.

that respondents incorporate various meanings and experiences, including health behaviors, emotions, use of health services, findings of medical examinations, physical capacity, and symptoms, in their answers to a question about self-perceived health (46-47).

Questions 2, 3, and 4 in the chart and box are designed to qualify further the information provided by the first question by focusing on the quality and functional impact of perceived physical and mental health during the immediate past. A recall period of 30 days was selected because it is long enough to capture variability in health status, while still being within the limits of most persons' memories. The use of a specific time period is justified by recent research showing that respondents use different frames of reference when answering questions about their health, according to an unpublished paper by Neal Krause and Gina Jay of the University of Michigan Institute for Social Research.

Questions 2 and 3 are represented in the model as independent and mutually exclusive conditions, but in reality they may overlap for some persons. In most cases, however, people appear to classify substandard health days as primarily physical or mental but not both. These two questions had face validity when asked in tandem, and respondents frequently provided different answers to each question. Question 4

estimates the actual number of activity limitation days during the period, which are intended to represent a subset of days when physical or mental health, or both, was "not good."

The model is also useful in identifying a positive HRQOL concept, that is, days (of the past 30) when both physical and mental health were good, which can be used by health agencies to mobilize public interest. This good health days concept is at the heart of the years of healthy life measure in "Healthy People 2000," and can be understood readily by a large segment of the population.

Conceptual model validation. The validity of this conceptual model was examined using the earliest available 1993 data for the four questions from more than 2,900 BRFSS respondents in six States. Table 1 shows the prevalence of recent limitation in physical health, table 2 in mental health, and table 3 in usual activities; and they demonstrate the relationship between self-perceived health and each of these impairment measures. Thirty-eight percent of respondents reported 1 or more days when physical health was "not good" within the past month. In comparison, smaller percentages of respondents had experienced diminished psychological well-being (33 percent) or limitations in usual activities (21 percent).

Table 3. Recent activity limitation (days grouped) by self-perceived health status, preliminary data for 2,961 persons in the 1993 Behavioral Risk Factor Surveillance System

Number of days limited	Excellent-very good		Good		Fair-poor		Total	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent
None	1,441	61.3	637	27.1	272	11.6	2,350	100
1-2.....	128	63.1	52	25.6	23	11.3	203	100
3-7.....	75	37.5	85	42.5	40	20.0	200	100
8 or more.....	41	19.7	38	18.3	129	62.0	208	100
Total.....	1,685		812		464		2,961	

NOTE: Chi-square = 411.6, degrees of freedom = 6, P <0.0001.

Table 4. Pattern of responses to four health related quality of life questions by 2,848 respondents, 1993 Behavioral Risk Factor Surveillance System preliminary data

Self-perceived health in past 30 days	Excellent-very good		Good		Fair-poor	
	Number	Percent	Number	Percent	Number	Percent
All physical and mental health days good or better	911	55	360	46	98	24
One or more days physical or mental health not good:						
Activity unlimited	513	31	260	33	144	34
Activity limited.....	223	14	164	21	175	42
Total.....	1,647	100	784	100	417	100

'In addition, self-perceived health is a good proxy indicator for chronic disease conditions that have a heavy burden of symptoms and result in a poor prognosis, and it has been shown to be sensitive to co-morbidity, or the presence of multiple disease conditions.'

Tables 1-3 also show that each of these three impairment measures is significantly associated with self-rated health in the expected direction.

Table 4 provides further validation of the conceptual model by showing the co-occurrence of responses to the four questions. As expected, the proportion of all "good" health days in the past 30 declines with more severe assessments of self-perceived health, while the proportion reporting 1 or more days of impaired health increases.

The table also illustrates that the questions addressing recent health and activity limitations, although related to the self-perceived health question as expected, are also different and therefore capable

of identifying sizeable subgroups within each response grouping of self-perceived health. For example, it is notable that 45 percent of those reporting excellent or very good health still report 1 or more days of impaired health in the past 30, while 24 percent of those with fair or poor health report no impaired days. Likewise, within each category of self-perceived health, about one-third of respondents had 1 or more days of impaired health but did not report any concomitant activity limitation.

The only area where the preliminary data did not validate the model was in the case of 30 respondents who indicated experiencing 1 or more days of limited activity because of poor health but no days in the past 30 when either physical or mental health was "not good." These apparently inconsistent responses have been excluded from table 4. In order to prevent these "false positive" responses, a skip pattern was instituted in the 1994 BRFSS so that Question 4 is not asked if the answers to both Questions 2 and 3 are "none."

Summary

In summary, the four HRQOL items for the 1993 BRFSS were structured to measure the key concepts of perceived health and functional status that reflect physiologic and psychological states and predict use

of health resources (48). Findings from national and other large-scale surveys, such as the NHIS and the ECA, have demonstrated that such items can distinguish HRQOL deficits among subpopulations. Along with other questions in the BRFSS, the four newly added measures of HRQOL can be used to establish the prevalence and correlates of suboptimal health status and disability within a State's population. This information is interpretable in terms of health care needs and the health risk behaviors and sociodemographic conditions associated with these needs. The BRFSS HRQOL measures thus provide a basis for projecting the demand for health services, developing targeted intervention programs, allocating resources, and evaluating intervention effects.

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