How Should We Measure Health-Related Quality of Life in Wisconsin?

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As we monitor progress toward improving health, we need to measure health-related quality of life as well as count the number of lives saved or deaths avoided. We have chosen the measure of "unhealthy days" as our primary measure of health-related quality of life.

This is the first of a new series of brief reports that the UW Population Health Institute will publish on a periodic basis. This particular brief stems from work on the "Making Wisconsin the Healthiest State" project. With funding from the Wisconsin Partnership Fund for a Healthy Future (Blue Cross Program), our goal for this 4-year project is to identify the most effective investments for Wisconsin to become the nation's healthiest state with less health disparity. Along the way, we are developing approaches for measuring the population health of Wisconsin and comparing it to that of other states. This report summarizes our review of alternative approaches and data sources for measuring health-related quality of life.
Loss of life is clearly a necessary measure of health but it is not a sufficient measure. At the national level, Healthy People 2010 recognizes the importance of quality of life, changing the first goal from “increase the span of healthy life” for Healthy People 2000 to “increase quality and years of healthy life” for 2010. In recent years, a number of measures of health-related quality of life have been developed for application in different settings. The purpose of this issue brief is to discuss the advantages and disadvantages of potential measures for monitoring Wisconsin’s population health.

The World Health Organization asserts that summary measures of population health allow us to
1. Compare the health of one population with another
2. Monitor change in the health of populations
3. Identify and quantify health inequalities within populations
4. Provide appropriate attention to non-fatal health outcomes
5. Inform debates on priorities for health service delivery and planning
6. Inform debates on priorities for research and development
7. Improve professional training in public health
8. Analyze and compare benefits of different health interventions

Ideally, summary measures of population health combine measures of both quantity and quality of life.

Healthy People 2010 defines quality of life as “a general sense of happiness and satisfaction with our lives and environment ... (that) encompasses all aspects of life, including health, recreation, culture, rights, values, beliefs, aspirations, and the conditions that support a life containing these elements” and health-related quality of life as “a personal sense of physical and mental health and the ability to react to factors in the physical and social environments.” Measuring health-related quality of life (HRQOL) is more subjective than measuring quantity of life. Many potential measures have been developed yet no clear winner has emerged. The UnitedHealth Foundation employs a measure of limited activity as its sole quality of life measure. The National Women’s Law Center also uses this measure in its report card on women’s health along with a measure of poor mental health. The UW Population Health Institute’s own Wisconsin County Health Rankings use a global assessment of health based on percentages reporting their health as “poor” or “fair”. In its state profiles, AARP uses this same global assessment and the measure of poor mental health while United Way uses days of physical and mental health.

Other measures of health-related quality of life, focus on specific diseases or rely on more detailed, and consequently, lengthier scales to capture multiple dimensions of health. Five of these measures are currently being evaluated by the Health Measurement Research Group at the UW School of Medicine and Public Health. Most of these measures can be combined with measures of mortality to create summary measures of population health such as quality-adjusted life years (QALY) and disability-adjusted life years (DALY). Although many of these measures have been shown to be both valid and reliable, none have been regularly implemented at the population level.

Two primary sources of population data support measurement of health-related quality of life on a national, state, or local basis: the US Census and the Behavioral Risk Factor Surveillance System (BRFSS). The US census included several “disability” questions in 1990 but changed them significantly for the 2000 Census. The year 2000 questions are included in the new American Community Survey (ACS), which is underway to increase data accuracy between the decennial census; however, the ACS was only operational in three Wisconsin counties in 2004. The ACS web site reports that when the survey is in full operation, data will be available every year for areas and population groups of 65,000 or more. Small areas and population groups of 20,000 or less will require five years to accumulate a sample large enough to provide accurate estimates on par with the decennial census.

The BRFSS is conducted annually in each state and includes four HRQOL items:

Q1. Self-Rated Health: Would you say that in general your health is excellent, very good, good, fair, or poor?
Q2. Recent Physical Health: Thinking about your physical health, which includes physical illness and injury, how many days during the past 30 days was your physical health not good?
Q3. Recent Mental Health: 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?
Q4. 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?
Using these questions, three measures are created that can be reported as either negative or positive constructs:

- Percent reporting poor or fair health (or excellent, very good, or good health)
- Average number of physically and mentally unhealthy days (or healthy days) in the past month
- Average number of activity limited days (or days without activity limitations) in the past month

The BRFSS, a sample-based survey, yields small sample sizes for some counties. But, combining multiple years of data provides reasonable county-level estimates. The four HRQOL questions have been asked each year since 1993 (except 2002 when two of the four questions were put into an optional module) providing detailed trend data not available from the US Census.

As Figures 1 and 2 show, all three HRQOL measures indicate a national increase in unhealthiness over time, but not necessarily for Wisconsin. The proportion of people in Wisconsin reporting poor or fair health has stayed consistently below the national rate. The number of unhealthy days in Wisconsin shows greater fluctuation in comparison to the national average. Activity limitations show less variation both nationally and for Wisconsin.

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Assessing reliability and validity is an important step in identifying measures. For example, the test-retest reliability for all three of these measures is moderate to excellent. Many studies have shown self-rated health to be an independent predictor of mortality. It is a particularly good predictor for those who have been diagnosed and experienced symptoms of chronic disease. This measure also predicts future health care utilization. However, there is debate about how self-rated health evaluations are reached: they could be a spontaneous assessment of one’s health status or an aspect of one’s enduring self-concept of health. Furthermore, it is not clear whether “perceived health” is the same as “health-related quality of life.” Asking people how they feel about their health is different from asking them how they perceive their quality of life. Health may be poor but quality of life good and vice versa. Also, mental health may be more important to health-related quality of life whereas physical functioning more important to health status.

Although the majority of the population tends to be healthy, in order to monitor health status and determine where there are people who could most benefit from interventions to improve health, we need measures that identify and distinguish those at the lower end of the health spectrum. Unhealthy days and limited activity days offer greater distinctions among the less healthy than percent reporting poor or fair health (self-rated health). Another advantage of the limited activity and unhealthy days measures is that they are easier to understand and interpret than self-rated health. Respondents are able to provide estimates of unhealthy and activity limited days in the past 30 days (even if only very rough) with very low non-response.

The
estimates are reported in terms of number of days per month (rather than proportions of the population) so that changes are easily interpreted. For example, an average improvement of 0.1 days in a sample that represents a population of 5 million persons corresponds to a 30-day gain of 500,000 (5,000,000 x 0.1) more healthy days for that population.\footnote{Moriarty DG, Zack MM, Kobau R. The Centers for Disease Control and Prevention's Healthy Days Measures – Population tracking of perceived physical and mental health over time. Health and Quality of Life Outcomes 2003, 1:37.}

The average number of unhealthy days is significantly higher than the average number of limited activity days. This suggests that unhealthy days capture more dimensions of health-related quality of life than days of limited activity. The unhealthy days measure combines two separate questions about physical and mental aspects of health but it is less clear whether the single limited activity question similarly captures both physical and mental health.

Based on these considerations, our Institute’s “Making Wisconsin the Healthiest State” project is adopting the measure of unhealthy days to monitor health-related quality of life. Future Issue Briefs will discuss other aspects of monitoring the health of the Wisconsin population and our efforts to identify the most effective interventions for increasing the quality and length of life.

\begin{footnotesize}
\begin{enumerate}
\item Andresen EM, Catlin TK, Wyrwich KW, Jackson-Thompson J. Retest reliability of surveillance questions on health related quality of life. Journal of Epidemiology and Community Health; May 2003; 57,339-343.
\item Smith KW, Avis NE, Assman SF. Distinguishing between quality of life and health status in quality of life research: a meta-analysis. Quality of Life Research 1999, 8: 447-459.
\item Bradley C. Importance of differentiating health status from quality of life. The Lancet 2001, 357; 7-8.
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