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Designer's Corner

Time, Space, and Motion: The Unanswered Challenges in Measuring Quality of Life

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By the beginning of the 18th century the measurement of longitude was one of the major challenges facing scientists. Errors in navigation resulted in wrecked ships with lives lost, failed explorations, and wasted time at sea. European powers were limited in their ability to wage war at sea, explore, discover, and claim new lands.

The Ptolemaic views of the universe and earth, with modifications, reigned for 1,400 years, and navigators charted their voyages and explorations accordingly. Claudius Ptolemaues believed that the earth was the stationary centre of the universe, the sun, moon, and stars revolving around it. As an astronomer and mathematician he used epicycles to account for the motions of the planets, and he mapped the location of 1,020 stars. As a geographer he created a map of the world marked off in a grid of longitudes and latitudes (Chernow & Vallasi, 1993).

But the Ptolemaic system was too imprecise for use in navigation. By measuring the position of the sun, at its zenith, on the horizon, 16th-century navigators could determine their latitude if they used tables to correct for the seasonal changes in the position of the sun. Astronomers, navigators, and explorers lacked the tools for determining longitude with any reasonable degree of accuracy. Spain, France, and England offered prizes for the discovery of precise methods of measuring it. The

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major prize, established by the English House of Commons in 1714, was £20,000 to a person or persons who could measure longitude with the accuracy of half a degree at the equator, an error term of 48.3 kilometres.

Contestants in the quest for longitude determination laid claim to the prizes with competing theories and methods. The main competitors were astronomers and watchmakers. Copernicus's theory of the universe, Kepler's laws of planetary motion, Newton's theory of gravitation and mathematical discoveries, and the invention of the telescope enabled astronomers to plot the motion of the sun, moon, and planets and map the position of the stars from different locations and at different times of the year. They strived to create systems of celestial navigation and precise instruments for observing the skies that could be used to establish longitude anywhere, in any season. The Académie Royale des Sciences in France and the Royal Society in England provided support and recognition for the leading astronomers of these two countries.

Navigators determined time by the position of the sun on the horizon. A ship-board clock that could accurately give the time in home port would allow them to calculate longitude as well as latitude. John Harrison and his son William designed and produced five clocks over the course of 35 years, the later clocks keeping time at sea with the degree of accuracy required for navigation. The committee responsible for awarding the British prize was dominated by mathematicians and astronomers; they tested the clocks under questionable conditions and changed the rules of the contest. John Harrison appealed to King George III, saying that his clocks were being judged unfairly. The King agreed and the Harrisons received recognition, and the prize, in 1773. The discovery has been celebrated in a symposium, at Harvard University in 1996, and a number of books (Andrews, 1996; Sobel, 1995).

Now we have Geographical Positioning Systems linked to satellites that tell the exact latitude and longitude of a given position. They are available as hand-held devices and modules that can be installed in notebook computers and in cars.

With respect to movement across the surface of the earth, time, space, and motion are now measured precisely.

The measurement of health status and quality of life is a major challenge facing health researchers. The task is to locate individuals within life space and show how health-related events impact on their life

space. The specific quest is for measures sensitive to changes in health status/quality of life that can be attributed to health problems and interventions. Pharmaceutical companies must demonstrate, to the agencies responsible for approving drugs, the impact of their products on the quantity and quality of life. Researchers need responsive, sensible instruments for assessing the efficacy and effectiveness of interventions in randomized controlled trials and clinical studies. Providers, managers, and policy-makers need to know the cost-effectiveness of interventions and programs. Outcomes information systems are introducing measures into managed care in the United States, for purposes of both management and marketing. National organizations in the United States, such as the National Council for Quality Assurance and the Foundation of Accountability, are requiring report cards for managing care that include assessments of outcome.

The creation, adaptation, and testing of measures has been a growth industry in Europe and North America over the past 20 years, as evidenced in publications, presentations at conferences, peer-reviewed grants, industry funding, graduate theses, seminars, workshops, consulting activities, and the commercialization of specific products. International collaborations and networks of providers are being formed to create new measures. Researchers and commercial enterprises compete for their share of the academic and private markets.

One might wonder about the state of the quest for measures. There is general agreement that health should be conceptualized in terms of physical, mental, and social well-being, rather than just the absence of disease (World Health Organization, 1958). There is further agreement that quality-of-life assessments should include measures of general health status, disease-specific measures, and measures of patient preferences. Spilker's (1996) edited work covers 215 measures. Bowling (1995, 1997) and McDowell and Newell (1996) offer thoughtful guides to the use of the more established measures. An entire journal, *Quality of Life Research*, is dedicated to the subject and several major journals have published special issues on it. My bookshelves hold more than 30 volumes related to the measurement of health status and quality of life, and my holdings are by no means exhaustive.

The range of measures reflects four basic strategies in creating them: pyschometric methods, clinimetric methods, deriving utilities, and Rasch modelling. In the absence of objective criteria for health status/quality of life, researchers have adapted items from existing measures and created items to reflect theoretical domains and concepts of interest. Psychometric methods are used for reducing the number of

items, identifying the factors or facets of the underlying structure of the responses, and testing the internal consistency of the responses. The measures are correlated with pre-existing measures to establish construct validity. Clinimetricians select items based on occurrences of symptoms and problems reported as important by providers and patients, or in other studies. The items are specific to the disease and interventions of interest, and they are gauged on clinical criteria. The selection and weighting of the final items are based in part on the declarations of importance. Validity is determined by how well the measures predict clinical outcomes. Researchers, working from concepts of economics and decision theory, derive utilities for given health states based on patient preferences. Typically, the methods produce a single value for each health state, ranging between 0.0 for death and 1.0 for perfect health. The standard gamble is the "cardinal method," as it is theoretically tied to the axiomatic theory of Von Neuman and Morgenstern (Drummond, O'Brien, Stoddart, & Torrance, 1997). Other measures are based on time-tradeoff methods, multi-attribute theory, and rating scales. Researchers employing the Rasch model for item-response theory focus on the scoring of responses of items, so the items can be weighted to reflect degree of health and quality and the respondents can be rated and scored on the underlying dimension of interest.

Brock (1995) summarizes the current state of the quest as follows: "While that literature provides little in the way of well-developed, philosophical accounts of the quality of life or of a good life, it is a rich body of analysis, data, and experience on which philosophical accounts of a good life can draw." The Ptolemaic conception of the universe and geography is more theoretically advanced than our theoretical and philosophical underpinnings of the concept(s) of health status/quality of life. The dimensions of longitude and latitude were correct; measuring them was the issue. While there is reference to the World Health Organization dimensions, researchers focus on the physical and mental dimensions of health, giving nominal attention to social dimension. There are attempts to broaden the definition and domains or attributes, such as the WHO Quality of Life Instrument (Szabo, 1996), and to recast the items accordingly, but this is a fledgling international collaboration. If we knew the dimensions of life, we could begin to focus on the precision with which location and motion might be measured.

The quest for longitude became important when the costs of navigational errors became intolerable. Random error in the measurement of key endpoints increases the size and costs of studies (Fleiss, 1986) and the difficulty in using the results to make key decisions in clinical policy and management of individuals (Nunnally, 1978). While authors

have defined the uses of the measures and have set stringent standards for the reliability and validity of responsiveness, most researchers ignore these and cite instead the standards of 25 years ago, for the initial development of measures (Kane & Kane, 1981; McDowell & Jenkinson, 1996; McHorney & Tarlov, 1995; Williams & Naylor, 1992; Wright & Feinstein, 1992).

Responsiveness is the Achilles' heel of measurement. A measure is responsive if it mirrors the status of individuals over time, whether it changes or not. It is difficult to identify true change and no change from random fluctuations in scores. I think this is so for two reasons. First, we drift in life; our points of view change subtly as we move through our experiences. Summary assessments of functioning, activities, moods, and feelings over the previous week or month may well shift from one time to another without assessment being either "wrong" or "unreliable." Second, as we encounter significant health events, our perspective or frame of reference may well shift. Even though a hip or knee may not work as well after total joint replacement as the normal joint, an individual can alter expectations for performance and redefine health status and quality of life accordingly. Qualitative researchers may have to provide quantitative researchers with directions as to how to reconstruct their concepts and methods (Kessler & Mroczek, 1996).

A reformulation of the theory and concepts of health status and quality of life is required, and the theory and concepts should stem from an idea of the good life. The advance of strategies and tools is contingent upon new ideas being in place rather than the constant production of new tools for old concepts. While Harrison the horologist won the prize, intelligent use of the clock was made possible by the Copernican view of the universe and the scientific theories of Kepler and Newton. This is what the quest for quality of life should be about.

References

Andrews, W.J.H. (Ed.). (1996). *The quest for longitude: The proceedings of the Longitude Symposium.* Cambridge, MA: Harvard University.

Bowling, A. (1995). *Measuring disease: A review of disease-specific quality of life measurement scales.* Philadelphia: Open University Press.

Bowling, A. (1997). *Measuring health: A review of life measurement scales* (2nd ed.). Philadelphia: Open University Press.

Brock, D. (1995). Quality of life measures in health care and medical ethics. In M. Craven Naussbaum & A. Kumar Sen (Eds.), *The quality of life* (pp. 95–132). New York: Oxford University Press.

Chernow, B.A., & Vallasi, G.A. (Eds). (1993). *The Columbia encyclopedia* (5th ed.; Ptolemy, p. 2239). New York: Columbia University Press.

Drummond, M.F., O'Brien, B., Stoddart, G.L., & Torrance, G.W. (1997). *Methods for economic evaluation of health care programmes* (2nd ed.). New York: Oxford University Press.

Fleiss, J.L. (1986). *The design and analysis of clinical experiments.* New York: John Wiley.

Kane, R.A., & Kane, R.L. (1981). *Assessing the elderly: A practical guide to measurement.* Toronto: Lexington.

Kessler, R.C., & Mroczek, D.K. (1996). Some methodological issues in the development of quality of life measures for the evaluation of medical interventions. *Journal of Evaluation in Clinical Practice, 2,* 181–191.

McDowell, I., & Jenkinson, C. (1996). Developing standards for health measures. *Journal of Health Services Research and Policy, 4*(1), 238–246.

McDowell, I., & Newell, C. (1996). *Measuring health: A guide to rating scales and questionnaires* (2nd ed.). New York: Oxford University Press.

McHorney, C.A., & Tarlov, A.R. (1995). Individual-patient monitoring in clinical practice: Are available health status surveys adequate? *Quality of Life Research, 4,* 298–307.

Nunnally, J.C. (1978). *Psychometric theory* (2nd ed.). New York: McGraw-Hill.

Sobel, D. (1995). *Longitude: The true story of a lone genius who solved the greatest scientific problem of his time.* New York: Penguin.

Spilker, B. (1996). *Quality of life and pharmaeconomics in clinical trials* (2nd ed.). Philadelphia: Lippincott-Raven.

Szabo, S. (on behalf of the WHOQOL Group). (1996). The World Health Organization Quality of Life (WHOQOL) assessment instrument. In B. Spilker, *Quality of life and pharmaeconomics in clinical trials* (2nd ed., pp. 355–362). Philadelphia: Lippincott-Raven.

Williams, J.I., & Naylor, C.D. (1992). How should health status measures be assessed? Cautionary notes on procrustean frameworks. *Journal of Clinical Epidemiology, 45,* 1347–1351.

World Health Organization. (1958). *The first ten years of the World Health Organization.* Geneva: Author.

Wright, J.G., & Feinstein. A.R. (1992). A comparative contrast of clinimetric and psychometric methods for constructing indexes and rating scales. *Journal of Clinical Epidemiology, 45,* 1201–1218.