Annotated Bibliography

Favorite and Classic Articles in *Quality of Life Research*

Aaronson NK, Ahmedzai S, Bergman B, Bullinger M, Cull A, Duez NJ, et al. The European Organization for Research and Treatment of Cancer QLQ-C30: a quality of life instrument for use in international clinical trials in oncology. J Natl Cancer Inst 1993; 85: 365-76. [Thierry Conroy]

Bergner M, Bobbitt RA, Carter WB, Gilson BS. The Sickness Impact Profile:development and final revision of a health status measure. Med Care. 1981. 19:787-805. "The essential citation for the SIP" [Albert Wu, MD]

Bergner M, Bobbitt RA, Kressel S, Pollard WE, Gilson BS, Morris JR. (1976) The Sickness Impact Profile: Conceptual formulation and methodology for the development of a health status measure. International Journal of Health Services, 6, 3, 393-415. [Giorgio Bertolotti, MD]

Bergner M. Quality of life, health status, and clinical research. Med Care 1989; 27 (suppl): S148-S156. [Ezequiel Consiglio, MD, MPH, PhD]

Bindman AB, Keane D, Lurie N. Measuring health changes among severely ill patients: the floor phenomenon. Med Care 1990; 28:1142-1152. "An accessible and clinically relevant explanation of the phenomenon" [Albert Wu, MD]

Bland JM, Altman DG. Comparing two methods of clinical measurement: A personal history. International Journal of Epidemiology 1995; 24 (3) Suppl. 1: s7-ss14. "a wonderful example of how to compare and constrast competing qol assessment tools. it is well written and cuts directly to the heart of the matter rather than trying to overly complicate matters [Jeff Sloan, PhD]

Cella DF, Tulsky DS, Gray G, Sarafian B, Linn E, Bonomi A et al. The Functional Assessment of Cancer Therapy scale: development and validation of the general measure. J Clin Oncol 1993 ; 11: 570-9. [Thierry Conroy]

Coates A et al. Improving the quality of life during chemotherapy for advanced breast cancer. A comparison of intermittent and continuous treatment strategies. NEJM 1987; 317: 1490-5. "Continuous chemotherapy improves both HRQL and survival." [Jordi Alonso, MD]

Coates A, Gebski V, Signorini D, Murray P, MacNeil D, Byrne M, Forbes JF. Prognostic value of quality-of-life scores during chemotherapy for advanced breast cancer. Australian New Zealand Breast Cancer Trials Group. J Clin Oncol 1992;10:1833-38.

Coates AS, Thomson D, McLeod GRM, Hersey P, Gill PG, Olver IN, et al. Prognostic value of quality of life scores in a trial of chemotherapy with or without interferon in patients with metastatic malignant melanoma. Eur J Cancer 1993;29A:1731-34.

"The above two references were among the first to indicate that HRQOL scores are better predictors of survival than is performance status." [David Osoba, MD]

Cohen J. Statistical Power Analysis for the Behavioural Sciences. New York, Academic Press 1977: 8. "A source for effect sizes." [David Osoba, MD]

Cox, DR, Fitzpatrick R. Quality-of-life Assessment: Can we keep it simple? J R Statis Soc 1992; 155: 353-393. "a detailed and cogent argument for demystifying and simplifying the assessment and analytical process" [Jeff Sloan, PhD]

Croog SH, Levine S, Testa MA, Brown B, Bulpitt CJ, Jenkins CD, Klerman GL, Williams GH. The effects of antihypertensive therapy on the quality of life. N Engl J Med. 1986;314:1657-64. "This was a fairly well-designed RCT with treatment group differences and published in a reputable journal. The findings really changed how HRQL data was used in marketing and there is a policy analysis that estimated that the study and related promotional activities resulted in an increase in $375-450 million in sales. It also got clinicians thinking about HRQL and other effects of these medications" [Dennis Revicki, PhD.][Ingela Wiklund, PhD]

Cronbach LJ. Coefficient alpha and the internal structure of tests. Psychometrika 1951; 16: 297-334.

DeBoer JB, Van Dam FS, Sprangers MAG. Health-related-quality-of-life evaluation in HIV-infected patients. Paharmacoeconomics 1995; 8:291-304. [Ezequiel Consiglio, MD, MPH, PhD]

Deyo RA, Diehr P, Patrick DL. Reproducibility and Responsiveness of Health Status Measures. Controlled Clinical Trials 1991;12:142S-158S. [Anandi V. Law, PhD][Ingela Wiklund, PhD]

Fayers PM, Hopwood P, Harvey A, Girling DJ, Machin D, Stephens R on behalf of the MRC Cancer Trials Office. Quality of life assessment in clinical trials-Guidelines and a checklist for protocol writers : the U.K. Medical Research Council Experience. Eur J Cancer 1997; 33 : 20-8. [Thierry Conroy]

Froberg DG, Kane RL. Methodology for measuring health-state preferences--I: Measurement strategies. J Clin Epidemiol. 1989;42:345-54. [Anandi V. Law, PhD]

Froberg DG, Kane RL. Methodology for measuring health-state preferences--II: Scaling methods. J Clin Epidemiol. 1989;42:459-71. [Anandi V. Law, PhD]

Froberg DG, Kane RL. Methodology for measuring health-state preferences--III: Population and context effects. J Clin Epidemiol. 1989;42:585-92. [Anandi V. Law, PhD]

Froberg DG, Kane RL.Methodology for measuring health-state preferences--IV: Progress and a research agenda. J Clin Epidemiol. 1989;42:675-85. [Anandi V. Law, PhD]

Gandek B, Ware JE, Aaronson NK, Alonso J, Apolone G, Bech P, Bjorner JB, Brazier JE, Bullinger M, Fukuhara S, Kaasa S, Keller SD, Lam CLK, Leplège A, Raczek AE, Razavi D, Ren XS, Sanson-Fisher RW, Sullivan M, Wagner AK, Wood-Dauphine S and the IQOLA Project Group. Translating functional health and well-being: International Quality of Life Assessment (IQOLA) Project studies of the SF-36 Health Survey. Journal of Clinical Epidemiology 1998; 51(11): 891-1214. [Monika Bullinger, PhD]

Gill TM, Feinstein AR. A critical appraisal of the quality of quality-of-life measurements. JAMA. 1994 ;272:619-26. "It was annoying and made some very important conceptual points" [Dennis Revicki, PhD]

Goldstein RS et al. Randomised controlled trial of respiratory rehabilitation. Lancet 1994; 344: 1394-7 "A rehabilitation program not improving the main phisiopathological variable of disease but improving function and health related quality of life" [Jordi Alonso, MD]

Guillemin F, Bombardier C & Beaton D. (1993) Cross-cultural adaptation of health-related quality of life measures: literature review and proposed guidelines. Journal of Clinical Epidemiology. 46:1417-1432. [Giorgio Bertolotti, MD]

Guyatt GH, Juniper EF, Walter SD, Griffith LE, Goldstein RS. Interpreting treatment effects in randomized trials. BMJ 1998; 316: 690-693. [Ezequiel Consiglio, MD, MPH, PhD]

Guyatt GH, Bombardier C, Tugwell PX. Measuring disease-specific quality of life in clinical trials. CMAJ 1986; 134: 889-895. "Good paper on questionnaire development" [Anandi V. Law, PhD] [Ingela Wiklund, PhD]

Hanley JA, McNeil BJ. The meaning and use of the area under the receiver operating characteristic (ROC) curve. Radiology. 1982;143:29-36. "Is there a statistically significant difference between the ROC areas?" [Albert Wu, MD]

Hays RD, Anderson RT, Revicki D. Assessing reliability and validity of measurement in clinical trials. In: Quality of Life Assessment in Clinical Trials, Staquet MJ, Hays RD, Fayers PM, eds. Oxford, Oxford University Press, 1998: 169-182. "An excellent explanation of the requirements for reliability and validity of questionnaires." [David Osoba, MD]

Helmstater GC. Principles of Psychological Measurement. New York: Appleton-Century-Crofts, 1964. "What is an adequate Cronbach's alpha for group comparisons?" [Albert Wu, MD]

Huisman SJ, van Dam FSAM, Aaronson NK, Hanewald GJFP.: On measuring complaints of cancer patients: some remarks on the time span of the questions. In: The Quality of Life of Cancer Patients edited by NK Aaronson, J Beckmann, New York Raven Press, 1997, pp 101-109. "A largely ignored paper showing why asking patients to assess their status over long intervals, e.g, 4 weeks, is confounded by personality traits. Ergo, long intervals should not be used -- but still are in some questionnaires!" [David Osoba, MD]

Idler EL, Angel RJ. Self-rated health and mortality in the NHANES-I epidemiologic follow-up study. Am J Public Health 1990; 80:446-452. "Demonstrates the predictive validity of self-rated health" [Albert Wu, MD]

Jaeschke R, Singer J, Guyatt G. Measurement of health status: Ascertaining the minimal clinically important difference. Controlled Clinical Trials 1989;10:40-415. [Kathleen Wyrich, Ph.D.][Ingela Wiklund, PhD] "This is the original reference to MID" [David Osoba, MD]

Jones PW, Quirk FH, Baveystock CM, Littlejohns P. A self-complete measure for chronic airflow limitation - the St George's Respiratory Questionnaire. Am Rev Respir Dis 1992; 145: 1321-1327. [Giorgio Bertolotti, MD]

Juniper, E F. Guyatt, G H. Feeny, D H. Ferrie, P J. Griffith, L E. Townsend, M. Measuring quality of life in children with asthma. 1996 (5): 35-46. Quality of Life Research [Kjell Reichenberg, MD, DrPH]

Juniper EF, Guyatt GH, Willan A, Griffith LE. Determining a minimal important change in a disease-specific quality of life questionnaire. Journal of Clinical Epidemiology. 1994; 47: 81-87. "Meaningfulness of quality of life results" [Anandi V. Law, Ph.D.]

"The seminal work in the most important area that will bring PRO-HRQOL measurement into mainstream medicine" [Joyce Cramer, PhD.][Ingela Wiklund, PhD]

Kaplan, RM, Bush, JW, Berry CC. Health status: Types of validity and the Index of Well-Being. Health Services Research 11(4):478-507, 1976. "This paper sets out the importance of construct validation for determning the performance characteristics of health status and quality-life measures" [Penny Erickson, PhD]

Karnofsky DA, Abelman WH, Craver LF, Burcheneal JH. The use of nitrogen mustards in the palliative treatment of carcinoma. Cancer. 1948; 1:634-656. "One of the first" [Albert Wu, MD]

Katz S, Ford AB, Moskowitz RW, Jackson BA, Jaffe MW. Studies of the aged: the Index of ADL: a standardized measure of biological and psychosocial function. JAMA. 1963;185:914- 919. "One of the original references for ADL measures" [Albert Wu, MD]

Kazis LE, Anderson JJ, Meenan RF. Effect sizes for interpreting changes in health status. Med Care 1989; 27 3 (suppl.): s178-s189. "A good application of intuitive standards for evaluation of the magnitude of change" [Jordi Alonso]

Kendall CJ, Russell AS, Skeith K. Lack of congruence in the ratings of patients' health status by patients and their physicians. Med Decis Making 2001 ;21:113-21. "Example of discrepancy between patient and physician in rating pain" [Olivier Chassany, MD, PhD]

King MT. The interpretation of scores from the EORTC Quality of Life Questionnaire QLQ-C30. Quality Life Research 1996;5:555-567. "Important for determining meaningful change in HRQOL scores" [David Osoba, MD]

Lydick E, Epstein RS. Interpretation of quality of life changes. Quality of life Research. 1993; 2:221-226. [Anandi V. Law, Ph.D.][Ingela Wiklund, PhD]

McHorney CA, Ware JE, Raczek AE. The MOS 36-Item Short-Form Health Survey (SF-36): II. Psychometrics and Clinical Test of Validity in Measuring Physical and Mental Health Constructs. Medical Care 1993; 31:247-263. "These articles incorporated sound psychometric principles, enhanced the scientific credibility and acceptance of quality-of-life assessments, and ignited an international mass movement." [Joe Capelleri, PhD]

McHorney CA, Ware JE, Lu, R, Sherbourne CD. The MOS 36-Item Short-Form Health Survey (SF-36): III. Tests of Data Quality, Scaling Assumptions, and Reliability Across Diverse Patient Groups. Medical Care 1994; 32:40-66. "These articles incorporated sound psychometric principles, enhanced the scientific credibility and acceptance of quality-of-life assessments, and ignited an international mass movement." [Joe Capelleri, PhD]

McHorney CA, Tarlov AR. Individual-patient monitoring in clinical practice: are available health status surveys adequate? Qual Life Res 1995; 4: 293-307. "This paper sets an adequate framework for the evaluation of performance of existing questionnaires and discusses the requirements for individualised use" [Jordi Alonso, MD]

Norman GR, Stratford P, Regehr G. Methodological problems in the retrospective computation of responsiveness to change: the lessons of Cronbach. Journal of Clinical Epidemiology 1997; 50:869-879. [Kathleen Wyrich, PhD]

Nunnally JC. Psychometric Theory, 2nd ed. New York: McGraw-Hill, 1978. [Albert Wu, MD]

Nunnally JC, Bernstein IH. Psychometric Theory (3rd edition), New York, McGraw-Hill, 1994; 264-265 "A more up to date citation of Nunnaly than the 2nd edition" [David Osoba, MD]

Osoba D, Rodrigues G, Myles J, Zee B, Pater J. Interpreting the significance of changes in health-related quality-of-life scores. J Clin Oncol 1998; 16: 139-44. [Thierry Conroy]

Patrick DL, Chiang YP. Measurement of health outcomes in treatment effectiveness evaluations: conceptual and methodological challenges. Med Care. 2000;38(9 Suppl):II14-25. An extension of Cleary and Wilson JAMA 1995 that incorporates survival.[Dennis Revicki, PhD]

Sechrest L, Fay, TL & Zaidi SFH. Problems of translation in cross-cultural research. (1972) Journal of Cross-Cultural Psychology. 3,1,41-56. [Giorgio Bertolotti, MD]

Spilker B, ed. Quality of Life and Pharmacoeconomics in Clinical Trials. New York: Raven Press, 1996 [Monika Bullinger, PhD]

Spilker B. Chapter 1. In, ed. Quality of Life and Pharmacoeconomics in Clinical Trials. New York: Raven Press, 1996 It gives great background on the field as a whole [Richard Willke, PhD]

Staquet M, R Hays R, Fayers P, eds. Quality of Life Assessment in Clinical Trials: Methods and Practice Oxford University Press, 1998 [Richard Willke, PhD]

Stewart AL and Ware JE, eds. Measuring Behavioral Functioning and Well-the Medical Outcomes Study Approach. Duke University Press. "Details on the entire MOS battery of scales" [Albert Wu, MD]

Study protocol for the World Health Organization project to develop a Quality of Life assessment instrument (WHOQOL). Qual Life Res. 1993;2:153-9. [Monika Bullinger, PhD]

Sullivan DF. A single index of mortality and morbidity. HSMHA Health Reports 86(4): 347-355, 1966 "This is the first paper to combine life expectancy and health status data to form a single, summary measure. The method Sullivan used is still widely used today for computing QALYs that are used for population monitoring as well as for economic analyses" [Penny Erickson, PhD]

Tannock IF Treating the patient, not just the cancer. N Engl J Med 1987; 317: 1534-1535. "Signaled a wake-up call to many in oncology research that there was indeed a need for assessing patient qol in oncology clinical trials." [Jeff Sloan, PhD]

Tarlov AR, Ware JE Jr., Greenfield S, et al. The Medical Outcomes Study: An application of methods for monitoring the results of medical care. JAMA 1989; 262:925-930. "How to design an outcome study" [Albert Wu, MD]

Tarlov AR. Message from the President. Medical Outcomes Trust Bulletin. 1994; 2(2):1. [Anandi V. Law, PhD]

Tarlov AR. The coming influence of a social sciences perspective on medical education. Acad Med. 1992;67:724-31. "Gives a strong conceptual background for quality of life and outcomes research" [Anandi V. Law, PhD]

Till JE, McNeil BJ, Bush RS. Measurements of multiple components of quality of life. Cancer Treatment Symposia 1984;1:777-181. "Still one of the best definitions of HRQOL." [David Osoba, MD]

Torrance G, Furlong W, Feeny D, Boyle M. Mult-attribute preference functions: Health utilities index. Pharmacoeconomics 1995; 7:503-520. "Self explanatory." [David Osoba, MD]

Ware JE, Jr., Shelbourne CD. The MOS 36-item short-form health survey (SF-36): I. Conceptual framework and item selection. Medical Care 1992;30:473-483. [Kathleen Wyrich, PhD]

"These articles incorporated sound psychometric principles, enhanced the scientific credibility and acceptance of quality-of-life assessments, and ignited an international mass movement." [Joe Capelleri, PhD]

Ware J, Kosinski M, Keller SD. SF-36 Physical and Mental Health Summary Scales: A User's Manual. Boston, The Health Institute, New England Medical Center 1994. "Has all the details." [David Osoba, MD]

Wilson IB, Cleary PD. Linking clinical variables with health-related quality of life. A conceptual model of patient outcomes. JAMA. 1995;273:59-65 "It laid out the field in a clinically-accessible way" [David Cella, PhD]
"The paper provides one of the few conceptualizations of the association between various health outcome measures from biological to quality of life [Dennis Revicki, PhD]

World Health Organization Quality of Life Assessment (WHOQOL): development and general psychometric properties. Soc Sci Med. 1998;46:1569-85. [Monika Bullinger, PhD]

World Health Organization: Constitution of World Health Organization, in Basic Document, WHO, Geneva, 1948. "The basis of many definitions of HRQOL." [David Osoba, MD]

Yohannes AM, Roomi J, Waters K, Connolly MJ. Quality of life in elderly patients with COPD: measurement and predictive factors. Respir Med 1998;92:1231-6 Nice example of added value of HRQL/PRO in COPD [Olivier Chassany, MD, PhD]