

International Society for Quality of Life Research

Volume 10 Issue 2

PRESIDENT'S MESSAGE

David Feeny, PhD Edmonton, AB, Canada

Does Anyone Have Just One Health Problem?

In clinical studies and trials and even in population health surveys, it is common to observe respondents who have more than one chronic condition or health problem. For instance, in a prospective cohort study of patients undergoing elective total hip arthroplasty, patients were asked whether or not they had each of 6 co-morbidities. The mean age of the patients was 69; 36% reported having hypertension; 15% reported having coronary artery disease; and 56% had one or more co-morbidities (Mahon et al. 2002). Similarly, in a study of primary-care patients at high risk for medication problems, the mean number of medical conditions was 4.5 (Blanchard, et al. 2004); the mean age was 67. Another example comes from a study of type-2 diabetes in the community, based on data from the 2000/2001 Canadian Community Health Survey. The mean age was 62; 21% of the type-2 diabetics also had heart disease (Maddigan et al. 2005).

The examples provided above are not necessarily representative and come from studies in which many subjects were middle-aged or older. The prevalence of co-morbidities would be much lower in younger adult and pediatric populations. Nonetheless, co-morbidities are common. The commonness of co-morbidities has three major implications.

First, as is well known, the generalizability of evidence from studies which exclude patients with co-mor-

Newsletter for ISOQOL Members

bidities is limited (see for instance Tunis et al. 2003). Evidence of the clinical effectiveness of interventions and the health-related quality of life consequences may not generalize to the types of patients seen in everyday settings.

Second, the prevalence of co-morbidities has implications for our choice of health-related quality of life instruments. Disease-specific instruments often focus on dimensions of health status and items within those dimensions that are of greatest relevance and importance to patients with that condition. Often disease-specific measures are more responsive than generic measures (see for instance Guyatt et al. 1999). Disease-specific measures may, however, miss the effects of co-morbidities and/or the side-effects of treatment. Thus, the advice found in a number of guidelines is to use both specific and generic measures (CCOHTA 1997; Gold et al. 1996).

Third, the prevalence of co-morbidities calls into question the burden of disease approach to assessing the healthrelated quality-of-life burden (or economic burden) of health problems (see for instance Murray et al. 2002). If a substantial proportion of the patients with diabetes, hypertension, or osteoarthritis, also have other chronic conditions, how does one attribute the burden among the various chronic conditions? Rather than taking the disease or health problem as the "unit of observation," it may be more useful to take the patient (or subject in a population health survey) as the unit of observation.

The practice of using both specific and generic measures in the same study has

become common in the field of healthrelated quality of life. The advantages of the approach include the focus and enhanced responsiveness of the specific measures, complemented by the ability of generic measures to pick up the effects of co-morbidities and facilitate broad comparisons. The approach, of course, may also increase the burden on respondents and investigators. Evidence on the value of the additional information provided by using both types of measures would help to inform users in the future.

September 2005

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President, continued on page 8

IN THIS ISSUE . . .

- A word from our Past President
- How to start an ISOQOL Membership Chapter
- Seeking an Associate Editor for *Quality of Life Research*

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Deadline for articles for our next issue is November 15, 2005

Send articles and/or suggestions to: info@isoqol.org

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PAST PRESIDENT'S COLUMN

Ivan Barofsky, PhD Sandwich, MA USA

One of the advantages of being a retired, retired former President of ISOQOL is that it gives you plenty of time to wander around the intellectual landscape. This I have been doing with great joy and as part of this I came across a paper I would like to recommend to you. Not too surprisingly I am recommending it because it supports a somewhat controversial paper I wrote (Barofsky, 2000: Medical Care 2000; 38: Supp II, 125-129.) about the difference between psychometric and cognitive equivalence. It also demonstrates how brain imaging studies may be a useful measurement modality for quality of life researchers.

The paper is by Stern et al. (Cerebral Cortex, 15(4), 394-402 2005) who used PET scans to study the cortical areas that are involved in a visual recognition memory task given to a group of 17 elderly and 20 young adults. What was particularly interesting about the study was that the investigators invited the respondents into their lab the day before the PET scan and determined how well they would remember the increasingly complex nonsense images they presented to them. They then decided to select the 75th percentile for each subject and present tasks that ranged around this level. Naturally, the elderly were not as able to remember as many complex tasks as the young, but by using the 75th percentile their subjects were all psychometrically equivalent meaning within their range of ability all the subjects were comparable.

But most importantly the PET scans were able to show that the two groups were not *cognitively equivalent*. What was found was that as the tasks became increasingly more difficult the young adults were able to activate the same neural pathways they used for simpler problems, but that the elderly neurally compensated, using alternative pathways to accomplish their tasks. So the next time you hear someone say to you "I don't care what a person was thinking about when they responded to an item, all I am interested in is their response", pause and remember that there may indeed be a big difference on how those responses were generated. To me these differences raise serious questions about the validity of our assessments, so how and what we are thinking when we fill out these assessments is worth studying. Also if anyone comes across brain imaging studies in which a person has been asked to rate their quality of life, I'd like to know (ibarofsky@adelphia.net). I see brain imaging studies of happiness but not on quality of life, per se.

Also, the sooner you retire, the happier you will be - I mean from being President of ISOQOL, of course.

NEW ISOQOL BOOK

"Advancing Health Outcomes Research Methods and Clinical Applications"

Edited by William R. Lenderking & Dennis A. Revicki

To be published Fall 2005, ISOQOL is pleased to offer a volume of invited papers from the recent Symposium "Advancing Health Outcomes Research Methods and Clinical Applications," which captures the heterogeneity, science, and creativity of our field.

The papers are not direct transcripts the talks presented, but rather chapters inspired by the presentations delivered at the Symposium. We sought to create a program that illuminated the state of the art of health outcomes research from the perspectives of statistical methodology, clinical applications, and theory. Rather than attempting to cover the entire breadth of the field, our aim was to invite leading investigators and thinkers in their field of specialization. This volume will be available to ISOQOL members for \$80 and \$95 for non-members. Bulk discounts are available for orders of 100 copies or more. For more details, please visit www.isoqol.org or email info@isoqol.org.

MEMBER NEWS

Anne Klassen, Assistant Professor in the Department of Pediatrics at the University of British Columbia (Vancouver), received two 5 year salary-support awards this year – a New Investigator award from the Canadian Institutes of Health Research New Investigator Award, and a Scholar Award from the Michael Smith Foundation for Health Research.

Laura Schwartzmann, MD from Montevideo, Uruguay, has won a contest through which she has been assigned Professor and Chairman of the Medical Psychology Department of the School of Medicine of the University of the Eastern Republic of Uruguay.

Alex C. Michalos, PhD, Director, Institute for Social Research & Evaluation, University of Northern British Columbia, received in June 2005, an Honorary Doctor of Letters degree from Thompson Rivers University, British Columbia, for his lifetime contributions to quality-of-life research.

Rick Berzon has accepted a position as HIV/AIDS Monitoring, Reporting and Evaluation Advisor within the Global Health Bureau of USAID/State Department in Washington, DC. His responsibilities are to develop and apply new epidemiological, clinical, demographic and statistical methods to outreach, monitor, evaluate and improve the effectiveness of health services delivery programs in developing countries, with a focus on HIV/AIDS programs. Travel will be primarily to Africa. Having been in the pharmaceutical and consulting industries for the past 12+ years, he looks forward to this new challenge.

Evidence-based interpretation guidelines for quality of life measures. Julia Brown and Kim Hawkins at the CTRU, University of Leeds have received a Project Grant from Cancer

Research UK in collaboration with Peter Fayers (University of Aberdeen), Madeleine King (CHERE, University of Technology, Sydney) and Galina Velikova (University of Leeds). The project will look at a novel application of meta-analysis to produce interpretation guidelines for the EORTC QLQ-C30 using published data from the questionnaire. The grant is for three years, at the end of which a protocol will be produced to guide similar work for other quality of life questionnaires. The project will use clinical and patient input to assess large, moderate and small changes in quality of life scores.

Sandra Marcia Ribeiro Lins de Albuquerque, MSc informs us that her PhD thesis presentation will be on August 4th. Its theme is: Active aging: challenges faced by health services in improving quality of life for the elderly. She participated in a meeting of Brasilian researchers of Quality of Life last year in Porto Alegre, Rio Grande do Sul State(August, 18-21st), coordinated by Dr. Marcelo Fleck, who is the Brasilian representative of OMS and validated the instruments WHOQOL-100 and WHOOOL- BREF. It was a great meeting and brought together important Quality of Life researchers such as Dr. John Ware.

Jane Speight MSc PhD has founded a new contract research consultancy, Applied Health Psychology (AHP) Research Ltd in Uxbridge, West London. AHP specialises in the development and use of patient reported outcomes measures to inform the evaluation of new medical treatments and services. AHP provides research, training and consultancy services to the pharmaceutical industry, medical devices industry, NHS and all organisations/individuals interested in patient-centred evaluation of healthcare. Contact Jane at jane.speight@healthpsy.net.

Elaine McColl, MSc from Newcastle upon Tyne, England has been awarded a PhD by the University of Newcastle for her work on "Patient Reported Outcomes: from selection to interpretation". This was based on her peer-reviewed publications in this area, and a contextual literature review."

DO YOU HAVE MEM-BER NEWS TO SHARE?

Members are encouraged to submit information about new positions, awards, assignments, and memberships of themselves and/or their colleagues.

Please keep announcements brief, i.e., one or two short paragraphs. Given space limitations, the editor reserves the right to abbreviate contributions exceeding the recommended length.

ISOQOL ELECTION RESULTS

ISOQOL would like to thank the following for their service:

David Feeny, President Oct 2004 - Oct 2005 Diane Fairclough, Secretary/Treasurer Oct 2002 - Oct 2005 Donna Lamping, Board Member Oct 2002 - Oct 2005 Carolyn Schwartz, Board Member Oct 2002 - Oct 2005 Ingela Wiklund, Board Member Oct 2002 - Oct 2005

... and welcome the following to the ISOQOL Board of Directors:

Madeleine King, President-Elect (Oct 2005 - Oct 2006) Rick Berzon, Secretary/Treasurer (Oct 2005 - Oct 2008) John Brazier, Board Member (Oct 2005 - Oct 2008) Cynthia Gross, Board Member (Oct 2005 - Oct 2008) Galina Velikova, Board Member (Oct 2005 - Oct 2008)

NEW ISOQOL CHAPTER: COMING SOON NEAR YOU!

Andrew Bottomley, Madeleine King, Laura Schwartzman and Kwok-fai Leung

Over the last couple of years, ISOQOL has been listening to its members to try and understand how best meet the needs of our growing international society. One of the key characteristics regarding ISOQOL is that it is a society that appeals to researchers, scientists and other professionals across the entire globe. Therefore, it is not surprising that one issue that has been recently noticed is the need to develop either national or regional access to ISOQOL.

In June 2004, the ISOQOL Board established a working group, led by Andrew Bottomley, with Madeleine King, Laura Schwartzman and Kwok-fai Leung. This group have been working to pull together some acceptable minimum standards along with instructions for establishing national and regional Chapters. These standards were discussed at the ISOQOL Board meeting in June 2005 and have been endorsed by the ISOQOL Board. These minimum standards provide members with clear guidelines on establishing an acceptable clear structure for each ISOQOL chapter. These are intended to be pragmatic, and practical, without being overly bureaucratic or prescriptive, allowing Chapters to naturally grow and develop according to local needs. If you would wish to have more information please visit our web site for more details (www.isoqol.org).

We hope you will be able to use ISOQOL Chapters as a way to network more effectively, to collaborate on regional or national QOL activities and further the needs of QOL research in general. Each Chapter will be encouraged to publish its activities via the ISOQOL web site and will be given the endorsement of ISOQOL Board and be able to use the ISOQOL logo to help promote their local activities.

We look forward to seeing ISOQOL Chapters very soon!

SEEKING AN ASSOCIATE EDITOR

Quality of Life Research, the official journal of the International Society of Quality of Life Research is seeking an Associate Editor. The candidate for Associate Editor should have:

- A broad knowledge of the field of quality of life research and its applications in health care settings.
- A strong commitment to the peerreview process for selection of manuscripts to be published.

Editorial responsibilities include:

- Identifying appropriate referees for submitted manuscripts
- Evaluating the merits of manuscripts, based on both referee reports and her/his own judgment, and making final decisions regarding the disposition of those manuscripts.
- Communicating effectively with authors, peer reviewers, other members of the editorial board, and the publisher (Springer Netherlands).
- Day-to-day administrative work (i.e., preparing correspondence, tracking of manuscripts, etc.) is kept to a minimum as these tasks are carried out primarily by the central editorial office of the journal.
- A commitment to contributing to the planning of the future of the journal.
- Previous experience with comparable editorial activities is desirable, but not required.

AEs can expect to spend at least onehalf day a week on their editorial duties. They do not receive financial compensation for their service, but previous AEs have found the experience to be rewarding. Many of them appreciated the opportunity to contribute to the advancement of quality of life research.

We invite applications from those with expertise in preference/utility mea-

surement or pediatrics, but applications are welcome, regardless of area of expertise. Multiple AEs will be selected. If you are interested, please submit an email with your curriculum vitae and a brief indication of your specific areas of interest and expertise to:

Ron D. Hays, PhD Editor-in-Chief *Quality of Life Research* UCLA Department of Medicine 911 Broxton Avenue, Room 110 Los Angeles, CA 90095-1736 Email address: drhays@ucla.edu

The deadline for submission of applications is **November 1, 2005.**

CALENDAR

October 19-22, 2005

12th Annual Scientific Meeting of the International Society for Quality of Life Research (ISOQOL), to be held at the Hyatt Regency Hotel in San Francisco, CA, USA.

October 21-24, 2005

27th Annual Meeting of the Society for Medical Decision Making (SMDM), to be held at the Hyatt Regency Hotel in San Francisco, CA, USA.

July 17-20, 2006

Seventh International Society of Quality of Life Studies (ISQOLS) Conference, to be held at Rhodes University, Grahamstown, South Africa. For details when available, please visit http:// market1.cob.vt.edu/isqols or contact conference@ehps2005.com.

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New Members, continued on page 6

New Members, continued from page 5

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We'll be conducting interviews at the upcoming ISOQOL annual conference. For more information, please contact our Director of Human Resources, Karen Heitzman, at <u>kheitzman@</u> <u>qualitymetric.com</u>, or view career opportunities at <u>www.qualitymetric.com/</u> <u>company</u>.

Outcomes Research

The National Cancer Institute (NCI) is conducting a search for an experienced scientist to join the staff of the Outcomes Research Branch (ORB) of the Division of Cancer Control and Population Sciences. Research supported within the ORB focuses on enhancing the state of the science in cancer outcomes measurement as well as in quality of cancer care research. The incumbent will be responsible for a range of outcomes research activities related to the assessment of prevention, early detection, and cancer treatment services delivered in clinical trials and health care delivery settings. Emphasis will be on the development, testing and application of patient-reported outcomes including health-related quality of life, symptom management,

and/or patient experience of and satisfaction with care.

The successful applicant will hold a Ph.D., M.D., or equivalent training. Expertise and experience is required in the conceptual basis, methodology and application of health outcome measures in the context of clinical trials, observational studies, and population level surveillance and cancer care evaluation. This position requires U.S. citizenship. The salary range is \$74,782 - \$97,213, depending on experience, with opportunities for promotion. Location is Rockville, Maryland. For further information, contact Dr. Steven Clauser, PhD, Chief, ORB, at clausers@mail.nih.gov.

Selection for this position will be solely on merit, with no discrimination for non-merit reasons such as race, color, gender, national origin, age, religion, sexual orientation, or physical or mental disability. NCI/NIH/DHHS is an equal opportunity employer.

BE A LIAISON!

Have you wanted to find a way to help ISOQOL and its members but you don't have a lot of time? Here's a simple way to use information you already have to help your colleagues.

ISOQOL is looking for assistance in helping its members stay aware of important happenings and meetings in organizations with complementary goals. To accomplish this, we are establishing a liaison program in which volunteers will identify key information, such as annual meeting dates and locations, abstract submission deadlines, major initiatives or changes within the organization, and other information in which ISOOOL members might be interested. Liaisons will forward this information to the Communications Committee quarterly and the information may be posted on the ISOOOL web site and/or mentioned in the newsletter. Liaisons need not hold paid memberships in these complementary organizations, but should have access to their listservs and/or newsletters.

Examples of the types of organizations for which we are currently seeking liaisons include:

- AcademyHealth
- American Cancer Society
- American Medical Informatics Association
- American Psychological Association
- American Psychosocial Oncology Society
- American Public Health Association
- American Society of Clinical Oncology
- American Statistical Association
- American Thoracic Society
- Australian Society for Quality-of-Life Studies
- Drug Information Association
- International Health Economics Association
- International Medical Informatics Association
- International Psycho-Oncology Society
- International Society for Pharmacoeconomics and Outcomes Research
- International Society for Quality-of-Life Studies
- Society for Behavioral Medicine
- Society for General Internal Medicine
- Society for Health Related Quality of Life
- Society for Medical Decision Making
- Society for Quality of Life Research

If you are an active participant in any of these organizations – or any other that you think would be of interest to ISOQOL's members – and would be willing to keep track and provide information about annual meetings and initiatives, please contact info@isoqol.org.

ISOQOL 12th Annual Conference San Francisco, CA, USA October 19 - 22, 2005

ISOQOL invites you to San Francisco, the city that is home to a little bit of everything!



DATES TO REMEMBER...

Workshops - October 19, 2005 Conference - October 20-22, 2005

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President, continued from page 1

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