Typically, clinicians use multiple indicators in arriving at a diagnosis or a judgement about whether or not the patient is improving. Relatively few clinical decisions are made on the basis of the result from a single test. Do our ideal normative standards reflect an implicit assumption that the health-related quality of life score would be the only criterion for making a decision?

Getting a handle on the realistic value added of using measures of health-related quality of life then depends on comparing situations in which such information is and is not made available. In the context of using health-related quality of life measure to assist in the clinical management of patients, several teams of investigators (for instance, Velikova et al. and Detmar et al.) have done just that. Both sets of investigators find evidence that in the context of medical oncology, making patient-reported information available matters and may even affect patient outcome in some circumstances. The measures of health-related quality of life used in these studies were well-validated measures (for instance, both studies included the EORTC QLQ-C30) that might not, however, be deemed acceptable for use in individual-level decision making according to our normative rules of thumb. But what is the alternative? We can refrain from using measures because they do not meet ideal standards or we can carefully assess the potential benefits and harms of using measures with sound but less than ideal track records.

Enough! I hope that you find these musings provocative. Sessions being planned for the 12th Annual Meeting in San Francisco October 19-22, 2005 will provide the real answers to the questions posed here. I look forward to seeing you there!

References


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- Call for Nominations: President’s Award
- Call for Submissions: 2004 Outstanding Article of the Year Award
- Member News . .and more!
AN INVITATION FROM THE 2005 SCIENTIFIC PROGRAM COMMITTEE

Ron Hays, PhD
Los Angeles, CA, USA

The 2005 ISOQOL meeting, “Building Bridges to Enhance Quality of Life,” will take place October 19-22 in San Francisco, CA at the Hyatt Regency Embarcadero. A variety of workshops will be offered on October 19 covering introduction to health-related quality of life assessment, preference/utility measurement, item response theory, longitudinal design and analysis, introduction to decision analysis, evaluating change in health-related quality of life, use of Bayesian analysis, and dynamic assessment of health-related quality of life.

The meeting will be kicked off on October 20 with a plenary talk by Dr. Robert Brook, Vice President, RAND, on “Measuring Health: Are We Ready for Prime Time?” In addition, we will have invited sessions on policy applications (Paul Kind, Galina Velikova, Michael Wolfson), health-related quality of life assessment in clinical practice (Paul Kind, Galina Velikova, Michael Wolfson), health-related quality of life assessment in clinical practice (Michael Barry, David Cella, David Osoba), and hearing from stakeholders (government, accreditation organizations, patient advocate, clinical trialist).

There will be a coordinated presentation from the presidents of ISOQOL (David Feeny) and the Society for Medical Decision Making (Karen Kuntz) as well as joint paper and poster sessions from ISOQOL and the Society for Medical Decision Making on October 22th.

We look forward to seeing you all in San Francisco for a great meeting!

CALL FOR NOMINATIONS: PRESIDENT’S AWARD

July 31, 2005 - Deadline for Nominations for the ISOQOL President’s Award

The goal of this award is to recognize outstanding contributions (by an individual or group) to the advancement of the quality of life field in one or more of the following areas: “education of professionals, patients or lay individuals about the value of quality of life assessment as related to health;” “promotion or execution of quality of life research or other scholarly activities;” and “facilitating or furthering policy initiatives that impact upon health-related quality of life.”

Please submit your nomination package consisting of 1) a letter from the nominator specifying the nominee’s contributions, 2) the curriculum vitae of the nominee, and 3) an external support letter. The deadline for nominations is July 31, 2005.

Please mail, email or fax your nomination package to: Dr. David Feeny, President, ISOQOL Executive Office, 6728 Old McLean Village Drive, McLean, VA 22101 USA, Email: info@isoqol.org, or Fax: 703-556-8729.

The award will be selected by the ISOQOL Executive Committee and approved by the Board of Directors. The award will consist of a plaque, a $1,000 honorarium and up to $1,000 in travel expenses if the recipient plans to attend this year’s Annual Conference in San Francisco, California, USA.
UPDATE TO NEWSLETTER ARTICLE FROM DECEMBER 2004 ISSUE: OUTSTANDING ARTICLE OF THE YEAR AWARD

Mirjam Sprangers, PhD
Amsterdam, The Netherlands

Editor’s Note: Information on last year’s ISOQOL Outstanding Article of the Year Award, presented at the Annual Meeting in Hong Kong, was inadvertently left out of the last issue of the Newsletter. We reproduce the article in its entirety below.

The ISOQOL “Outstanding Article of the Year Award” is given annually to recognize and honor the single best article dedicated to health-related quality of life research that was published in a peer-reviewed journal during the previous calendar year. This award recognizes the authors for significant intellectual contributions that promise to advance the state of the art in health-related quality of life research methods or theory.

This year, six high-quality papers were submitted for this award. These include:


These papers covered a wide range of important topics and each paper represented a significant intellectual contribution to the field of health-related quality of life.

This year’s committee consisted of the three former ISOQOL presidents, including Ivan Barofsky, David Osoba, and Mirjam Sprangers (chair). We feel very pleased and honored to announce this year’s recipients of the “Outstanding Article of the Year Award”: Jakob Bjorner, Mark Kosinski, and John Ware for their paper “Calibration of an item pool for assessing the burden of headaches: an application of item response theory to the Headache Impact Test”, published in Quality of Life Research.

This paper describes the development of an item pool that can be used for a computerized adaptive test of headache impact. The authors analyzed responses to four tests of headache impact from a population-based sample of recent headache sufferers. They used confirmatory factor analysis and analyses based on item response theory. They thus established a suitable item pool of 47 items. By simulating a computerized adaptive health test, they showed that the item pool could be used as a basis for a computerized adaptive test of headache impact.

The committee has chosen this paper as the single best article of 2003 for primarily two reasons. First, computerized adaptive testing is considered to be an issue of key importance, as it has potential advantages over traditional fixed-length tests in terms of precision, relevance, completion time involved, quality control, and flexibility. This paper documents the psychometric work underlying the development of the Headache Impact Test, the first computerized adaptive test of any health outcome. Second, this paper provides the most detailed description of the development of an item pool for computerized assessment of health outcomes that has been published in the literature so far. Given its clarity and didactic approach, this paper will pave the way for others who intend to build similar item pools. We therefore expect this paper to be seminal.

One final issue merits attention. This paper is part of a special issue of Quality of Life Research, including nine papers that combined, provide a comprehensive description of how item response theory and computer adaptive testing can be applied to the field of health-related quality of life. While we believe that this set of articles represents an outstanding contribution to our field, we have only reviewed the two submitted papers. We would like to recommend the entire special issue to those interested in this topic.
ANNOUNCING THE CALL FOR THE ISOQOL “OUTSTANDING ARTICLE OF THE YEAR” AWARD

ISOQOL will continue to award the Article of the Year Award to recognize and honor the single best article dedicated to health-related quality of life (HRQL) research that was published in a peer-reviewed journal during the previous calendar year. This award recognizes the author(s) for significant intellectual contributions that promise to advance the state of the art in HRQL research methods or theory. The ISOQOL Article of the Year Award will be presented during the award ceremony at the annual meeting of the Society. The first author of the winning article will receive a plaque and the other authors will receive a certificate recognizing the outstanding research. In addition, four new ISOQOL memberships will be available to the winners, to be distributed at their discretion.

Any HRQL research article written by any author(s) that was published for the first time during the previous calendar year in a peer reviewed journal, will be eligible if nominated for this award by an active member of ISOQOL. Any ISOQOL member may nominate an article by completing and submitting a nomination package. Self-nomination is permitted. If more than one person nominates a particular published article for this award, a Lead Nominator will be assigned to assemble all nomination documents, submit the nomination package, and serve as the correspondent for all questions regarding the nomination. The deadline to submit a nomination is July 15, 2005.

For each nomination, a Nomination Package consisting of the following should be submitted to the ISOQOL Article of the Year Taskforce (Note: materials that are submitted with the nomination CANNOT be returned):

1. A complete copy of the published article must accompany the nomination.

2. A nomination letter should be provided that states why the article represents an outstanding contribution to the field of HRQL and describes how it advances HRQL research, clinical application or affects health policy.

3. Nomination will identify the author(s) and provide the full citation for the article.

The ISOQOL Board of Directors will appoint a Jury of ISOQOL members and a Jury Chair to serve as reviewers for this award. Jury members will be chosen based on their expertise in areas addressed in the articles submitted. If an article written by a member of the jury panel is nominated for the award, that Jury member will be removed from the Jury for the current year and the Board of Directors will appoint another ISOQOL member to serve on the Jury in his or her place.

After each member of the Jury reviews each article, the Jury will recommend the single article that promises to be the most significant advancement to HRQL research from all those nominated each year based on its scientific quality and societal relevance.

Should you have any questions regarding the Article of the Year award, please contact the ISOQOL Executive Office at info@isoqol.org or call 703-556-9222.

DO YOU HAVE MEMBER NEWS TO SHARE?

This column about ISOQOL members will appear as often as there is news worthy of note. 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.

MEMBER NEWS

Luis Prieto, PhD from Madrid Spain, has joined SERONO IBERIA as Health Economics Manager for Spain and Portugal.

Barbara L. Andersen, Professor of Psychology at the Ohio State University, was inducted as a Fellow in the American Association for the Advancement of Science (AAAS) at the annual meeting in Washington DC in February 2005. She is also recently received the John P. Minton Hero of Hope Award from the Ohio division of the American Cancer Society for her lifetime achievements and contributions in cancer research.

Susan Bauer-Wu, DNsc, RN, director of The Phyllis F. Cantor Center for Research in Nursing & Patient Care Services at Dana-Farber Cancer Institute, Boston, MA, and Instructor of Medicine at Harvard Medical School, is the 2005 recipient of the Oncology Nursing Foundation’s Mara Mogensen Flaherty Memorial Lectureship Award. This annual award is given to nurses and other health care professionals who have demonstrated sustained and significant contributions in the field of psychosocial oncology. Bauer-Wu will deliver a keynote lecture entitled, “Seeds of Hope, Blossoms of Meaning,” at the Oncology Nursing Society’s 30th Annual Congress in April.

Dorothy Keininger has accepted a position as Manager, Health Economics with Ovation Research Group, a leading health economics and outcomes research firm. Building on her economics training at The University of Arizona and her experience with the Mapi Group, Dorothy has responsibility for health economics-related research studies, reports, and models in support of new and existing healthcare technologies.
ISOQOL WELCOMES
NEW MEMBERS

Karine Barrau
Marseille, France

Peter Bruce, MA
Arlington, VA

Yuan Yuan Cheng
Perth, Australia

Kuan-Chun Chuang
Taipei, Taiwan

Carolyn Czoski Murray, MSc
Sheffield, United Kingdom

Amylou Dueck, MS
Mesa, AZ

M. Haim Erder, PhD
Jersey City, NJ

Sepideh Farivar, MPH
Thousand Oaks, CA

Charu Gandhi, DPM
Bangalore, India

Ashu Rajan Gandhi, MD
Bangalore, India

Tiecheng Guo, MD
Wuhan, China

Mark P. Haggard, PhD
Cambridge, United Kingdom

Cheryl Hankin, PhD
San Jose, CA

Janel Hamner, MD, PhD
Madison, WI

Yuan Tao Hao, PhD
Guangzhou, China

Kim Hawkins, MSc
Leeds, United Kingdom

Amy P.Y. Ho, PhD
Hong Kong, China

Zorianna Hyworon, BSc
Winnipeg, MB, Canada

Faustina Idu
Benin, Nigeria

Edward Ip, PhD
Winston-Salem, NC

Maria Kolotowska-Haggstrom, MD
Uppsala, Sweden

Eiji Kusumi, MD
Tokyo, Japan

Chi Ching Law, FRCR
Hong Kong, China

Alain Leplege, MD
Amiens, France

Karen Leyton, MBA
Wallingford, CT

Fengbin Liu, PhD
Guangzhou, China

Maria Cristina Lunic
Buenos Aires, Argentina

Wing Chit Mak, MBChB
Hong Kong, China

Oleg Malievskey, MD
Ufa, Russia

Rosemary Martino, PhD
Toronto, ON, Canada

Nancy Mayo, PhD
Montreal, QC, Canada

Charles McMellon, PhD
Hempstead, NY

Catherine Meer
Lyon, France

Anja Mehnert, PhD
Hamburg, Germany

Lillian Mellars, MS
Kenilworth, NJ

Elizabeth Merikle, PhD
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Harriet Nuwagaba-Birbonwoha, MBChB
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Aihua Ou, BS
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Amherst, NY

Jolie Rangish, MD
Toronto, ON, Canada

Stephane Robitail, MD
Marseille, France

Richard Sawatzky, MSN
Langley, BC, Canada

David Gwyn Seymour, MD
Aberdeen, United Kingdom

Jun Su, MD, MSc
Wallingford, CT

Yoshimi Suzukamo, PhD
Kyoto, Japan

Edwin Tsang, MPhil
Hong Kong, China

Sau Han Yau, FRCR
Hong Kong, China

Michael Yin, BA
Taipei, Taiwan

Otto Walter, PhD
Berlin, Germany

Lillian Yu-Jen Wang, MSc
Taipei, Taiwan

Eric Wery, MPH
Braine-l’Alleud, Belgium

Amanda Wheeler, PGDipPsy
Auckland, New Zealand

Jill M. Winters, PhD
Milwaukee, WI

ASSESSING QUALITY OF LIFE IN CLINICAL TRIALS METHODS AND PRACTICE

ISOQOL members Peter Fayers, PhD, Department of Public Health, Aberdeen Medical School and Ron Hays, PhD, Division of GIM and Health Services Research, UCLA School of Medicine have edited a Second Edition of Assessing Quality of Life in Clinical Trials: Methods and Practice, published April 2005.

Researchers in all clinical fields are fully aware of the importance of Quality of Life measurements in judging the efficacy of a given treatment. Psychological criteria play an important role in this evaluation. Assessment of Quality of Life in Clinical Trials: Methods and Practice explores the current state of the art and illustrates the benefits and potential of health related quality of life assessment in clinical trials. It covers a wide range of analytical issues, emphasizing new and innovative approaches that are of practical and clinical importance. The book will have widespread appeal to clinical trialists and researchers from a wide range of specialties.

The 464 page book is available for $75, plus shipping & handling, from Oxford University Press (www.oup.com). To receive a 20% discount as a member of ISOQOL, visit the Members Only section of the web site, then click on Member Publications.
In the second section of the questionnaire, potential future benefits were listed and respondents were asked to indicate their level of support for each benefit. For most of the potential benefits, in excess of 50% of respondents indicated that they ‘Might Want’ or ‘Definitely Want’ it; only for electronic access to teaching and learning resources relevant to QoL research in languages other than English did the percentage endorsing ‘Do Not Want’ exceed 50% (this probably reflects the geographic base of the respondents). Looking only at those endorsing ‘Definitely Want’, there was greater variability of views. The most desired benefit, by this criterion, was web-site access to an electronic database of QoL articles; electronic access to English-language teaching and learning resources relevant to QoL research, web-site links to QoL grant information, and web-site access to electronic database of QoL data are also popular. Only about 20% of respondents ‘Definitely Want’ inclusion of subscription to *Quality of Life Research* as a universal benefit, and electronic access to teaching and learning resources relevant to QoL research in languages other than English, web-chats with established scholars/experts in the field of QoL, web-chats with other ISOQOL members (e.g. for SIGs), discounts on subscriptions to journals other than Quality of Life Research and discount for joint membership with other societies were not in great demand either.

The final section of the questionnaire asked for demographic data. Of those respondents who answered the question on gender, 55% are female, 45% male. The majority of respondents were in the 36-55 year old age groups. 72 countries across all five continents were represented amongst the respondents, though most came from the United States, Canada, the United Kingdom, Sweden or the Netherlands. The vast majority of respondents were regular (full) members; 12% were students and 6% from non-industrialised nations (the latter two categories benefiting from reduced membership fees). Over 60% of respondents reported paying their own membership fees, but the pattern was reversed with regards to payment of registration fees for the annual scientific meeting, when two-thirds of fees are paid by employers. The majority (65%) of respondents indicated that their primary work area is academia, with 14% coming from clinical settings and 11% from industry. Similarly, the majority (81%) of respondents self-categorised their QoL activity/role as ‘researcher’, with almost all the rest (12%) describing themselves as ‘clinicians’. A wide range of educational/training backgrounds were observed, though ‘medicine’, ‘psychology’ and ‘epidemiology’ dominated.

The findings from this survey have been considered by the ISOQOL Board and the chairs of the standing committees, and are now being used to inform and prioritise activities and initiatives of the Society. In this way, we aim to make the Society responsive to the needs and demands of you, the membership. Thank you for sharing your views with us!

Watch for your 2005 ISOQOL Ballot in the mail soon. Make your vote count!
Western University of Health Sciences College of Pharmacy, Pomona, CA, is seeking qualified candidates for its 2005-2006 OUTCOMES RESEARCH FELLOWSHIP. The goal of the program is to provide comprehensive postgraduate training in conducting independent evaluative outcomes research for application in various settings. PharmD or MS/PhD with pharmacy training required. If interested, please email Anandi V. Law (alaw@westernu.edu) before June 15, 2005.

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 Embarcadero 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.

August 31 - September 3, 2005
The 19th Annual Conference of the European Health Psychology Society will be held at the National University of Ireland, Galway. Further details of the conference can be obtained from www.ehps2005.com or you can contact us at conference@ehps2005.com.

ISOQOL MEMBERSHIP DUES FOR 2005

The membership dues for ISOQOL have been fixed for at least 7 years. However, the costs of running the society have increased with inflation. During the October meeting, the ISOQOL board voted to increase the annual dues, with a modest increase for Regular, Student and Retired members. Reflecting the educational goals of the society, the dues for Students remain significantly lower than the dues for Regular members. The Board also voted to change the category of “Members from Developing Countries” to “Special” and tie eligibility for this category to income, rather than residence. The reduced fee for this category will hopefully encourage more members from less developed countries to join, while recognizing that there are many potential members residing in countries that do not qualify as developing countries under the criteria used previously. Finally, the Board voted to allow a 3% increase across all dues in future years to match inflation.

2005 Dues Structure:

- Regular (professionals in the field) $ 90.00 US
- Contributing (suppliers/supporters) $ 200.00 US
- Student: pre-doc, post-doc, resident, fellow  $ 36.00 US
- Retired  $ 36.00 US
- Special (income of $15,000 US or less annually) $ 25.00 US
ISOQOL invites you to San Francisco, the city that is home to a little bit of everything!

For more information visit us at www.isoqol.org

ISOQOL MEMBERSHIP BENEFITS

Know someone who might benefit from ISOQOL membership? Share these benefits with them and encourage them to join today!

- Online Membership Directory
- Participation in a variety of Special Interest Groups
- Reduced subscription rate for the Quality of Life Research Journal
- Reduced conference registration rates
- Annual meetings of the International Society for Quality of Life
- Opportunity to present and hear cutting edge research presentations and posters
- Opportunity to have special interest group meetings at the annual meeting
- Access to the “Members Only” section of the ISOQOL website – an invaluable resource tool!
- Participation in a variety of committees
- Participation in the ISOQOL listserv - email communication with other QOL experts
- Exposure to and participation with other professionals involved in quality of life research activities
- Discount on annual subscriptions to the Quality of Life Instruments Database, offered by MAPI Research Institute
- Complimentary receipt of newsletters published 3-times/year
- Complimentary copies of QualityMetric’s CD series “Understanding Health Outcomes: An Accredited Educational Series on CD-ROM,” Includes “Health Status: Concepts, Measures, and Applications” and “Measuring Specific Conditions Monitoring Outcomes” (while supplies last)
- 20% discount on the purchase of Assessing Quality of Life in Clinical Trials: Methods and Practice, Second Edition edited by Peter Fayers, PhD and Ron Hays, PhD

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