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The use and value of health status and HRQOL measurement

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Abstract
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The Use and Value of Health Status & HRQOL Measurement

Jan Sansoni

Australian Health Outcomes Collaboration
University of Wollongong
HO more encompassing term in Australia - health practice improvement and better patient outcomes are the common threads

Health Outcomes – focus on use of HRQOL and health status measurement for

- population health surveys
- to evaluate the effects of health interventions and to monitor patient outcomes at the clinical level and
- for pharmaceutical registration and reimbursement (PBS)
National Health Survey

- Surveys also contain items on health conditions, service use, health behaviours, socio-demographic aspects
- Value seen in identifying disease profiles for self reported health conditions, and for across disease comparisons. Provides useful normative data
- Not much analysis of health related actions/service use in relation to SF-36 in 1995
- Other later, related, projects confirmed previous associations of SF-36 with survival, future health, health utilization/expenditures etc.
Instruments Used: Major Health Surveys

- SF-36V1 \((PSM\ 1995,\ NHS\ 95,\ WHA,\ CCHOP,\ State\ Surveys)\)
- SF-12, GHQ12, Kessler 10, CIDI \((NMHWBS\ 1997)\)
- EQ-5D \((NSW\ 1998\ –\ note\ recent\ UK\ developments)\)
- Kessler -10 \((NSW\ 1998,\ NHS\ 2001,2004,\ 2008;\ 45\ and\ up)\)
- SF-36V2 \((SAHOS\ 2004)\)

A major value has been the provision of normative data supporting clinical research and the use of surveys to trial some instruments for proposed HO research and monitoring initiatives.
SF-36 Subscale Scores by Depression (NHS ‘95)
Women’s Health Australia

- 20-year longitudinal cohort study of the health and well-being of Australian women, Newcastle & Queensland Unis
- Commenced 1996 and continuing
- Funded by Commonwealth Dept. of Health & Ageing
- Postal surveys and linkage to Medicare database
- Social view of health:
  - physical health and symptoms, emotional well-being
  - health service use, access and satisfaction, demographics
  - health behaviours, time use, life events

Web site is at www.newcastle.edu.au/centre/wha
Goal

- to determine social, psychological, physical and environmental factors which determine health among in women throughout adult life
- to contribute to the development of policy and practice in key areas for women’s health
  - National Health Priority Areas - diabetes, asthma …
  - Health Targets e.g. Ageing Well, Continence, Quality Use of Medicines, National Tobacco Strategy, Watching Australia’s Weight, Active Australia …
- Cohorts = Young (18-25) Mid (45-50) Older (70-75) at commencement (1996). Cohorts 12,500 – 14,000 with high retention rates, follow up 3 - 5 years….longitudinal ‘snapshots’
Stiff or Painful Joints and Change in SF-36 Physical Health: Mid and Older Women

NB: change scores are adjusted for Survey 1 scores
Health Service Delivery: Coordinated Care Trials

- Trials which examined ‘fund pooling’ models to provide coordinated care for elderly with chronic conditions vs. usual GP care
- Hypothesized to improve outcomes… or maintain / slow rate of decline – given nature of trial population?
- SF-36 used to monitor outcomes of all comparison/control groups; disease specific measures and patient satisfaction were unique to each particular trial
- Few SF-36 differences detected – no surprise given subtle nature of intervention - access to services ? and timeframe ??
- Conclusions reflect poor understanding of HRQOL assessment?
Clinical Monitoring: Mental Health

- Review of consumer outcome measures – Andrews et al, 1994
- Small trial of potential consumer measures (BASIS, MHI, SF-36) and provider measures (HoNOS, LSP, RFS)
- Development of MH Classification and Service Costs Project MH-CASC (HoNOS, LSP, RUGS-ADL).
- Routine Implementation – HoNOS, LSP for all inpatients plus chosen consumer measure (K-10, BASIS, MHI) - latter also used for outpatients
Clinical Monitoring

- Benchmarking of service comparisons – outcomes results adjusted for patient mix - Casemix Adjusted Relative Mean Improvement (CARMI)…..but some issues

- HoNOS - assumed predictor of cost also a good predictor of outcome

- Is a clinician severity rating measure a good measure for monitoring patient outcomes over time?

- Australian Rehabilitation Outcomes Centre (AROC) - Similar benchmarking initiatives in rehabilitation (FIM) → web enabling

- Issues of real time feedback are critical for clinical use, static databases are not the answer
The Continuum of Care and Health Outcomes Project

- A longitudinal study of 7154 inpatients including both retrospective and prospective data (1995-96)
- Develop profiles on health outcomes, care, service use and financial costs
- Compare various patient and population groups in their service use and health outcomes
- Use the findings to help clinicians and administrators improve their decision making - implement and develop outcomes management model
Mean Pain Scores (SF-36) for Surgical and Medical Patients

- **Day only Surgical** (n=1167)
- **Other Surgical** (n=1611)
- **ACT Population**
- **Medical** (n=4163)
CCHOP to DiscoverQuick

- Need to streamline system for use in routine care and research settings
- DiscoverQuick is a web enabled intelligent knowledge management system for outcomes management - providing real time feedback to clinicians
- Allows recruitment to RCTs and HSR studies while providing support for patient care
- Integrates EBM knowledge bases, guidelines, in developing decision support algorithms
- Includes HRQOL data with settings which can be linked to instrument review repositories and provide feedback to these
DiscoverQuick

Overwhelmingly enthusiastic response

Neonatology
Pain management
Gastroenterology
Orthopaedics/Cardiology
Diabetes Educators Association
CLP Project
Arthritis ACT, SA, Qld, Tas
Academic medicine unit
Endometriosis (gynaecology)
Respiratory and Sleep Medicine
Mental health (working towards a start)
Rheumatology (under discussion)
Registrar training (under discussion)
Anaesthetics (under discussion)

Minimisation Group
< 7 years old & Not Overweight

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<th>Score</th>
<th>Treatment As Usual</th>
<th>Prescribed Treatment</th>
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Grand Total 52

Mean Depression (+/-95% CI)

Baseline n=73, 1 month n=45, 4 months n=38, 8 months n=21
HRQOL: Needs Assessment

- Community and Primary Care - Initial Needs Assessment, Ongoing Needs Assessment, Health and Community Care Screening, Aged Care Assessment, Provision of Appliances for Disabled Persons
- Tiered approaches, screening and follow up assessment to determine needs and assign services
- Use of ADL and IADL functional skills profiles (Modified Barthel, FIM, Lawton’s IADL)
- Mainly needs assessment but also for outcomes monitoring in some projects
Aged Care Assessment

- Desire to standardise aged care assessments nationally – great goals - given the diversity of these assessments
- Screening and follow up assessments
- Ensure all clients receive a cognitive assessment
- Desire for valid and reliable assessment……but do committee choices really reflect this aspect?
## Summary of Ratings for Cognitive Assessment Instruments

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Weight</th>
<th>MMMSE (3MS)</th>
<th>SMMSE</th>
<th>RUDAS&lt;sup&gt;a&lt;/sup&gt;</th>
<th>KICA-COG</th>
<th>KICA-CARER</th>
<th>IQCODE</th>
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<td>Length/feasibility of instrument for inclusion in battery</td>
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<td>Complexity of administration/cognitive burden</td>
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<td>Sensitivity</td>
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<td>Reliability evidence</td>
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<td>2&lt;sup&gt;b&lt;/sup&gt;</td>
<td>2&lt;sup&gt;b&lt;/sup&gt;</td>
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<td>Validity evidence</td>
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<td>Cost of the instrument</td>
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<td>Cost of instrument administration</td>
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**Weighted Total**

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<th>MMMSE (3MS)</th>
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<td>SMMSE</td>
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<tr>
<td>IQCODE</td>
<td>68.5</td>
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Based on the DOMs review in 2008 – this review needs to be updated

b. Scored as 2 or 2.5 because of there being limited evidence/publications or independent publications but what there is indicates good sensitivity, validity and/or reliability.

c. Rated as 2 vs. 1 as the costs are minimal and estimated at 12 cents per use

SAHOS: User Pays Survey

- 3000 sample community survey used by researchers and government
- 2004 survey compared utility measures EQ5D, AQOL, HUI3, SF-6DV2, 15D in relation to incontinence items and also deriving interim norms for SF-36V2
- Also reflects earlier government interest in developing outcome measurement suites (e.g. dementia, continence)…standardizing use of measures/items…for clinical applications
Effect of urinary incontinence on HRQoL by gender

Means and 95% CIs for perceived quality of life (AQoL, EQ5D, HUI3, 15D, SF6D) across levels of urinary incontinence problem (UDI) for Males and Females.
Regulatory Aspects: PBS

- Pharmaceutical Benefit Scheme (PBS) 1992 – required to conduct economic evaluation (with a focus on outcomes including HRQOL) for drug registration to attract government subsidy
- Subsidised medicine prices capped with a patient co-payment @ $5.60 healthcare card, others $34.20
- Reference Pricing … a ‘me too’ drug price will be set at the price of the lowest comparable drug (CMA). To gain a higher price for a new drug one must show relative benefit per $ over existing drugs…CEA, CUA analyses
- HRQOL data particularly relevant for submissions for chronic conditions and need to justify psychometric properties of selected instruments (PBAC Guidelines)
Types of Economic Evaluation

From Wilson 2004
Pharmaceutical Benefits Scheme

- Quality of economic evaluations - 67% had some methodological flaw (Hill et al, 2000 … analysis, interpretation, est. comparative clinical efficacy, modeling)

- More recent revisions of PBAC guidelines… but need for greater expertise and greater ‘genuine’ transparency?

- Despite these issues – a very effective scheme for pricing

- See www.health.gov.au/pbs
Some Issues

- Plenty of use but sometimes not gaining as much value – reflects lack of familiarity with assessment and interpretation of HRQOL data (e.g. reliability and validity rhetoric vs. reality)
- Instrument selection issues … need to relate to purpose of assessment, develop more wisdom concerning the use of measures
- Convenient/routine follow up assessment points may not always be the most informative
- Easier to collect data than to use it to inform practice
- HRQOL assessment issues may need more thought and the development of greater expertise
Future Directions

- Becoming more sophisticated – and an increasing recognition of HRQOL measurement issues
- A number of national (large scale) initiatives (e.g. 45 and up study, WHA) and increasing implementation in clinical practice
- A focus on improving technology to facilitate outcomes monitoring and service comparisons for practice improvement
**CLINICAL ASSESSMENT**

**Risk Assessments and Diagnoses**

- **Breast Cancer**: Breast Cancer
- **Early unilateral single primary invasive BC**: Early unilateral single primary invasive BC
- **In Patient**: In Patient
- **Follow up phase**: Follow up phase

**Average Vitality Levels (+/- SD) over time comparing Patient against Group**

**Patient progress**

- **Vitality by time**

**Graph**

- Average Score vs Duration Weeks
- Patient compared to Group
- Group: Ph 173

**Notes**

- **Hospital Device, DOB**: 1/1/1945
- **Assessed By**: Dr. Bruce Shadbolt
Distribution of HRQoL utility scores by instrument

- **AQoL:**
  - Nice even distribution

- **HUI3:**
  - Nice even distribution

- **SF6D:**
  - Most cases 0.80-1.00
  - Almost none <0.40

- **EQ5D:**
  - Inconsistent distribution

- **15D:**
  - 74% cases >0.90
  - Almost none <0.50