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The use and value of health status & HRQOL measurement

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Abstract
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The Use and Value of Health Status & HRQOL Measurement

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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 \textit{(PSM 1995, NHS 95, WHA, CCHOP, State Surveys)}
- SF-12, GHQ12, Kessler 10, CIDI \textit{(NMHWBS 1997)}
- EQ-5D \textit{(NSW 1998 – note recent UK developments)}
- SF-36V2 \textit{(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)

No Depression

Depression
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 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)

Duration (wks) post-discharge

Pre-admission
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)

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<table>
<thead>
<tr>
<th>Treatment groups</th>
<th>&lt; 7 years old &amp; Not Overweight</th>
<th>7 + years old &amp; Not Overweight</th>
<th>7 + years old &amp; Overweight</th>
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<td>TAU</td>
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<td>17</td>
<td>7</td>
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<tr>
<td>PT</td>
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<td>14</td>
<td>6</td>
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</table>

Grand Total: 52

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Mean Depression (+/-95% CI)

Baseline n=73, 1 month n=45, 4 months n=39, 8 months n=21

Number of symptoms at 20 minutes

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Parent to Parent of Georgia
Roadmap to Services

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Additional Resources
Recreation & Camps
Child Care
Advocacy & Law
Insurance & Care Plan
Parent & Family Support
Diagnosis & Intervention
Education
Welcome Center

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Parent is Parent of the ROADMAP
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>
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<tr>
<th>Criteria</th>
<th>Weight</th>
<th>MMMSE (3MS)</th>
<th>SMMSE</th>
<th>RUDAS(^a)</th>
<th>KICA-COG</th>
<th>KICA-CARER</th>
<th>IQCODE</th>
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<td>Availability of comparison data</td>
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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>2.5(^b)</td>
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<tr>
<td>Validity evidence</td>
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<td>3</td>
<td>2.5(^b)</td>
<td>2.5(^b)</td>
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<tr>
<td>Cost of the instrument</td>
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<td>2(^c)</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

![Graph showing the effect of urinary incontinence on HRQoL by gender](image)

- **Males**
- **Females**

Level of urinary incontinence problem (UDI)

- None
- Slight
- Moderate
- Problem
- Major

Mean utility (95% CIs)

- AQoL
- EQ5D
- HUI3
- 15D
- SF6D
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
Patient progress

Vitality by time

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

Risk Assessments and Diagnoses

Breast Cancer

Severity

Early unilateral single primary invasive BC

Setting

In Patient

Status

Follow up phase

A. Tumour size (invasive)

21 - 50 mm

B. Tumour margin

0 mm

C. Nipple involvement

Yes

D. Widespread disease

No

E. Nodal categories

No regional lymph node metastasis
Distribution of HRQoL utility scores by instrument

- **AQoL**: Nice even distribution
- **HUI3**: Nice even distribution
- **15D**: 74% cases >0.90, almost none <0.50
- **SF6D**: Nice even distribution
- **EQ5D**: Most cases 0.80-1.00, almost none <0.40

![Graph showing the distribution of HRQoL utility scores by instrument](image)