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Quality of life assessment in people living with psychosis

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Abstract *Background* The value of measuring health-related quality of life (HRQoL) among people with persisting psychotic disorders is contentious, despite the call for it in treatment outcome and economic evaluation. Our aim was to investigate the validity of psychotic patients' self-report regarding their HRQoL, using the WHOQOL-Brèf, a generic measure, and the Assessment of Quality of Life (AQoL), a utility instrument. *Methods* Community-dwelling patients (N = 173) with a longstanding psychotic disorder who were attending an inner-city mental health service completed the WHOQOL and AQoL, and measures of their symptoms, disability and living conditions. Case managers completed the measures as proxies. *Results* Both instruments were acceptable and completed readily. There were significant differences by instrument dimension, with social relationships obtaining the worst scores. Patients' and case managers' scores correlated moderately, with case managers' being lower. When examined by other study instruments, correlations varied according to who completed the instrument, which suggested bias by instrument completer. Patients' scores correlated better with a neutral estimator of health status, suggesting there are areas of patients' lives that clinicians know little about. When examined against population data, patients experienced significantly worse HRQoL. *Conclusions* The WHOQOL-Brèf and AQoL are sensitive to the HRQoL status of those with long-term mental illness. We found no evidence to reject patient self-reports. Given systematic differences between patient and case manager reports, patient perspectives should be preferred in evaluation research. Utility measurement and generic HRQoL assessment are feasible and important in this population.

Key words health-related quality of life measurement – validity – psychosis – WHOQOL-Brèf – Assessment of Quality of Life – proxies – psychometrics – mental health

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Introduction

People living with persisting psychotic disorders need adequate and continuing treatments in a stable, safe and stimulating environment. Although the efficacy of several treatments is known, this knowledge is disseminated and applied poorly (Davidson and McGlashan 1997). The field now requires evaluation of interventions in cohorts of patients in regular clinical settings. Otherwise, 'there is pressure to repeat old mistakes in new settings, and to neglect long-term patients living in hospital and community settings in the face of opportunities for providing services to people with apparently more to gain' (Abrahamson 1993, p. 537).

Evaluating service and intervention effectiveness requires outcome measures on several dimensions. These include changes in HRQoL from the patient's perspective, as well as objective measures of mortality, morbidity, symptoms and disability (Warner et al. 1998). The use of appropriate HRQoL measures is important in highlighting needs and outcomes that are significant to individuals and their families (Lehman 1996), and

HRQoL has become an acknowledged outcome of mental health services (Taylor et al. 1998).

Yet, assessing HRQoL in psychosis has had mixed results. People living with long-term psychosis report worse HRQoL than the general population or patients with physical illness (Bobes and Gonzalez 1997), and lower HRQoL when hospitalized compared with community dwelling (Taylor et al. 1998). However, the expressed levels of life satisfaction tend to be high (Barry and Crosby 1996), and the use of HRQoL indicators as outcome measures is questioned. Extensive changes in external circumstances and intensive community care for people living with psychosis have not produced significant HRQoL changes over time (Barry and Crosby 1996; Taylor et al. 1998). This lack of effect may be explained by mental health services, even the best, failing to use the 'active ingredients of treatment' likely to produce changes in mental health and functioning which would be reflected in improved HRQoL (Taylor et al. 1998). The 'inner experiences' of patients may not change even with major improvements in living circumstances (Skantze et al. 1992).

In addition, expectations or the horizons of personal experience affect subjective HRQoL evaluations (Atkinson et al. 1997; Warner et al. 1998), as may adaptation (Frederick and Loewenstein 1999). For these reasons, and because of affective, cognitive or reality distortions, many are skeptical of the validity of psychotic patients' self-reports as an outcome measure, where validity refers to establishing an appropriate relationship between the manifest measurement and the underlying construct of interest (Cronbach and Meehl 1955).

However, to abandon HRQoL and utility measurement runs the risk of marginalizing people with mental illness in the resource allocation process (Chisholm et al. 1997). Given the null findings outlined above, the development of HRQoL instruments more sensitive to the experience of people living with mental disorders is a priority (Mangalore 2000). Two recent instruments which may hold this promise are the World Health Organization's (WHO) short Quality of Life (QoL) instrument (WHOQOL-Brèf) and the Assessment of Quality of Life (AQoL) instrument. The WHOQOL-Brèf was chosen because it was designed to be applicable to people living under different circumstances, conditions and cultures (WHOQOL Group 1998a; 1998b), and the AQoL because it was developed from a theoretical understanding of HRQoL based on the WHO definitions of health, disease, disability and handicap (Hawthorne et al. 2000).

We are unaware of previous reports on the validation of generic or utility instruments in people living with mental illnesses. This study aimed to assess the validity of the WHOQOL-Brèf and the AQoL for measuring the subjective HRQoL in people receiving long-term community treatment for psychosis, and thereby clarify the use of HRQoL as an outcome measure in mental health. Our hypothesis was that self-reported HRQoL by psychotic patients would be just as valid as reports by their most intimate health professionals, their case managers, and that we would establish this through assessing the extent to which patients' and case managers' scores systematically agreed when compared with each other and varied when compared against a range of other indicators.

Subjects and methods

Defining and measuring HRQoL

The WHO defines HRQoL as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (Sartorius 1990, p. 11). This multi-dimensional concept incorporates a person's physical health, psychological state, level of independence, social relationships, personal beliefs and relationship with salient features of the environment (Sartorius 1990). Generally, HRQoL is considered a relatively stable internal construct reflecting the evaluation of cumulative experiences (Orley et al. 1998). Change to this central construct usually occurs gradually, even in the face of dramatic life circumstances. Adaptation will also occur (Frederick and Loewenstein 1999), and the critical issue with chronic illnesses is how far adaptation to a health state may 'invalidate' an individual's valuations.

When measuring HRQoL there are two critical issues. The first is whether the measurement should be generic or specific to a disorder or circumstance. The second relates to the perspective adopted: should it be externally assessed by an observer (e. g. a clinician), or be the subjective assessment of the patient, who is recognized as the expert (Orley et al. 1998; Voruganti et al. 1998). In general, the literature suggests it should be the latter.

The WHO Quality of Life Assessment (WHOQOL) is a generic quality of life instrument in that it was designed to be applicable to people living under different circumstances, conditions and cultures (WHOQOL Group 1998a; 1998b). Two versions are available: the full WHOQOL with 100 items and the WHOQOL-Brèf with 26 items. We used the WHOQOL-Brèf for reasons of brevity. It provides unweighted measurement on four domains: physical, psychological, social and the environment. Scores are presented on rating scales, where the best possible quality of life is represented by a score of '100'.

The Assessment of Quality of Life (AQoL) instrument was chosen because it was developed from a theoretical understanding of HRQoL based on the WHO definitions of health, disease, disability and handicap (Hawthorne, Richardson, Day, Osborne et al. 2000), and as such gives more weighting to social disability than other utility instruments (Hawthorne et al. 2001a; 2001b). It is a multi-attribute utility instrument, where utility refers to a preference-weighted index that reflects societal values for respondents' quality of life health states. It was designed for use in economic cost-utility evaluations. The AQoL comprises 15 questions, measuring five dimensions of HRQoL: illness, independent living, social relationships, physical senses and psychological wellbeing. The latter four dimensions (12 items) are used to generate the utility index. AQoL utility scores are presented on a life-death scale, where the lower boundary is –0.04 representing QoL health states worse than death (i. e. respondents obtaining these scores would prefer to be dead rather than living in their current HRQoL state), 0.00 represents death-equivalent HRQoL states, and the upper boundary, 1.00, represents full HRQoL equivalent states. The weights used in scoring the AQoL were obtained from a representative sample of the Australian population using the time-trade off procedure (Hawthorne et al. 2001a; 2001b; Hawthorne et al. 1999).

The WHOQOL and AQoL were each designed for use alongside measures of symptoms, side effects and disability and so far neither has been used extensively in people with psychosis. To date, disorder-specific instruments have been used to plan services and assess intervention effects in mental health (Barry and Zissi 1997; Lehman 1996; Oliver et al. 1997). For example, previous work eliciting utility values for people living with mental illnesses has used specific vignettes describing the experience of mental illness (Chouinard and Albright 1997; Revicki et al. 1996). These estimates provide direct information about the impact of illness, but have limited application to comparative summative or economic evaluation. The use of self-report generic or utility instruments will become more widespread because of the growing importance of economic evaluation, to which HRQoL measurement is integral (Kavanagh and Stewart 1995).

Generic and multi-attribute utility instruments allow comparison of the effects of different disorders, whether mental or physical, and the various treatments given. Generic profile instruments, like the WHOQOL-Brèf, are useful in clinical and service evaluations. On the other hand, a utility index is relevant when mental health services need to justify resource use compared with other health services (Wilkinson et al. 1992). Utility measures enable calculation of the quality-adjusted life year (QALY), which may relate to health gain or maintenance. Utility measurement is, thus, an important aid to planning and priority setting, although debated fervently on technical and ethical grounds (Chisholm et al. 1997).

Sampling frame

The study population comprised all people aged 18–64 years with a chart diagnosis of a psychotic disorder (ICD-9 diagnosis between 290.1 and 299.9; ten patients with unspecified psychotic disorders were also included), with recorded contact with community-based services at St Vincent's Mental Health Service (SVMHS) in the 6 months prior to study commencement, and who were initially registered at least 2 years before this key contact. SVMHS is an area mental health service, covering two local government areas in inner Melbourne (total population = 200,000 people). SVMHS operates through two sectors, each with a community mental health clinic and associated domiciliary teams and inpatient services. All people meeting these criteria were listed from the person-linked psychiatric database covering all Victorian state-funded mental health services. There were 766 patients in the population.

Participants

The case managers were asked to identify eligible patients and to contact them and invite study participation. Eight potential patients were deceased, 33 did not have a diagnosis or experience of psychosis according to the case manager, 44 did not speak sufficient English to complete the questionnaires, 257 did not present for treatment and/or could not be contacted during the study period, 5 suffered physical impairment preventing participation, 16 were so intellectually disabled they could not participate, and 74 were judged as too unwell to contact for this purpose. Of the 329 in scope, 173 agreed to participate and were interviewed; a 53 % recruitment rate. After complete description of the study to the participants, written informed consent was obtained.

Administration of instruments and data analysis

All interviews were conducted by one of the researchers (Ms Thomas). Patients were administered, in interview, a demographic questionnaire followed by self-administration within interview of an instrument battery including the *WHOQOL-Brèf* (WHOQOL Group 1998a), *AQoL* (Hawthorne et al. 1999), the *Beck Depression Inventory* (Beck et al. 1961), the *Beck Hopelessness Scale* (Beck et al. 1974), the *SF-36* (a health status profile instrument) (Ware et al. 1993) and the *LUNSER* (a medication side-effect measure) (Day et al. 1995). In a separate interview the case managers completed the *WHOQOL-Brèf* and *AQoL* as a proxy for their clients, as well as the *General Assessment of Functioning Scale* (GAF) (Endicott et al. 1976) and the *Health of the Nation Outcomes Scale* (HONOS) (Beevor and Curtis 1995). Case managers were not present at the participant interview and were blinded as to participants' responses.

Case managers were selected because they are mental health clinicians who are responsible for the continuing care of patients and organizing links with other services and supports as required. In addition, over 80 % of our sample reported living without any significant other in their lives; for these patients the case manager was the significant other.

Data analysis used non-parametric and parametric tests as determined by the nature of the data and its distribution, based on tests of skewness and kurtosis. The data were analysed using SPSS Versions 6 and 10 (SPSS 1996; 2000). The relative efficiency test (the ratio of *t*-values squared) was used to compare instrument sensitivities (Fayers and Machin 2000; Liang et al. 1985; Wright and Young 1997).

Results

Descriptive statistics (Table 1) demonstrate the predominance of males, the relatively poor educational levels, and the very low proportion of the cohort employed or currently married. The characteristics of the sampling frame were also noted. Fifty-six per cent were males, 29 % were aged 20–34 years and 44 % aged 35–49 years, 69 % were Australian-born, 19 % had post-school education and 7 % were employed. When participants were compared with this study population, participants were more likely to be Australian-born, to have completed post-school education and to be employed (χ^2 test, $p < 0.01$). There were no significant differences by age and gender.

Participants' health status is also shown in Table 1. From the patient records, 70 % had an ICD-10 diagnosis of schizophrenia. Twenty-two per cent reported moderate or severe depressive symptoms and 33 % moderate or severe hopelessness. These symptom levels are high, but not unexpected in a population receiving treatment for a persisting psychotic disorder. Seventy-nine per cent were using anti-psychotic medications (42 % of these were using 'atypical', 30 % 'depot' and 28 % other (older) types; not shown in the table) and 53 % were using more than one medication. Most respondents reported unwanted side effects, with 31 % reporting high or very high levels. Although not shown in the table, 26 (15 %) respondents reported involuntary tongue movements, 5 (3 %) had been arrested and 13 (8 %) reported an overdose of drugs or another form of deliberate self-harm in the previous year.

The two HRQoL instruments were self-completed as designed in a face-to-face interview: 7 respondents required assistance. Both instruments were reported to be acceptable, except that 14 (8 %) respondents found the WHOQOL-Brèf question on sexual behaviour inapplicable; they reported no sexual desires or contacts.

The WHOQOL-Brèf and AQoL scores

Table 2 shows the WHOQOL-Brèf and AQoL scores reported by patients and case managers. The WHOQOL-Brèf domain scores fell between 50 and 60 % of the potential scale range, and AQoL dimensions and utility scores covered 40-90 %.

Case managers consistently scored patients lower

Table 1 Demographic details and health status of participants

	Category	Number (N = 173)	(%)
Gender	Male	109	(63 %)
	Female	64	(37 %)
Age	20–34 years	53	(31 %)
	35–49 years	75	(43 %)
	50–65 years	45	(26 %)
Country of birth	Australia	137	(79 %)
Marital status	Single	117	(68 %)
	Married/De facto	17	(10 %)
	Divorced/separated	39	(23 %)
Education	Primary/other	95	(55 %)
	Secondary	31	(18 %)
	Post-secondary	47	(27 %)
Employment status	Employed	26	(15 %)
Income source	Wages only	15	(9 %)
	Social security pension	152	(88 %)
	Insurance/annuity	4	(2 %)
Accommodation arrangements	Own home	19	(11 %)
	Rented home	73	(42 %)
	Rented room	15	(9 %)
	Family home	21	(12 %)
	Crisis/sheltered room	16	(9 %)
	Group/supported house	13	(8 %)
	Institution[a]	15	(9 %)
Primary diagnosis[b]	Schizophrenia	121	(70 %)
	Schizoaffective disorder	23	(13 %)
	Psychotic (organic)	8	(5 %)
	Bipolar affective disorder	10	(6 %)
	Other	11	(6 %)
Depression[c]	Mild	31	(18 %)
	Moderate	23	(13 %)
	Severe	16	(9 %)
Hopelessness[d]	Mild	58	(34 %)
	Moderate	34	(20 %)
	Severe	22	(13 %)
HONOS global scores[e]	Mean ± sd	10.8 ± 5.6	
GAF functioning scores[f]	Mean ± sd	51.0 ± 16.8	
Medication	Antipsychotic	137	(79 %)
	Antidepressant	10	(6 %)
	Mood stabiliser	18	(10 %)
	Tranquilliser	2	(1 %)
	No medication/unknown	6	(3 %)
Number of drugs being taken	0	5	(3 %)
	1	78	(45 %)
	2	60	(35 %)
	3+	30	(18 %)
Medication side effects[g]	Very low/low	34	(19 %)
	Average	86	(50 %)
	High/very high	50	(31 %)
Health status (SF-36)	Physical (PCS) (Mean ± sd)	48.1 ± 9.1	
	Mental (MCS) (Mean ± sd)	42.2 ± 11.2	

[a] Hostel, nursing home, hospital

[b] ICD-10 diagnosis made most recently by service psychiatrists, taken from working clinical records

[c] Beck Depression Inventory (BDI) scores

[d] Beck Hopelessness Scale (BHS) scores

[e] Health of the Nation Outcome Scales (HONOS) scores

[f] Global Assessment of Functioning Scale (GAF) scores

[g] Liverpool University Side Effects Rating Scale (LUNSER)

than the patients did themselves on the WHOQOL-Brèf: 6 % for the Physical domain, 10 % for the Psychological, 15 % for Social Relationships and 9 % for the Environment domains. For the AQoL, case managers' valuations were significantly lower than patients' for the Social Relationships (14 %) dimension and the AQoL utility scores (10 %), and significantly higher for the Physical Senses (4 %) dimension.

When the relationship between the case managers' and the patients' scores was examined, the obtained correlations were modest (range: 0.07–0.55); the average WHOQOL-Brèf correlation was 0.37, while for the five AQoL dimensions it was 0.27. The details are given in Table 3.

When patients' scores were examined by their demographic characteristics, there were no significant differences in WHOQOL-Brèf domain scores, although the data were suggestive for gender on the Environment domain (mean (sd); males: 59.6 (13.6), females 63.6 (14.0), ANOVA, F = 3.50, p = 0.06) and for work status on the Social Relationships domain (employed: 58.3 (16.2), other: 50.0 (20.7), ANOVA, F = 3.80, p = 0.05). For the AQoL significant differences were observed by age (20–34 years: 0.56 (0.29); 35–49 years: 0.52 (0.31); 50–65 years: 0.40 (0.31), ANOVA, F = 3.60, p = 0.03), marital (single: 0.49 (0.30); married/de facto: 0.67 (0.24); and divorced/separated: 0.46 (0.32), ANOVA, F = 3.25, p = 0.04) and working status (employed: 0.64 (0.23); other: 0.48 (0.31), ANOVA, F = 6.66, p = 0.01).

Table 4 shows correlations between both case managers' and patients' HRQoL scores, the clinical indicators and the SF-36 PCS and MCS. Regarding correlations between patient-completed instruments and patient-completed WHOQOL-Brèf and AQoL, the correlations fell within the range $r = 0.14–0.69$. This may be compared with that between patient-completed instruments and the manager-completed WHOQOL-Brèf and AQoL where the range was $r = 0.06–0.39$.

The correlations between manager-completed instruments and patient-completed WHOQOL-Brèf and AQoL were within the range $r = 0.05–0.34$, and correlations between manager-completed instruments and manager-completed WHOQOL-Brèf and AQoL were within the range $r = 0.22–0.56$.

These differences are striking, and reflect differences between those instruments completed by the patients (BDI, BHS, LUNSER and SF-36) and those completed by the case managers (HONOS and GAF). When we used Cohen's q to examine these differences in correlations, the analyses showed that 54 % (19/35) of comparisons were significant, as marked in Table 4.

These results suggest that the criteria indicators (BDI, BHS, HONOS, GAF, LUNSER and SF-36) were biased by who completed them, and that correlational analyses of case managers' and patients' scores reflect these biases. To avoid this, a neutral indicator of patients' health status was created based on the first WHOQOL-Brèf question. This question probes the respondents' health status and was completed by both case managers

Table 2 Details of patients' and case managers' AQoL and WHOQOL-Brèf scores

		Patients		Case managers		Statistics[a]
		Mean	Sd	Mean	Sd	
WHOQOL-Brèf[b]	Physical	60.7	15.4	57.0	12.5	t = −3.07, df = 167, p < 0.01
	Psychological	56.8	17.4	51.1	13.0	t = −3.96, df = 167, p < 0.01
	Social	51.3	20.3	43.4	18.8	t = −4.24, df = 167, p < 0.01
	Environment	61.1	13.8	55.4	13.5	t = −4.54, df = 167, p < 0.01
AQoL[c]	Illness[d]	0.40	0.27	0.41	0.24	z = −0.57, p = 0.57
	Independent living	0.87	0.18	0.85	0.18	z = −1.74, p = 0.08
	Social relationships	0.63	0.32	0.54	0.27	z = −3.70, p < 0.01
	Physical senses	0.92	0.13	0.96	0.07	z = −2.98, p < 0.01
	Psychological wellbeing	0.85	0.18	0.90	0.10	z = −1.43, p = 0.15
	AQoL utility[e]	0.50	0.31	0.45	0.24	t = −2.21, df = 165, p = 0.03

[a] WHOQOL-Brèf domains: t-test
AQoL dimensions: Wilcoxon matched-pairs signed ranks test
AQoL utility: t-test

[b] Transformed scores: scale range 0–100; the higher the score the better the health state

[c] Transformed scores: scale range 0–100, where 0 = dimension worst health state and 1.00 = dimension best health state

[d] Not used in computation of utility score: a measure of the use of medications and other health care resources

[e] Utility scale: −0.04–1.00, where negative scores represent health states worse than death, 0.00 = death and 1.00 = normal health. The higher the utility the better the HRQoL

Table 3 Correlations between case managers' and patients' WHOQOL-Brèf and AQoL scores

		Correlations	p	Correlation type
WHOQOL-Brèf	Physical	0.47	< 0.01	Pearson
	Psychological	0.33	< 0.01	
	Social	0.31	< 0.01	
	Environment	0.35	< 0.01	
AQoL	Illness[a]	0.07	0.34	Spearman
	Independent living	0.23	< 0.01	
	Social relationships	0.50	< 0.01	
	Physical senses	0.20	0.01	
	Psychological wellbeing	0.43	< 0.01	
	AQoL utility	0.55	< 0.01	Pearson

[a] Not used in computation of utility score

and patients; the average score was taken and then assigned to a ranked answer consistent with the interval within which the score fell.

The validity of case manager and patient scores for the WHOQOL-Brèf and AQoL was then examined against this index, where validity was indicated by a monotonic relationship; i.e. as health status declined so should HRQoL. The results, provided in Table 5, showed the expected monotonic relationship between health status and obtained scores, except for three instances involving the case managers. On the WHOQOL-Brèf Physical domain, case managers rated the HRQoL of those in good health the same as those in very good health, and on the WHOQOL-Brèf Environment domain, case managers rated the HRQoL of those in very good health and in good health similarly to those in excellent health.

For all levels of the WHOQoL-Brèf case managers' scores were 9–14 % lower (i.e. indicating worse HRQOL) than the patients' scores. There was one exception to this involving patients rated as having poor health; these patients were assigned a similar rating by the case managers on the WHOQoL-Brèf Physical domain ($t = 0.71$, $p = 0.48$). For the AQoL, patients assigned to excellent health were rated by the case managers 23 % worse than by the patients themselves, yet for those with poor health the case managers rated their HRQoL 65 % better than did the patients themselves (ANOVA, $F = 24.93$, $p < 0.01$).

The data suggested that both instruments were highly sensitive to differences in health status (Table 5), irrespective of who completed them. When we calculated the relative efficiency (Fayers and Machin 2000; Liang et al. 1985; Wright and Young 1997), setting the case managers' scores to 1.00, patients' scores showed greater sensitivity on the WHOQOL-Brèf Physical ($RE = 1.25$) and Environment domains ($RE = 1.48$) and also on the AQoL ($RE = 2.19$). For the WHOQOL-Brèf Psychological and Social Relationship domains the case managers' scores showed greater sensitivity ($RE = 0.73$ and 0.66, respectively). These differences do not, of course, imply that one or the other was 'correct', but rather are evidence of the sensitivity of the instruments (were the instruments insensitive, we would expect the F-values in Table 5 to be close to 0.00 and the RE statistic to be always close to 1.00).

We compared our findings with population norms (Hawthorne, Richardson, Day, & McNeil 2000). Patients' scores were significantly lower on all WHOQOL-Brèf domains and AQoL dimensions and utility scale (ANOVAs, F-range: 15.14–193.07; $p < 0.01$* for all comparisons). On average WHOQOL-Brèf patient scores were 23 % lower than the population norm. For AQoL dimensions, patient scores were 19 % lower, and utility

Table 4 Correlations between clinical indicators, SF–36 and WHOQOL-Brèf domain scores and AQoL utility score

Who[a]	Instrument	WHOQOL-Brèf								AQoL	
		Physical		Psychological		Social		Environment			
		Patients	Managers	Patients	Managers	Patients	Managers	Patients	Managers	Patients	Managers
Patients	Depression (BDI)	–0.63[b, d]	–0.39[b]	–0.59[b, d]	–0.36[b]	–0.41[b]	–0.32[b]	–0.41[b, e]	–0.17[c]	–0.55[b, d]	–0.21[b]
Patients	Hopelessness (BHS)	–0.33[b]	–0.19[c]	–0.49[b, e]	–0.30[b]	–0.36[b]	–0.27[b]	–0.40[b, d]	–0.09	–0.32[b]	–0.23[b]
Patients	Medication side effects (LUNSER)	–0.59[b, e]	–0.39[b]	–0.45[b, e]	–0.25[b]	–0.31[c]	–0.19[c]	–0.37[b, e]	–0.15	–0.46[b, d]	–0.15
Patients	SF-36 PCS	+0.40[b]	+0.38[b]	+0.14	+0.11	+0.16[c]	+0.12	+0.22[b]	+0.14	+0.33[b, d]	+0.06
Patients	SF-36 MCS	+0.62[b, d]	+0.34[b]	+0.69[b, d]	+0.37[b]	+0.47[b]	+0.34[b]	+0.55[b, d]	+0.12	+0.47[b, e]	+0.28[b]
Managers	Functional ability (GAF)	+0.18[c]	+0.28[b]	+0.10[e]	+0.31[b]	+0.05	+0.22[b]	+0.13	+0.27[b]	+0.28[b, e]	+0.47[b]
Managers	Functional status (HONOS)	–0.20[c]	–0.30[b]	–0.13	–0.31[b]	–0.05[e]	–0.35[b]	–0.25[b]	–0.33[b]	–0.34[b, d]	–0.56[b]

[a] Who completed the instrument
[b] Pearson correlation, $p \leq 0.01$, between instrument scores
[c] Pearson correlation, $p \leq 0.05$, between instrument scores
[d] Cohen's q, $p \leq 0.01$, testing for differences in correlations between patients and managers
[e] Cohen's q, $p \leq 0.05$, testing for differences in correlations between patients and managers

Table 5 Mean scores by computed health status

			Health status index level[a]					Statistics[b]
			1 Excellent	2 Very good	3 Good	4 Fair	5 Poor	
N			16	49	45	49	15	
WHOQOL	Physical	Patient	71.21 (15.29)	65.20 (11.72)	63.81 (11.64)	56.49 (14.37)	38.33 (15.94)	F = 16.23, $p < 0.01$[c]
		Case manager	64.96 (13.31)	59.97 (10.79)	60.79 (10.12)	52.84 (11.29)	41.90 (10.84)	F = 12.96, $p < 0.01$[d]
	Psychological	Patient	71.61 (16.33)	62.69 (12.73)	57.78 (14.50)	50.77 (16.70)	38.33 (20.42)	F = 12.38, $p < 0.01$[e]
		Case manager	61.72 (12.00)	56.40 (10.22)	53.80 (10.76)	44.56 (11.85)	37.50 (10.08)	F = 16.88, $p < 0.01$[f]
	Social relationships	Patient	60.94 (26.83)	57.56 (17.14)	53.33 (15.01)	44.22 (20.28)	35.56 (21.24)	F = 6.55, $p < 0.01$[g]
		Case manager	51.56 (16.73)	50.19 (16.11)	48.70 (18.88)	34.52 (15.87)	28.33 (17.76)	F = 9.98, $p < 0.01$[h]
	Environment	Patient	71.29 (15.53)	65.99 (9.40)	62.99 (12.08)	54.97 (13.38)	47.92 (14.45)	F = 11.75, $p < 0.01$[i]
		Case manager	58.40 (9.11)	60.32 (11.09)	59.31 (11.36)	49.17 (14.85)	46.46 (14.12)	F = 7.96, $p < 0.01$[j]
AQoL		Patient	0.78 (0.21)	0.55 (0.28)	0.54 (0.28)	0.41 (0.30)	0.20 (0.22)	F = 10.49, $p < 0.01$[k]
		Case manager	0.60 (0.19)	0.50 (0.22)	0.47 (0.25)	0.38 (0.23)	0.33 (0.19)	F = 4.78, $p < 0.01$[l]

[a] Composite index based on both patient and case manager estimates of health (see the text for an explanation)
[b] Analysis of variance
[c] Tukey HSD: 5 < 4, 3, 2, 1; 4 < 2, 1
[d] Tukey HSD: 5 < 4, 3, 2, 1; 4 < 3, 2, 1
[e] Tukey HSD: 5 < 3, 2, 1; 4 < 2, 1; 3 < 1
[f] Tukey HSD: 5 < 3, 2, 1; 4 < 3, 2, 1
[g] Tukey HSD: 5 < 3, 2, 1; 4 < 2, 1
[h] Tukey HSD: 5 < 3, 2, 1; 4 < 3, 2, 1
[i] Tukey HSD: 5 < 3, 2, 1; 4 < 3, 2, 1
[j] Tukey HSD: 5 < 3, 2; 4 < 3, 2
[k] Tukey HSD: 5 < 3, 2, 1; 4 < 1, 3 < 1, 2 < 1
[l] Tukey HSD: 5 < 1; 4 < 1

scores 37% lower. These findings are consistent with previous research into the HRQoL of people living with psychosis (Bobes and Gonzalez 1997). An interesting comparison is with those attending general hospital outpatient departments with other illnesses (Hawthorne, Richardson, Day, & McNeil 2000); essentially the study participants were outpatients of St Vincent's Hospital. This analysis is shown in Table 6. On three of the WHOQOL-Brèf domains, and two AQoL dimensions, patients' scores were significantly lower than general hospital outpatients'. On the utility scale, our study patients' scores were 21% lower.

Table 6 Study patients' versus general hospital outpatients' AQoL and WHOQOL-Brèf scores

		Respondents		Outpatients[a]		Statistics[b]
		Mean	Sd	Mean	Sd	
WHOQOL-Brèf[c]	Physical	60.7	15.4	61.5	22.5	t = 0.44, df = 465, p = 0.69
	Psychological	56.8	17.4	65.4	18.0	t = 5.12, df = 495, $p < 0.01$
	Social	51.3	20.3	62.9	23.5	t = 5.75, df = 399, $p < 0.01$
	Environment	61.1	13.8	67.9	16.8	t = 4.87, df = 413, $p < 0.01$
		Median	IQR	Median	IQR	
AQoL[d]	Illness[e]	0.42	0.39	0.53	0.72	U = 24593.5, p = 0.02
	Independent living	0.90	0.21	1.00	0.17	U = 26877.5, p = 0.38
	Social relationships	0.77	0.61	0.94	0.18	U = 15797.0, $p < 0.01$
	Physical senses	0.94	0.09	1.00	0.09	U = 27640.5, p = 0.79
	Psychological wellbeing	0.91	0.10	0.89	0.10	U = 22095.5, $p < 0.01$
		Mean	sd	Mean	sd	
	AQoL utility[f]	0.50	0.31	0.63	0.27	t = 4.51, df = 321, $p < 0.01$

[a] Data from the Hawthorne et al. utility instrument validation study. Patients were list sampled from two major teaching hospitals' outpatients departments in Melbourne, Australia (Hawthorne, Richardson, Day, & McNeil, 2000)

[b] WHOQOL-Brèf domains: t-test
AQoL dimensions: Mann-Whitney U-test
AQoL utility: t-test

[c] Transformed scores: scale range 0–100; the higher the score the better the health state

[d] Transformed scores: scale range 0–100, where 0 = dimension worst health state and 1.00 = dimension best health state

[e] Not used in computation of utility score

[f] Utility scale: −0.04–1.00, where negative scores represent health states worse than death, 0.00 = death and 1.00 = normal health. The higher the utility the better the HRQoL

[g] Note that the WHOQOL-Brèf and the AQoL Psychological domain/dimension scores are a function of different scale contents. The items in the former measure need for medical treatment, enjoyment of life, purpose (meaning) in life, energy for everyday life, satisfaction with work capacity and self-satisfaction. The Psychological dimension of the AQoL measures quality of sleep, feeling anxious, worried or depressed and the level of pain experienced

Discussion

This study showed that the WHOQOL-Brèf and AQoL can be completed with little difficulty by people who have persisting psychotic disorders, who are on medications and who are living in the community, even those with limited formal education and significant levels of symptoms and disability. Scores on the WHOQOL-Brèf were stable by demographic characteristics. For the AQoL, scores were stable for gender, country of birth and education; they varied by age, marital and employment status, consistent with the literature on HRQoL and with previous AQoL research (Barry and Zissi 1997; Hawthorne et al. 1999; Lehman 1996).

On both instruments the physical was ranked higher than most other domains/dimensions, and social relationships lower (Table 2). This is consistent with the salience of social isolation as a source and consequence of disability associated with psychotic disorders (Jablensky et al. 2000). The mean score on the AQoL Independent Living dimension (0.87) reflected the fact that most participants were living independently, even though socially isolated.

The evaluations provided by the case managers showed a similar pattern, but the scores were consistently lower than the patients' own. The biggest discrepancy was in the social relationships domain/dimension. Case managers would probably have the least knowledge about their patients in this area. Adaptation or a lowering of expectations may also be operating for those living with the persisting condition. These findings are consistent with previous reports that proxies provide lower valuations than those provided by patients, particularly in social relationships (Sainfort et al. 1996; Sneeuw et al. 1997; Sprangers and Aaronson 1992). Some authors have regarded this discrepancy as a threat to validity of self-report instruments in patients with schizophrenia (Atkinson et al. 1997). Conversely, however, as long as other indicators of validity are present, these observations may reasonably be seen to infer sensitivity and discriminatory power, as in other patient groups.

If the discrepancy was due to clinicians' lack of knowledge about some aspects of patients' lives, then this would suggest invalidity. The fact that clinician-rated scores were not monotonic with the neutral health status estimator (Table 5) provides some evidence supporting the argument that clinicians may not have insight into all aspects of their patients' lives. Alongside the evidence that there were few difficulties with self-completion, this suggests that patient self-report should be collected for the insights which only patients can provide (Katschnig 1997; Orley et al. 1998). The further observation that the WHOQOL and AQoL scores were each correlated more closely with the self-completion than the clinician-completed study instruments reinforces this interpretation. The findings strongly suggested bias related to who completed the instruments.

The degree of sensitivity implicit in the RE statistic implies that the WHOQOL-Brèf and AQoL may be relevant to the situation and needs of people with psychosis and other mental illnesses. There was insufficient evidence to assert that the patients' evaluations were biased. The implications are that psychotic patient self-report HRQoL should be included in outcome evaluation, along with the views of both family and clinician; they should be regarded as complementary to each other in clinical assessments.

We would caution, however, that patient and clinician assessments should not be mixed in the same analysis; obviously, where patient evaluations are not available and clinicians' are, then clinicians' evaluations should be used as proxies in full awareness of their differences and limitations. The patient perspective allows evaluation of the important subjective view; and it is possible that the clinician perspective may correct for the effects of adaptation (although this has not been shown in this study). The patients' perspective on HRQoL may assist in understanding the effects of psychosis and could become an established part of the multi-dimensional approach to studying outcomes (Thornicroft and Tansella 1996).

The study is subject to a number of caveats. Participants were living in the community, and seen at St Vincent's Mental Health Service for at least 2 years, and this may limit comparisons with other populations of those living with a psychotic disorder. Also, we depended on case managers to approach potential participants. This could have introduced sampling bias through case managers selecting those they thought suitable for study; given the response rate of 53 % of those within scope there was room for this to occur. Study participants were more likely to be Australian-born, and to be employed. The fact that there were no differences by gender or age suggests that selection biases were slight.

Conclusion

Given the increasing emphasis on program and economic evaluation, and hence HRQoL measurement, a critical issue is the validity of self-report generic and utility instruments among people living with mental illness. We found that both the WHOQOL-Brèf and AQoL are suitable for use in studies involving people living with persisting psychotic disorders; the findings presented in this study strongly support the validity of such self-reports.

This conclusion is supported by: (i) their sensitivity to the different health and social states experienced by respondents; (ii) the different evaluations from patients and case managers; and (iii) the correlation between scores and the self-completion criteria instruments – correlations which were significantly stronger than those obtained by the case managers.

The study of program outcomes in psychiatry has been frequently overlooked because of the difficulty in capturing the patients' perspective. This has been one factor in leaving a critical gap in understanding the effectiveness of treatments for psychosis. Our findings may help to redress this by providing evidence that self-report evaluation of HRQoL and utility using the WHOQOL-Brèf and AQoL can be undertaken with confidence.

Our findings have implications for clinical research involving people with psychotic disorders, and for the management of such people. Further studies are needed to examine instrument sensitivity in relation to changes occurring with treatment and care and to validate these instruments for use with people with a range of mental disorders, including those with acute and recent onset psychotic disorders.

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