Quality of life of people with schizophrenia, bipolar disorder and other psychotic disorders[†]

Samuli I. Saarni, Satu Viertiö, Jonna Perälä, Seppo Koskinen, Jouko Lönnqvist and Jaana Suvisaari

Background
Health utility and quality of life (QoL) are increasingly important outcome measures in healthcare and health economics.

Aims
To compare the loss of subjective QoL and utility-based health-related quality of life (HRQoL) associated with psychotic disorders.

Method
A representative sample of 8028 Finns was screened for psychotic disorders and bipolar I disorder. Lifetime psychotic disorders were diagnosed using the Structured Clinical Interview for DSM–IV and/or case records. Health-related quality of life was measured with EQ–5D and 15D, and QoL was measured with a 10-point scale.

Results
Schizoaffective disorder was associated with the largest losses of QoL and HRQoL, with bipolar I disorder associated with similar or smaller losses than schizophrenia. Current depressive symptoms explained most of the losses.

Conclusions
Depressive symptoms are the strongest predictors of poor QoL/HRQoL in psychotic disorders. Subjective loss of QoL associated with psychotic disorders may be smaller than objective loss of functioning suggests. The EQ–5D is problematic as an outcome measure in psychotic disorders.

Declarations of interest
None.

Quality of life (QoL) is becoming an increasingly important outcome of healthcare for several reasons. Subjective valuations, autonomy and the needs of patients are increasingly respected. Generic measures are needed to directly compare the burden of different conditions and treatments. Health policy and economic evaluations favour quality-adjusted life-years (QALYs)[1] that can be based on health-related quality of life (HRQoL) measures. With psychotic disorders, deinstitutionalisation has further emphasised the importance of optimising functional status. Positive psychotic symptoms, the traditional target of antipsychotic drug treatment, are not strong determinants of either ability to function or QoL.[2–5]

Psychotic disorders are a heterogeneous group, and comparisons of disorders using generic QoL/HRQoL are scarce. Most studies on QoL/HRQoL and psychotic disorders have investigated selected clinical samples, so information on the severity of these disorders in the general population is lacking. Which symptoms determine QoL/HRQoL is also poorly known. Using a representative population sample, we investigated:

(a) the comparative burden of different functional psychotic disorders on QoL/HRQoL;

(b) how different disorders decrease subjective QoL relative to utility-based HRQoL, and which dimensions of HRQoL are influenced;

(c) the correlation between different psychotic symptoms, depression, clinician-assessed outcome and QoL/HRQoL.

Method

Health 2000 survey

The data come from the Health 2000 survey, a representative study of the Finnish population aged 30 and over, and its substudy – Psychoses in Finland. The methods and basic results of the Health

2000 survey have been published previously[6] (available at www.terveys2000.fi/indexe.html). Briefly, the survey had a two-stage, stratified cluster sampling design. The original sample included 8028 people, with double-sampling of people over 80 years of age, giving a response rate of 93% for any part of the survey. The survey consisted of a health interview, a thorough health examination, laboratory tests, a structured mental health interview (the Munich version of the Composite International Diagnostic Interview, CIDI)[7] and several self-report questionnaires. The data were collected between August 2000 and July 2001.

Psychiatric diagnostics

The Psychoses in Finland study methodology has been described in detail previously.[8] People from the Health 2000 survey were included in the Psychoses in Finland study if they reported ever having had a psychotic disorder, were diagnosed by the physician conducting the health examination to have a definite or probable psychotic disorder, or had a lifetime history of psychotic or manic symptoms in the CIDI interview. Register-based screening was also used, covering hospital treatments in Finland for psychotic disorders, free antipsychotic medication, mood-stabilising medication use without diagnosis of a relevant somatic disorder or disability pension because of a psychotic disorder. As CIDI is not reliable in diagnosing psychotic disorders, people identified using CIDI were re-interviewed with the Research Version of the Structured Clinical Interview for DSM–IV (SCID–I).[9] All case notes from hospital and out-patient treatments were collected, even from those who were not interviewed. The ethics committees of the National Institute for Health and Welfare (former National Public Health Institute) and the Hospital District of Helsinki and Uusimaa approved the studies. Participants provided written informed consent. Three experienced clinicians (J.P., J.S. and S.I.S.) made the final best-estimate lifetime DSM–IV diagnoses based on a systematic evaluation of all available data. The Kappa values between the raters ranged from 0.74 to 0.97 for different psychotic disorders, and were either good or excellent regardless

[†]See pp. 348–349, this issue.

of whether the diagnosis was based on both the SCID–I interview and case records or on case records alone.[8]

Lifetime diagnoses of psychotic disorders were classified into schizophrenia, other non-affective psychosis (including schizoaffective disorder, schizophreniform disorder, delusional disorder, brief psychotic disorder and psychotic disorder not otherwise specified) and affective psychosis (major depressive disorder with psychotic features and bipolar I disorder). The main focus of this study was on these groups, but we also examined separately the most common individual psychotic disorders (Table 1). This study considers lifetime disorders that had their onset before participants completed the QoL/HRQoL questionnaires as part of the Health 2000 study.

Health-related and subjective quality-of-life measurement

Health-related quality of life is the part of QoL that can potentially be influenced by health and healthcare. As there is no gold standard for HRQoL measurement,[10,11] we used two well-established, generic self-report preference-based HRQoL measures: the EQ–5D[12] and the 15D.[13]

Preference-based HRQoL questionnaires include several dimensions that can be summarised as a single score using utility theory and preferences elicited from the population. The result is a quantitative measure of the severity of health states as people value them, referred to as health utility. Health utilities range from 0, being equal to death, and 1, which is perfect health. They form the quality-component of QALYs, which combine length and quality of life into a single metric.[14] For example, the National Institute for Health and Clinical Excellence uses QALYs as their preferred outcome measure in cost-effectiveness analyses.[1]

The 15D[13,15,16] has 15 dimensions with five categories of severity: mobility, vision, hearing, breathing, sleeping, eating, speech, elimination, usual activities, mental function, discomfort and symptoms, depression, distress, vitality and sexual activity (www.15d-instrument.net). The 15D utility index[15] ranges between 1 (full health) and 0 (death). We included participants with 12 or more completed 15D dimensions, imputing missing values as recommended.[13] Changes of over 0.02–0.03 points on the 15D are considered clinically important.[16] The EQ–5D[12,17,18] has five dimensions with three categories of severity: mobility, self-care, usual activities, pain or discomfort, and anxiety or depression (www.euroqol.org). The EQ–5D UK time trade-off index[19] ranges between 1 (full health) and –0.59 (0 is death). A time trade-off index is based on hypothetical trade-offs between length of life and symptoms. Only participants who fully completed the EQ–5D questionnaire were included. Although there is no unequivocally agreed threshold for a minimum clinically important change on the EQ–5D, thresholds of 0.07 points have been observed.[20]

Both the 15D and EQ–5D enquire about the health state of the respondent 'today'. The 15D compares favourably with similar HRQoL instruments in most of the important properties.[13,15,16,21,22] Although EQ–5D is among the most extensively evaluated HRQoL measure,[23] it is problematic in general population samples due to its low sensitivity in detecting deviations from full health.[11]

Whereas the HRQoL instruments used require answers to a predefined set of questions concerning symptoms and functioning, the subjective QoL here means global life satisfaction as defined by the respondent. Subjective QoL was measured by asking the respondents to rate their current QoL as a whole, over the past 30 days, on a visual-analogue scale (VAS) from 0 to 10, anchored at best and worst possible QoL.

Sociodemographic variables, somatic conditions and depressed mood

Data on sociodemographic variables and chronic somatic diseases were collected using structured interviews at home or institution. As the relationship between HRQoL and age is not linear, age was categorised as 30–44, 45–54, 55–64, 65–74, 75–85 and over 85 years. Education was categorised as basic, secondary or higher. Household income, derived from registers on taxes and welfare benefits, was adjusted for family size[24] and divided into quintiles. Marital status was classified into two categories: married or cohabiting, and others. Chronic somatic conditions were diagnosed by asking, separately for each condition, whether the participant had ever been diagnosed by a physician with one of the 25 included conditions.[11] Depressed mood was assessed with the Beck Depression Inventory (BDI).[25]

Symptom measures

For lifetime symptoms of psychotic disorders, we used the Major Symptoms of Schizophrenia Scale (MSSS)[26,27] and some global ratings from the Scale for the Assessment of Positive Symptoms (SAPS)[28] and from the Scale for the Assessment of Negative Symptoms (SANS).[29] These were completed based on the SCID–I interview and all medical records on a lifetime basis.[30]

The symptoms in the MSSS are rated from 1, clearly not present, to 5, severe; the symptoms in the SANS and SAPS are coded on a six-point scale, ranging from 0, not at all, to 5, severe. The following symptom and course ratings were used in the analysis: hallucinations, delusions, positive formal thought disorder, catatonia, affective deterioration, negative formal thought disorder, depression, mania, course and outcome. From these ratings, we formed summary scores for positive symptoms (delusions and hallucinations), disorganised symptoms (positive thought disorder and bizarre behaviour) and negative symptoms (negative thought disorder, avolition–apathy, anhedonia–asociality and affective deterioration).

Statistical methods

To analyse non-response, we investigated whether people with psychotic disorders who completed the QoL/HRQoL measures differed from non-responders using information from the ratings for psychotic symptoms. The following symptom and course ratings were used in the analysis: hallucinations, delusions, positive formal thought disorder, catatonia, affective deterioration, negative formal thought disorder, depression, mania, course and outcome. Differences between responders and non-responders were tested with the Kruskal–Wallis test. The following groups were investigated: schizophrenia, other non-affective psychosis and affective psychoses. From the latter two groups, schizo-affective disorder, delusional disorder, bipolar I disorder and major depressive disorder with psychotic features were investigated separately.

To estimate the association between different disorders and loss of HRQoL or QoL, we created separate multiple regression models using each of the instruments (15D, EQ–D, QoL) as dependent variables. To estimate the effects covariates, we created three sets of regression models in a stepwise manner: the first model controlled for age and gender, the second added education, income and marital status, and the third the 25 somatic conditions. To estimate the effect of depression, we added a fourth model with BDI. The covariates were entered as dummy variables except for BDI, which was entered as a continuous variable. Linear regression for survey data was used to analyse subjective QoL. As the HRQoL measures have a ceiling effect (55.4% of respondents

Table 1 Prevalence of psychotic disorders, age, somatic and psychiatric comorbidity and health-related quality of life (HRQoL) scores of respondents

	No psychosis	Schizophrenia	Other non-affective psychoses[a]	Schizoaffective disorder	Delusional disorder	Psychotic disorder NOS	Affective psychoses	Bipolar I disorder	Major depressive disorder with psychotic features
n^b									
All	7826	67	86	24	15	38	49	20	29
HRQoL	6514	55	72	19	12	34	40	14	26
QoL	6486	53	69	18	12	33	41	14	27
Prevalence, %		0.9	1.1	0.3	0.2	0.5	0.6	0.2	0.4
Age,[c] years: mean	54.2	53.7	57.6	49.9	68.0	59.7	55.8	52.4	58.2
Female,[c] %	54.6	56.7	65.1	79.2	60.0	68.4	46.9	45.0	48.3
Education, %									
Low	40	55	54	40	66	58	43	55	36
Middle	33	25	25	30	26	18	16	6	22
High	27	20	21	30	8	24	41	39	42
Income, €:[c] mean (s.e.)	25560 (840)	11550 (1250)	15630 (1280)	13820 (1970)	16500 (3470)	15340 (2020)	22740 (2480)	27900 (5630)	19890 (1950)
Married or cohabiting, %	68.8	20.3	39.5	45.1	36.8	34.5	55.1	61.1	51.8
Number of somatic conditions, mean (s.e.)	1.9 (0.02)	2.2 (0.3)	2.2 (0.3)	1.6 (0.4)	2.5 (0.6)	2.9 (0.5)	1.6 (0.3)	2.1 (0.4)	1.4 (0.3)
15D score, mean (s.e.)	0.912 (0.001)	0.842 (0.019)	0.832 (0.015)	0.815 (0.023)	0.834 (0.021)	0.829 (0.025)	0.863 (0.018)	0.865 (0.031)	0.862 (0.022)
EQ–5D score, mean (s.e.)	0.838 (0.003)	0.715 (0.041)	0.667 (0.035)	0.681 (0.069)	0.807 (0.056)	0.639 (0.052)	0.763 (0.043)	0.863 (0.036)	0.707 (0.061)
BDI score, mean (s.e.)	6.9 (0.1)	13.7 (1.8)	15.3 (1.6)	18.4 (2.8)	14.4 (2.7)	14.4 (2.4)	11.9 (1.5)	8.1 (2.6)	14.1 (1.7)
Subjective QoL, mean (s.e.)	7.66 (0.02)	7.06 (0.30)	6.10 (0.24)	5.71 (0.50)	5.94 (0.60)	6.36 (0.37)	6.69 (0.37)	7.22 (0.44)	6.41 (0.50)

NOS, not otherwise specified; BDI, Beck Depression Inventory; QoL, quality of life.
a. Also includes schizophreniform disorder (n=5) and brief psychotic disorder (n=4).
b. Diagnoses are available for the whole sample; HRQoL respondents includes those with valid EQ–5D or 15D scores.
c. Age, gender and income information is gathered from register information available for the whole sample.

scored full health on EQ–D and 17.3% on 15D) we used a Tobit model to account for this censoring.[11,31,32] We report the marginal effects of the unconditional expected value of the HRQoL score, valued at the means of the explanatory variables.[33] These marginal effects are interpreted comparably to beta-coefficients of linear regression, i.e. as the change in HRQoL score (health utility) associated with each psychotic disorder (adjusted for age or age and other covariates), compared with people without the disorder.

To investigate which dimensions of HRQoL were affected by schizophrenia, schizoaffective disorder and bipolar I disorder, we created 15D profiles using linear regression to adjust the losses on each 15D dimension for age and gender. As the 15D preference-based scoring system scales all dimensions between 0 and 1, the losses are comparable. To investigate the correlations between QoL/HRQoL ratings and clinician-rated symptom severity and outcome, we calculated Spearman rank-order correlations as partial correlations, adjusting for age and gender. Regression analyses were conducted using Stata 8.2 for Windows, and the other analyses on SAS 9.1.3 on Windows. Analyses accounted for the two-stage sampling design. Post-stratification weights were used to correct for non-response (based on register information on the whole sample) and for oversampling of people aged over 80 years.[6]

Results

Background variables

The sociodemographic characteristics of the sample, somatic conditions and BDI scores are presented in Table 1. People with non-affective psychoses were more often living alone, had lower education and less income than people with affective psychoses or the general population. Mean BDI scores were elevated (about 14–18) for all disorders except bipolar I disorder, where they were close to that of the general population.

Analysis of non-response

Response rates are presented in Table 1 (see online supplement for symptom-specific details). Briefly, QoL information was available for 85.1%, EQ–5D for 78.5% and 15D for 80.2% of the sample.

Loss of QoL/HRQoL in different disorders

Unadjusted HRQoL and QoL scores are presented in Table 1, and adjusted scores in Tables 2 and 3. The results of only two models are presented in Table 3, as the results of the omitted models were essentially similar to the first model controlling only for age and gender.

Participants with non-affective psychoses other than schizophrenia had the lowest unadjusted HRQoL scores; their mean 15D score was 0.08 and EQ–5D score 0.17 points lower than the mean of the population without psychosis. For schizophrenia these differences were 0.07 and 0.12 respectively. When controlling for age and gender, schizophrenia, other non-affective psychosis and affective psychoses were all associated with decreases of 0.05–0.06 points on the 15D. On the EQ–5D, the decreases were 0.12 for schizophrenia, 0.11 for other non-affective psychosis and 0.06 for affective psychoses. Considering individual disorders, people with schizoaffective disorder had the largest age- and gender-adjusted losses of HRQoL: −0.09 on the 15D and −0.15 on the EQ–5D. Whereas all disorders were associated with statistically significant and clinically important decreases on the 15D, the EQ–5D did not detect any HRQoL losses for delusional or bipolar I disorders.

Table 2 Health-related quality of life (HRQoL) (15D and EQ–5D) and subjective quality of life (QoL) decrements associated with main groups of psychotic disorders, adjusted stepwise for age, gender, income, marital status, education, somatic conditions and Beck Depression Inventory score, reporting marginal effects for HRQoL and beta coefficients for QoL (95% CI)

	Schizophrenia	Other non-affective psychosis	Affective psychosis
15D HRQoL			
Age and gender	−0.056 (−0.087 to −0.025)***	−0.059 (−0.082 to −0.036)***	−0.048 (−0.076 to −0.020)**
+ income, marital status, education	−0.043 (−0.076 to −0.011)**	−0.053 (−0.075 to −0.031)***	−0.046 (−0.075 to −0.018)
+ somatic conditions	−0.046 (−0.073 to −0.019)**	−0.051 (−0.073 to −0.029)***	−0.051 (−0.080 to −0.022)**
+ Beck Depression Inventory	−0.027 (−0.049 to −0.004)*	−0.012 (−0.029 to 0.006)	−0.022 (−0.046 to 0.001)
EQ−5D HRQoL			
Age and gender	−0.119 (−0.176 to −0.062)***	−0.113 (−0.158 to −0.069)***	−0.064 (−0.127 to −0.001)*
+ income, marital status, education	−0.088 (−0.146 to −0.029)**	−0.098 (−0.140 to −0.055)***	−0.068 (−0.131 to −0.005)*
+ somatic conditions	−0.091 (−0.156 to −0.026)**	−0.090 (−0.134 to −0.046)***	−0.069 (−0.129 to −0.009)*
+ Beck Depression Inventory	−0.043 (−0.092 to 0.005)	−0.028 (−0.071 to 0.015)	−0.020 (−0.071 to 0.031)
Subjective QoL			
Age and gender	−0.642 (−1.232 to −0.052)*	−1.437 (−1.891 to −0.983)***	−0.893 (−1.617 to −0.169)*
+ income, marital status, education	−0.247 (−0.881 to 0.387)	−1.227 (−1.664 to −0.790)***	−0.835 (−1.564 to −0.105)*
+ somatic conditions	−0.186 (−0.798 to 0.426)	−1.216 (−1.666 to −0.766)***	−0.800 (−1.456 to −0.144)*
+ Beck Depression Inventory	−0.096 (−0.569 to 0.376)	−0.455 (−0.868 to −0.043)*	−0.305 (−0.823 to 0.213)

*$P<0.05$, **$P<0.01$, ***$P<0.001$.

Table 3 Health-related quality of life (HRQoL) (15D and EQ–5D) and subjective quality of life (QoL) decrements associated with different psychotic disorders, adjusted stepwise for age and gender, or age, gender, income, marital status, education, somatic conditions and Beck Depression Inventory (BDI) score, reporting marginal effects for HRQoL and beta-coefficients for QoL (95% CI)

	Schizoaffective disorder	Delusional disorder	Psychotic disorder NOS	Bipolar I disorder	Major depressive disorders with psychotic features
15D HRQoL					
Age and gender	−0.094 (−0.130 to −0.057)***	−0.041 (−0.077 to −0.005)*	−0.051 (−0.091 to −0.012)*	−0.054 (−0.106 to −0.003)*	−0.044 (−0.075 to −0.013)**
Fully controlled	−0.036 (−0.071 to −0.001)*	−0.014 (−0.059 to 0.030)	0.005 (−0.023 to 0.033)	−0.034 (−0.069 to 0.000)	−0.015 (−0.046 to 0.016)
EQ−5D HRQoL					
Age and gender	−0.154 (−0.245 to −0.062)**	0.013 (−0.111 to 0.136)	−0.115 (−0.182 to −0.048)**	−0.007 (−0.090 to 0.076)	−0.094 (−0.176 to −0.012)*
Fully controlled	−0.056 (−0.139 to 0.027)	0.011 (−0.107 to 0.129)	−0.020 (−0.081 to 0.041)	0.005 (−0.060 to 0.070)	−0.035 (−0.104 to 0.035)
Subjective QoL					
Age and gender	−2.105 (−3.044 to −1.166)***	−1.324 (−2.59 to 0.059)*	−1.080 (−1.776 to −0.384)**	−0.466 (−1.340 to 0.408)	−1.117 (−2.115 to −0.119)*
Fully controlled	−0.505 (−1.285 to 0.275)	−1.087 (−2.160 to −0.0147)*	−0.070 (−0.577 to 0.437)	−0.277 (−1.073 to 0.520)	−0.320 (−1.007 to 0.367)

NOS, not otherwise specified.
*$P<0.05$, **$P<0.01$, ***$P<0.001$.

The other non-affective psychosis group also had the lowest unadjusted QoL scores: their mean QoL was 1.6 points below the population without psychosis, whereas this difference was 0.6 for schizophrenia. People in the other non-affective psychosis group also had the largest reductions of QoL in all the regression models. The schizophrenia group had statistically significant reductions of QoL when controlling for age and gender only, whereas the affective psychoses group fell between the other groups. Of individual disorders, people with schizoaffective disorder had the worst QoL, whereas those with bipolar I disorder did not have a statistically significant reduction of QoL.

Effect of current depression

The stepwise entering of socioeconomic variables and somatic conditions into regression models changed the HRQoL results relatively little. However, adding BDI score into the models mostly diminished the impact of disorders on HRQoL. Only

schizophrenia and schizoaffective disorder were associated with statistically significant reductions of the 15D after controlling for the BDI, whereas the EQ–5D detected no statistically significant effects of diagnoses after controlling for the BDI.

For QoL the picture was similar and the BDI explained most of the observed decreases, with two exceptions: for schizophrenia, socioeconomic variables explained most of the reduction of QoL. Delusional disorder was the only disorder where QoL was still statistically significantly reduced after controlling for the BDI.

Dimensions of HRQoL influenced by different disorders

The HRQoL profiles are presented in Fig. 1, in the form of age- and gender-adjusted decreases from population averages. The decreases were widespread for schizophrenia (11 of 15 dimensions statistically significantly decreased) and schizoaffective disorder (10 of 15) but less so for bipolar I disorder (3 of 15).
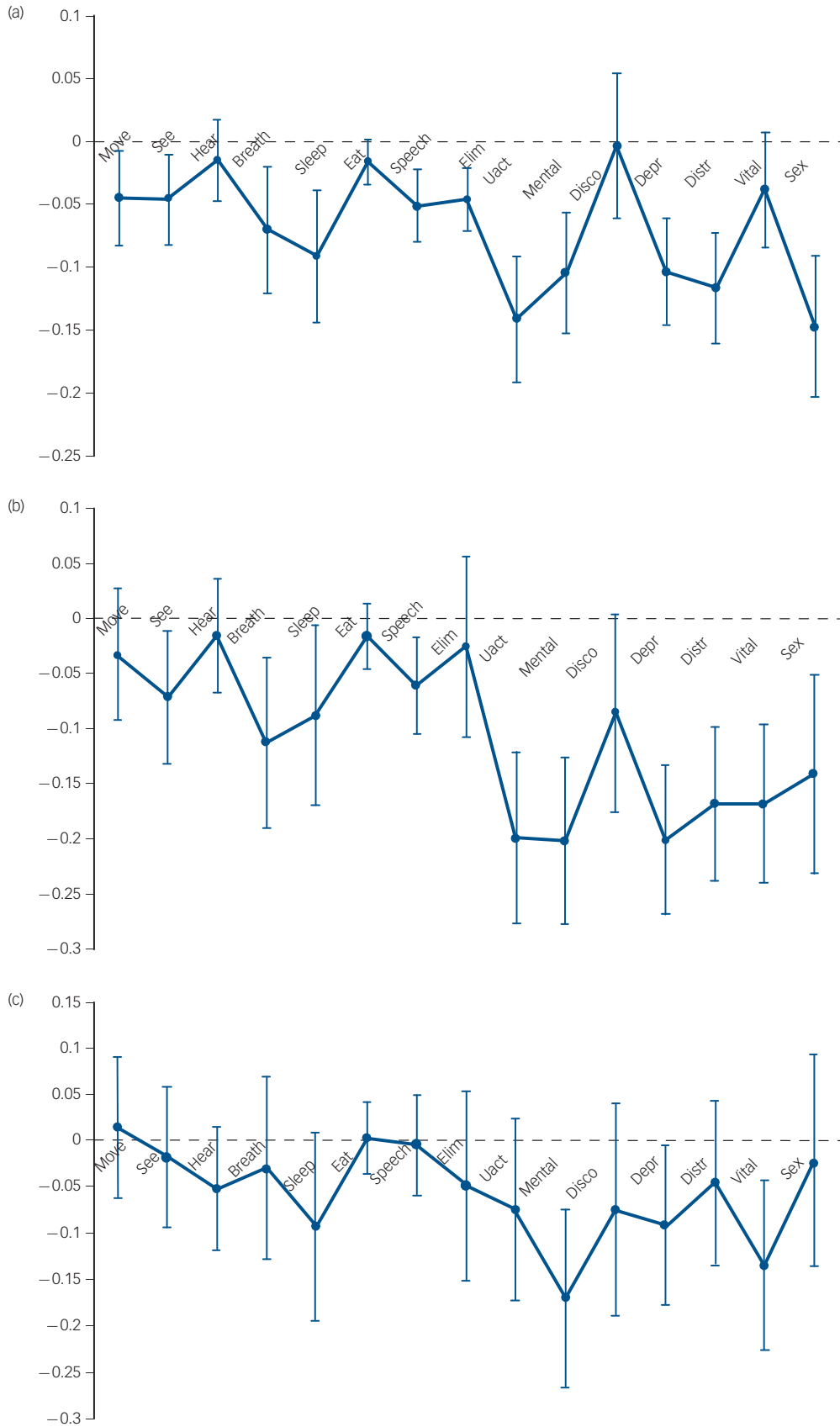
Fig. 1 Age- and gender-adjusted losses on different health-related quality of life (15D) dimensions with 95% CI. (a) Schizophrenia, (b) schizoaffective disorder, (c) bipolar I disorder.

The 15 dimensions: Move, mobility; See, vision; Hear, hearing; Breath, breathing; Sleep, sleeping; Eat, eating; Speech, speaking; Elim, elimination; Uact, usual activity; Mental, mental function; Disco, discomfort and symptoms; Depr, depression; Distr, distress; Vital, vitality; Sex, sexuality.

Clinician-rated psychotic symptoms, outcome and QoL/HRQoL

Online Table DS1 presents the Spearman correlations between QoL/HRQoL and lifetime ratings of positive, negative, disorganisation, depressive symptoms, course and outcome.

For all psychotic disorders combined, depressive and negative symptoms had small (0.1–0.3) correlations with QoL/HRQoL. Positive symptoms were not correlated with QoL/HRQoL. There was a trend for small positive correlations between mania, disorganisation symptoms and QoL/HRQoL, although this was statistically significant only for QoL and disorganisation. Clinician-rated course and outcome variables had small correlations with all QoL/HRQoL measures.

For schizophrenia, correlations were generally small and not statistically significant except for the correlation between depressive symptoms and QoL. For schizoaffective disorder, there were large (<−0.5) negative correlations between negative symptoms, course, outcome and QoL/HRQoL measures. For delusional disorders, none of the correlations were statistically significant, although the correlation coefficients between course and especially the EQ–5D and QoL were large. For bipolar I disorder, negative correlations between depressive symptoms and HRQoL measures were large, and moderate (−0.3 to −0.5) between depression and QoL. Correlations were positive – although not statistically significant – between lifetime mania ratings and QoL/HRQoL scores. Negative correlations between course, outcome and QoL/HRQoL ratings were mostly moderate or large. For major depressive disorders with psychotic features, negative correlations were large for negative symptoms and the EQ–5D and QoL. Negative correlations between course, outcome and QoL/HRQoL ratings were mostly moderate or large.

Discussion

Comparison with previous studies

Our results can be compared with several types of studies: those studying the impact of psychotic disorders on health utility or subjective QoL; those comparing the impact of different psychotic disorders using almost any global outcome measure; and those studying the correlation of global outcomes and different symptomatic measures. As the main strength of our data is general population representativeness, we will concentrate here on studies comparing the severity of different disorders.

Studies of health utility and psychotic disorders

Our previous study comparing HRQoL in 29 psychiatric and somatic disorders showed that people with self-reported psychotic disorders ranked third in severity, after Parkinson's disease and major depressive disorder.[11] Further examination of non-psychotic disorders present within the past 12 months showed that HRQoL losses on the 15D (EQ–5D) were −0.04 (−0.07) for alcohol dependence, −0.07 (−0.13) for major depressive disorder and between −0.13 and −0.14 (−0.23 and −0.27) for dysthymia, social phobia, agoraphobia and generalised anxiety disorders.[34] This puts the severity of lifetime schizoaffective disorder between 12-month major depressive disorder and anxiety disorders, and schizophrenia between 12-month major depressive disorder and alcohol dependence.

The Dutch Netherlands Mental Health Survey and Incidence Study (NEMESIS) originally showed that all 36-item Short Form Health Survey (SF–36) subscale scores for people with bipolar I disorder were lower than healthy controls.[35] However, after a thorough diagnostic check (SCID–I), the remaining individuals

with bipolar disorder did not differ from controls on the SF–36 or on the EQ–5D.[36] This may have been as a result of the small sample size, as the EQ–5D score was 0.82 for the people with bipolar disorder and 0.88 for controls. Further, the response rate was only 47%. Still, an EQ–5D value of 0.82 is clearly lower than that observed in our study, even though our participants with bipolar I disorder were 10 years older.

Generalisations from clinical studies are difficult, as the inclusion criteria vary and adjusting for age would be essential given that HRQoL decreases with age.[11] Participants commonly report low HRQoL values: EQ–5D scores have been between 0.52 and 0.57 in recent studies of schizophrenia.[37–39] These values are much lower than our results. Studies with people not actively seeking treatment have yielded results closer to ours. A UK study selecting stable out-patients obtained a EQ–5D value of 0.86.[40] A German study of out-patients with non-affective psychoses (93% schizophrenia or schizoaffective disorder) found a mean EQ–5D value of 0.71.[41]

In sum, this comparison emphasises the selected nature of participants seen in clinical trials that often recruit individuals who need some change of treatment. Care is needed when extrapolating from the results of clinical studies to population-level burden-of-disease estimations.

Studies comparing different psychotic disorders on any QoL/HRQoL measures

A review of the literature up to the year 2002 using a very wide conceptualisation of HRQoL (including, for example, Global Assessment of Functioning (GAF)) found 65 studies.[42] Eight of the nine studies comparing bipolar disorder with schizophrenia suggested better HRQoL for people with bipolar disorder. Another review up to 2004 included 28 articles with five studies comparing bipolar disorder with other conditions.[43] Most of these showed bipolar disorder to be comparable or milder than schizophrenia. Two studies suggested that the HRQoL of participants with bipolar disorder was equivalent to that of the general population.

In a US study on community-dwelling patients, no statistically significant differences were found between people with schizophrenia and bipolar I disorder on the Quality of Well-Being scale or SF–36.[44] Another study comparing treatment-seeking individuals with bipolar I disorder and schizoaffective disorder found the EQ–5D scores of participants with bipolar to be significantly higher than those of participants with schizoaffective disorder (0.77 and 0.67 respectively).[45] Participants with schizoaffective disorder had more depressive symptoms than the group with bipolar I disorder, in line with our results. A third study including out-patients with schizophrenia and schizoaffective disorder noted that those with schizoaffective disorder had significantly lower subjective QoL.[5]

Our results fit with the previous literature in suggesting that, on average, schizoaffective disorder is associated with more severe HRQoL impairment than schizophrenia. Bipolar I disorder has been associated with a smaller or similar HRQoL impact to schizophrenia, depending on the sample and the measures used.

Studies of the association between symptoms, HRQoL and QoL

In line with our findings, two previous schizophrenia studies found current depressive[5] or depressive/anxiety[4] symptoms to have the strongest correlation with QoL; correlations with positive, negative or disorganisation symptoms were not significant. One previous study investigating non-affective psychoses found EQ–5D to be correlated with positive and

negative symptoms, but even then the strongest correlation was with depressive symptoms.[41]

For bipolar disorder, previous reviews of different phases of bipolar disorder have generally concluded that the HRQoL or QoL of people with bipolar disorder is lowered even in a euthymic phase, although clearly less so than in a manic phase. Depressive or mixed episodes are generally considered to be the worst, and current depressive symptomatology is a major predictor of lowered HRQoL.[46] Results concerning the impact of the longitudinal course of bipolar disorder on HRQoL of currently euthymic patients are variable,[43,44,47,48] but most studies have found that depressive symptoms are most strongly correlated with HRQoL and that they affect several domains of HRQoL. This fits well with our findings that the BDI score explains most of the lost HRQoL/QoL in bipolar disorder, and the lifetime severity of depressive symptoms strongly correlates with HRQoL.

Validity of self-reported QoL and HRQoL

Our study agrees with previous studies in showing that generic QoL/HRQoL instruments produce interesting but somewhat problematic results as outcome measures for psychotic disorders. They do not correlate well with all symptom dimensions or with clinician-assessed outcomes for all disorders, or with socio-economic disadvantage.[49] In contrast, current depression explains a major part of the loss in QoL/HRQoL. This poses a challenge for health-economic analyses of psychotic disorders: medical treatments commonly target positive symptom reduction, but their effect may go unnoticed when utility-based HRQoL is used as an outcome measure. The EQ–5D appears especially problematic. Disorder-specific measures should be used to complement generic HRQoL measures; in clinical use at least, depressive symptoms are likely to be better measured with depression scales than HRQoL instruments.

However, the alternative interpretation is also important to consider: as we used three different QoL/HRQoL measures, some construct validity of these instruments is likely. Previous studies converge in that depressive symptoms are extremely important for the subjective well-being of people with most psychiatric disorders. Our results show that people with schizophrenia have significant depressive symptoms that reduce their well-being substantially. Further, our results also offer some room for optimism concerning the QoL/HRQoL of people with bipolar disorder and schizophrenia. More general population studies are clearly needed.

The reliability of self-reports of people with psychotic disorders is sometimes questioned. Except for the most acute phases of illness, it has repeatedly been shown that people in stable phases of psychotic illnesses can assess their health states reasonably reliably and validly – even using cognitively demanding methods such as direct utility estimation.[40,50] However, equally consistent is the finding that people with stable schizophrenia tend to rank their health utility higher than healthy people[51] or professionals[3] would. So, although our results suggest that people with common anxiety disorders and dysthymia rate their HRQoL lower than people with schizophrenia, bipolar disorder or even schizoaffective disorder, this must be interpreted in the light of larger socioeconomic disadvantage and loss of functioning associated with psychotic disorders.[49,52,53]

The aforementioned results – individuals reporting higher subjective well-being than professionals estimate or patients' actual functional status or socioeconomic circumstances suggests – provide caregivers with an ethical dilemma. If the higher valuations are not clearly 'flawed', i.e. caused by cognitive, affective or psychotic misunderstandings, they may still be caused by

psychological adaptation to the condition and its limitations or lowered expectations. A theoretical key component to subjective QoL is the balance between expectations and opportunities.[54] The ethical dilemma is to what extent the lowered expectations should be accepted? Taking at face value the high life satisfaction of people with psychoses appears problematic when objective indicators show great room for improvement. But excluding the subjective experience is also unacceptable.

Strengths and weaknesses

The significant strengths or our study are the use of a general population-based sample, the thorough diagnostics and the high participation rate. Our collection of case notes allowed us to compare the severity and symptoms of non-respondents with respondents. This revealed that people with more severe affective psychoses seemed to be somewhat underrepresented. On the other hand, people with the bipolar type of schizoaffective disorder were less likely to participate than those with the depressive type. These may have somewhat exaggerated our findings of the low burden of affective psychoses and the high burden of schizoaffective disorder, relative to schizophrenia. The group with delusional disorder was quite small. More general population studies that control for residual depressive symptoms are clearly needed.

It is important to emphasise that our results represent the individual disability and suffering of respondents. It thus underestimates the total burden of psychotic disorders because mortality and the burden on caregivers are not taken into account. A further possible source of underestimation is the age limit of our study. Psychotic disorders commonly have an onset before age 30, and the impact of psychoses may be relatively larger in young people when somatic conditions are rare and HRQoL usually high.

Depression had a large influence on HRQoL and QoL. Sociodemographic factors and chronic conditions had less influence than BDI score. However, as both the HRQoL measures used included questions relating to depression, this is also partly as a result of overlapping instruments. However, depression also affects subjective QoL and this supports the validity of this finding.

Implications

Schizoaffective disorder was associated with the lowest well-being in all measures used, followed by schizophrenia and bipolar I disorder. Schizophrenia and bipolar disorder were associated with a relatively larger loss of HRQoL than subjective QoL, whereas the contrary was true for delusional disorder and major depressive disorder with psychotic symptoms.

The results suggest that the subjective suffering reported by people with schizophrenia is smaller than the loss of objectively measured functioning. This discrepancy between self-reported well-being and functioning may be clinically relevant and also needs to be taken into account when HRQoL results are used for health policy or health economics purposes. The results also highlight the importance of minimising the side-effects of treatments, which may actually decrease health utility as much as the symptoms themselves.[40]

Current depressive symptoms explained most of the loss of HRQoL and QoL found. In particular, EQ–5D seems to be insensitive and measures mostly current depressive symptoms. Although depressive symptoms are important with regard to the well-being of people with psychotic disorders, this questions the utility of utility-based HRQoL measurements as sole outcome measures in psychotic disorders.

Given that even participants with schizoaffective disorder had smaller HRQoL losses than people with dysthymia, generalised anxiety disorder, agoraphobia and social phobia,[34] our results suggest some optimism concerning the subjective outcomes of psychotic disorders. However, although low QoL invites careful consideration of treatment alternatives, moderate subjective QoL does not warrant complacency in the treatment of psychotic disorders.

Samuli I. Saarni, MD, PhD, MSocSc, Department of Mental Health and Substance Abuse Services, National Institute for Health and Welfare, and the Department of Psychiatry, University of Helsinki and Helsinki University Central Hospital, Helsinki; **Satu Viertiö**, MSc, **Jonna Perälä**, MD, Department of Mental Health and Substance Abuse Services, National Institute for Health and Welfare, Helsinki; **Seppo Koskinen**, MD, PhD, MSocSc, Department of Health, Functional Capacity and Welfare, National Institute for Health and Welfare, Helsinki; **Jouko Lönnqvist** MD, PhD, Department of Mental Health and Substance Abuse Services, National Institute for Health and Welfare, and the Department of Psychiatry, University of Helsinki and Helsinki University Central Hospital, Helsinki; **Jaana Suvisaari**, MD, PhD, Department of Mental Health and Substance Abuse Services, National Institute for Health and Welfare, Helsinki, Finland

Correspondence: Samuli I. Saarni, MD, PhD, MSocSc, Department of Mental Health and Substance Abuse Services, National Institute for Health and Welfare, PO Box 30, 00270 Helsinki, Finland. Email: samuli.saarni@helsinki.fi

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EXTRA CONTENT ONLINE

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psychiatrists in 19th-century fiction

Shirley Hall Asylum: Or the Memoirs of a Monomaniac (1863)
by William Gilbert (1804–1890)

Fiona Subotsky

William Gilbert, another medical author, was the father of a more famous son, W. S. Gilbert, the dramatist and librettist. The former wrote a number of non-fiction works, usually concerned with the conditions of the poor, and then achieved considerable success with the novel *Shirley Hall Asylum*, told from the point of view of a lunatic.

The narrator does not consider himself to be insane, but merely overstressed by the problems and expense of inventing a perpetual motion device, first for ships and then for locomotives. He settles in at Shirley Hall, a private asylum with two buildings, one for the seriously ill, the other for people who appear at first acquaintance to be well, but later turn out to be 'monomaniacs'. In charge is the assistant physician Dr Meadows, a 'talented, amiable man, [who] treated those whose misfortunes had placed them under his care with the greatest skill, kindness, and consideration.' He tries, in the best fashion of the time, to treat his well-bred patients as guests, or part of a family. In the narrator's view, however, the doctor is no less a monomaniac, being obsessed with building and improving an organ, which is gradually taking over his study.

The doctor and the narrator are soon on good terms, which provides the opportunity for recounting the stories of many of the patients, mostly somewhat absurd, even though the symptoms have frequently been triggered by bereavement. Indeed, the general tone seems to be set by one of the inmates, labelled 'the cynic', who is unable to control his urge for mockery because of a lifetime of minor disappointments.

Eventually Dr Meadows' good humour deserts him, as the requirements of his hobby outpace his income: 'from being excessively courteous and patient, he became extremely caustic and irritable'. The narrator leads an unsuccessful patient revolt, and then decides to escape. While at large, however, he becomes depressed at the feats of the spiritualist levitator Mr Home, whose command of mechanical forces seems so much greater than his own. He concludes that this must be Satanic and, convinced Home is pursuing him, he takes refuge in another asylum. The reader is not informed of the fate of Dr Meadows.

Harrington Tuke, writing on 'Monomania' in this *Journal*'s predecessor in 1867, clarified that the term, coined by Esquirol, was etymologically misleading: it was generally applied to cases of partial insanity including melancholia. Cases of a single fixed delusion, with cheerfulness, were rare but could include 'believers in the ghostly power of Hume [sic]', though this was not necessarily a sign of disease. Dr Gilbert clearly preferred the popular to the medical view.