# Measuring outcome priorities and preferences in people with schizophrenia

ROBERT ROSENHECK, SCOTT STROUP, RICHARD S. E. KEEFE, JOSEPH McEVOY, MARVIN SWARTZ, DIANA PERKINS, JOHN HSIAO, MARTHA SHUMWAY and JEFFREY LIEBERMAN

**Background** Measures have not taken account of the relative importance patients place on various outcomes.

**Aims** To construct and evaluate a multidimensional, preference-weighted mental health index.

**Method** Each of over 1200 patients identified the relative importance of improvement in six domains: social life, energy, work, symptoms, confusion and side-effects. A mental health index was created in which measures of well-being in these six domains were weighted for their personal importance.

Results The strongest preference was placed on reducing confusion and the least on reducing side-effects. There was no significant difference between the unweighted and preference-weighted mental health status measures and they had similar correlations with global health status measures. Patients with greater preference for functional activities such as work had less preference for medical model goals such as reducing symptoms and had less symptoms.

**Conclusions** A preference-weighted mental health index demonstrated no advantage over an unweighted index.

**Declaration of interest** None.

One of the most important developments in the delivery of mental health services in the USA over the past 40 years has been the growing emphasis on 'consumer choice' (Grob, 1991). In the 1960s, 'consumer survivors' and legal advocates successfully limited the reach of involuntary commitment, and established the right to refuse treatment (Frese & Davis, 1997). Patient choice was further strengthened by the mandate that written informed consent be obtained prior to participation in research, by the emergence of a growing self-help movement among mental health service users, and by the increased involvement of service users as service providers (Solomon, 2004). Most recently, a 'recovery' movement emphasising patient choice, hope, and opportunity for mainstream employment has been endorsed by patients and professionals alike (Anthony, 1993). This movement and its values won firm support in the USA in the final report of the President's New Freedom Commission on Mental Health (2003), which urged that mental healthcare should be, above all else, consumer and family driven.

Although 'consumer choice' has become an ever larger presence in clinical practice, it has made far less of a mark on research and especially on outcome assessment. Although methods for measuring health state preferences have received considerable attention in other areas of medicine, studies have tended to focus on health state evaluation by the general public rather than the preferences of individual patients (Gold et al, 1996), and with a few exceptions (Rosenheck et al, 1988; Lenert et al, 2000; Sherbourne et al, 2001) such measures have been little used in psychiatric research. Scales used to measure symptoms, side-effects and quality of life in mental health outcome research have been developed by psychometricians with little or no input from service users, and in most cases rely either on clinician ratings based on professional judgement, or on patients' responses to structured questions (Guy, 1976; Heinrichs et al, 1984; Kay et al, 1987; Barnes, 1989). One measure that has been used occasionally in studies of psychosocial treatment asks participants to rate diverse features of their lives and their feelings about their life as whole on a 1–7 ('delighted' to 'terrible') scale (Lehman, 1988). Use of this measure has been limited, especially in the evaluation of medications.

Preference assessment is especially important in serious mental illness in which many domains of life may be affected. Whereas some patients might be especially troubled by symptoms or side-effects, others might be more concerned with employment or social relationships. As a result, two people with identical scores on a set of outcome measures might feel very differently about their lives if they had different priorities about various life domains. Although the incorporation of patient preference into outcome assessment has been neglected in clinical research, standardised methods are available that could allow systematic comparisons across participants within particular studies and allow generalisation across studies.

Our study uses baseline data from a large, multisite clinical trial to illustrate a method of quantifying patient preferences; to determine whether specific sociodemographic or clinical characteristics are associated with various preferences; to demonstrate an approach to using measured preferences to construct a preference-weighted, multidimensional mental health status index, and to evaluate the plausibility of this index by determining whether it is more strongly correlated with several measures of current global health status than an unweighted version of the same index. We thus hope to demonstrate a method for incorporating patient preferences into conventional mental health status assessment and to determine if doing so has the potential to make a difference in the ultimate interpretation of study results.

#### **METHOD**

The Clinical Antipsychotic Trial for Intervention Effectiveness (CATIE) schizophrenia study was designed to compare the cost-effectiveness of currently available atypical and conventional antipsychotic medications through a randomised controlled trial involving a large sample of

patients treated for schizophrenia at multiple sites, including both academic and more representative community settings. Participants gave written informed consent to participate in protocols approved by local institutional review boards. Details of the study design and entry criteria have been presented elsewhere (Stroup et al, 2003). The study reported here relies exclusively on baseline data collected before randomisation and the initiation of experimental treatments.

#### **Measures**

# Assessment of preferences

Preferences were assessed using a modified version of a method developed for a previous study (Fisher *et al*, 2002). Participants were first presented with a list of goals in six domains and asked to rank them in order of importance. The six goals, identified through focus groups with mental health service users, were:

- (a) increase energy and interest;
- (b) improve social relations;
- (c) reduce disturbing or unusual experiences, such as hallucinations and delusions;
- (d) reduce confusion and difficulty in concentrating;
- (e) reduce medication side-effects;
- (f) increase productive activities, such as having a job.

To assess the magnitude of these relative preferences, participants were further asked how many times more important each item was than the least important item, with a maximum value of 99. To recalibrate these preferences on a uniform scale with possible values ranging from 0.01 to 1, each magnitude assessment was divided by the largest magnitude assessment, i.e. the one associated with the topranked goal. The simple 1–6 ranking and the more nuanced preference scale, which was used in subsequent analyses, were highly correlated with each other (r=0.86, P<0.0001).

### Client characteristics

Questions concerning socio-demographic status documented age, ethnicity, gender, marital and educational status, income (including both earned income and public support payments) and days of paid employment in the past 30 days.

The diagnosis of schizophrenia was confirmed by using the Structured Clinical Interview for DSM–IV (SCID; First et al, 1996) for all participants. Symptoms of schizophrenia were assessed with the rater-administered Positive and Negative Syndrome Scale (PANSS; Kay et al, 1987), which yields a total average symptom score based on 31 items rated 1–7 (with higher scores indicating more severe symptoms), as well as sub-scale scores that reflect positive, negative and general symptoms (Kay et al, 1987).

The Heinrichs-Carpenter Quality of Life Scale (QoLS; Heinrichs et al, 1984) is a rater-administered scale that assesses overall quality of life and functioning on 22 items rated 0–6 (with higher scores reflecting better quality of life) and yields measures on four sub-scales that address social activity, instrumental functioning (e.g. employment, housework), use of objects and participation in activities, and intrapsychic functioning (e.g. motivation, anhedonia and empathy).

Medication side-effects were assessed with the Barnes Akathisia Rating Scale (Barnes, 1989; possible range 0–14), the Abnormal Involuntary Movement Scale (AIMS; Guy, 1976) for tardive dyskinesia (possible range 0–40) and the Simpson–Angus scale for extrapyramidal side-effects (Simpson & Angus, 1970; possible range 0–40).

Depression was measured with the Calgary Depression Rating Scale (Addington *et al*, 1996) and substance use by the Alcohol Use and Drug Use Scales (Drake *et al*, 1990).

Neurocognitive functioning was measured by separate test scores, described in a previous publication (Keefe *et al*, 2003), which were converted to *z* scores and combined to construct five separate scales that were themselves averaged to form an overall neurocognitive functioning scale.

- (a) Processing speed was the average of three components, the Grooved Pegboard test, the Wechsler Abbreviated Scale of Intelligence Revised Digit Symbol Coding Test, and the average of the Controlled Oral Word Association Test and Category Instances.
- (b) Verbal memory was assessed with the Hopkins Verbal Learning Test (average of three trials).
- (c) A vigilance summary score was based on the Continuous Performance Test

- d-prime scores (average of two-digit, three-digit and four-digit scores).
- (d) The reasoning summary score was the average of scores on the Wisconsin Card Sorting Test and Wechsler Intelligence Scale for Children – Revised Mazes.
- (e) The working memory summary score was the average of a computerised test of visuospatial working memory (sign reversed) and letter-number sequencing.

The *neurocognitive composite score* was the average of these five sub-scale summary scores.

#### Global status measures

Global self-reported well-being was assessed using the single global quality-of-life item measured on the 'terrible-delighted' scale from the Lehman Quality of Life Interview (QoLI; Lehman, 1988), which is also used in the Lancashire Quality of Life Profile (Meijer et al, 2002). The EuroQol 'feeling thermometer' item, in which patients are asked to rate their health overall on a vertical scale from 0 (worst possible health) to 100 (perfect health), was also included (Kind, 1996). The Clinical Global Impression scale (Guy, 1976) summarises the clinical rater's assessment of mental health status on a scale of 1-7, where 7 represents poorer health. Finally, a dichotomous variable identified patients who had entered the study during a period of exacerbation of illness, in contrast to those whose clinical status was judged to be stable.

# **Analysis**

Baseline characteristics of participants with complete data (n=1281; 88%) were compared with those with missing data (n=179; 12%) using bivariate  $\chi^2$  and t-tests, followed by multivariable logistic regression to identify factors that independently differentiated the groups. Second, paired t-tests were used to determine the statistical significance of differences in average preference rating for each of the six goals. Next, a series of bivariate correlations were used to determine whether preference for some domains was associated with preference for others. A third set of bivariate correlations was used to identify patient characteristics that were associated with high preferences for each of the six domains. We predicted that areas of poorer functioning would be given higher preferences, for example that greater symptom severity on the PANSS would be associated with greater priority for reduced symptoms, and that poorer neurocognitive functioning would be associated with greater preference for reducing confusion.

We then developed two mental health status indexes, one unweighted and one weighted for patient preferences. The unweighted scale was based on the average of six standardised scores representing better health on measures corresponding to each of the six preference domains. Standardised or Z scores are calculated as follows: the individual score for each participant less the mean value for the entire sample is divided by the standard deviation of the mean. The Z scores on various measures can be averaged to create measures such that a change of one unit represents a change of 1 s.d. on the component measures. In constructing these measures, social relationships were represented by the social relationship scale of the QoLS and work by the instrumental activities sub-scale of the QoLS. Energy was represented by the intrapsychic functioning scale of the QoLS, the negative symptom subscale of the PANSS and the Calgary depression scale, with the PANSS negative sub-scale and Calgary scores each multiplied by -1 so that higher scores consistently represented better health. Symptoms such as disturbing or unusual experiences were represented by the positive sub-scale of the PANSS, and confusion by the summary neurocognitive scale. Side-effects were represented by the average standardised scores of the Barnes scale for akathisia, the AIMS for tardive dyskinesia and the Simpson-Angus scale for extrapyramidal symptoms.

In the weighted version of the index, each of the six standardised component scores was multiplied by the preference weight on that domain for that particular individual. These individual weighted scores were then averaged and divided by the average of all the weights. Thus if all the weights were the same, the weighted index would have the same value as the unweighted index. If the areas of high current well-being are those given greater priority, the weighted index would be greater than the unweighted. If the areas of lowest current well-being are given greater priority, the weighted index would be lower than the unweighted. Paired *t*-tests were used to compare the six unweighted and six preference-weighted domain scores

and the overall mental health status indices averaging the six scores.

To compare the plausibility of the weighted and unweighted domain measures and the two aggregate indices, we examined the correlation of the unweighted and weighted measures with the two patient-rated global measures of well-being: the CGI and the dichotomous indicator of whether or not the participant was hospitalised and/or experiencing an exacerbation of the illness.

Because we found an intriguing tendency for preferences in the domains of energy, social relations and work to be correlated, a cluster analysis was conducted to identify patients with such recovery-oriented preferences in contrast to those with more medically oriented preferences (i.e. for improvement in symptoms, confusion and side-effects). Stepwise multiple regression with forward selection was then used to identify a parsimonious set of characteristics that differentiated these two groups.

#### **RESULTS**

#### Sample

The sample with complete data (n=1281) differed from those with missing data (n=179) on only one independent factor: they had poorer neurocognitive functioning (P < 0.01). Participants in the analytic sample averaged 40.3 years of age, 73.4% were male, 34% were Black and 12% Hispanic, and 12% were married whereas another 59% had never married (Table 1). On average they had been ill for over 16 years and had worked only 2.4 days in the previous month. About a quarter of the sample (27%) entered the study during a period of hospitalisation or illness exacerbation. Other sample characteristics are presented in Table 1.

#### **Preferences**

Across the sample the strongest priorities were placed on reducing confusion and increasing energy, and the least on social life and reducing side-effects (Table 2). Paired *t*-tests comparing average priority ratings showed significant differences on all but one of 15 paired comparisons, indicating a clear hierarchy of goal priorities for this sample.

Examination of the intercorrelation of preference ratings showed that the three goals related to functioning and recovery

(social relationships, work and personal energy) were positively and significantly correlated with one another (Table 3). At the same time, concern about confusion was positively correlated with concern about both symptoms and side-effects. In contrast, correlations between the first group of 'recovery-oriented' measures and the second group of 'illness or medical model' measures were, for the most part, significant and negative.

The six columns on the right-hand side of Table 1 present bivariate correlation coefficients reflecting the association between preferences and personal characteristics.

### Individual correlates of personal preferences

There were few significant correlations with the recovery-oriented preferences. Those who were eager to improve their social lives were more likely to be Black, were less educated and had lower neurocognitive functioning scores. Those who were eager to work had less disability income, fewer positive symptoms, less depression and akathisia as well as higher scores on the QoLS, especially the intrapsychic functioning sub-scale. It is notable that those who put a high preference on work did not work any more days than others and scored no higher on the instrumental role functioning sub-scale of the QoLS (see Table 1). A preference for having more energy was associated with less depression and drug use (see Table 2).

Preference ratings that put greater emphasis on either reducing confusion or symptoms were correlated with several of the same personal characteristics. Black participants were more concerned with symptoms, whereas participants in rehabilitation were concerned with both confusion and symptoms, as were those with more severe psychopathology as measured by both more severe positive symptoms and depression, and lower quality-of-life scores. Alcohol use was also associated with greater concern with symptoms. Unexpectedly, poorer neurocognitive functioning was not associated with greater priority about reducing confusion. Curiously, preference for reduced side-effects was not associated with severity of side-effects on any measure, but was associated with greater age, 12 years of education, less depression and poorer neurocognitive functioning.

Clearer and more consistent patterns emerge between preferences and global assessments of well-being or clinical

 Table I
 Socio-demographic characteristics, clinical status and quality of life, and correlation with preferences (n=1281)

			Correlation coefficients						
	Mean (s.d.)	n (%)	Social life	Work	Energy	Symptoms	Confusion	Side-effects	
Socio-demographic factors									
Age, years	40.3 (10.9)		NS	NS	NS	NS	NS	0.08**	
Gender (male)		939 (73.4)	NS	NS	NS	NS	NS	NS	
Ethnicity									
White		776 (60.6)	NS	NS	NS	NS	NS	NS	
Black		434 (33.9)	0.06*	NS	NS	0.06*	NS	NS	
Other		71 (5.5)	NS	NS	NS	NS	NS	NS	
Hispanic		153 (11.9)	NS	NS	NS	NS	NS	NS	
Education									
Less than high school (12 years)		317 (24.7)	0.06*	NS	NS	NS	NS	NS	
High school graduate		448 (34.9)	NS	NS	NS	0.06*	NS	0.08**	
Greater than high school		516 (40.3)	NS	NS	NS	<b>-0.07**</b>	NS	-0.08**	
Marital status		. ,							
Married		155 (12.1)	NS	NS	NS	NS	NS	NS	
Divorced/separated		344 (26.8)	NS	NS	NS	NS	NS	NS	
Never married		750 (58.5)	NS	NS	NS	NS	NS	NS	
Widowed		32 (2.5)	NS	NS	NS	NS	NS	NS	
Income, US \$		( ,							
Earned income	123 (475)		NS	NS	NS	NS	NS	NS	
Public support income	578 (576)		NS	-0.06*	NS	NS	NS	NS	
Days worked	2.38 (5.90)		NS	NS	NS	NS	NS	NS	
Participation in rehabilitation	2.55 (5.75)	98 (7.6)	NS	NS	NS	0.06*	0.07*	NS	
Clinical status		70 (7.0)	. 10	140	. 10	0.00	0.07	140	
Schizophrenia symptoms (PANSS s	cores)								
Total	75.2 (17.4)		NS	NS	NS	NS	0.11***	NS	
Positive	18.4 (5.6)		NS	-0.0 <b>7</b> *	NS	0.11****	0.10***	NS	
Negative	20.0 (6.4)		NS	NS	NS	NS	0.06*	NS	
General	36.8 (9.2)		NS	NS	NS	NS	0.10***	NS	
Years of illness	16.3 (10.7)		NS	NS	NS	NS	NS NS	NS	
Depression (Calgary)	1.57 (0.556)		NS	-0.08**	-0.058*	0.10***	0.12***	-0.08**	
Drug use	1.46 (0.72)		NS	NS	-0.038 -0.07*	NS	NS	-0.00 NS	
Alcohol use	3.95 (0.94)		NS	NS	NS	-0.09***	NS	NS	
Side-effects	3.73 (0.74)		143	143	143	-0.09	143	143	
Tardive dyskinesia (AIMS)	0.255 (0.456)		NS	NS	NS	NS	NS	NS	
, , ,			NS	- 0.06*	NS	NS	NS	NS	
Akathisia (Barnes)	0.36 (0.55)		NS NS	-0.06	NS NS	NS NS	NS	NS NS	
EPS (Simpson-Angus)	0.217 (0.324)		142	INO	INO	142	INO	1/13	
Quality of life Total score	2 (7 (1 04)		NS	0.06*	NIC	<b>-0.07</b> *	<b>-0.08**</b>	NIC	
	2.67 (1.06)				NS			NS NS	
Social relationships	2.54 (1.29)		NS	NS	NS	-0.07*	NS 0.05*	NS	
Instrumental activity	1.99 (1.67)		NS	NS	NS	NS 0.07***	-0.05*	NS	
Objects/activity	3.23 (1.36)		NS	NS 0.07***	NS	0.07**	-0.09**	NS	
Intrapsychic functioning	3.00 (1.15)		NS	0.07**	NS	NS	-0.10***	NS	
Hip-waist ratio	0.02 (0.08)		NS 0.00***	NS	NS	NS	NS	NS 0.14***	
Neurocognitive functioning	0.00 (0.64)		<b>-0.09***</b>	NS	NS	NS	NS	-0.I4***	
Quality of life/global health	4.20 (1.0)		<b>.</b>	NG		A 11-desired		0.044	
Lehman QoLI	4.32 (1.4)		NS	NS	NS	-0.11***	-0.09**	0.06*	
EuroQol 0–100 scale	59.88 (26.98)		0.11****	0.11****	0.09***	-0.16****	-0.11****		
CGI (severity of illness)	3.95 (0.94)		NS	NS	NS	0.10***	NS	NS	
Exacerbation of illness	348 (0.271)		NS	NS	-0.06*	0.06*	NS	0.07*	

AIMS, Abnormal Involuntary Movement Scale; CGI, Clinical Global Impression; EPS, extrapyramidal symptoms; NS, not significant; PANSS, Positive and Negative Syndrome Scale, QoLI, Quality of Life Interview. \*P < 0.05, \*\*P < 0.01, \*\*\*P < 0.001, \*\*\*P < 0.001, \*\*\*P < 0.0001.

Table 2 Paired comparison of preferences: paired t-tests

	Mean	(s.d.)	Energy	Symptoms	Work	Social life	Side-effects
Confusion	0.606	(0.326)	1.95*	4.19****	6.29***	6.43****	11.31****
Energy	0.580	(0.335)		1.96*	4.96****	5.17****	8.51****
Symptoms	0.550	(0.380)			1.99*	2.09*	6.04****
Work	0.519	(0.345)				0.14	3.89****
Social life	0.517	(0.347)					3.79***
Side-effects	0.461	(0.359)					

<sup>\*</sup>P < 0.05, \*\*P < 0.01, \*\*\*P < 0.001, \*\*\*\*P < 0.0001.

**Table 3** Correlation of preference ratings with each other (Pearson's r)

	Work	Energy	Confusion	Symptoms	Side-effects
Social life	0.10***	0.17***	<b>-0.09***</b>		-0.10***
Work		0.15****	-0.10***	<b>-0.23***</b>	-0.12***
Energy			NS	-0.19***	NS
Confusion				0.08***	0.10***
Symptoms					NS

<sup>\*</sup>P<0.05, \*\*P<0.01, \*\*\*P<0.001, \*\*\*\*P<0.0001.

status. Taken together, greater well-being, especially as measured on the EuroQol 100-point scale, was associated with greater interest in social relations, work and personal energy, and with less interest in symptoms and confusion. Being less well off on all four global health instruments was association with greater concern with symptoms, and (in the case of the Lehman QoLI scale and the EuroQol item) with greater concern with confusion. Higher Lehman QoLI scores were associated with greater concern with side-effects, suggesting that side-effects may not be seen as a priority until a basic level of well-being has been established. On the other hand,

concern with side-effects was also associated with exacerbation of illness.

# Weighted health status measure

Comparison of six unweighted and six weighted domain scores revealed significant difference only in the symptom domain score: unweighted mean 0.0 (s.d.=1), weighted mean -0.044 (s.d.=0.67); t=2.7, P=0.007. The overall unweighted mental health index, that is the average of the six z-scored outcome domain measures (mean 0.00, s.d.=0.52) was not significantly different from the preference-weighted mental health index (mean

0.024, s.d.=1.14; t=1.30, P=0.19). The unweighted and weighted indices were highly correlated with one another (r=0.94, P<0.0001). They were also significantly related to the global measures of well-being and clinical status (Table 4). Counter to our expectation, however, the magnitude of correlations between unweighted measures and measures of global well-being and clinical status were slightly greater than those of the weighted measures (Table 4).

# **Recovery orientation**

Cluster analysis using the six preference measures revealed a recovery cluster (n=666; 52%), in which participants had higher preferences for improving social relationships, work and personal energy, and a medical model cluster (n=615, 48%), in which participants had higher preferences for improving symptoms, confusion and side-effects. Stepwise regression showed that members of the recovery cluster could be parsimoniously differentiated by three measures: they had higher wellbeing scores on the EuroQol, greater total income, and lower positive sub-scale scores on the PANSS (model  $r^2=0.05$ ).

# **DISCUSSION**

Our study used data from a large sample of people treated for schizophrenia to evaluate their personal outcome preferences and priorities and to construct a multidimensional, preference-weighted mental health index. We found a clear hierarchy of preferences in which reducing confusion was the highest priority and reducing side-effects was the lowest. We had expected that the highest preference ratings would be found

Table 4 Association of health status measures with global quality of life and global health status: bivariate correlation coefficients

	Lehman QoLI		EuroQol		CGI		Exacerbation	
	Unweighted	Weighted	Unweighted	Weighted	Unweighted	Weighted	Unweighted	Weighted
Total score	0.22****	0.20****	0.27***	0.26****	-0.48***	-0.46***	-0.068*	-0.064*
Social life	0.24***	0.22****	0.15****	0.14***	-0.23****	-0.17****	-0.03	-0.05
Work	0.15****	0.13****	0.16****	0.15****	<b>-0.24</b> ****	-0.20****	<b>-0.07*</b>	-0.04
Energy	0.32****	0.30****	0.33****	0.29****	-0.40****	-0.34***	-0.03	-0.05
No confusion	<b>-0.04</b>	-0.06*	0.04	0.03	-0.13****	-0.0 <b>9*</b> *	-0.0 I	-0.01
Low symptoms	0.08**	0.08**	0.20****	0.15****	-0.56****	-0.45***	-0.10***	-0.06*
Low side-effects	0.05	0.01	0.12****	0.08**	-0.11****	-0.08**	0.03	0.03

CGI, Clinical Global Impression; QoLI, Quality of Life Interview.

<sup>\*</sup>P < 0.05, \*\*P < 0.01, \*\*\*P < 0.001, \*\*\*\*P < 0.0001

in outcome domains in which patients had the most severe problems as assessed by conventional measures. This proved not to be the case, with the sole exception that positive symptoms of schizophrenia were associated with a greater preference for symptom improvement. This is not likely to reflect inadequate statistical power, since we had 90% power to detect even weak correlations of 0.09. It appears that the preferences documented here reflect idiosyncratic differences in patient valuation of various outcomes.

# Recovery-oriented v. medical model preferences

The most consistent pattern of relationships was found between preferences and global measures of well-being and of clinical status. On these measures those who were best off were most interested in recoveryoriented goals such as improved social relationships, employment and personal energy, and those with the most problems were more concerned with symptoms, confusion or side-effects. Although there has been great emphasis recently on the development of recovery attitudes or models of care, we know of only one other empirical study of correlates of recovery attitudes (Resnick et al, 2004), which it also found severity of psychopathology - especially depression - to be inversely related to the strength of recovery orientation.

# Effect of preference-weighting

Our preference-weighted multidimensional mental health index was not significantly different from a version of the index that was not weighted for preferences, and this no doubt reflects the fact that domain preferences were not, for the most part, associated with status in each domain. If, as we had predicted, the areas of lowest current well-being had been the areas to which participants gave the greatest priority, the weighted index would have been smaller than the unweighted index. In the absence of such correlations, the preferenceweighted index was not much different from the unweighted index and showed similar (and even slightly weaker) correlations with both domain-specific and global measures of well-being. Efforts to weight preferences in other areas have similarly found that weighting did not increase the validity of the assessment (Mikes & Hulin, 1968; Trauer & Mackinnon, 2001). Some have speculated that importance is already embedded in such ratings; for example, people who are more distressed by their symptoms or side-effects will discuss them in such a way that they will be given higher scores, or will report more distress on a self-report measure. However, had this been the case we would have expected to have seen stronger correlations between preferences and healthy state measures.

The fact that the expressed preferences of participants in this study were largely unrelated to their health status in specific domains suggests that their understanding of the descriptions of the six preference categories did not correspond precisely to what is measured by psychometric tests, perhaps because the assessments were based on observer ratings rather than selfreport data or because preferences concern future health states rather than current ones. For example, priority for improving social relationships was greatest among those with poorer neurocognitive functioning rather than among those with the poorest social relationships, and preference for going to work was greatest among those with less depression and akathisia and superior intrapsychic functioning, not among those who worked least or had worse intrapsychic functioning. Thus, although our analyses did not generate a superior measure of health status, they did highlight illuminating associations with personal preferences, and consistently demonstrated that recovery-oriented preferences were consistently associated with global well-being. This result was confirmed by the results of our cluster analysis and subsequent comparison of the recovery-oriented and medical modeloriented patients. When the CATIE study is completed it will be possible to determine whether longitudinal improvement results in changes in preferences. These crosssectional data suggest that as individuals with severe symptoms improve, their priorities may shift towards more recovery-oriented goals.

# Limitations

Several methodological limitations require comment. First, the range of preference domains that were addressed was limited to six pre-established domains. Some respondents may well have had other areas that were of even greater importance that were not encompassed in our limited framework. In addition, we do not know how well respondents understood the brief

descriptions of the six domains. Qualitative debriefing on how they experienced the preference assessment, how they understood the individual items and why they placed priority on some rather than others would have been informative. In addition, we do not know how representative the CATIE sample is or how generalisable our results are.

Although we have shown that it is possible to elicit outcome preferences from patients with schizophrenia, we found these preferences to be only weakly associated with patient characteristics and there was no substantive difference between unweighted and preference-weighted mental health status measures. Patients who put a higher preference on recovery-oriented activities had better functioning and had less symptoms than those who put a higher preference on medical model goals such as reducing symptoms, confusion and side-effects. It thus appears that the recovery and medical models are not in opposition to one another. Rather, effective treatment of symptoms, confusion and side-effects, in themselves, may help foster a recovery orientation, although additional formal and informal services such as supported employment and peer support are likely to be needed.

# **ACKNOWLEDGEMENTS**

This article was based on results from the Clinical Antipsychotic Trials of Intervention Effectiveness project, supported with Federal funds from the National Institute of Mental Health (NIMH) under contract NOI MH90001. The aim of this project is to examine the comparative effectiveness of antipsychotic drugs in conditions for which their use is clinically indicated, including schizophrenia and Alzheimer's disease. The project was carried out by principal investigators from the University of North Carolina, Duke University, the University of Southern California, the University of Rochester. and Yale University in association with Quintiles, Inc.; the program staff of the Division of Interventions and Services Research of the NIMH; and investigators from 84 sites in the USA. AstraZeneca Pharmaceuticals LP, Bristol-Myers Squibb Company, Forest Pharmaceuticals Inc., Janssen Pharmaceutica Products LP, Eli Lilly and Company, Otsuka Pharmaceutical Co. Ltd, Pfizer Inc. and Zenith Goldline Pharmaceuticals Inc. provided medications for the studies. This work was also supported by the Foundation of Hope of Raleigh, North Carolina. The CATIE Study Investigators Group includes Lawrence Adler, MD, Clinical Insights; Mohammed Bari, MD, Synergy Clinical Research; Irving Belz, MD, Tri-County/MHMR; Raymond Bland, MD, SIU School of Medicine; Thomas Blocher, MD, MHMRA of Harris County; Brent Bolyard, MD, Cox North Hospital; Alan Buffenstein, MD, The Queen's Medical Center; John Burruss, MD, Baylor College of Medicine; Matthew Byerly, MD, University of Texas Southwestern Medical Center at Dallas; Jose Canive, MD, Albuquerque VA Medical Center; Stanley Caroff, MD, Behavioral Health Service; Charles Casat, MD, Behavioral Health Center; Eugenio Chavez-Rice, MD, El Paso Community MHMR Center; John Csernansky, MD, Washington University School of Medicine; Pedro Delgado, MD, University Hospitals of Cleveland; Richardson Douyon, MD, VA Medical Center; Cyril D'Souza, MD, Connecticut Mental Health Center; Ira Glick, MD, Stanford University School of Medicine; Donald Goff, MD. Massachusetts General Hospital: Silvia Gratz, MD, Eastern Pennsylvania Psychiatric Institute; George T. Grossberg, MD, St Louis University School of Medicine - Wohl Institute; Mahlon Hale, MD, New Britain General Hospital; Mark Hamner, MD, Medical University of South Carolina and Veterans Affairs Medical Center; Richard Jaffe, MD, Belmont Center for Comprehensive Treatment; Dilip Jeste, MD, University of California-San Diego, VA Medical Center; Anita Kablinger, MD, Louisiana State University Health Sciences Center; Ahsan Khan, MD. Psychiatric Research Institute: Steven Lamberti. MD, University of Rochester Medical Center; Michael T. Levy, MD, PC, Staten Island University Hospital; Jeffrey Lieberman, MD, University of North Carolina at Chapel Hill; Gerald Maguire, MD, University of California-Irvine; Theo Manschreck, MD, Corrigan Mental Health Center; Joseph McEvoy, MD. Duke University Medical Center: Mark McGee. MD, Appalachian Psychiatric Healthcare System; Herbert Meltzer, MD, Vanderbilt University Medical Center; Alexander Miller, MD, University of Texas Health Science Center at San Antonio; Del D. Miller, MD, University of Iowa; Henry Nasrallah, MD, University of Cincinnati Medical Center; Charles Nemeroff, MD, PhD, Emory University School of Medicine; Stephen Olson, MD, University of Minnesota Medical School; Gregory F. Oxenkrug, MD, St Elizabeth's Medical Center; Jayendra Patel, MD, University of Massachusetts Health Care; Frederick Reimherr, MD, University of Utah Medical Center; Silvana Riggio, MD, Mount Sinai Medical Center-Bronx VA Medical Center; Samuel Risch, MD. University of California-San Francisco: Bruce Saltz, MD, Henderson Mental Health Center; Thomas Simpatico, MD, Northwestern University; George Simpson, MD, University of Southern California Medical Center; Michael Smith, MD, Harbor-UCLA Medical Center; Roger Sommi, PharmD, University of Missouri; Richard M. Steinbook, MD, University of Miami School of Medicine; Michael Stevens, MD, Valley Mental Health; Andre Tapp, MD, VA Puget Sound Health Care System; Rafael Torres, MD, University of Mississippi; Peter Weiden, MD, SUNY Downstate Medical Center; and James Wolberg, MD, Mount Sinai Medical Center. Richard Kachzynski, PhD, conducted the cluster and stepwise regression analyses.

# **REFERENCES**

Addington, D., Addington, J. & Maticka-Tyndale, E. (1996) A depression rating scale for schizophrenics. *Schizophrenia Research*, **3**, 247–251.

#### **CLINICAL IMPLICATIONS**

- Patients with schizophrenia express clear differences in the priority they place on areas of improvement.
- These priorities cannot be inferred from the patient's health status in various domains.
- Patients with greater preference for functional activities such as work have less preference for medical model goals such as reducing symptoms.

### LIMITATIONS

- Only six preference domains were studied.
- Patients were not invited to name the domains that were most important to them.
- The sample was limited to people with schizophrenia.

ROBERT ROSENHECK, MD, VA Northeast Program Evaluation Center, West Haven and Yale University, New Haven, Connecticut; SCOTT STROUP, MD, MPH, University of North Carolina, Chapel Hill, North Carolina; RICHARD S. E. KEEFE, PhD, JOSEPH McEVOY, MD, MARVIN SWARTZ, MD, Duke University, Durham, North Carolina; DIANA PERKINS, MD, MPH, University of North Carolina, Chapel Hill, North Carolina; JOHN HSIAO, National Institutes of Mental Health, Bethesda, Maryland; MARTHA SHUMWAY, PhD, University of California at San Francisco, San Francisco, California; JEFFREY LIEBERMAN, MD, University of North Carolina, Chapel Hill, North Carolina, USA

Correspondence: Dr Robert Rosenheck, Northeast Program Evaluation Center (182), VA Connecticut Health Care System, 950 Campbell Avenue, West Haven, CT 06516, USA. Tel: +1 203 937 3850; fax: +1 203 937 3433: e-mail: Robert.Rosenheck@Yale.edu

(First received 29 September 2004, final revision 6 January 2005, accepted 18 January 2005)

**Anthony, W. A. (1993)** Recovery from mental illness: the guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabilitation Journal*, **16**, II–24.

**Barnes, T. R. (1989)** A rating scale for drug-induced akathisia. *British Journal of Psychiatry*, **154**, 672–676.

Drake, R. E., Osher, F. C., Noordsy, D. L., et al (1990) Diagnosis of alcohol use disorders in schizophrenia. Schizophrenia Bulletin, 16, 57–67.

First, M. B., Spitzer, R. L., Gibbon, M. B., et al (1996) Structured Clinical Interview for Axes I and II DSM IV Disorders — Patient Edition (SCID-I/P). New York: Biometrics Research Institute, New York State Psychiatric Institute.

**Fisher, E. P., Shumway, M. & Owen, R. R. (2002)** Priorities of consumers, providers and family members in the treatment of schizophrenia. *Psychiatric Services*, **53**, 724–730.

Frese, F. J. & Davis, W. W. (1997) The consumersurvivor movement, recovery, and consumer professionals. *Professional Psychology: Research and Practice*, **28**, 243–245.

**Gold, M. R., Siegel, J. E., Russell, L. B., et al (1996)**Cost Effectiveness in Health and Medicine. New York:
Oxford University Press.

**Grob, G. N. (1991)** From Asylum to Community. Princeton: Princeton University Press.

Guy, W. (1976) Abnormal involuntary movements. In ECDEU Assessment Manual for Psychopharmacology (ed. W. Guy). DHEW No. ADM 76-338. Rockville, MD: National Institute for Mental Health.

**Heinrichs, D. W., Hanlon, E. T. & Carpenter, W. T.** (1984) The quality of life scale: an instrument for rating the schizophrenic deficit syndrome. *Schizophrenia Bulletin*, 10, 388–398.

**Kay, S. R., Fiszbein, G. & Opler, D. R. (1987)** The positive and negative syndrome scale (PANSS) for schizophrenia. *Schizophrenia Bulletin*, **13**, 261–276.

**Keefe, R. S., Mohs, R. C., Bilder, R. M., et al (2003)** Neurocognitive assessment in the Clinical Antipsychotic Trials of Intervention Effectiveness (CATIE) project schizophrenia trial: development, methodology, and rationale. *Schizophrenia Bulletin*, **29**, 45–55.

**Kind, P. (1996)** The EuroQol instrument: an index of health-related quality of life. In *Quality of Life and Pharmacoeconomics* (ed. B. Spilker), pp. 191–203. Philadelphia: Lippincott-Raven.

**Lehman, A. (1988)** A quality of life interview for the chronically mentally ill. *Evaluation and Program Planning*, **II**. 51–62.

Lenert, L. A., Ziegler, J., Lee, T., et al (2000)
Differences in health values among patients, family members, and providers for outcomes in schizophrenia.

Medical Care, 38, 1001–1021.

Meijer, C. J., Schene, A. H. & Koeter, M. W. (2002) Quality of life in schizophrenia measured by the MOS SF–36 and the Lancashire Quality of Life Profile: a comparison. *Acta Psychiatrica Scandinavica*, **105**, 293–300.

Mikes, P. S. & Hulin, C. L. (1968) Use of importance as a weighting component of job satisfaction. *Journal of Applied Psychology*, **52**, 394–398.

President's New Freedom Commission on Mental Health (2003) Achieving the Promise: Transforming Mental Health Care in America. Subcommittee on Acute Care Report. DHHS Pub. No. SAM-03-3832. Rockville, MD: National Institute for Mental Health.

Resnick, S., Rosenheck, R. A. & Lehman, A. (2004) An exploratory analysis of correlates of recovery. *Psychiatric Services*, **55**, 540–547.

Rosenheck, R. A., Cramer, J., Xu, W., et al (1998) Multiple outcome assessment in a study of the costeffectiveness of clozapine in the treatment of refractory schizophrenia. Health Services Research, 33, 1235–1259.

**Sherbourne, C., Unutzer, J., Schoenbaum, M., et al** (2001) Can utility-weighted health-related quality-of-life estimates capture health effects of quality improvement for depression? *Medical Care*, **39**, 1246–1259.

**Simpson, G. M. & Angus, J.W. S. (1970)** A rating scale for extrapyramidal side effects. *Acta Psychiatrica Scandinavica Supplementum*, **212**, II–19.

**Solomon, P. (2004)** Peer support/peer provided services: underlying processes, benefits, and critical ingredients. *Psychiatric Rehabilitation Journal*, **27**, 392–401.

Stroup, T. S., McEvoy, J. P., Swartz, M. S., et al (2003) The National Institute of Mental Health Clinical Antipsychotic Trials of Intervention Effectiveness (CATIE) project: schizophrenia trial design and protocol development. Schizophrenia Bulletin, 29, 15–31.

**Trauer, T. & Mackinnon, A. (2001)** Why are we weighting? The role of importance ratings in quality of life measurement. *Quality of Life Research*, **10**, 579–585.