Measuring outcome priorities and preferences in people with schizophrenia

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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 re-calibrate these preferences on a uniform scale, item rankings were used 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 identify patient characteristics that were 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.

**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 χ² 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 un-
weighted scale was based on the average
of six standardised scores representing bet-
ter health on measures corresponding to
each of the six preference domains. Standard-
ised or Z scores are calculated as follows: the individual score for each participant less the mean value for the en-
tire sample is divided by the standard devia-
tion of the mean. The Z scores on various
measures can be averaged to create mea-
sures such that a change of one unit repres-
ents 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 repre-
sented by the intrapsychic functioning scale
of the QoLS, the negative symptom sub-
scale of the PANSS and the Calgary de-
pression 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 examin-
ed the correlation of the unweighted and
weighted measures with the two patient-
rated global measures of well-being: the
global and the dichotomous indicator of
whether or not the participant was hospita-
lised and/or experiencing an exacerbation
of the illness.

Because we found an intriguing ten-
dency 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, confu-
sion 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 sam-
ple 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 aver-
age 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 in-
creasing 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 so-
cial 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 function-
ing 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 pre-
ference for having more energy was asso-
ciated 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 rehabili-
tation were concerned with both confusion
and symptoms, as were those with more
severe psychopathology as measured by
both more severe positive symptoms and de-
pression, 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 redu-
ing 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 1  Socio-demographic characteristics, clinical status and quality of life, and correlation with preferences (n=1281)

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

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 < 0.0001.
Table 2  Paired comparison of preferences: paired t-tests

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

*p < 0.05, **p < 0.01, ***p < 0.001, ****p < 0.0001.

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

<table>
<thead>
<tr>
<th></th>
<th>Work</th>
<th>Energy</th>
<th>Confusion</th>
<th>Symptoms</th>
<th>Side-effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social life</td>
<td>0.10***</td>
<td>0.17****</td>
<td>-0.09***</td>
<td>-0.24****</td>
<td>-0.10***</td>
</tr>
<tr>
<td>Work</td>
<td>0.15****</td>
<td>-0.10***</td>
<td>-0.23****</td>
<td>-0.12****</td>
<td></td>
</tr>
<tr>
<td>Energy</td>
<td>NS</td>
<td>-0.19****</td>
<td>NS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Confusion</td>
<td>0.08***</td>
<td>0.10***</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Symptoms</td>
<td>NS</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*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 associated with greater concern with symptoms, and (in the case of the Lehman QoL scale and the EuroQol item) with greater concern with confusion. Higher Lehman QoL 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. = 0.32) 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 well-being scores on the EuroQol, greater total income, and lower positive sub-scale scores on the PANSS (model r² = 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

<table>
<thead>
<tr>
<th></th>
<th>Lehman QoL</th>
<th>EuroQol</th>
<th>CGI</th>
<th>Exacerbation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unweighted</td>
<td>Weighted</td>
<td>Unweighted</td>
<td>Weighted</td>
<td>Unweighted</td>
</tr>
<tr>
<td>Total score</td>
<td>0.22****</td>
<td>0.20****</td>
<td>0.27****</td>
<td>0.26****</td>
</tr>
<tr>
<td>Social life</td>
<td>0.24****</td>
<td>0.22****</td>
<td>0.15****</td>
<td>0.14****</td>
</tr>
<tr>
<td>Work</td>
<td>0.15****</td>
<td>0.13****</td>
<td>0.16****</td>
<td>0.15****</td>
</tr>
<tr>
<td>Energy</td>
<td>0.32****</td>
<td>0.30****</td>
<td>0.33****</td>
<td>0.29****</td>
</tr>
<tr>
<td>No confusion</td>
<td>-0.04</td>
<td>-0.06*</td>
<td>0.04</td>
<td>0.03</td>
</tr>
<tr>
<td>Low symptoms</td>
<td>0.08**</td>
<td>0.08**</td>
<td>0.20****</td>
<td>0.15****</td>
</tr>
<tr>
<td>Low side-effects</td>
<td>0.05</td>
<td>0.01</td>
<td>0.12****</td>
<td>0.08**</td>
</tr>
</tbody>
</table>

CGI: Clinical Global Impression; QoL: Quality of Life Interview.
*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 vs. 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 recovery-oriented 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 preference-weighted 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 self-report 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 model-oriented patients. When the CATIE study is completed it will be possible to determine whether longitudinal improvement results in changes in preferences. These cross-sectional 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.

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REFERENCES


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.

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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

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