

## ORIGINAL PAPER

Durk Wiersma · Jooske van Busschbach

# Are needs and satisfaction of care associated with quality of life?

## An epidemiological survey among the severely mentally ill in the Netherlands

Received: 27 July 2001 / Accepted: 6 August 2001

**Abstract** Is the quality of life of severe mentally ill patients influenced by the intensity of the care provided, their satisfaction with services and/or the amount of unmet needs? The interrelatedness of these three outcome measures was investigated in a sample of 101 patients dependent on long-term psychiatric care in the North-east of the Netherlands. Instruments used were the Camberwell Assessment of Needs, the Verona Service Satisfaction Schedule and a health related quality of life instrument, the EuroQoL.

Quality of life was unrelated to satisfaction with services but was strongly associated with unmet needs in the area of mental and physical health, and of rehabilitation. Quality of life decreased as needs increased. Needs were also strongly related to diagnosis and cognitive functioning. Furthermore, more intensive care settings were provided as needs increased. Demographic, diagnostic and treatment variables did not explain much extra variance in quality of life. Despite the availability of various services in the region there was a lack of tailor made care which took into account specific unmet needs with regard to information, social contacts, and daily activities.

**Key words** Needs assessment · Satisfaction · Quality of life · Severe mental illness · Schizophrenia

### Introduction

Effectuated by the awareness of the patient as a consumer and the necessity to justify the interventions offered to

people with severe psychiatric handicaps, the question of the quality of care becomes more and more important. Threats that service costs could be cut also make it necessary to provide adequate information in the form of outcome measures to evaluate services based on quality. Need assessment instruments, questionnaires on satisfaction with services and self-report indicators of health-related quality of life are currently considered appropriate measures of quality of care. However, the interrelationship between these three outcome measures is quite complex and warrants further exploration.

In studies with physically ill patients, a strong association has been found between patient satisfaction and administrative measures of quality of care (Druss et al. 1999). Also, patient satisfaction was shown to contribute to both physical and mental health-related quality of life (Guldvog 1999). In patient populations dependent on mental health care, there is evidence that the same relation exists between satisfaction with services and quality of life, social functioning and one year prognoses (Berghofer et al. 2001). Some authors, however, give warning that patients can be biased by their mental state or the effects of medication (Jenkins 1992). In a mail survey with 815 respondents, for example, it was found that people with schizophrenia reported greater service and life satisfaction than persons with other diagnoses (Rohland 2000). In a thorough study to investigate the differences in self-reported quality of life, Atkinson (1997) found that patients with mood disorders were found to have lower scores on quality of life scales although they experienced less objectively aversive life circumstances than patients with schizophrenia; he concluded that the validity of self-report measures of life satisfaction can be questioned, particularly for use in effectively disturbed populations. Alternative measures of quality of life, using health states weighted by utility values gained from community surveys, are available (like the QALY's (Quality Adjusted Life score) De Wit et al. 2000). But until now, the validity of these measures in samples of patient dependent on mental health care is not clear.

D. Wiersma (✉) · J. van Busschbach  
Department of Psychiatry  
WHO Collaborating Centre  
University Hospital Groningen  
P. O.Box 30001  
9700 RB Groningen, The Netherlands  
Tel.: +31-50/3613839  
Fax: +31-50/3619722  
E-Mail: d.wiersma@med.rug.nl

Need-of-care assessment can be another tool in measuring quality of care, particularly when the so-called 'unmet' needs are taken into account. Several studies to date have reported the prevalence and kind of needs in various chronic patient populations (Issakidis and Teesson 1999; Middleboe et al. 2001; Slade et al. 1996, 1998, 1999; Wiersma et al. 1996, 1998). The association of needs with quality of life has been studied by Bengtsson and Hannsson (1999), Heinze et al. (1997) and Slade et al. (1999) suggesting that in specific populations met and unmet needs were negatively associated with reported quality of life. It remains unclear whether this is a general finding for the whole population of the severely mentally ill in all kinds of treatment settings or specific for patients with schizophrenia and spectrum disorders only. And, even more important, the question arises as to whether it is the amount of help needed or the inadequate match between help needed and provided that is associated with a lower quality of life.

In this article, the interrelatedness of these different outcome measures is analyzed using patient self-report questionnaires. Data are used from a representative sample of 101 patients with severe mental disorders in various mental health care settings in the Northeast of the Netherlands. The study aimed to find answers to questions like how adequate mental health care fulfills the needs of the long-term patients, how satisfied these patients are with their care and to what extent innovations like home or day care and sheltered community living are associated with a better quality of life. These answers may be of some importance to rehabilitation strategies or to improve the effectiveness of care.

The analyses are focused on the following four issues:

- The number and kind of needs of care and the differences between diagnostic groups and various in- and outpatient treatment settings;
- Satisfaction with services provided and the relation with type of services, diagnostic groups and (un)met needs;
- The correlations between measures of self-evaluated quality of life and utility valued states of health (Quality's), and (un)met needs and satisfaction with services.
- The relative importance of need and satisfaction variables together with patient characteristics to predict Quality adjusted Life scores.

## Selection of patient population

In a prevalence study (Wiersma et al. 1997), we estimated the proportion of the population with long-term care (> 2 years) for psychiatric problems in the Netherlands. Data from three surveys and two psychiatric case registers covering five different areas in the Netherlands provided an estimate of about 3.5 per 1,000 of the population of 20 years and older. Only one third received a diagnosis of schizophrenia or related psychotic disorder. The long-term care was to a large extent (40 %) pro-

vided in hospitals and sheltered accommodations in the community, and the role of day services were relatively insignificant.

To gain information on patient's evaluation of care and quality of life, a random sample was drawn from one of the administrative prevalence surveys which in the years 1993 included all 715 patients at the age of 20 years or older, living in Northeast Groningen (population at risk of 235,000 inhabitants; 171 per km<sup>2</sup>), and in treatment in any kind of mental health service (mental hospital, outpatient department, regional institute for ambulatory care (RIAGG) and sheltered accommodation). These patients were initially selected from the files by the administrations of the services and were reviewed by the professionals involved according to the criteria of clinical diagnosis (DSM-III), disability, duration, and a continuous care period of at least two years (Bachrach 1988), including a check on double counts. Nearly 200 patients from the 715 identified in 1993 were contacted four years later for a follow-up interview: 29 % appeared to be unreachable because of death (7 %), moving (9 %) or lack of response of clinician (13 %) and in 20 % of the cases no permission for an interview was given by the patient himself (14 %) or by the clinician (6 %). Finally, a sample of 101 patients was personally interviewed about their needs, satisfaction and quality of life. Compared to the total population of the severely mentally ill, the sample was fairly representative in terms of demography and diagnosis, but less in terms of service utilization (see Table 1). The main difference rested in the under-representation of those who were in the hospital at prevalence date and who had a long history (> 10 years) of mental health care with multiple admissions. For this there were two reasons. We aimed at somewhat more patients in care in more innovative settings (home & day

**Table 1** Population and sample of long-term psychiatric patients (percentages)

	Sample in 1998 N = 101	Population in 1993 N = 715
Male	46	48
Mean age (sd)	49 yrs (15)	53 yrs (15)
Diagnosis:		
Psycho-organic syndrome	8	12
Schizophrenia	24	27
Affective disorders	31	30
Anxiety or other axis I	19	16
Personality disorder (axis II)	19	15
Treatment setting:		
Psychiatric hospital	15	31
Sheltered accommodation	17	23
Home /day care	13	8
Outpatient care	36	38
No mental health care/GP	20	–
First MH care contact:		
More than 10 yrs ago	48	68
Between 5 to 10 yrs	23	18
Less than 5 yrs ago	29	14
Hospital admissions:		
More than 5	17	25
Between 1 and 5	67	63
No admissions	17	12

care) than from the relatively large group of patients in long stay wards. But also, there was a higher dropout rate in this latter group because patients were difficult to interview as they were too ill, refused or had passed away in the mean time.

## Diagnosis and treatment setting

Affective disorders (31%) and schizophrenia (24%) were the most frequent diagnoses followed by other axis I (mainly anxiety) and axis II (personality disorders) diagnoses. Data from two simple cognitive tests, one for verbal memory and learning (CVLT, Delis et al. 1987) and one performance task of attention and concentration (Trail making, Vink and Jolles 1985) indicated that the level of cognitive functioning was relatively poor. A large number of patients failed to perform on the two tests: 29% did not receive a score on the verbal memory test because they could not memorize the first list of words. The performance test was not finished by 40% because they lacked concentration and/or had difficulty with the alphabet. Both tests correlated significantly ( $r=.47$ ). Only patients with psycho-organic syndromes or schizophrenia appeared to do worse on the verbal memory task.

Nearly one third in the sample lived either in 24-hour supervised institutional settings like the mental hospital (15%) or in sheltered community accommodations (17%) in contrast to home and day care facilities (13%) and outpatient care (36%). Twenty percent of the patients who were included in the prevalence survey (1993) were, about four years later, for at least one year out of specialized mental health care, but mostly still in the hands of the general practitioner. Nearly all patients received medication and some form of individual therapy. Recreational therapy was frequent in the hospital, home and day care setting. Social therapy was relatively often (30–40%) provided in day and outpatient care.

In more than half of the cases, the first mental health contact dated back more than 10 years and was followed by multiple admissions to a mental hospital.

## Method

We used three instruments in the interview with the patient: the Camberwell Assessment of Need or the CAN (Slade et al. 1999), the Verona Service Satisfaction Schedule or the VSSS-32 (32-item version, Ruggeri et al. 1994) and the EuroQoL (the EuroQol Group 1990).

With the CAN, a semi-structured interview that can be conducted with both patient and central care giver, need is assessed in 22 areas ranging from accommodation, food and self-care to physical health and psychotic symptoms to budgeting and benefits. For logistic and availability reasons no interviews were held with the staff so the need rating reflects the opinion of the patient only and not that of the carer or professional. The presence of a problem or a need is rated on a three-point scale ("0=no problem, 1=no or moderate problem because of continuing intervention indicating a met need; and 2=current serious problem or unmet need"). If there is a need (a rating of a 1 or 2), then further questions are asked about help received from informal sources (friends or relatives), help received from services (for-

mal help, paid staff) and the level of help the patient thinks is needed from services. The response of the patient is directly recorded in the schedule and reflects his opinion on his felt need of care, including the intensity of received and needed help. The intensity of help is rated on a 4-point scale ("0=none, 1=low, 2=moderate, 3=high").

For the sake of simplicity and conceptual reasons in view of the required tasks of staff or disciplines, we re-arranged the 22 items of the CAN into four dimensions of needs with respect to basic Activities of Daily Living (ADL consisting of 4 items: accommodation, food, self-care, looking after the home; average inter-correlation is 0.50), to Mental Health Care (MHC consisting of 8 items: physical health, psychotic symptoms, information, psychological distress, safety to self and others, alcohol, drugs; average inter-correlation is 0.17), to REHABilitation (REHAB consisting of 5 items: daytime activities, company, intimate relationship, sexual expression, child care; average inter-correlation is 0.20) and to SERVICes (SERVI consisting of 5 items: education, telephone, transport, money, benefits; average inter-correlation is 0.30). The dimensions are significantly inter-correlated except for ADL with MHC and REHAB; the strongest correlations are between ADL and SERVI (0.59) and between MHC and REHAB (0.44). In the analysis we used these summed indices for number of met and unmet needs, total and for each of the dimensions, and indices for the intensity of informal and formal help, including the difference between given and needed help.

The VSSS consists of an 18-item self-report questionnaire which is summarized in five dimensions on a) global satisfaction, b) satisfaction on skills and behavior of the professional, c) the delivery of information on diagnosis and treatment, d) the efficacy and accessibility of care, and e) relative's involvement. If the patient had difficulty reading, a structured interview was conducted. The response to each question is recorded on a 5-point scale ("1=terrible, 2=mostly unsatisfactory, 3=mixed, 4=mostly satisfactory, 5=excellent"). In addition, the questionnaire also contains 14 questions (not reported here) on types of interventions like admission, individual therapy, sheltered work, etc. regarding its reception and satisfaction during the last year.

The EuroQoL contains a 5-item self-report questionnaire with respect to mobility, self-care, usual activities, pain/discomfort and anxiety/depression. This instrument is developed as a preference-based measure of health-related quality of life to be used in the evaluation of different health care interventions (EuroQol Group 1990, Brooks 1996). Response is recorded on a 3-point scale as to felt limitations (I am or I have... "1=no problem, 2=some problems, 3=unable to or extreme problems") in functioning on each of the five dimensions. Each combination of scores represents a health state. In principle, there are 243 theoretically possible health states, which have been valued according to the preferences of a representative sample from the general population. We used the formula developed by Dolan and Phil (1997) based on a large sample in the UK which produces an estimate of the Quality adjusted Life (1.00 is perfect health and 0 or even negative values represent an evaluation of health worse than death). The EuroQoL further contains a question on a comparison of the current health situation with one year ago ("1=better, 2=same, 3=worse") and consists of a Visual Analogue Scale (VAS) in the form of a thermometer with endpoints of worst (score 0) and best imaginable health state (score 100). Patients mark the line rating their health on the day of the investigation.

## Analysis

The statistical analysis is focused on the interrelationship between demographic background of the patients, their diagnostic and mental health care history, their treatment setting on the one hand, and the number and kind of (un)met needs, satisfaction of care and quality of life on the other hand by means of Pearson correlations and analysis of variance. The leading question is: are there statistical significant correlations between these background variables and the outcome variables.

In a multiple regression analysis we explored the predictive value of background variables together with needs and satisfaction with care on the health-related quality adjusted life measure. Quality of life is taken here as the final outcome, resulting from the presence of needs and feelings of satisfaction as perceived by the patient. The leading question is whether specific met or unmet needs predict quality of life.

## Results

### ■ Prevalence of needs and help

The number of needs was on average 8.0 (sd=4.0) per patient, varying from 1 to 17. Psychotic symptoms (73%), physical health (63%), psychological distress (61%), daily activities (59%), looking after the home (58%), company (55%), and accommodation and food (both 53%) were the most frequent needs; problems with alcohol, drugs and risk to others were reported infrequently (< 10%) (Table 2).

On average 2.0 needs (sd=2.3) were indicated as unmet, in particular in the areas of company, psychological distress and information on treatment (> 20%). Women had somewhat more needs of accommodation, information and money. Older patients (> 65 years) had relatively more needs in the area of accommodation, money, self-care, physical health, use of telephone, and transportation.

**Table 2** Prevalence of needs and help (percentages (N=101))

	Total Need	Unmet* Needs	Without* informal care	Without* formal care
ADL: Activities Daily Living				
Looking after home	58	10	55	34
Accommodation	53	23	58	17
Food	53	6	68	36
Self-care	23	5	78	26
MHC: Mental Health Care				
Psychotic symptoms	73	18	55	7
Physical health	63	13	44	16
Psychological distress	61	34	41	18
Information	46	41	61	33
Safety to self	24	38	50	17
Alcohol	10	40	60	30
Safety to others	8	38	50	13
Drugs	5	80	0	60
REHAB: Rehabilitation				
Daytime activities	59	27	58	17
Company	55	42	18	24
Intimate relations	30	50	43	30
Sexual expression	22	73	59	55
Childcare	13	38	46	54
SERVI: Services				
Education	40	8	65	33
Transportation	38	21	42	34
Money	36	22	58	31
Benefits	20	40	65	35
Telephone	17	18	82	18

\* percentages of number of total need

Informal care was provided in, on average, 3.6 needs with an intensity score of 1.9 (slightly less than 'moderate'); 15% of the patients had no informal help at all. Except for four patients all received some professional help in, on average, 6.0 needs with an intensity score of 2.0. Professional help is relatively lacking in areas of looking after home, food, information, company, education, transportation, sexuality, psychological distress and money.

In an average of 1.1 needs there was no match between provided and needed professional help: more help was needed in, on average, 0.9 needs and less help in 0.2 needs. More than half of the patients (54%) experienced such a discrepancy in one or more areas which indicates at least a subjectively felt inadequacy of care, in particular with respect to daily activities, information, personal safety, psychological distress, intimate relations, sexual expression and child care.

In general, there are only a few statistically significant relationships between gender, age and the cognitive tests, on the one hand, and the number of (un)met needs, intensity of (in)formal help on the other. Correlations (N=101) are low: older patients had somewhat more needs (0.20), received less informal help (-0.24), more formal help (0.35) and more adequate care (-0.20).

Worse performance on the attention test was related to more needs (-0.32). Surprisingly, the occurrence of inadequate professional care correlated significantly with the intensity of informal help, but not with that of formal, professional care. In other words, the amount (intensity) of professional help did not influence patient's evaluation of adequacy, but the amount of support by family members increased with the number of needs with inadequate care.

### ■ Diagnosis

The number of met and unmet needs is related to diagnostic category (Table 3): relatively high for patients with psycho-organic syndromes, schizophrenia and personality disorders and low for affective disorders and anxiety. Unmet needs were very frequent among patients with personality disorders (42% were unmet).

Patients with psycho-organic syndromes expressed more needs in the area of ADL and SERVI. Remarkably, needs in the area of mental health care (MHC-needs) were evenly distributed over the diagnostic categories. Unmet needs in the area of rehabilitation were more frequent among patients with psycho-organic syndromes, schizophrenia and personality disorders.

### ■ Treatment setting

There is a strong relationship between number of needs and setting of mental health care (Table 4): the higher the number of needs, the more intense the care. Even among those who were outside mental health care but



**Table 3** Needs of care in relation to diagnosis (means and percentages (N=101))

	Total Needs	% Unmet	ADL*	MHC*	REHAB*	SERVI*
Psycho-organic syndrome (n=8)	11.8	22%	3.4	2.8	2.1	3.5
Schizophrenia (n=24)	8.9	22%	2.3	3.0	2.1	1.5
Personality disorder (n=19)	8.6	42%	1.6	3.2	2.2	1.6
Anxiety & other axis I (n=19)	7.8	19%	1.8	3.1	1.4	1.5
Affective disorder (n=31)	6.0	22%	1.3	2.5	1.4	0.8
Significance	F=4.72 Df=4,96 p=0.002	F=2.93 Df=4,96 p=0.025	F=3.95 Df=4,96 p=0.005	F=0.85 Df=4,96 p=0.50	F=2.26 Df=4,96 p=0.07	F=6.60 Df=4,96 p<0.000

ADL needs of basic activities of daily living; MHC needs of mental and physical health care; REHAB needs of social rehabilitation; SERVI needs of educational and welfare services

mostly in the hands of their GP, needs were quite prevalent (6.0). Unmet needs were prevalent in every treatment setting, but mostly in hospital and outpatient settings (30% were unmet in both). Patients in sheltered community accommodations had the lowest number of unmet needs (14%).

MHC-needs were evenly distributed over the various treatment settings, but this did not apply to other kinds of needs: ADL-needs were more frequent in sheltered accommodation and the hospital, REHAB-needs more frequent in home and day care and in the hospital, and SERVI-needs were mostly observed in the psychiatric hospital.

### ■ Satisfaction with care

Satisfaction with mental health care is represented by the five dimensions on which a mean score of 3 indicates a mixed judgment and a score of 4 or higher a (very) good judgment. The patients (81 < N > 90) scored 3.9 (sd=0.8) on skills and behavior of the professional, 3.7 (sd=1.0) on global satisfaction, 3.7 (sd=0.8) on accessibility of care, 3.5 (sd=0.6) on efficacy, 3.4 (sd=1.2) on information and 3.1 (sd=1.3; N=44) on involvement of the family. With respect to family involvement, there are only a few satisfaction scores as the majority of patients either had no more family, did not want to see them, or had no interest in involving them in their treatment. In case they still had contact with them, satisfaction was low as to how mental health professionals had involved

the family. The average scores on the VSSS dimensions are in accordance with those reported by Parkman et al. (1997) among 114 white UK-born patients with psychosis in South London.

There was no statistically significant relationship between gender, age, diagnosis or treatment setting and satisfaction with services. Also there were no significant relationships with the total number of needs and the amount of care provided, i.e., patients who were more dependent on care were not less or more satisfied with services than others. However, there was a strong correlation between satisfaction and the number of unmet needs (between -0.36 and -0.50), particularly in the area of mental health care, rehabilitation and services.

### ■ Quality of life

EuroQoL-scores in our sample (N=97) on the five dimensions of mobility, self-care, usual activities, pain/discomfort and anxiety/depression were compared with a patient population with acute schizophrenia who were indicated for a change in medication (Bardia et al. 2000), a patient population with chronic pain and with a healthy sample from the Dutch general population (Essink-Bot et al. 1995) (Table 5).

The severely mentally ill fell in between the large acute schizophrenia group and the somatic pain group. The healthy controls – although not at all free from pain/discomfort or anxiety/depression – rated their

**Table 4** Needs of care in relation to treatment setting (means and percentages (N=101))

Treatment setting	Total needs	% Unmet	ADL*	MHC*	REHAB*	SERVI*
No MH care/GP only (n=20)	6.0	24%	1.1	2.5	1.4	1.0
Outpatient MH care (n=36)	7.2	30%	1.4	3.0	1.6	1.3
Home/day care (n=13)	7.5	26%	1.2	3.0	2.5	0.8
Sheltered accommodation (n=17)	8.6	14%	2.9	2.5	1.4	1.7
Psychiatric hospital (n=15)	12.2	30%	3.4	3.3	2.5	3.0
Significance	F=7.38 Df 4,96 p<0.000	F=2.93 Df=4,96 p=0.025	F=13.43 Df=4,96 p<0.000	F=0.98 Df=4,96 p=0.42	F=3.21 Df=4,96 p=0.01	F=6.60 Df=4,96 p<0.000

\* ADL needs of basic activities daily living; MHC needs of mental and physical health care; REHAB needs of social rehabilitation; SERVI needs of educational and welfare services

**Table 5** Health-related quality of life (EuroQol) of severely mentally ill compared to schizophrenic outpatients, chronic headache patients, and healthy normals. Proportions patients with problems, in percentages and means

	Severely mentally ill (N=97)	Schizophrenia* outpatients (N=2128)	Headache** patients (N=436)	Healthy** normals (N=575)
Mobility	34%	33%	17%	13%
Self-care	24%	43%	3%	2%
Usual activities	41%	85%	28%	17%
Pain/discomfort	51%	52%	50%	33%
Anxiety/depression	54%	82%	27%	15%
VAS scale (mean)	67	49	77	83

\* Badia et al. 2000; \*\* Essink-Bot et al. 1995

health much better than the patient groups. The VAS scale had a mean of 67 (sd=17.9; min 8 max 100).

In our research sample the average EuroQol-index (i. e., Quality adjusted Life years or QuaLys) score was 0.63 (sd =0.32, min -0.35, max 1.0). Women, older patients and patients with a longer mental health history had lower scores on the EuroQoL-index, i. e., lower quality of life (correlation about -0.20;  $p < 0.05$ ). Diagnosis was also statistically significant related to quality of life ( $F=2.526$ ;  $df=4,92$ ;  $p < 0.05$ ) with lower scores for psycho-organic syndrome (0.53) and personality disorder (0.50) and a relatively high score for affective disorder (0.77) with those for schizophrenia and anxiety (each 0.60) in between. The cognitive tests did not correlate significantly with the EuroQoL index.

The treatment setting was significantly related to quality of life ( $F=2.965$ ;  $df=4,92$ ;  $p < .05$ ): lower scores for hospital (0.42) and outpatient treatment (0.58), and higher scores for GP care (0.71), home/day care (0.73) and sheltered community accommodation (0.73).

Neither satisfaction with care nor the intensity of (in)formal help held a significant relationship with quality of life. Met as well as unmet needs, however, were strongly associated with the EuroQoL index: generally, more needs leads to less quality of life.

We evaluated the relative importance of these need and satisfaction variables together with the demographic, diagnostic and treatment variables in several stepwise multiple regression analyses of the Quality adjusted Life score (Table 6). First, the prediction by needs and satisfaction was investigated. The demographic, diagnostic and treatment variables were added stepwise. In the end the following model came about which most

sparingly explained the variance of the Quality index: four variables: number of met ADL-needs, unmet MH care- and unmet Rehabilitation-needs together with the health comparison with one year ago, explained 36% (adjusted 34%) of the variance. Further improvements were marginal and non-significant.

## Discussion

Needs assessment, satisfaction with care and quality of life are key factors in the evaluation of care provided for the severely mentally ill. In our analysis we have tried to disentangle these different outcome measures and provide some baseline information on this group of patients in Dutch mental health care. The results reported here must be considered in the light of this study's strengths and limitations. The focus of this study lies primarily on the view of the patient on his or her own situation. An interview with a professional carer was not possible for logistic reasons so we do not know how 'realistic' these results actually were. In the case of unmet needs, a professional opinion could shed light on how meetable those needs were, whether an effective intervention was available in the service or a referral should have been considered. Also, it could illuminate the existence of needs, which were unthought of before. It is not unlikely that the opinion of the clinician would have diverged substantially from that of the patient. Other studies demonstrate that clinicians and patients differ in their perceptions of need: for example, Slade et al. (1996 & 1999) found that patients reported 0.6 to 0.7 needs more than the clinicians while Issakidis and Teeson (1999) found that staff identified 1.3 needs more than the patients ( $p < 0.05$ ), with large differences in the areas of company, relationships and sexual expression, although this was less marked in case of unmet needs. The kind of need assessment procedure that is followed is also important (Wiersma et al. 1998): a clinician based contextual rating of problems, intervention and resulting need status versus a straightforward rating of a problem or need.

Our study consisted of 101 patients randomly drawn from the files of the mental health services. They were to a fair degree representative of the population of severely mentally ill in the region, except for the longer hospitalized patient group which may constitute a bias. But if

**Table 6** Regression analysis of quality adjusted life years (EuroQol)

	Standardized coefficient beta	t	Significance
Met ADL needs	-0.305	-3.545	0.001
Unmet MHC needs	-0.255	-2.771	0.007
Unmet REHAB needs	-0.201	-2.258	0.026
Health worse than 1 yr ago	-0.269	-3.061	0.003
R	0.60	F=13.084	< 0.000
R2 (adjusted)	0.36 (0.34)		

\* ADL needs of basic activities of daily living; MHC needs of mental and physical health care; REHAB needs of social rehabilitation

there is bias due to difficulties to get in touch with people a few years later and because of refusals then it is possibly in the unfavorable direction as to functional and need status. They represented a diagnostically rather heterogeneous group of patients in a variety of treatment settings. However, the size of the sample may limit the generalizability of the findings.

We found that the prevalence of met and unmet needs as reported by the patients, is dependent on diagnosis and cognitive functioning. Prevalence of needs is, to a large extent, reflected in the corresponding level of provided care: the more intensive and institutionalized the treatment setting, the higher the number of needs, which nicely parallels the different 'echelons of care'. One might argue that hospitalization in itself could have influenced the needs assessment here. In such a cross-sectional study like ours, causes and consequences are difficult to entangle, but the findings seem to reflect that most intensive care indeed is given to those who need it most. In a large community sample Middleboe et al. (2001) found that severity of symptoms and social dysfunctioning strongly predicted total number of needs.

On average two needs per patient or 25 % of the mean total number of 8.0 needs were serious and not sufficiently or adequately fulfilled by the mental health services. Psycho-organic syndromes, schizophrenia and personality disorders were associated with significantly higher numbers of needs. Those who had severe cognitive limitations (partly those with a diagnosis of psycho-organic syndromes and schizophrenia) had a higher number of needs but not more unmet needs. One might wonder the validity of needs assessment in these patients with cognitive deficits. Probably, the semi-structured interview of the CAN which allowed the investigator to probe with further questions and to compensate for possible misunderstanding by the patient has prevented a serious bias. In such a case one would have expected a lower number of needs instead of higher. Moreover, the lack of a significant correlation between the cognitive tests and the QoL scores point in the same direction.

The proportion of unmet need according to the patient (25%) as found in this study is not uncommon if compared with those from other studies: Slade et al. (1998) reported 6.7 needs of which 27% were unmet among a representative sample of 137 chronic psychotic patients in South London, Wiersma et al. (1998a) found 4.2 needs of which 26% were unmet among 30 schizophrenic patients after a 17 year follow-up since first onset, and Issakidis and Teeson (1999) 6.0 needs of which 30% were unmet among 78 chronic patients in Sydney. Bengtsson-Tops and Hansson (1999) reported a higher proportion of 61% unmet of 8.2 needs in a study of 120 schizophrenic outpatients in Sweden, and similarly Middleboe et al. (2001) with 42% unmet of 6.2 needs in a community sample of 418 outpatients with schizophrenia in the Nordic countries. In all studies, unmet needs were prevalent in the areas of occupation, psychotic symptoms, distress, company, intimate relations, and

sexual expression. Clinicians in all kinds of treatment settings do not seem to be very responsive to these kinds of needs and apparently do not know how to handle them. This could be a special task for psychosocial rehabilitation as a defined service response. For example, in a naturalistic follow-up study among 35 long-term patients mostly with schizophrenia, we could demonstrate a significant effect of an innovative rehabilitation approach on the number of met and unmet needs (Busschbach and Wiersma 2001).

It is remarkable that, in our study, satisfaction with care was not significantly related to the total number of needs but only to the number of unmet needs (in particular to needs in the area of mental health). Among others, this suggests that the need response did not simply reflect an inclination to complain. Indeed, the patients did not always indicate that they needed more help and their evaluation of adequacy did not simply correlate with the amount or intensity of professional help. The fact that when the number of unmet needs increased, the amount of support by family members increased, suggests that the family played a role in compensating for inadequate professional care.

As with self-reported needs and clinicians-based needs rates, the correlation between self-rated and more objectively rated quality of life scores has been reported to be low (e.g., Trauer et al. 1998). In our analyses we focused mainly on the Quality Adjusted Life scores as we assumed those to be less satisfaction-oriented and less influenced by mental state, poor insight or the effects of hospitalization. This assumption seems to hold true as lower QoL's were only found in patients with a longer history of care and in patients with a psycho-organic syndrome. Cognitive deficits did not influence the QoL ratings. And, in contrast with the findings from studies that focused on subjectively rated quality of care (Atkinson 1997; Rohland 2000), patients with schizophrenia had lower QoL's than people with affective disorders. Nor did we find a correlation between service satisfaction and the quality of life scores as represented in the QoL's. Supposedly this correlation is only there when a more subjective rating of quality of life score is applied; see for example the findings reported by Slade et al. (1999) and Bengtsson and Hansson (1999) who used a more extensive measure of satisfaction with several life areas (Lanquashire Quality of Life Profile) in contrast to our measure of health-related problem rating (Euro-QoL).

Thus, which factors do influence quality of life of patients in long-term mental health care if service satisfaction does not? In our analyses, demographic, psychiatric factors and treatment setting or type of service did not hold as in other comparative studies (Barry and Zissi 1997). However, strong evidence was found for the correlation between quality of life and needs: more than one third (36%) of the variance in the Quality adjusted Life years index could be explained by indicators of unmet and met needs. This relationship held more for unmet than for met needs, and more for needs in the area

of mental health care and rehabilitation than in other areas. It is in these areas of social relations, daily activities and information provision that a substantial improvement of subjective quality of life could probably be attained.

## References

- Atkinson M, Zibin S, Chuang H (1997) Characterizing quality of life among patients with chronic mental illness: a critical examination of the self-report methodology. *Am J Psychiatry* 154: 99–105
- Bachrach LL (1988) Defining chronic mental illness: a concept paper. *Hospital & Community Psychiatry* 39: 383–388
- Badia X, Casado A, Sacrsitan JA, Gomez JC, Gregor KJ, Gavart S, EFESO Study Group (2000) Antipsychotic treatment and changes in health related quality of life in schizophrenic patients using the EQ-5D. The Tenth Biennial Winter Workshop on Schizophrenia Davos, Switzerland, 5–11 February
- Barry MM, Zissi A (1997) Quality of life as an outcome measure in evaluating mental health services: a review of the empirical evidence. *Soc Psych Psychiatr Epidemiol* 32: 38–47
- Bengtsson-Tops A, Hansson L (1999) Clinical and social needs of schizophrenic outpatients living in the community: the relationship between needs and subjective quality of life. *Soc Psych Psychiatr Epidemiol* 34: 513–518
- Berghofer G, Lang A, Henkel H, Schmidl F, Rudas S, Schmitz M (2001) Satisfaction of inpatients and outpatients with staff, environment, and other patients. *Psychiatr Services* 52: 104–106
- Brooks R (1996) EuroQol: the current state of play. *Health Policy* 37: 53–72
- Busschbach J van, Wiersma D (2001) Does rehabilitation meet the needs of care and improve the quality of life of patients with schizophrenia or other chronic mental disorders? *Community Ment Health J* (in press)
- Delis DC, Kramer JH, Kaplan E, Ober BA (1987) California Verbal learning Test (CVLT) Manual. New York: The Psychological Corporation
- De Wit GA, Busschbach JJ van, De Charro FT (2000) Sensitivity and perspective in the valuation of health status: whose values count? *Health Econ* 9: 109–126
- Dolan P, Phil D (1997) Modeling valuations for EuroQol health states. *Med Care* 35: 1095–1108
- Druss BG, Rosenheck RA, Stolar M (1999) Patient satisfaction and administrative measures as indicators of the quality of mental health care. *Psychiatr Serv* 50: 1053–1058
- Essink-Bot ML, van Royen L, Krabbe P, Bonsel GJ, Rutten FF (1995) The impact of migraine on health status. *Headache* 35: 200–206
- EuroQol Group (1990) EuroQol – a new facility for the measurement of health related quality of life. *Health Policy* 16: 199–208
- Guldvog B (1999) Can patient satisfaction improve health among patients with angina pectoris? *Int J Qual Health Care* 11: 223–240
- Heinze M, Taylor RE, Priebe S, Thornicroft G (1997) The quality of life of patients with paranoid schizophrenia in London and Berlin. *Soc Psych Psychiatr Epidemiol* 32: 292–297
- Issakidis C, Teesson M (1999) Measurement of need for care: a trial of the Camberwell Assessment of Need and the Health of the Nation Outcome Scales. *Aust N Z J Psychiatry* 33: 754–759
- Jenkins CD (1992) Assessment of outcome of health intervention. *Soc Sc Med* 35: 367–375
- Middleboe T, Mackeprang T, Hansson L, Werdelin G, Karlsson H, Bjarnason O, Bengtsson-Tops A, Dybbro J, Nilsson LL, Sandlund M, Sörngaard KW (2001) The Nordic study on schizophrenic patients living in the community. Subjective needs and perceived help. *Eur Psychiatry* 16:201–215
- Parkman S, Davies S, Leese M, Phelan M, Thornicroft G (1997) Ethnic differences in satisfaction with mental health services among representative people with psychosis in South London: PRISM study 4. *Br J Psychiatry* 171: 260–264
- Rohland B, Langbehn DR, Rohrer JE (2000) Relationship between service effectiveness and satisfaction among persons receiving Medicaid mental health services. *Psychiatr Serv* 51: 248–250
- Ruggeri M, Dall'Agnola R, Agostini C, Bisoffi G (1994) Acceptability, sensitivity and content validity of the VECS and VSSS in measuring expectations and satisfaction in psychiatric patients and their relatives. *Soc Psych Psychiatr Epidemiol* 29: 265–276
- Slade M, Phelan M, Thornicroft G, Parkman S (1996) The Camberwell Assessment of Need (CAN): comparison of assessments by staff and patients of the needs of the severely mentally ill. *Soc Psych Psychiatr Epidemiol* 31: 109–113
- Slade M, Leese M, Taylor R, Thornicroft G (1999) The association between needs and quality of life in an epidemiologically representative sample of people with psychosis. *Acta Psychiatr Scand* 100: 149–157
- Slade M, Phelan M, Thornicroft G (1998) A comparison of needs assessed by staff and by an epidemiologically representative sample of patients with psychosis. *Psychol Med* 28: 543–550
- Trauer T, Duckmanton RA, Chiu E (1998) A study of the quality of life of the severely mentally ill. *Int J Soc Psychiatr* 44: 79–91
- Vink M, Jolles J (1985) A new version of the Trail Making Test as an information processing task. *J Clin Neuropsychol* 7: 162
- Wiersma D, Giel R, de Jong A, Nienhuis FJ, Slooff CJ (1996) Assessment of the need for care 15 years after onset of a Dutch cohort of patients with schizophrenia, and an international comparison. *Soc Psych Psychiatr Epidemiol* 31: 114–121
- Wiersma D, Sytema S, Busschbach J van, Schreurs M, Kroon H, Driessen G (1997) Prevalence of long-term mental health care utilization in the Netherlands. *Acta Psychiatr Scand* 96: 247–253
- Wiersma D, Nienhuis FJ, Giel R, Slooff CJ (1998) Stability and change in needs of patients with schizophrenic disorders: a 15- and 17-year follow-up from first onset of psychosis, and a comparison between 'objective' and 'subjective' assessments of needs for care. *Soc Psych Psychiatr Epidemiol* 33: 49–56