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**Are factors associated with subjective quality of life in people with severe
mental illness consistent over time? – A 6-year follow-up study**

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ABSTRACT

Objective: To investigate the cross-sectional relationship between subjective quality of life and sociodemographic clinical and social factors over three points of assessment during a 6-year follow up, and to investigate longitudinal predictors of subjective quality of life.

Method: We investigated a sample of people with severe mental illness (N=92), mainly with a psychosis diagnosis, at baseline and at an 18-month and 6-year follow-up. Measures included the Lancashire quality of life profile, Manchester short assessment of quality of life, Symptom Check List 90, Camberwell Assessment of Needs and the Interview Schedule for Social Interaction.

Results: Cross-sectionally subjective quality of life was associated to self-reported symptoms, social network and unmet needs. However, these determinants varied in importance between points of assessment. Longitudinal predictors of subjective quality of life were changes in self-reported symptoms and social network.

Conclusion: There was a rather consistent set of determinants of subjective quality of life over time. Social network seems to be an important factor with relevance for improvements in subjective quality of life, however largely overlooked in earlier studies within the field.

Key words: Subjective quality of life, social network, unmet needs, severe mental illness

INTRODUCTION

Empirical findings from a rather large body of cross-sectional quality of life studies including people with severe mental illness have shown that sociodemographic characteristics have a weak or no relationship with global subjective quality of life (1). Studies of the impact of clinical variables such as severity of psychiatric symptoms and needs for care have revealed that symptoms of depression have been most consistently and most strongly related to subjective quality of life (2). Most studies regarding mood state have focused on depressive symptoms, but a few recent studies have demonstrated that anxiety symptoms may play a role as important as symptoms of depression in lowering quality of life (3).

The structured assessment of patient needs has been proposed to be an essential input and basis for planning and implementation of interventions with an assumption that satisfaction of needs would have a beneficial impact on outcome in terms of subjective quality of life. This hypothesis has been investigated in rather few, mainly cross-sectional studies, showing an robust association between more unmet needs and a worse subjective quality of life (4-7). Recent longitudinal studies have also showed an impact of unmet needs on subjective quality of life (7-8). The association between quality of life and met needs has not been convincingly demonstrated.

Studies investigating the relationship between social support and quality of life in people with severe mental illness have shown associations both regarding size and qualitative aspects of the social network. A larger social network has been moderately associated to a better quality of life (9). Satisfaction with the social network or social relations has also been demonstrated to be associated with a better subjective quality of life (10). Enduring self-related traits such as mastery, autonomy, locus of control, sense of coherence in life, self efficacy and self-esteem have been suggested to be important mediating factors and predictors of the appraisal

of subjective quality of life. Empirical studies have also confirmed that these constructs are related to subjective quality of life, perhaps most convincingly shown regarding self-esteem (11).

Changes over time in subjective quality of life has been the subject of a few naturalistic follow-up studies which have found significant improvements in subjective quality of life, while others have failed to show this (12). Examinations of predictors of changes in quality of life in these studies have likewise not shown any consistent picture. Some studies have shown a positive impact of a decrease in depressive symptoms (13), anxiety symptoms (14) or negative symptoms (15). Changes in self related factors such as self-esteem, and self-efficacy have also been related to improvements in subjective quality of life (12) as well as changes in social support (16) and a reduction in unmet needs for care (17).

Aims of the study

The present study is an effort to overcome some of these inconsistencies. By using repeated assessments of subjective quality of life in a sample of people with severe mental illness we aim to investigate if cross-sectional co-variables of subjective quality of life are consistent over time, which would give a more firm knowledge of essential factors associated to quality of life. We also aim to investigate factors predicting subjective quality of life in a long-term longitudinal perspective. The specific two research questions are the following:

1. Is there a uniform and consistent pattern of sociodemographic, clinical, social or self-related factors associated to subjective quality of life in three assessments over a six-year period?
2. What are the long-term and short-term predictors of subjective quality of life, and are there any differences in the two time perspectives?

MATERIAL AND METHODS

The present study is part of a 6-year follow-up of patients admitted to ten pilot services with case management in Sweden. Patients were interviewed at baseline, at an 18-month and a six-year follow-up. Patient outcome of attending case management services at the 18-month follow-up has been presented elsewhere (18). At all three points of assessment patients were interviewed with regard to subjective quality of life, social network, psychosocial functioning, needs for care, psychiatric symptoms and social and demographic characteristics. The 6-year follow-up interviews furthermore contained information concerning empowerment, experiences of stigma, use of services, and satisfaction with services, not presented in this paper. Interviews generally lasted for 60-90 minutes. In a few cases the interview was performed at two occasions, due to the condition of the patient. The interviews were performed by interviewers trained for the purpose and performed either at the case management service or in the patient's home, dependent on the patient's request. All scales were assessed by the same interviewer, although it was not the same interviewer throughout the three interview occasions. The study was initiated by the Swedish National Board of Health and Welfare and participation was based on informed consent from the patients.

Participants

The subjects included were participating in a follow-up study of 10 Swedish case management services (18). The original sample consisted of 176 subjects participating in the 18-month follow-up. At a further 6-year follow-up, 14 persons had died, 16 could not be traced, and 21 were judged to be too ill to complete an interview. Of the remaining 125, 33 rejected further participation and the final follow-up 6-year follow-up sample thus consisted of 92 persons. Comparisons between the 92 remaining patients and the total number of dropouts, 84 patients, showed no significant differences regarding initial background characteristics such as sex, age, civil status, level of education, living situation, work

situation, duration of illness or diagnostic subgroup. Further, no significant differences were found regarding baseline levels of psychosocial functioning, needs for care, psychiatric symptoms, social network or subjective quality of life. The present sample may thus be regarded as fairly representative of the originally included patients.

Table 1. Background characteristics of the baseline sample and the follow-up sample at baseline and at the 6-year follow-up

	Baseline sample (N=176)	%	Follow-up sample at baseline (N=92)	%	Follow-up sample at 6-year follow-up (N=92)	%
Sex						
Male	94	53	43	47		
Female	82	47	49	53		
Age (m, range)	41 (20-77)		41 (22-61)		47 (29-68)	
Education (N=174, N=90)						
Primary school	69	40	33	37	30	33
College	75	43	42	47	37	41
University	30	17	15	16	23	26
Civil status (N=88)						
Married	15	9	2	2	2	2
Divorced	34	19	15	17	15	17
Never married	127	72	71	81	71	81
Living situation						
Alone	142	81	74	80	75	82
Partner	14	8	4	4	5	5
Parents	11	6	8	9	7	8
Other	9	5	6	7	5	5
Accommodation (N=91)						
Own apartment	152	86	80	88	73	80
Lodger	4	2	1	1	3	3
Supported housing	7	4	1	1	9	10
Other	13	7	9	10	6	7
Work situation (N=91)						
Competitive work	9	5	9	10	8	9
Supported work	20	11	8	9	8	9
Unemployed	23	13	12	13	5	5
Student	6	3	2	2	6	7
Disability pension	118	67	59	65	64	70
Diagnosis (N=138, N=77)						
Schizophrenia	74	54	46	60		
Other psychosis	26	19	14	18		
Non psychosis	38	27	17	22		
Duration of illness (m, range)	16 (2-38)		16 (1-38)		22 (7-44)	

Some background characteristics at the time of follow up are presented in Table 1. Most subjects were living alone in own flats, were not working and mainly on a disability pension. Approximately 60 % of the subjects had a schizophrenia diagnosis and a further 20% other psychosis diagnoses. The 17 persons with non psychosis diagnosis consisted of 9 cases of anxiety disorder, 6 cases of personality disorder and 2 cases of depressive disorder.

Measures

Subjective quality of life at baseline and the 18-month follow-up was assessed by the Lancashire Quality of Life Profile (LQOLP) (19). The LQOLP is a structured self-report interview which assesses objective quality of life and subjective life satisfaction in nine life domains work/education; leisure/activities; religion; finances; living situation; legal and safety; family relations; social relations; health. It also includes an affect balance scale measuring mood state, and a self-esteem scale (the Rosenberg self esteem scale). The LQOLP has shown satisfactory results in reliability and validity tests (20-22). At the 6-year follow-up a short version of the LQOLP was used, the Manchester Short Assessment of Quality of Life (MANSA). It contains 16 questions, four of them assessing objective quality of life and 12 assessing satisfaction with life as a whole, job, financial situation, friendships, leisure activities, accommodation, personal safety, sex life, people the person live with, family and health. Satisfaction is in both instruments rated on a 7-point scale ranging from 1= could not be worse to 7= could not be better, and an overall mean score of subjective quality of life may be calculated (range 1-7). MANSA has been tested for concurrent and construct validity with LQLP and shown satisfactory psychometric properties (23, 24).

Psychosocial functioning was rated according to the Strauss Carpenter scale which assesses the situation during the month before index contact with regard to social contacts and

psychiatric symptoms, and with regard to the previous year concerning employment and use of psychiatric inpatient services (25). Needs for care was at baseline and 18-month follow-up assessed by Camberwell Assessment of Needs interview (26). The CAN assesses needs for care in 22 different domains as well as support and help offered in these areas, and has been tested for reliability and validity (27, 28). At the 6-year-follow-up a short version of CAN, the Camberwell Assessment of Needs Short Assessment interview (CANSAS) (21) was used. The CANSAS assesses needs for care in the same 22 domains. In each domain it is possible to distinguish between met and unmet needs.

Psychiatric symptoms were rated by the Hopkins Symptom Check List-90 (SCL-90) (29). The SCL-90 is a 90-item self-rating scale containing symptoms related to mental illness. Symptoms are rated on a five-point scale from 0 = not at all to 4 = extremely. The instrument consists of nine subscales. Scores of the mean of all items for each subscale can be calculated as well as an overall score, labeled General Severity Index (GSI).

Social network was investigated by means of a self-report scale, the Interview Schedule for Social Interaction (ISSI) (30). The scale intends to measure social integration and attachment and has 30 items divided into four subscales; availability of social integration measuring access to social contacts; adequacy of social integration measuring satisfaction with social contacts; availability of emotional relations measuring access to emotional relationships, and adequacy of emotional relations measuring satisfaction with emotional relationships. An overall score of the social network is also available. The reliability and validity of the scale has been tested and found to be satisfactory (30).

Statistics

Paired t-test was used to explore changes over time. Stepwise multiple regression analyses were used to investigate predictors of subjective quality of life at the 6-year follow-up and for analyses of the cross-sectional co-variation of a number of independent variables and subjective quality of life at the three points of assessments. Total mean score of LQOLP and MANSA was used as the dependent variable assessing subjective quality of life. Sex, age, independent living situation or not, living alone or not, working or not, higher education or not, psychosocial functioning according to the Strauss-Carpenter scale, symptoms according to SCL-90, met and unmet needs according to CAN/CANSAS, social network according to ISSI, self esteem according to the Rosenberg scale and the affect balance scale included in the LQOLP were used as independent variables. In some of the analyses change scores between baseline and 6-year follow-up of measures of psychosocial functioning, symptoms, needs and social network were used as independent variables. The statistical software package used was SPSS 11.5.

RESULTS

At the time of the six-year follow-up the social and clinical situation of the 92 persons included in the follow-up had improved in several aspects. Number of needs for care had diminished (5.9 vs. 7.1, $p = .016$) as well as number of unmet needs (1.5 vs. 2.5, $p = .002$) and psychiatric symptoms (76.8 vs. 99.1, $p = .004$). Subjective quality of life (4.7 vs. 4.5, $p = .027$), social network (17.4 vs. 12.9, $p = .001$) and psychosocial functioning according to the Strauss-Carpenter scale (11.6 vs. 9.8, $p = .001$) had improved.

Table 2. Regression analyses of cross-sectional co-variates of subjective quality of life at three points of assessment (N=92)

	Baseline			18- months			6-years		
	Beta	P-value	Expl. variance	Beta	P-value	Expl. variance	Beta	P-value	Expl variance
Symptoms (SCL-90)	-.54	.000	41.3	-.36	.001	42.6	-.37	.000	15.9
Social network (ISSI)	.42	.000	16.2	.28	.006	5.7	.43	.000	51.3
Unmet needs (CAN)				-.34	.001	12.7	-.22	.006	3.3
Total variance			57.5			61.0			70.5

Stepwise multiple regression models were tested to investigate cross-sectional co-variates of subjective quality of life. As shown in table 2 there was a rather uniform pattern of variables significantly associated with subjective quality of life at the three points of assessment. In all instances self-reported symptoms and social network were included in the model, and in the two latter assessments unmet needs as well. At baseline less self-reported symptoms (41.3%) and a better social network (16.2%) accounted for a total of 57.5% of the variance in subjective quality of life. At the 18-month follow up the total variance accounted for was 61%. Less symptoms (42.6%), less unmet needs (12.7%) and a better social network (5.7%) was associated to a better subjective quality of life. Subjective quality of life at the six-year follow-up was mainly associated to social network, accounting for 51.3% of the variance in the former. In addition self-reported symptoms (15.3%) and unmet needs (3.3%) were included in the model, which in total accounted for 70.5% of the variance in subjective quality of life. No social or sociodemographic characteristics entered the three final models, nor did measures of self-esteem or affect balance.

Investigations of long-term predictors of subjective quality of life at the six-year follow-up showed, controlling for baseline subjective quality of life, that no baseline social or demographic characteristics, level of self-reported symptoms, psychosocial functioning, needs

or social network entered the model. Subjective quality of life was only predicted by baseline subjective quality of life which accounted for 34.2% of subjective quality of life at the six-year follow-up. An analysis of short-term predictors of subjective quality of life at the 18-month follow-up showed the same results. The only predictor was baseline subjective quality of life accounting for 40.3% of the variance.

Table 3. Predictors of subjective quality of life at the six-year follow-up (N=92).

	Beta	P-value	Expl. Variance
Baseline quality of life	.65	.000	34.7
Changes in social network (ISSI)	.37	.000	12.9
Changes in symptoms (SCL-90)	-.29	.002	7.7
Total variance explained			55.3

An analysis of whether changes in the social or clinical situation of the patient during the 6-year period had any impact on subjective quality of life at the 6-year follow-up was finally performed, Table 3. Controlling for baseline subjective quality of life, which accounted for 34.2% of the variance, it was shown that a greater improvement in social network (12.9%) and a greater reduction in self-reported symptoms (7.7%) was predicting a better subjective quality of life. Baseline characteristics, changes in psychosocial functioning, met or unmet needs did not enter this model. An additional regression analysis, further investigating the role of different aspects of social network, showed that baseline subjective quality of life, accounted for 31.6% of the variance and the subscale adequacy of social integration accounted for another 31.1.% of the variance. The latter subscale assesses satisfaction with friends and social relations. Changes in self-reported symptoms did not enter this model.

DISCUSSION

A number of cross-sectional studies have convincingly associated a better subjective quality of life with less self-reported symptoms, in particular symptoms of depression and anxiety, and less unmet needs (31). Other studies, which have mainly focused social network or self-

related variables have also in these areas noted significant associations with subjective quality of life (9, 10). A bias in these studies, which might influence results is that few, if any, studies have included all these factors in comprehensive analyses of determinants of subjective quality of life. For example, one presentation from the South-Verona Outcome Project found subjective quality of life to be cross-sectionally associated mainly to service satisfaction, but did not include needs, perceptions of social network or self-reported symptoms in their analyses (32). The EPSILON study performed an analysis of the relationship between needs and quality of life without accounting for other co-variables than psychosocial functioning (6). A similar bias is found in longitudinal studies of predictors of quality of life (7, 33). Using comprehensive sets of co-variables and predictors with an established association with subjective quality of life would diminish the risk of performing partial analyses giving misleading results, and add to our knowledge of what the essential co-variables are.

In the present study we made efforts to include a comprehensive set of factors which in earlier studies have been related to subjective quality of life, cross-sectionally or in a longitudinal perspective. The cross-sectional analyses at three assessment points showed rather uniform results, with regard to what factors were associated to subjective quality of life. In all three analyses self-reported symptoms and social network showed an association to subjective quality of life although the relative importance varied over time. In two of three analyses self-reported symptoms were the major determinant, accounting for around 40% of the variance in subjective quality of life. In the third analyses, at the 6-year follow-up, social network accounted for around 50% of the variance. Unmet needs, which in several earlier studies have been an important factor, were associated to quality of life in two of the analyses accounting for 5.7% and 3.3% of the variance respectively. A number of other factors with evidence of a relationship with quality of life did not enter the regression models. It seems that the crucial factor here was the inclusion of social network in the analyses, which by and large have not

been done in earlier studies. These results are in accordance with an earlier study including patients with schizophrenia where, having controlled for positive and negative symptoms, social network was cross-sectionally related to quality of life and longitudinally determined changes in subjective quality of life (10).

The pattern of factors associated with quality of life through the three assessment points indicates that self-reported symptoms and unmet needs seems to play a diminishing role over time, while the impact of the social network increases dramatically. One hypothesis is that, taking into account that the present sample was a follow-up of a case-management intervention where quality of life, needs and self-reported symptoms improved significantly, these changes in determinants of quality of life reflects a clinical course of improvement which alters the importance of factors influencing quality of life. Unmet needs and symptoms may be more important determinants when the patient is clinically worse off, whereas size and satisfaction with emotional and social relations become more important when the patient is improving. This hypothesis needs further testing, but if it is valid the consequences are that research aiming at further establishing factors influencing quality of life, must include considerations of the clinical status and characteristics of samples studied. It might be that factors with an impact on subjective quality of life are different, or vary in importance regarding for example patients newly admitted to or discharged from a service, or cross-sectional samples of people with a mental illness living in the community. If there is a variation in this respect it will have an importance for what interventions are of value in order to improve quality of life in people with mental illness, and recommendations have to be differentiated.

In a longitudinal perspective the present study showed that the only baseline predictor of subjective quality of life at the 6-year follow-up was baseline quality of life. The investigation

of changes during the follow-up indicated that, having controlled for this, an additional 13% of the variance was accounted for by changes in the social network and a further 8% by changes in self-reported symptoms. All in all the regression model explained 55% of the variance in subjective quality of life at the 6-year follow-up. It is notable that no demographic or clinical characteristics or self-related factors were included in the regression model, nor changes in needs. These results strengthen the results from the cross-sectional analyses that social network and social relations are of importance for improvements in subjective quality of life, accounting for a number of other potential influences. A further exploration of the role of the social network revealed that specifically changes in the perceived adequacy and satisfaction with social relations were an important predictor of subjective quality of life. This is in line with an earlier study (10) and emphasizes that interventions directed towards an understanding and improvement of the social network in people with a severe mental illness would be of importance for the improvement of subjective quality of life.

An important limitation of the present study is that over the 6 years almost half of the patients were lost to the 6-year follow-up. Although this figure would be in line with other long-term follow-up studies, it still raises the question of the representativity of the sample finally analyzed. We could not detect any baseline differences between patients included in the follow-up and lost to follow-up with regard to a number of clinical and social aspects. Nevertheless the sample included might have had a more beneficial course of illness, as indicated by the fact that a number of patients judged too ill to participate were excluded, and also indicated by the fact that a number of patients were deceased. However it is not obvious how this potential bias might have influenced our results and it is not obvious that a set of other predictors would be applicable to the patients lost to follow-up. This bias is perhaps more essential for analyses of the outcome of the intervention that was the main purpose of this study, and which will be presented elsewhere.

In conclusion, the present study showed that irrespective of point of assessment, there was a rather consistent set of determinants of subjective quality of life. However, these determinants varied in importance between points of assessment. Social network seem to be an important factor with relevance for improvements in subjective quality of life, however largely overlooked in earlier studies within the field.

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