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The quality of life of patients with paranoid schizophrenia in London and Berlin

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Abstract This study compared the subjective and objective quality of life and needs of patients with paranoid schizophrenia between inner city areas in Berlin (69 patients) and London (75 patients). Quality of life was assessed by means of the Lancashire Quality of Life Profile (German version Berliner Lebensqualitätsprofil), and need was quantified using the Camberwell Assessment of Need (German version Berliner Bedürfnisinventar). The hypotheses tested were that although Berlin patients may rate more highly on objective quality of life measures, the subjective quality of life would be similar as patients would judge their quality of life against their local expectations. The findings supported the first part of the hypothesis as on the objective measures the Berlin group was significantly better off financially and in living conditions, and had significantly fewer material needs. However, despite having more severe psychopathology, the Berlin groups' scores on global subjective quality of life were also higher. On particular life domains, subjective quality of life did not always reflect objective measures and sometimes went in the reverse direction. We concluded that the relationship between subjective and objective quality of life is complex, and great caution must be exercised in making quality of life comparisons between different cultures.

Introduction

Although international research in the evaluation of community care is performed increasingly often, it is

not yet clear how far these results are comparable and can be generalized. In particular, it is unclear to what extent the populations of patients being treated in the community care systems of different countries are similar. This study is an initial attempt to explore these questions by comparing quality of life and needs data of patients with paranoid schizophrenia (ICD 10: F20.OX) [16] in two metropolitan catchment areas: the Nunhead sector of the Camberwell district of London and the Charlottenburg district of Berlin. Both districts are developing psychiatric community care systems and both have been the subject of several studies [3, 4, 7, 11–15], making them suitable for a comparative study. Both are metropolitan areas of capital cities with roughly the same population (Camberwell = 210,000; Charlottenburg = 180,000). Nevertheless, in their social characteristics they differ substantially: Camberwell has a high proportion of minority ethnic groups and is one of the most socially deprived areas in Britain. Charlottenburg, on the other hand, is a district with a mixed structure of developed middle-class areas and some socially deprived areas and with fewer ethnic minority inhabitants. A methodological difficulty inherent in any attempt to make such a comparison between two countries is that both the social care and health care systems will differ, making it difficult to attribute the cause of differences found.

Our study focused upon the question: are quality of life and needs of patients with paranoid schizophrenia different in the two districts? Our hypothesis was that the objective data about the standard of living should show significant differences that would not be explained by differences in the psychopathological status of the clients. Furthermore, we hypothesized that whilst the objective data should show substantial differences, the subjective data would not differ. The latter hypothesis was based on the assumption that patients would compare themselves to those around them, rather than evaluate their life situation according to some objective standard [2, 6, 14].

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Method

London sample

The Nunhead sector of the Camberwell district service is the subject of a larger prospective study (the PRISM study) of a representative sample of patients with psychosis. The PRISM study (to be reported in detail in future papers) is examining the impact of introducing two community mental health teams, one for acute patients (PACE team) and the other for continuing care patients (PACT team). The geographical sector is largely working class with about 11% in minority ethnic groups.

The data for this study were collected as part of the PRISM study, which involved interviewing a sample of 206 psychotic patients living in South-east London who had been identified via a case-finding technique. A subsample of 75 patients was available with quality of life and needs data. These data were collected at baseline (before the introduction of the community mental health teams) when mental health services were still essentially hospital based. Because patients were found by a case identification technique, not all were in contact with the psychiatric services.

Berlin sample

In Berlin all patients under treatment at the department of social psychiatry were asked to participate in a larger study on quality of life and need. This care system is oriented towards providing long-term treatment for all patients in Charlottenburg with severe and chronic mental illnesses. It includes three partial hospitalization programmes, various out-patient facilities and community-based services such as a day-care centre, a drop-in centre and sheltered accommodation. These different components function as a network, with patients easily transferred from one form of care to another according to their current condition and needs. Interviews were completed for 89% of patients in the care system. The drop-out was due either to patients refusing to take part (8%), being unavailable (3%) or being so unwell that their mental state rendered them unable to cooperate (1%).

Instruments

Diagnosis was made by OPCRIT [17] rating of case notes and SCAN (PSE 10) interviews in the London group and by consultant diagnoses according to ICD 10 research diagnostic criteria in the Berlin group. In both groups, psychopathology was assessed using the Brief Psychiatric Rating Scale (BPRS) [9] and the Global Assessment of Functioning Scale (GAF) [1]. For evaluation of the subjective perception of the quality of life and need, the 1993 versions of the Lancashire Quality of Life Profile (LQoL) [8] and the Camberwell Assessment of Need (CAN) [10] were used for the London group and their respective German instruments for the Berlin group, the Berliner Lebensqualitätsprofil (BELP) and the Berliner Bedürfnisinventar (BeBI) [11]. The LQoL has 11 sections on different aspects of life (i.e. work, leisure, religion, finances, legal and safety issues, family relations, social relations and health). Each section consists of questions about the objective situation and of satisfaction ratings for the aspect in question using a scale from 1 to 7. The CAN assesses, both in the view of the client and the case manager, if there are any problems in 22 areas of life. If the patient or carer identifies a problem, enquiry is made as to the help being received for it.

Statistical analysis

As the PRISM study and the Berlin services include a heterogeneous spread of patients with severe mental illness, only patients with

an diagnosis of paranoid schizophrenia (ICD10 F200X) were included in this comparison in order to increase the comparability of the patient groups. Only data from five sections of the Lancashire Quality of Life Profile (occupation, living conditions, finances, social life and security) were used for comparison. From the need profiles, only the first question of each section (i.e. whether there was a problem at all answered from the users' perspective) was included, resulting in a score summing up all problems rated, and subscores were devised for material, social and psychopathological problems.

From the remaining data, the general satisfaction with life and the mean score of the need profiles, as rated by the patients, were treated as the main criteria for judging differences in the subjective perceptions of life quality and need. All continuous variables including the satisfaction scales, showed a non-normal distribution and therefore were compared using the Mann-Whitney *U* test. The categorical variables were compared using the chi-square test. Scores are reported as means with their respective standard deviations.

In order to exclude factors that are known to influence outcome (age, gender and ethnic origin) different comparisons were performed. Besides comparing both groups as a whole, we stratified by ethnic group, by gender and by age (± 3 years). We also defined pairs of patients whom, in addition to matching by gender and age, we also matched by psychopathology and social functioning (BPRS ± 5 and GAF ± 5). These matched couples were statistically treated as pairs and their data were compared using the Mann-Whitney *U* test for related samples and the McNemar test.

Results

Socio-demographic characteristics

The data of 69 patients from Berlin and 75 patients from London were used for comparison. The mean duration of the illness was 17.8 years in London (SD 11.9, range 0–52) and 15 years in Berlin (SD 8.7, range 3–47). There was a higher, but not significant, proportion of females (48% vs 32%) in the Berlin group. The gender difference did not account for the difference in the duration of illness. The groups were comparable in age (mean 43.6 years, SD 10.6 in Berlin; mean 42.9 years, SD 13.2 in London). The London distribution was wider (range: 17–75 years) because the Berlin department (range: 24–69 years) does not treat adolescent or older patients. The groups showed a highly significant difference in the BPRS total score (mean 37.4, SD 13.1 in Berlin; mean 28.8, SD 10.8 in London; $P < 0.001$). The Berlin group had generally higher ratings in the BPRS subscales [Asthma: 6.2 (SD 2.9) cf. 3.9 (SD 1.5); Anxiety/Depression: 9.9 (SD 4.4) cf. 8.4 (SD 4.8); Anergia: 9.1 (SD 4.0) cf. 5.7 (SD 3.0); Hostility: 5.0 (SD 2.6) cf. 4.7 (SD 2.4); Thought disorder: 7.1 (SD 3.6) cf. 6.6 (SD 4.0)], with the first three differences being significant. The GAF scores were not significantly different (mean 58.3, SD 17.8 in Berlin; mean 58.5, SD 17.2 in London). The proportion who were members of ethnic minorities (7% in Berlin, 35% in London) differed significantly ($P < 0.001$).

Subjective perception of well-being and problems

The answer to the question: "How satisfied are you with your life in general?" (Table 1) showed a significant difference, with a satisfaction value of 4.8 (SD 1.5) in Berlin and 4.2 (SD 1.7) in London. This means that Berlin patients in general were more satisfied with their quality of life. We saw the same differences in the needs assessment. In London, patients indicated significantly more problems. Although the London group scored a higher number of problems on all three areas of need, only the difference in material needs reached significance, but not the social and psychopathological need subscores. There was a lower subjective rating of all items of quality of life in the British group. The quality of life subscores indicated that this might be due to differences in the material aspect of life and therefore confirmed that it was in the material aspect of life that the most substantial differences between the two groups were demonstrated.

Quality of life in different life domains

In *occupation* there was a higher rate of people (Table 2) working or otherwise being occupied in Berlin, but this difference was not significant. There was no difference in the satisfaction with occupation, both groups showing a high satisfaction with their occupation despite the overall lower London satisfaction rates. There was a wide and significant difference in the satisfaction with being unemployed or not having an occupation. In *finances* all objective measures demonstrated highly significant differences favouring the Berlin group. Despite the enormous objective differences (income: Berlin DM 1376 (SD 707), London DM 859 (SD 519) per month; DM 1.00 = £0.45) the financial satisfaction rate did not differ significantly and was similar to the general satisfaction rate.

In *living conditions* more or less the same numbers of patients were able to live independently, but London patients were more likely to want to move and they shared their apartments with more people. In this area we found very high satisfaction rates for the Berlin group and larger differences between Berlin and London. In particular, satisfaction with privacy was higher in Germany, possibly reflecting the high occupancy of

London apartments. In this area satisfaction differences generally reflected objective differences.

The area of *social life* was complex and cannot be summarized by any one trend in the data. More Berlin patients had a partner and they could not imagine living without friends, while more London patients had contact with relatives. In general, the Berlin group was more satisfied with their social life, but the differences on these ratings were not significant and they differed less than the general satisfaction difference. Finally, in *security*, there was no difference in satisfaction with the security generally, but there was a significant difference in the satisfaction with the security in the local area. This indicates that the Camberwell district included more local areas that were perceived to be unsafe.

Analysis of matched groups

Matching the two groups by gender and age (known to influence outcome) we identified two groups each of 55 patients (36 males, 19 females) with a mean age of 41 years (SD years 11.1). The same tests as for the overall samples yielded essentially similar results. Only the items satisfaction with the ability to relate socially (P value: 0.015; previous value: 0.076) and the sum of psychopathological problems rated (P value: 0.015; previous value: 0.071) now showed significant differences. The proportion of patients with a steady partner and the sum of material problems rated were no longer significant.

In order to reduce the influence of ethnicity, data on white Europeans only were analysed separately. The 64 patients from Berlin (34 male, 30 female) and the 49 patients from London (37 male, 12 female) included in this comparison had an average age of 44.3 years in Berlin and 46.0 years in London. Significant differences were now also found in the rate of patients living independently (P value: 0.003; previous value: 0.32), satisfaction with family contacts (P value: 0.04; previous value: 0.1), the sum of social problems rated (P value: 0.014; previous value: 0.064), and the duration of illness (P value: < 0.001 ; previous value: 0.24). The proportion of patients having a partner or having a frequent contact with family members now no longer differed significantly, nor did the depression subscore of the BPRS or satisfaction with the privacy in the living arrangements.

Table 1 Results of general subjective ratings: general satisfaction rated on scale of 1 to 7 (LQoL and BELP; 1 = can't be worse, 7 = can't be better); sums of problems rated in needs questionnaire by patients (CAN and BEBI, high figure indicating more problems in this field)

	Berlin	London	Test value	P value
General satisfaction with quality of life	4.8 SD 1.5	4.2 SD 1.7	$U = 2065.0$	< 0.05
Sum of problems rated	3.7 SD 2.9	5.1 SD 3.0	$U = 1752.0$	< 0.01
Material problems rated	0.7 SD 0.8	1.0 SD 0.8	$U = 1822.5$	< 0.05
Social problems rated	1.4 SD 1.5	1.8 SD 1.5	$U = 2018.5$	n.s. (0.064)
Psychopathological problems rated	0.9 SD 1.0	1.1 SD 0.9	$U = 2033.0$	n.s. (0.071)

Table 2 Results of quality of life ratings: objective and subjective data (satisfaction rated on a 7 scale) from quality of life questionnaires (LQoL and BFLP) for the Berlin and London sample

	Berlin	London	Test value	P value
<i>Occupation</i>				
Has occupation	44%	28%	-	n.s.
Satisfaction with occupation (n = 27/n = 20)	4.8 SD 1.3	4.7 SD 1.7	-	n.s.
Satisfaction with not having an occupation (n = 42/n = 47)	4.6 SD 1.9	3.7 SD 1.7	U = 685.0	< 0.05
<i>Finances</i>				
Income (DM/month)	1376 SD 707	859 SD 519	U = 1207.0	< 0.001
Receives benefits	44%	84%	Chi ² = 25.80	< 0.001
Lacked money last year	28%	49%	Chi ² = 7.09	< 0.01
Satisfaction with finances	4.3 SD 1.7	3.8 SD 1.6	U = 2140.0	n.s. (0.069)
<i>Living</i>				
Lives independently	56%	68%	-	n.s.
No. of persons patient lives with	1.3 SD 2.9	3.3 SD 5.8	U = 1595.0	< 0.001
Wants to move	35%	58%	Chi ² = 6.99	< 0.01
Satisfaction with living conditions	5.0 SD 1.6	4.3 SD 1.6	U = 1917.09	< 0.01
Satisfaction with privacy there	5.5 SD 1.3	4.5 SD 1.7	U = 1576.5	< 0.001
Satisfaction with the expectation to live there for a long time	5.1 SD 1.7	4.1 SD 1.8	U = 1693.0	< 0.01
<i>Social life</i>				
Has a partner	30%	15%	Chi ² = 4.98	< 0.05
Contact with relatives more than once a week	39%	36%	Chi ² = 5.05	< 0.05
Could imagine living without friends	39%	52%	Chi ² = 16.42	< 0.001
Has at least one friend	71%	71%	-	n.s.
Satisfaction with partnership (n = 32/n = 10)	4.9 SD 1.5	4.7 SD 1.8	-	n.s.
Satisfaction with family relations	4.8 SD 1.6	4.7 SD 1.6	-	n.s.
Satisfaction with ability to relate socially	5.1 SD 1.1	4.7 SD 1.4	U = 2068.0	n.s. (0.076)
Satisfaction with no of friends	4.8 SD 1.6	4.4 SD 1.6	U = 2095.5	n.s. (0.10)
<i>Security</i>				
Was accused or charged	4%	10%	-	n.s.
Was victim of assault	13%	8%	-	n.s.
Satisfaction with security	4.7 SD 1.5	4.4 SD 1.6	-	n.s.
Satisfaction with security in local area	5.3 SD 1.2	4.2 SD 1.5	U = 1465.5	< 0.001

Matching patients not only by age and gender, but also by severity of psychopathology, generated ten pairs (eight male, two female) with an average age of 42 years, a BPRS of 31 and a GAF of 60. This comparison, despite the reduction in confounding factors, yielded no further information because of the restricted sample size, with only the sum of the material problems rated still showing a significant difference (*P* value 0.043).

In a final step, we tested whether the influence of the London/Berlin difference in patients' subjective ratings was explained by objective factors. The groups showed the greatest difference in satisfaction with living conditions, general satisfaction and the sum of problems rated. These three criteria were each taken as dependent variables in a step-wise forward multiple regression analysis. All socio-demographic and objective clinical data from the study were included as independent variables (e.g. gender, age, income, occupation,

BPRS, GAF). In predicting general satisfaction, three factors [age (beta = 0.21), the question of whether patients had at least one friend (beta = 0.22) and GAF (beta = 0.21)] were included in the equation, resulting in a multiple *r* of 0.39. For the sum of problems rated, a multiple *r* of 0.47, with gender (beta = 0.26), income (beta = 0.21) and GAF (beta = 0.25) as significant predictors, was found. In predicting satisfaction with living conditions, only one significant predictor was identified with a multiple *r* of 0.22, and this was whether patients lived in London or in Berlin.

Discussion

Data from the comparison of these two groups were consistent with our hypothesis that the objective standard of living of chronic schizophrenic patients differs

greatly between Berlin and London. Differences were marked in the areas of finances and living conditions, probably due to the differing support given by the British and German social systems. That a higher proportion of patients in Berlin lived in partnerships and could not imagine living without friends suggests that the social anchoring of the Berlin patients was better. On the other hand, patients in London had more contact with their relatives, which might be related to their living closer to family members, i.e. sharing the same house.

It seems that the German group, despite exhibiting higher psychopathology, achieved a better quality of life, as well as a similar global social functioning, because of their better socio-economic conditions. The different level of psychopathology makes the quality of life differences even more striking. If patients with a similar psychopathology were compared, the objective quality of life differences would probably be even wider. However, the samples were drawn from different study settings: the Berlin patients were being treated in a model service for severely ill and chronic patients. The London group was a community sample of people with psychosis, and therefore included more post-acute and less chronic states. Also, the interviews in Berlin and London were performed for different purposes. The Berlin patients had been in the treatment system for a longer time and had been interviewed in order to evaluate long-term care. In London, the interviews were performed as part of a larger study of representative cases of psychosis in a population-based study. The data were collected as the baseline stage, when mental health services were still essentially hospital based, and not all patients were in contact with mental health services at the time they were interviewed.

Our hypothesis that the differences in subjective ratings of quality of life would not be directly related to the objective differences was not supported for all life areas. There was a lower satisfaction with quality of life in the London group in general, and we found both patterns of relationship between subjective and objective ratings; in some areas (occupation, finances, social life) the differences in the subjective ratings were less than the differences in the objective data, even though the latter differences sometimes seemed dramatic. Here one can observe that the subjective perception did not automatically follow the objective situation, suggesting that there are other factors influencing satisfaction with quality of life. We have discussed these possible other factors elsewhere [5, 6, 11]. In the area of living conditions, however, the subjective ratings not only followed the trends of the objective data, but showed a wider difference. In summary, it appears that the objective parameters were influential on the subjective perception of life quality, but were not the only influence. The single observation that the satisfaction with being unemployed differed so much between London and Berlin could be explained by the fact that the German social

security system offers a higher level of support for unemployed patients.

There were some methodological problems in comparing the two groups. Although it was not statistically significant, there was a difference in the sex ratio between the two groups; however, this was unlikely to affect the quality of life results as a separate analysis showed no sex difference in quality of life. The districts of Camberwell and Charlottenburg are not totally comparable, and so some items of the questionnaires used in this study were not included in the statistical comparison. This study was necessarily naturalistic, and any such study making international comparisons would share the same problems of heterogeneity within the samples in terms of age, gender, ethnicity, etc. The strategy adopted here of matching for these potentially important variables meets the problem of small numbers and, therefore, the likelihood of type 2 errors with no differences being found. Thus, this study and the shortcomings of the matched pair approach illustrated some of the methodological limitations that are associated with any naturalistic comparison of community care samples in different countries. The other inherent problem is that between two countries both the health service and the social infrastructure will differ making it impossible to tease out the influence of each on any outcome measure.

Single item comparisons are essentially problematic. For example, the differences in income should be corrected for the standard of living in the two cities. In the social field, the understanding of the importance of family relations, partnership or friendship might be quite different in London and Berlin, and this should be taken into account in the comparison. Methodologically, it is impossible to account for all such influences. In particular, broad cultural differences may not be quantifiable. Matching of parameters classically regarded as highly influential (gender, age) did not help to explain the differences, but the importance of ethnicity was demonstrated. A number of differences achieved significance when comparing white Europeans only, and so we can assume that the differences were masked in the earlier comparisons because of ethnic heterogeneity. Similarly, partnership and family contact were no longer significant when minority ethnic group patients were excluded. Living and social conditions in general seemed to be different within the London group between white Europeans and minority ethnic groups, and the differences between the Berlin and London population might be smaller for white patients in both cities than between different ethnic groups in one city. We have to assume that the differences that were found in the general comparison (apart from partnerships and more frequent family contact in London) were mainly due to different living conditions of the ethnic minorities or the different cultural surroundings of ethnic groups. We would like to draw attention to the finding that the sum of material problems rated still showed

significant differences under the conditions of the matched-pairs comparison. This indicates that the differences between the material aspect of life quality was a robust finding independent of age, gender or psychopathology.

The multiple regression analyses were not able to predict very large proportions of the variance in any of the three dependant variables. It is interesting that with the dependant variable "satisfaction with living conditions", the variable Berlin London had some impact that was not explained by any of the other variables examined in our study. Although the multiple r was modest, this finding indicated that the local surroundings patients live in are relevant to the interpretation of the results of quality of life research.

In conclusion, we demonstrated that the relationship between subjective and objective Quality of Life is not straightforward, and that when comparing such data between different cultures, complex interactions of factors exist that must be taken into account. In order for this to be possible there is a need for more studies in which such international comparisons are made, and further discussion of the inherent methodological difficulties is inevitable.

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