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Comprehensive Psychiatry 56 (2015) 133-140

Quality of life in a 20-year follow-up study of people suffering from schizophrenia

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Abstract

Aims: 1. To assess the changes in quality of life indicators in schizophrenia sufferers at three measurement points: 7, 12 and 20 years after the first hospitalization. 2. To assess changes in the level of functioning and psychopathological state. 3. To assess the relationships between quality of life, the level of functioning and the severity of symptoms.

Method: A sample group of fifty-two people diagnosed with schizophrenia was investigated using the Lehman's QOLQ, the GAF scale and BPRS. Results: A deterioration was noted in the subjective and objective areas of family life and health, subjectively assessed social relationships and objectively assessed finances. The better functioning sub-group returned better scores for the following objective quality of life indicators: free time, family life, health, social relationships and financial situation. The sub-group in remission obtained better results for general, subjective quality of life and for subjectively assessed health, as well as better scores for objectively assessed free time, social relationships, financial situation and health. An improvement in general, subjective quality of life was seen in the sub-group whose symptoms had grown more severe.

Conclusions: The decline in subjective and objective quality of life in the areas of health and family life, in the subjective evaluation of social relationships and in the objective assessment of financial situation was associated with a deterioration in functioning and an absence of symptom remission. The improvement in general, subjective quality of life in the sub-group with severe symptoms may be evidence of the formation of adaptive mechanisms.

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1. Introduction

In recent decades quality of life has been recognized as a significant indicator in the treatment outcomes of people with serious mental disorders, including those who have been diagnosed with schizophrenia [1–3]. Among the reasons for this has been the transition in the model of psychiatric treatment in Western countries, which begun at the end of the 1950s and has seen a move from an asylum-based model to a community-based one. In Poland these changes were delayed by approximately two decades due to political factors. They therefore began only in the late 1980s and early 1990s. Our research initiative, whose aim was to observe the fate of eighty people diagnosed with schizophrenia over a period of

20 years and to evaluate their treatment outcomes, their social functioning and the changes in their quality of life, also began towards the end of the 1980s.

It has been demonstrated in the existing body of research that quality of life depends not only on the severity of the psychopathological symptoms [4] but also on a series of other factors [5]. A relationship has been established between quality of life and the following: the neuro-cognitive functions [6], theory of mind [7], cognitive functions and social cognition [8,9], unmet need [10–13], insight into the symptoms of the disorder [14] and the social network [15]. Research into patients diagnosed as schizophrenic and into improvement in their quality of life is also important because, as a number of research initiatives have indicated, the

The study was conducted by the Cracow Schizophrenia Research Group.

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diagnosis is associated with the risk of recurrence of psychotic symptoms [16]. There have, however, been few prospective studies of quality of life.

The present work is the result of the observation of changes in quality of life in people diagnosed as schizophrenic according to *DSM IV* in a prospective, 20-year follow-up study. In addition to the long-term observation of a diagnostically homogeneous group, the important features of this study are the stable, community-based therapeutic environment and the search for—besides psychopathology—a relationship with the overall level of functioning. This is a continuation of earlier studies completed in Kraków, which concerned shorter time intervals [3,15,17]. It also fills a certain gap in the geographical distribution of quality of life research [18].

2. Methods

2.1. Study design and sample

Quality of life was investigated at three measurement points: 7 (n = 66), 12 (n = 71) and 20 (n = 61) years after the first hospitalization. The analyses were restricted to fifty-two people who were examined at all three measurement points.

2.2. Measurements

General functioning was evaluated with the aid of the Global Assessment of Functioning (GAF) scale. GAF forms a part of the DSM multi-axial system for assessment, which is intended as a reflection of the evaluating clinician's judgement concerning the patient's ability to function in daily life. The 100-point scale measures psychological, social and occupational functioning. Patients with scores of up to 59 points on the GAF scale were assigned to the sub-group with worse general functioning, while those with scores of 60 and above—the threshold value established by researchers as indicating recovery [19]—to the sub-group with better general functioning. The Brief Psychiatric Rating Scale (BPRS), a tool constructed in 1960 by Overall and Gorham [20], was employed to determine the severity of the psychopathological symptoms. In our study we used the extended version by Lukoff et al. [21], which is composed of twenty-four symptoms, each assessed on a seven-degree scale from 1 to 7. The sub-groups were obtained by assigning those with results on the BPRS scale of ≤ 2 to the group with less severe symptoms and assigning those with results on that scale of >2 to the group with more severe symptoms. At the symptomatic level, then, we adopted more demanding remission criteria than did, for example, Andreasen et al. [22].

The Polish version of Anthony Lehman's Quality of Life Questionnaire [23] was used to assess quality of life. First, information was collected on the objective indicators, which refer to a variety of aspects of quality of life, and then on the subjective attitude of the respondents to them. The resulting objective and subjective quality of life indicators for the

areas studied formed the base for the quality of life assessment model. The objective indicators concern the assessment of functioning, such as the frequency of social contacts or activity during the course of the day, access to resources, such as financial means and types of care, and the extent to which the respondent is able to take advantage of them. All of the subjective quality of life indicators were evaluated by the sample based on a seven-point 'satisfaction scale'. General satisfaction with life was measured as the average of the assessments at the beginning and at the end of the questionnaire.

All subjects' data were collected in ambulatory setting, with wholly voluntary participation. At each assessment an informed consent was sought from the patients and their family members. They were informed of the objective, methods and the course of the assessment. The study has been approved by the Bioethical Committee of the Collegium Medicum, Jagiellonian University, Cracow.

2.3. Statistical analyses

The difference between the demographic indicators at the three measurement points was assessed using the McNemar and Wilcoxon tests. The dynamics of the changes in psychopathological state, general functioning and quality of life, as well as the relationships between them, were evaluated with the aid of analysis of variance with repeated measures and one between-group factor.

3. Results

3.1. Sample demographics

During the research period, across all time intervals, there were statistically significant changes in the sample regarding the number drawing incapacity benefit and regarding life context. After 20 years of being ill, 79% of the sample were drawing incapacity benefit and the risk of disability and incapacity to work was higher the longer the illness had lasted. The number of people living with their family of origin fell markedly from 48 to 27%, the number of people living independently rose from 8 to 19% and the number living with a procreational family rose from 44 to 52% (Table 1.).

3.2. Changes in clinical indicators

In the first time interval between 7 and 12 years from the first hospitalization the GAF indicator of general functioning showed statistically significant growth (p < 0.001) before, in the second interval between 12 and 20 years, returning a statistically significant decline (p = 0.035). An increase in the intensity of symptoms throughout the successive time intervals was observed in all of the psychopathological syndromes assessed on the BPRS scale: in the general assessment between 7 and 12 years (p = 0.029), 7 and 20 years (p < 0.001) and 12 and 20 years (p = 0.001) from the first hospitalization; in the positive syndrome between 7

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