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A two-year follow-up study of people with severe mental illness involved in psychosocial rehabilitation

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Abstract

Backgrounds

A focus on psychiatric rehabilitation in order to support recovery among persons with severe mental illness (SMI) has been given great attention in research and mental health policy, but less impact on clinical practice. Despite the potential impact of psychiatric rehabilitation on health and wellbeing, there is a lack of research regarding the model called “Psychiatric Rehabilitation Approach from Boston University (BPR)”.

Aim: The aim was to investigate the outcome of the BPR intervention regarding changes in life situation, use of health care services, quality of life, health, psychosocial functioning and empowerment.

Methods: The study has a prospective longitudinal design and the setting was seven mental health services who worked with the BPR in the county of Halland in Sweden. In total 71 clients completed the assessment at baseline and of these 49 completed the 2-year follow-up assessments.

Results: The most significant finding was an improved psychosocial functioning at the follow-up assessment. Furthermore, 65% of the clients reported that they had mainly or almost completely achieved their self-formulated rehabilitation goals at the 2-year follow-up. There were significant differences with regard to health, empowerment, quality of life and psychosocial functioning for those who reported that they had mainly/completely had achieved their self-formulated rehabilitation goals compared to those who reported that they only had to a small extent or not at all reached their goals.

Conclusions: Our results indicate that the BPR approach has impact on clients' health, empowerment, quality of life and in particular concerning psychosocial functioning.

Key words: psychiatric rehabilitation, psychosocial rehabilitation, severe mental illness, Choose–Get–Keep Model, Boston psychiatric rehabilitation approach

Background

A focus on psychiatric rehabilitation in order to support recovery among persons with severe mental illness (SMI) has been given great attention in research and mental health policy, but still lacks implementation in clinical practice in a broader perspective [1] [2]. The development of mental health systems in Sweden have in recent decades been characterized by a shift from traditionally hospital-based care to community-based care [3]. However, moving toward a recovery-oriented approach takes time and presents several challenges for mental health services [4]. With the increasing emphasis on an evidence-based practice and research findings which confirm that people with SMI can recover from their illness [5] there is a promising future for a further focus on recovery-oriented mental health care services [2].

The development of new models for psychiatric rehabilitation have resulted in a number of intervention programs designed to improve health, social functioning and the quality of life of persons with SMI. Common elements of these programs are that they offer extensive and person-centred support aimed at strengthening the person's ability to take responsibility for their lives and thereby improve their quality of life [6]. Most programs include interventions aimed to improve social skills, to create opportunities for independent living, to get persons into work and actions to achieve a meaningful leisure time. The most common rehabilitation oriented models are the Fountain House model of psychiatric rehabilitation [7], case-management [8] [9], assertive community treatment (ACT) [10] [11] [2] and supported employment (SE) [12]. Both ACT [13] [14] and supported employment according to the IPS model [12] [15] have been identified as evidence-based practices that support people with severe mental illness. Despite the potential impact of psychiatric rehabilitation on wellbeing and health, there is a lack of research regarding the model called Psychiatric Rehabilitation Approach from Boston University (BPR)¹ [16] [17] although it is established in clinical practice in a number of countries. The BPR model has been investigated in some empirical studies from United States [18] [19] and in a few studies from European countries [20-23]. Four of these studies used a randomized controlled design [18] [19] [22] [23]. Swildens et al [22] showed that the BPR was effective in supporting persons with SMI in societal participation and to achieve self-formulated goals, but no effects were found regarding social functioning, needs for care, and quality of life. Rogers, Anthony, Lyss and Penk [18] found no significant differences between the intervention group and a control group regarding

¹ Sometimes called Choose-Get-Keep Model (CGK)

vocational and clinical outcomes such as self-esteem, quality of life and symptoms. Shern et al [19] showed that quality of life and mental health status was improved among homeless persons with SMI. Gigantesco et al [23] found significant differences between the intervention group and a control group regarding improvement in functioning. Van Busschbach & Wiersma [20] found in their one-year prospective study that BPR was successful in supporting the clients to achieve their self-formulated goals and in reduction of the number of perceived needs, but the level of symptom did not change over time. In the study by Swildens et al [21] the authors used a pre/post design and the results showed after a two year follow up that 57% achieved goals to live independently and to find a paid job. To our knowledge no empirical studies have been performed regarding the BPR model in Sweden.

This study was conducted as a part of an implementation project in the county of Halland that aimed to develop mental health rehabilitation services and to initiate a recovery-oriented approach for persons with severe mental illness. The implementation project was based on the BPR model from Boston University.

Aims

The aims of the present study were to investigate outcome of the intervention in terms of changes in life situation, use of health care services, quality of life, health, psychosocial functioning and empowerment. A further aim was to investigate to what extent the clients' self-formulated rehabilitation goals were attained.

The specific research questions were:

1. Does BPR lead to a better life situation in terms of external living conditions such as housing, employment, education, leisure activities and social relationships?
2. Does BPR lead to a better quality of life, health, empowerment and psychosocial functioning?
3. Does BPR lead to a reduced utilization of psychiatric care?
4. To what extent are self-formulated rehabilitation goals met for the persons participating in the BPR intervention?

Material and Methods

Design

The study has a prospective longitudinal design and the data collection at baseline started in August 2007 and a 2-year follow-up data collection ended in December 2010. At both baseline and follow-up all clients were interviewed by either of two of the authors (PS or HJ). The interviewers had no involvement in the clients' care or rehabilitation.

Settings and participants

The setting was seven mental health services who implemented the BPR approach in the county of Halland in Sweden. Six of these were municipal services for persons with mental illness and one was an outpatient specialist psychiatric service. Two of the six municipal services only provided vocational rehabilitation. The study sample consisted of clients in contact with these services and the criteria for inclusion were that the clients were treated in accordance with BPR, had a severe mental illness (SMI), were over 18 years of age, and presented a need for change in their living situations in areas such as housing, education, work / employment and / or recreational activities.

A total of 71 clients consented to participate and completed the assessment at baseline, and of these 49 completed the 2-year follow-up data collection. Of the 22 clients not participating in the 2 year follow-up, 18 clients could not be reached and 4 clients declined to take part.

Intervention

The BPR approach is based on the principles and practices of psychiatric rehabilitation developed by Anthony, Cohen and Farkas [24] at Boston University. The model was first applied in vocational rehabilitation, and then extended to educational and housing situations [17]. The model is highly individualized and is based entirely on the individual's unique needs and preferences. The design of the intervention is created in the interaction between the client and his/her key-worker. Very clear and concrete self-formulated goals and timetables are made up in order to support the client in achieving a satisfying life situation.

The purpose of the BPR intervention in Halland was to support and guide the client to formulate and achieve his/her own goals for various life areas such as work/occupation,

housing, education and leisure time. The intervention comprises three different phases where the professional and the client together work with; 1) a diagnostic phase including a comprehensive assessment of the clients abilities and resources, an assessment of resources in the person's environment, readiness for rehabilitation and ending in an overall self-formulated goal for the rehabilitation, 2) a planning phase including planning for interventions in order to strengthen skills development and resource development, 3) an intervention phase focusing on learning and developing of personal skills as well as a resource coordination and modification in order to make it realistic for the client to achieve his/her goals.

All staff working in the services had completed an education in the overall BPR methodology and had also received supervised training in providing the different phases of the rehabilitation process. A program fidelity evaluation was carried out using a new instrument developed by the research group inspired by a Dutch questionnaire [25]. The procedures of this evaluation as well as the results and discussion of these will be described elsewhere [26].

Outcome measures

Subjective quality of life was assessed by the Manchester Short Assessment of Quality of Life scale. The instrument contains 16 items including satisfaction with work, finances, social relations, leisure, living situation, safety, family relations, sexual relations, and health using a 7-point scale ranging from could not be worse to could not be better. The instrument has shown good reliability and validity [27] [28].

Needs of care were measured using the Camberwell Assessment of Needs Short Appraisal Schedule, (CANSAS) [29]. The instrument contains 22 different domains where psychiatric care might be needed and for each domain it distinguishes between no need, met need and unmet need.

Empowerment was appraised by the Making Decisions questionnaire, developed by Rogers et al. [30]. This is a 28-item self-report questionnaire with five subscales: self-efficacy–self-esteem, power–powerlessness, community activism, righteous anger and optimism towards and control over the future. Statements are responded to on a four-point agreement scale. A psychometric evaluation has been performed of the Swedish version [31].

Psychosocial function was measured by GAF (Global Assessment of Functioning, symptoms and disabilities) [32]. The instrument uses a scale ranging from 0 – 100 where a higher score indicates a better psychosocial functioning.

The subjective experience of health was measured by the instrument HQ. This is a 22-item self-report questionnaire with three subscales: autonomy, social involvement and comprehensibility. The ratings are made on a five-point scale from 1 = ‘never’ to 5 = ‘always’. The instrument has showed good reliability and validity in a Swedish context [33-35].

Data regarding social, clinical and demographic characteristics as well as service use was also collected by means of self rating-questionnaires.

Ethics

The study was approved by the Regional Ethical Review Board for southern Sweden, Dnr 316/2007. All participants were informed both orally and in writing about the purpose and the structure of the study before they gave their informed consent. Participation was voluntary, and the participants were informed about the ethical considerations of confidentiality and that they could withdraw from the study at any time.

Statistical analysis

Differences between baseline and 2-year follow-up were analyzed with Student’s t-test. Analyses of differences between subcategories of clients were made using the χ^2 test. Significant differences were set at $p < .05$. Effect-sizes (ES) were calculated to determine the strength of the differences between baseline and follow-up where 0.2 – 0.5 was considered as a small, 0.5 - 0.8 as a moderate and > 0.8 as a large ES [36]. The statistical software used was SPSS version 15.

Results

Socio-demographic characteristics

The mean age of the participants was 36 years (range 19- 57) and most participants were male (57.1 %). The mean years since first admission were 8 years (range 0-24). A majority (57 %) of the participants were single, 30.6 % were married or co-habiting and 98% had an independent living. In terms of diagnosis, 36.7% of the subjects had an affective disorder,

16.3% had a diagnosis of schizophrenia, 2.0% had an eating disorder, 6.1% had ADHD/Autism or Asperger and 38.7% had other diagnoses. With regard to education 55.1 % had completed upper secondary school and 38.8 % compulsory comprehensive school and the rest had completed undergraduate studies. Demographic characteristics of the clients are presented in Table 1. The patients who did not participate in the follow-up were not different in any of the sociodemographic variables measured at baseline compared with the patients who completed the study (See table 1).

External life situation

The clients' external life situation in terms of housing, education and leisure activities showed no significant differences between baseline and the two-year follow-up. There were, however, significant changes (.001) concerning work situation, with an increased number of clients who had a competitive employment (baseline n=4, follow up n=8) and sheltered employment/job training (baseline n=4, follow up n=7), as well as a reduced number of clients who had a disability pension at follow up (baseline n=29, follow up n=25).

Quality of life, health, empowerment and psychosocial functioning

Quality of life, health, empowerment as well as psychosocial functioning were significantly improved between baseline and the two year follow up (table 2). In terms of quality of life the results show that clients were more satisfied with their finances and their physical and mental health at the two-year follow-up. In terms of empowerment the clients' perceptions of power had improved. In terms of health, the clients' experiences of social involvement were improved. Effect sizes for all these domains were generally small, with the exception of psychosocial functioning where the effect size was large.

Changes in service utilization and needs of care

The number of clients in contact with psychiatric care decreased significantly between baseline and two year follow up (table 3). The number of needs for care was reduced significantly (0.042) between baseline (mean 6.8 sd 3.6) and two year follow up (mean 5.7 sd 4.0), the effect size was however quite small (0.11).

Achievement of self-formulated rehabilitation goals

Rehabilitation goals could be made in various domains of life and 53 % of the clients formulated goals referring to work/occupation, 5.6 % regarding leisure, 4.2 % regarding education and 1.4 % of the clients in the area of housing. At the two-year follow-up 12 clients (24%) had completed their rehabilitation and fully achieved their goals. Thirty-two of the clients (65%) considered that they mainly or almost completely had achieved their goals. The rest of the clients (35%) considered that they had to a small extent or not at all reached their goals. Those clients who reported that they had mainly/completely achieved their goals also had a significantly better outcome with regard to health, empowerment, quality of life and psychosocial functioning in comparison with the clients who reported that they had to a small extent or not at all achieved their goals. The effect sizes for all these outcome domains were generally large, Table 4.

Discussion

The most significant finding of the present study was an improved psychosocial functioning (large effect size) at the two-year follow-up. Furthermore, 65% of the clients reported that they largely or almost completely had achieved their self-formulated goals at the 2-year follow-up. Health, empowerment, quality of life and psychosocial functioning improved over time, with large significant differences between clients who mainly/completely achieved their self-formulated rehabilitation goals and the clients who only to a small extent or not at all achieved their goals. This indicates the importance of a thorough evaluation process in the initial phase of rehabilitation and supporting the client in formulating personally relevant and realistic rehabilitation goals.

The present study showed an increased number of people in competitive employment and sheltered employment/job training, and a decrease in number of people with disability pension while no changes were shown concerning housing situation, education and leisure time. It is important to notice that 53 % of the clients formulated goals referring to work/occupation and to a much lesser extent regarding housing situation, education or leisure time, which maybe the background to these results. Another explanation could be that two of the six included municipal services only provided vocational rehabilitation. These findings are comparable to the results of the study by Swildens et al [21], which showed that 12% of 58 clients had a paid job at the two-year follow-up. In the study by Swildens et al [22] the BPR intervention was more successful in terms of work and educational goals (56%) in comparison to care as usual

(28%), but not in the area of living situation. In the study by Rogers, Anthony and Farkas [17] there were no significant differences between the intervention group and the control group regarding work situation at a two-year follow up. It is, however, important to consider that outcomes regarding work may also reflect differences in the unemployment welfare system in different countries. They could also reflect differences regarding work capacity and the risk of being granted disability pension, where socio-demographic characteristics, such as female sex, higher age, low socioeconomic status and living in a rural area, have previously been associated with rates of disability pension [37].

The results showed that the clients' quality of life, health, empowerment and psychosocial functioning were significantly increased during the two year follow up. The effect sizes regarding psychosocial functioning were notably large. These findings are consistent with earlier research that showing that the BPR approach improved functioning [23] as well as quality of life and mental health status [19] among persons with SMI. However, Swildens et al [22] and Rogers, Anthony and Farkas [17] found no effects regarding social functioning, self-esteem and quality of life. The results in the present study also showed that the clients' empowerment, especially concerning power and social belonging, improved during the two year follow up. This is in agreement with the aims of the BPR approach [17], where clients are being viewed as full partners and involved in shared decision making with rehabilitation staff.

The present study showed that the number of clients with ongoing contacts with mental health services was reduced significantly between baseline and the two-year follow-up and that the number of unmet needs of care and support had diminished significantly during the period. This is not congruent with the study by Swildens et al [22] which did not find any differences in use of care between the intervention and control group. Van Busschbach and Wiersma [20] found that BPR was successful in reducing perceived needs, which also was the case in the present study.

Comparisons between the clients who to a lesser extent achieved their self-formulated rehabilitation goals, and the clients, who had achieved their goals to a greater extent, showed that the latter group had a better outcome regarding psychosocial functioning, health, empowerment and quality of life, and that the effect sizes were notably large. A possible conclusion is that an intervention such as BPR that focuses on the relationship between a

person's self-formulated goals and their values for the future promotes health related issues and facilitates recovery. Earlier research [20] [22] has also found that BPR was successful in supporting the clients to achieve their self-formulated goals, but to our knowledge the present study is the first to show a relationship between goal attainment and health related outcomes.

Some methodological considerations should be discussed. The study was mainly based on self-reported data from validated international instruments with a low rate of missing data. Furthermore, the appropriateness of using the client self-rated estimation of service use of psychiatry might be considered. We can only draw the conclusion that there was a decrease in contacts with psychiatric care, and may not infer any causality between this and that the clients' quality of life, health, empowerment and psychosocial functioning were increased. However, the results would have been strengthened if we had established more knowledge of the reasons for the decrease in contacts with the psychiatric services. A further issue of concern is whether the population in the actual community setting is a representative group of clients with SMI. The clients self-reported their diagnosis and the results show that there was heterogeneity in the sample regarding diagnosis. There is a risk regarding self-reported data that the client under-estimate their symptoms and dysfunction as well as diagnosis. Ruggeri et al [38] stated that, irrespective of diagnosis and psychotic disorder, the most important criteria of SMI are the duration of illness and the severe dysfunction. Our population is representative for clients with SMI since the most of the clients have a long duration of treatment, ongoing psychiatric care, disability pension and have a severe dysfunction. The major limitation of the present study is that we did not use a randomized controlled design with a control group, which limits conclusions about the effectiveness of BPR from this study. The main reason for this was that we considered it unethical to use a RCT design in a case where a client inclusion criterion was a defined need of rehabilitation and no alternative rehabilitation model was present in the services included in the study. The background to this was that the focus of the project was mainly implementation and that the investigation of individual client outcomes in order to get an appreciation of the clinical usefulness of BPR in a local context was deemed to be of value. A further argument was that there is a rather widespread implementation of the BPR approach but a lack of clinical studies focusing the evidence of the approach. In spite of these limitations we still suggest that the BPR approach can be an important factor in improving clients' clinical and social situation. Firstly a number of significant positive changes were identified in some life areas. If changes were random or merely reflecting a natural course of disease, some of these changes could be in a negative direction. Secondly,

many of the changes are close to the aims of the BPR approach such as improving empowerment, quality of life and psychosocial function. Thirdly, the changes have in some cases a large effect size which, given the participants relatively long duration of illness, are unlikely without any impact of the BPR approach. Furthermore most of the results are supported by the few studies that have used a control group in investigations of the BPR approach.

Conclusion

In conclusion this study provides support for that BPR contribute to an improved life situation in terms of employment and sheltered employment/job training, and a decrease in number of people with disability pension, while no changes were shown concerning housing situation, education and leisure time. This study also provides support for that BPR contribute to an increased quality of life, health, empowerment and psychosocial functioning as well as to a reduced utilization of psychiatric services.

Implications

Our findings have policy-making implications since the BPR approach is dependent on organizational preconditions in mental health services necessary to support participation and shared decision-making among persons with SMI. In this regard, further research is needed to study how cultural and organizational variances in different countries are affecting the preconditions to implement the BPR approach in mental health services. Future research should also investigate fidelity of an implemented intervention and cost effectiveness regarding improvement of the total care process in relation to health outcomes.

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Table 1. Sociodemographic characteristics of clients who completed the study (n= 49) versus drop out clients (n=22).

| | n=49 | | n=22 drop out | |
|------------------------------------|------------|------|---------------|------|
| | n | % | n | % |
| Gender | | | | |
| Male | 28 | 57.1 | 11 | 50.0 |
| Female | 21 | 42.9 | 11 | 50.0 |
| Age | | | | |
| (mean, range) | 36 (19-57) | | 37 (21-56) | |
| Education | | | | |
| Compulsory comprehensive school | 3 | 6.1 | 1 | 4.4 |
| Upper secondary school | 32 | 65.3 | 11 | 50.0 |
| Undergraduate studies | 14 | 28.6 | 9 | 40.9 |
| Missing | | | 1 | 4.5 |
| Living situation | | | | |
| Single | 28 | 57.1 | 6 | 27.3 |
| Married/co-habiting | 15 | 30.6 | 10 | 45.5 |
| Parents | 5 | 10.2 | 4 | 18.2 |
| Other | 1 | 2.0 | 2 | 9.1 |
| Housing situation | | | | |
| Independently * | 48 | 98 | 18 | 81.8 |
| Second hand lodging | 1 | 2.0 | 0 | 0 |
| Supported housing | 0 | 0 | 1 | 4.5 |
| Other | 0 | 0 | 3 | 13.6 |
| Diagnosis | | | | |
| Schizophrenia/ psychosis | 8 | 16.3 | 0 | 0 |
| Affective disorder | 18 | 36.7 | 7 | 31.8 |
| Eating disorder | 1 | 2.0 | 0 | 0 |
| Adhd/Autism/Asperger | 3 | 6.1 | 1 | 4.5 |
| Other diagnosis ** | 13 | 26.5 | 3 | 13.6 |
| Missing | 6 | 12.2 | 11 | 50 |
| Psychiatric care history | | | | |
| Years since first admission (mean, | 8 (0-24) | | 9 (2-27) | |

| | | | | |
|--------|--|--|--|--|
| range) | | | | |
|--------|--|--|--|--|

*Independent living - owning or renting one's own house or apartment, alone or with others.

**other diagnosis includes diagnoses such as posttraumatic stress disorder, drug abuse, social phobia, personality disorders and obsessive compulsive disorder.

Table 2. Outcome measures at baseline and the two-year follow-up N= 49

| | Baseline M (sd) | Two years follow up M (sd) | Significance* | Effect size |
|---|--------------------|-------------------------------|---------------|-------------|
| Psychosocial functioning | 56.3 (7.39) | 65.5 (12.46) | .001 | 0.93 |
| Empowerment (total scale) | 2.8 (.31) | 2.9 (.31) | .013 | 0.32 |
| Self-esteem | 2.7 (.57) | 2.9 (.52) | ns | |
| Power | 2.5 (.32) | 2.6 (.33) | .002 | 0.31 |
| Community activism | 3.3 (.45) | 3.4 (.41) | ns | |
| Optimism towards and control over the future | 2.9 (.50) | 3.0 (.48) | ns | |
| Righteous anger | 2.6 (.61) | 2.7 (.53) | ns | |
| Quality of life | 4.4 (.95) | 4.6 (.96) | .039 | 0.21 |
| Work | 4.6 (1.8) | 4.6 (1.7) | ns | |
| Finances | 3.3 (1.8) | 3.9 (1.7) | .025 | 0.34 |
| Friends | 4.8 (1.8) | 5.1 (1.7) | ns | |
| Leisure time | 4.4 (1.7) | 4.4 (1.4) | ns | |
| Housing | 5.3 (1.4) | 5.1 (1.5) | ns | |
| <i>Safety</i> | 5.1 (1.6) | 5.3 (1.5) | ns | |
| <i>Living situation alone/or with other</i> | 5.2 (1.6) | 5.2 (1.6) | ns | |
| <i>Sexual relations</i> | 3.8 (1.9) | 4.2 (1.9) | ns | |
| <i>Family relations</i> | 5.1 (1.6) | 5.0 (1.9) | ns | |
| Physical health | 3.7 (1.5) | 4.3 (1.4) | .007 | 0.41 |
| Mental health | 3.4 (1.6) | 4.1 (1.5) | .001 | 0.45 |
| Health | 3.5 (.71) | 3.7 (.72) | .037 | 0.28 |
| Autonomy | 3.4 (.73) | 3.6 (.78) | ns | |
| Social involvement | 3.5 (.77) | 3.7 (.78) | .033 | 0.26 |
| Comprehensibility | 3.6 (.79) | 3.7 (.72) | ns | |

*Student's paired t-test

Table 3. Changes in the clients' contact pattern with care and service between baseline and the two-year follow-up (n=49)

| | Baseline | | Two years follow up | |
|---------------------------------|----------|-------------|---------------------|----------------|
| | n | % | n | % |
| Ongoing care and support | | | | |
| Psychiatric care | 45 | 91.8 | 29 | 59.2 ** |
| Social services | 10 | 20.4 | 13 | 26.5 |
| Primary care | 14 | 28.6 | 12 | 24.5 |
| Welfare insurance office | 23 | 46.9 | 26 | 53.1 |
| Employment service | 6 | 12.2 | 13 | 26.5 |

Chi² test : ** =p<.01

Table 4. Comparisons for health outcomes between clients with high/low goal attainment (n=49)

| | Goal attainment ^a | | Significance* | Effect size |
|---------------------------------|------------------------------|-----------------|---------------|-------------|
| | Yes ^b | No ^c | | |
| Psychosocial functioning | 70.7 (12.1) | 55.8 (5.1) | .001 | 1.73 |
| Health | 3.9 (.68) | 3.2 (.51) | .001 | 1.18 |
| Quality of life | 4.9 (.97) | 4.0 (.63) | .001 | 1.25 |
| Empowerment | 3.0 (.28) | 2.7 (.24) | .001 | 1.15 |

^a Goal attainment reported by the patients

^b Patients (n= 32) who felt that they mainly/completely achieved their goals

^c Patients (n= 17) who considered that they to a small extent or not at all had achieved their goals

* Independent samples t-test