Societal participation: examining the impact of a rehabilitation approach for young people with schizophrenia

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Keywords: nurses, rehabilitation, schizophrenia, social workers, societal participation, young people

Accessible summary

• In addition to medical and psychosocial treatment of impairments, societal participation should be recognized as an important treatment goal for patients with schizophrenia, and it can be applied in daily practice by nurses and social workers, even when psychiatric impairments require acute care.
• Our research indicated that rehabilitation counselling by nurses and social workers within a multidisciplinary team helps to increase the societal participation level of young people with schizophrenia, while their impairments scores remained stable.
• Patients with more mild impairments seemed to profit more from rehabilitation counselling while patients whose impairments were more severe seemed to profit less. Our research also indicated that patients with similar levels of impairment did not show differences in their level of societal participation, regardless of drug use.
• Drug use as such is not a contraindication for rehabilitation counselling. Treatment of impairments, including management of drug addiction, should be closely interwoven with support for a patient’s rehabilitation goals.

Abstract

This paper is based on research that focuses on the impact of a rehabilitation approach with respect to 99 young people diagnosed with schizophrenia in a Dutch mental health facility. The approach focused on societal participation goals. Nurses and social workers play a key role in such treatment. The research focused on developmental trajectories and showed significant improvement with respect to societal participation levels. Impairment scores remained stable. The results indicate that rehabilitation counselling by nurses and social workers, in addition to medication and psychosocial treatment and integrated in a multidisciplinary team, can make a difference in a patient’s societal participation.

Introduction

Present day treatment of schizophrenia is based on three important components (World Health Organization 2001, p. 68).

1. Medication is used to relieve psychotic symptoms and prevent relapses;

2. Psychosocial treatment helps to relieve symptoms and prevent relapse by assisting patients and their families to cope with the impairment;

3. Rehabilitation as a means of supporting patients as they participate in society, for instance to develop a higher level of educational or occupational functioning.
The treatment of schizophrenia should ideally include all three components. However, treatment routines in daily practice usually focus solely on the reduction of psychotic symptoms and the prevention of relapses. A patient’s increased societal participation is not always appreciated as an important treatment goal (Lloyd et al. 2000, Killackey et al. 2006, Woodside et al. 2007). Additionally, scientific research focuses mainly on impairment and much less on a patient’s active participation in society (Wiersma et al. 2000, Moore et al. 2007).

Our purpose is to add to the ongoing discussion about impairment-oriented treatment in mental health care and expand awareness among patients and carers regarding the importance and successes of rehabilitation, while recognizing the importance of multidisciplinary collaboration among mental health nurses, social workers and medical staff.

Level of societal participation is a key concept in our study. Here, societal participation is defined in terms of a patient’s involvement in outside activities in a variety of work, living, educational and leisure settings, and in terms of one’s contacts with family and friends. We describe treatment modalities as they were implemented within a Dutch mental health facility (named ‘ABC’) for young people with schizophrenia. ABC utilizes the Boston rehabilitation approach (Anthony et al. 2002) as the foundation for overall treatment. The first goal is to minimize the patient’s psychotic symptoms using medication and psychosocial treatment, while at the same time supporting a patient’s participation in society. With respect to participation in society it is critical that patients set personal goals concerning such participation.

The patients were followed using standardized instruments, which allowed the institution to track societal participation levels of the group as a whole. These results were also used as a feedback mechanism for all individual participants.

In this paper, we summarize the results of this approach and discuss its advantages and disadvantages, and the important role that nurses and social workers play in this process.

Research questions

The study discussed here is based on programme evaluation. The evaluation took place to examine the relevance of rehabilitation, using a multidisciplinary mental health care team, for young people with schizophrenia. The evaluation focused on two main questions:

1. Are patients’ impairments sufficiently stabilized during their treatment with ABC; and

2. Does the societal participation level of these patients increase during treatment?

We will examine the effect that the impairments might have had on one’s societal participation level. Additionally, we study the influence of drug use.

Treatment and rehabilitation

The first manifestation of psychosis in a patient generally occurs during young adulthood. It is vital to begin medication and psychosocial treatment as soon as possible after the onset of psychotic symptoms. The period of time during which psychosis is left untreated, implying delayed treatment with antipsychotic medication in early schizophrenia, increases the risk of relapse (Bottlender et al. 2003, Harrigan et al. 2003). The length of delay in psychosocial treatment is a predictive factor in the length of eventual hospitalization (de Haan et al. 2003). In short, the longer the psychosis goes untreated, the poorer the prognosis becomes.

Treatment of psychotic symptoms is only partly successful. Approximately one-third of patients in this group have no relief from psychotic symptoms even when treated with medication and cognitive therapy (van Os & Kapur 2009). The treatment by medication of negative symptoms such as the reduced production of thought, affective blunting and reduced social functioning is unsuccessful (Buckley & Stahl 2007). Psychosocial treatment, especially cognitive therapy, has been shown to provide some success in this respect (National Institute for Health and Clinical Excellence 2009). Treatment directed at cognitive impairments such as incomprehensible speech and poor attention span can be successful; that is, cognitive remediation can improve cognitive performance, but this has no direct impact on a patient’s level of social participation in outside environments.

Rehabilitation seems to be effective for some symptoms. It seems to improve a patient’s capacity for self care, social functioning and to lessen apathy (Burns et al. 2009), and more hopeful results can be expected (Twamley et al. 2003, van Os & Kapur 2009, Swildens et al. 2011). Burns et al. (2009) showed that rehabilitation does not have a measurable impact on a patient’s hallucinations and delusions. Societal participation, however, is an important goal in itself. Medication and psychosocial treatment can improve societal participation, but only when combined with rehabilitation directed specifically at a patients’ goals in this area (McGurk et al. 2007). In short, rehabilitation does not lessen symptoms such as hallucinations or delusions, but some success can be realized in areas of self care and social functioning. As stated by the World Health Organization (2001),...
a patient’s societal participation goals should be recognized as an independent and focal point of treatment.

Nurses are generally the professionals who have the most frequent contact with patients, and they play a key role in the treatment of schizophrenia, particularly in the alleviation of psychotic symptoms and physical health problems. They offer important psychosocial guidance by providing information about impairments and treatments, advice on how to cope with symptoms, help with daily life skills and support for societal participation. The integration of rehabilitation counselling techniques during treatment is particularly useful when dealing with specific life stage problems seen in younger schizophrenia patients. The normal developmental challenges of becoming an adult are far more difficult for people with a psychosis. Patients battle with their confused perception and interpretation of the world outside, as well as apathy and mental disorganization. It is, therefore, even more difficult to achieve their societal participation goals. Most patients are more willing to accept support when it is directly connected to the achievement of their personal societal participation goals.

A nurse – the patient’s key professional – is the most natural choice for this part of the treatment. These rehabilitation tasks have not traditionally been part of a mental health nurse’s training in the Netherlands, but this is slowly changing.

The ABC treatment

ABC is a department for young people with a first non-affective psychosis, usually schizophrenia. It is located within a large general mental hospital in the centre of the city Utrecht in the Netherlands, though its physical location is outside the hospital area. It offers a 20-bed open facility with 24-h supervision, and ambulatory care for in total 200 patients. Beside the individual medical and psychosocial treatment by two psychiatrists, one assistant physician and two psychologists, patients take part in various treatment groups, for example, concerning medication, psycho-education, addiction, cognitive therapy, sports and multifamily groups.

The rehabilitation counselling is individually performed by six nurses and ten social workers, as well as one vocational rehabilitation specialist. Nurses and social workers perform rehabilitation counselling in equal measure. In the Netherlands, mental health nurses and social workers have very different educational backgrounds. The former are mainly trained in medical assistance and the care of individual patients, while the latter are trained to improve a patient’s quality of life and develop their potential. Social workers are also trained to handle groups. Nurses and social workers work together in this way for an important reason: to support the social model of rehabilitation and prevent the medical aspect of care from becoming dominant. In this manner, nurses and social workers are not solely focused on impairments. They help patients with their goals pertaining to school, work, living, leisure activities and social contacts. All relevant opinions from significant others, such as the parents and guardians, are taken into account. The patient’s skill training is connected to the goal. This implies that the development of skills is highly individualized and fits a rehabilitation goal as closely as possible. In addition to skills assessment and development, resources are assessed, used and/or developed that are critical for achieving the rehabilitation goal.

ABC staff are trained and supervised in how to apply this rehabilitation approach. Nurses and social workers take part in eleven 4-h training sessions within the course of one year. In addition to the weekly hour in group session, there are two rehabilitation experts available for individual consultation. All thirty ABC employees are committed to this rehabilitation approach, from research assistants and secretarial staff to higher management. Research on the above-mentioned rehabilitation approach shows mainly positive results (Shern et al. 2000, Gigantesco et al. 2006, Rogers et al. 2006a,b, Swildens et al. 2011).

The programme evaluation presented here examines the long-term results of ABC rehabilitation treatment at the group level.

Method

Patients

The current research data include 260 measurements from 99 patients between February 2004 and November 2008. All patients subjected to at least two measurements were included in this study. The patients were all under 32 years of age (average at first measurement 23.3 years, SD 3.3 years). Seventeen (17%) were not born in the Netherlands. There were twenty-four women (24%) and seventy-five men (76%). At the time of the first measurement, almost half the patients (47%) used drugs, generally cannabis. All patients were diagnosed with schizophrenia and all patients who wanted the ABC treatment were accepted, except those who had a current indication for a closed department.

Treatment

The ABC treatment usually takes three to five years. About half of the patients were clinically admitted at ABC (with an average of 100 days). Simultaneous with the regular medical and psychosocial treatment, focused on patients’ impairments, rehabilitation counselling directed at their
societal participation goals took place. The rehabilitation counselling by nurses and social workers usually consisted of one session every two to three weeks, or more frequently if contact was only possible for a limited amount of time. Rehabilitation was specifically directed at the personal societal participation goals of the patients. The goals focused on daily life domains, such as living skills, (voluntary) work, educational and leisure activities, and social contacts. The nurses and social workers were trained and supervised to highly individualize patient’s skills training, using resources that were critical for achieving their societal participation goals. If desired, a full-time rehabilitation specialist in the field of (voluntary) work and education was also available.

**Measurements**

The first measurement took place soon after a patient was referred to ABC. Subsequent measurements were obtained after the first year of treatment. While this process was structured in theory, in practice the measurements were irregular – some patients were measured as often as five times and others only twice. Other variables were location and changes to the treatment: some patients received ambulatory ABC treatment while they lived in a protective housing organization, while others lived more or less on their own. Some had changed their treatment from ambulatory to hospitalized care while others had done the reverse. As a consequence, there was a different amount of time between measurements for each patient.

The first measurement instrument concerned current ‘Societal Participation Level’ (SPL), as measured by the Questionnaire Functioning Level (van Wel et al. 2003). This instrument contains 37 questions. Each item can be scored at three levels: high functionality (2), functionality with some disabilities (1) or functionality with many disabilities (0). The main nurse or social worker administered the survey at each measurement moment, which took approximately 15 min per patient. No prior training was required. This nurse or social worker was the most reliable administrator of this survey because the questions related to concrete behaviours with a minimum need for interpretation, such as ‘Does one’s own shopping’, ‘Has a (voluntary) job’, ‘Is able to use public transportation’, and ‘Receives visitors’. This survey generates a single score. A higher score indicates a higher societal participation level. In our sample, the reliability of the scale was 0.83 (Cronbach’s Alpha).

The second measurement instrument was the Health of the Nation Outcome Scales, or HoNOS (Wing et al. 1998). This clinician-rated 12-item questionnaire focuses on a patient’s impairments and social problems, and each item is scored on a five-point scale. The Dutch translation was used in this case (Mulder et al. 2004). The HoNOS offers a sensitive, reliable and valid indication of a patient’s (mental) health and is suitable for more severe mental disorders (Wing et al. 1998). The assigned nurse or social worker filled out this questionnaire under the supervision of a research assistant. We used the total score of items 1, 2 and 4 to 8, a higher score signifying greater impairment. This subscale is named HoNOS Impairments. Items 9 to 12 were excluded because they concentrate on a patient’s social problems, and this overlaps with the more detailed SPL score. Item 3 is used separately as a time-variant indicator of drug use (1) or not (0). The reliability of the resulting HoNOS Impairment score in our clinical sample was 0.61 (Cronbach’s Alpha).

**Analysis**

The available data require a flexible treatment of time, as the number of measurements varies, as well as the period of time between measurements (Singer & Willett 2003). As our primary interest is in the development of the patients during their treatment at ABC, a latent growth model was used with two dependent variables: (1) SPL; and (2) HoNOS Impairment score. Our secondary interest is to identify predictors that help us to understand this development. The srss procedure MIXED was used for our analysis (SPSS Inc. 2007).

**Results**

Table 1 shows the mean levels and standard deviations for the HoNOS Impairment score and the SPL score. The standard deviations of both scales indicate that there were substantive differences between patients. For our analyses we used Latent Growth Modeling, which is a statistical technique to estimate growth over a period of time.

Figure 1 demonstrates the large variation in developmental trajectories between nine selected patients. It shows the differences in the number of measurements as well as the varying periods of time between measurements. The zero point on the time scale indicates the start of treatment.

<table>
<thead>
<tr>
<th></th>
<th>T1</th>
<th>Overall</th>
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<tbody>
<tr>
<td>HoNOS Impairment score</td>
<td>4.4 (3.5)</td>
<td>4.3 (3.5)</td>
</tr>
<tr>
<td>SPL score</td>
<td>59.2 (8.6)</td>
<td>61.9 (9.7)</td>
</tr>
</tbody>
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HoNOS, Health of the Nation Outcome Scales; SD, standard deviation; SPL, Societal Participation Level; T1, first measurement.
In Fig. 1 each patient obtains his/her own line, i.e. their own Initial Level and Rate of Change. The mean development in the group as a whole can be summarized in a single line.

Our first question concerns the patients’ HoNOS Impairment score during treatment. Our analyses show that the mean Rate of Change in the HoNOS Impairment score was nearly zero at the group level (not statistically significant) with extensive variance. So, while there was no mean change over time in the patients’ HoNOS Impairment score, there were considerable differences among individual patients.

Our analyses show that drug use is a relevant predictor for these differences among patients: patients who used drugs had a higher mean HoNOS Impairment score of 1.5 (significance level of <0.05). Also, drug use explains developmental differences with a significant Rate of Change at the <0.05 level. (Additional analyses showed no effects of sex and age).

Concerning our second research question, the Latent Growth Models show the development of the patient’s SPL. There is a mean growth of 1.6 per year on this scale (statistically significant at <0.001 level), while the variation in Rate of Change is insignificant. There is no significant correlation between Initial Status and Rate of Change, so that it can be concluded that a higher initial SPL is not predictive of the amount of change during treatment. Drug use is not a relevant predictor for SPL while the HoNOS Impairment score is. A lower score on HoNOS Impairment results in a higher initial SPL score (significance level of <0.001), while an increase in time with a higher HoNOS Impairment score results in a lower SPL in the mean within the group (significance level of <0.001).

**Discussion**

The main conclusion from this study is that the societal participation level of 99 young people with schizophrenia increased during their treatment at ABC. At the group level, psychiatric impairments remained stable. There were, however, considerable differences in the developmental trajectories of these patients. These differences confirm observations made by van Os & Kapur (2009), who contended that the outcome of schizophrenia is mainly characterized by unexplained heterogeneity. The fact that our research showed modest gains at the group level fits with the positive results of long-term follow-up studies (National Institute for Health and Clinical Excellence 2009). However, it
is unusual considering the recent onset of schizophrenia in the overall ABC population.

We found that the degree of severity of the impairments had a significant effect on societal participation level: patients with milder impairments seemed to profit more from the treatment. We did not find a direct effect of drug use on the development of the societal participation level. Rather, our research showed that drug use had an influence on actual impairments, and impairments are an important predictor for societal participation. We were unable to find studies documenting the consequences of drug use that make a distinction between impairments and societal participation, as identified by the World Health Organization (Minozzi et al. 2010). The distinction between impairment and societal participation is important in daily practice because of the misunderstanding that drug use causes a negative prognosis for societal participation, and is consequently often seen as a contraindicator for rehabilitation counselling. Our research shows that patients with similar levels of impairment do not show differences in their level of societal participation, regardless of drug use. Therefore, drug use as such is not a contraindication for rehabilitation counselling. However, a high impairment level often interferes with a positive societal participation outcome. Simultaneously, we conclude that the amelioration of (psychiatric) impairments may also promote increased societal participation. In agreement with other research (Lloyd et al. 2000, World Health Organization 2001, Killackey et al. 2006, Woodside et al. 2007), our results show that rehabilitation, in addition to medication and psychosocial treatment, can make a positive difference in a patient's societal participation. Treatment of impairments, including the management of drug addiction, should be closely interwoven with support for a patient's rehabilitation goals. Our evaluation also indicates that nurses and social workers can apply rehabilitation counselling in daily practice even when psychiatric impairments require acute care. Focusing on rehabilitation pays off: a person's societal participation level increases, while impairments stabilize. It does not, however, work for every patient; especially patients with deteriorating impairments demonstrate a decrease in their societal participation levels.

The limitations of our research relate to the irregular measurements that the data are based on. We do not have a control group without treatment at our disposal, nor do we have a control time period without treatment. These research requirements would negatively impact everyday treatment and practice. As a result of these deficits, both the internal and external validity of our research is limited. However, this integration of research methods as part of treatment serves several important purposes: first, using the reported results, we are able to discuss the long-term successes in a more systematic manner with the staff. Second, the group results are used in presentations to patients and their parents to illustrate the results of treatment. It is not always possible to see progress in the development of an individual patient, and the presented long-term results show that the ABC approach makes sense. Third, the internal annual reports to hospital management and external financiers help to reinforce the value of ABC as a small and highly specialized department.

Both from the point of view of treatment and research, rehabilitation outcome criteria could be more differentiated. First, goal attainment could be evaluated more directly by counting and weighing different personal goals, the extent to which these goals are achieved, and the period of time required to achieve them. Second, more factual and measurable criteria are useful, such as the increase in the number of social contacts, number of social appointments, number of appointments kept, hours spent doing (voluntary) work, or hours spent in a school setting. Third, the research could be improved by evaluating patient's impairments and their societal participation through the inclusion of their personal perspective on these topics, for instance by using the Behavior And Symptom Identification Scale (BASIS-32). In addition to the type of study we conducted, further research should include qualitative research which would focus on patients' lived experiences in order to highlight the importance of supporting their societal participation goals.

Certain improvements to the rehabilitation process would decrease the gap between theory and practice. Further investment is necessary to train and supervise staff to help patients set obtainable goals, define and evaluate critical skills and resources and achieve those goals. Our experience also shows that it is vital to regularly check the fidelity of the rehabilitation trajectory with the patient. It remains an ongoing challenge to direct the often chaotic stream of events in everyday life of these patients into a structured pattern in which important life goals can be obtained.

References


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