Bottom-up rehabilitation in schizophrenia
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6. A bottom-up rehabilitation programme.

6.1 Introduction.

In section 1.5 it is concluded that rehabilitation strategy in psychiatry changed from a 'top down' to a 'bottom up' method. The focus has shifted to training starting at the level of information processing and basic skills. Until now, research on training cognitive functions has repeatedly shown that this training is beneficial to controlled cognitive operations requiring mental effort. The pilot study (chapter 4) shows that together with improved cognitive functioning, the negative symptoms also decrease. However, generalization to general behaviour could not be determined. In order to overcome this shortcoming, it is concluded that more time should be spent on repeating exercises, rehearsing, and on remembering and recalling cognitive strategies with the purpose of enhancing executive control.

A second shortcoming of 'bottom up rehabilitation' is related to the fact that dealing with emotional processes related to accepting a label of mental illness, for instance with the help of psycho-education and counselling, may also be regarded as a basic 'ingredient' of rehabilitation. Therefore, just as in grief-therapy, besides training and activation of behavioural skills, 'acceptance of the loss' should be a central component in rehabilitation practice.

Until now, no studies are known in which cognitive skills training, psycho-education and counselling are combined to develop a stable foundation for the development of role behaviour and the achievement of a gratifying position in the community. Based upon this fact, a bottom-up clinical rehabilitation programme was designed including both basic components of rehabilitation and 'regular' rehabilitation ingredients. The effect of this programme on cognitive functioning, coping, social skills, general functioning, symptoms, accommodation and daily activities will be established.

As stated in chapter 1, in the present study a differentiation is made between 'remediation' of cognitive disturbances and 'taking into account' the presence of cognitive disturbances. It is assumed that whether cognitive functions are trained or not, a general training methodology is needed which guides the learning process and takes into account the impeding consequences of cognitive disturbances. In order to establish the surplus value of explicit cognitive training, in one condition of the programme an individual cognitive skills training will be applied, while in the other condition extra counselling will be given to patients.

The programme has been designed for patients with chronic schizophrenia who have either experienced long term institutionalization or have been referred to long stay wards. The programme aims to prevent hospitalization. To decide whether patients are 'better off' with this programme, the effects will be compared with the drop-outs of the present study and to effects of traditional long stay ward programmes. Therefore, in this chapter, after describing the rehabilitation programme, the traditional long stay ward programmes serving as control conditions are described.
6.2 Content of the rehabilitation programme.

The rehabilitation programme has a duration of eight months and is divided into two stages of four months each. The first stage is directed at learning to accept and how deal with vulnerability for psychotic decompensation, at the development of executive control and at the training of basic skills. Using the tactics as described in chapter 3, the training methodology guides the gradual transition of controlled declarative knowledge to 'production systems' with automatized procedural knowledge.

The second stage focuses on learning how to deal with external sources of stress, optimalizing self-care and social skills, seeking appropriate accommodation and developing daily activities.

The standard programme is carried out in groups of maximal eight participants. However, the various trainings will be individualized as far as possible. Consequently, in principle, the participants will follow the programme at their own levels. Programme subdivisions and training areas are shown in table 6.1 and will be described in the next subsections. Manuals including all sessions of all subdivisions are available in Dutch (Slooff et al., 1994a,b).

Table 6.1: A bottom-up rehabilitation programme.

<table>
<thead>
<tr>
<th>Stage</th>
<th>Subdivision</th>
<th>Time p. week (hours)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 &amp; 2 month:</td>
<td>Psycho-education (participants)</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Psycho-education (relatives)</td>
<td>3 (3 weekly)</td>
</tr>
<tr>
<td>1 to 8</td>
<td>Weekly-evaluation</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Planning/agenda training</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Planning/spending group activities</td>
<td>2 evenings</td>
</tr>
<tr>
<td></td>
<td>News orientation</td>
<td>every day</td>
</tr>
<tr>
<td></td>
<td>Individual counseling</td>
<td>1</td>
</tr>
<tr>
<td>1 month:</td>
<td>Cognitive skills training (condition 1)</td>
<td>3 x 20 min.</td>
</tr>
<tr>
<td></td>
<td>Extra counseling (condition 2)</td>
<td>1</td>
</tr>
<tr>
<td>1 to 4</td>
<td>Psychomotor skills training</td>
<td>3 x 20 min.</td>
</tr>
<tr>
<td></td>
<td>Basic vocational therapy</td>
<td>3 x 2.5</td>
</tr>
<tr>
<td></td>
<td>Menu planning &amp; cooking training</td>
<td>1 x 3</td>
</tr>
<tr>
<td></td>
<td>Household skills training</td>
<td>3 x 1</td>
</tr>
<tr>
<td></td>
<td>Grooming skills training</td>
<td>1 x 2</td>
</tr>
<tr>
<td></td>
<td>Sports</td>
<td>1 x 1</td>
</tr>
<tr>
<td>2 month:</td>
<td>Social skills training</td>
<td>3 x 1</td>
</tr>
<tr>
<td>5 to 8</td>
<td>Community skills training</td>
<td>1 x 2</td>
</tr>
<tr>
<td></td>
<td>Vocational therapy</td>
<td>3 x 3</td>
</tr>
<tr>
<td></td>
<td>Physical condition training</td>
<td>2 x 1</td>
</tr>
<tr>
<td></td>
<td>Housekeeping and cooking</td>
<td>every day</td>
</tr>
</tbody>
</table>

6.2.1 Subdivisions at the first and second stage.

Seven programme subdivisions are applied during both the first and second stage of the programme. Thus, during these eight months patients receive psycho-education (1 x...
1 hour/week), once a week a weekly-evaluation is held, planning/agenda training is applied (1 x 1 hour/week), group activities are planned and performed (two evenings/week), patients watch the daily news, and individual counselling sessions are held once a week (one hour). Psycho-education is also provided for relatives (1 x 3 hours / 3 weeks).

Psycho-education of participants.

The acquisition of new role behaviour cannot occur without acceptance of one's present situation and position. In this sense, psycho-education serves to 'expose' patients to 'the facts' of schizophrenia and its consequences, and is directed at removing denial of vulnerability or the risk of becoming psychotic. Having an overview of the situation and limitations of the possibilities enables a patient to accept schizophrenia, to detach from the 'patient role' and to develop other residual capabilities. Therefore, applying information about schizophrenia, including all aspects of the psychosis, is central to this sub-division.

During psycho-education, prodromal signs are discussed as well as symptoms, causes and course, chronic factors, various successful and ineffective treatments including (antipsychotic) medication, symptom management (relapse prevention) and coping styles, side effects of medication, and the social and legal consequences of a chronic psychosis. In addition an explanation is given of the various concepts of the vulnerability model. Furthermore, besides discussing former treatment experiences of participants, emotional, grief related processes such as aggression, jealousy, rebellion, despair and hope, and in a broader sense, acceptance and self-esteem, are discussed. Finally, participants may choose to discuss issues such as anxiety, sexuality, sleep disturbances, psychosomatic symptoms, personality traits, or the use of addictive substances.

In view of the emotional content of the topics, a non-directive form of discussion in order to express feelings and reduce possible aggressiveness, follows the 'lecture style' presentation of information, which lasts no longer than twenty minutes as it may cause overstimulation.

Psycho-education of relatives.

Experience shows that many family members have been struggling with the problems of their 'sick' child or partner for years and that they have never been able to talk openly with 'co-sufferers' and those in charge of treatment. In a study on grief in parents with a schizophrenic child, Atkinson (1994) found that these parents suffer from ongoing grief reactions and chronic grief. This finding illustrates the importance of psycho-education of the relatives. Therefore, in addition to information about the programme, the participants' relatives also receive information about schizophrenia. Besides topics as lectured in the psycho-education for participants, exchanging experiences is one of the main purposes of these sessions. As described in section 4.6 psycho-education of relatives also includes training of skills focusing on how to cope with and react to psychotic behaviours. After teaching basic behavioural therapeutic principles such as reinforcement and punishment, assertive communication is trained. Relatives introduce difficult social situations and assertive reactions are discussed and role played.

Weekly evaluation.

Besides general evaluation of individual participation, during the weekly evaluation current practical and interpersonal problems of participants are discussed. With
the aid of W-questions the trainer, a psychiatric-nurse, guides the group towards solutions.

Trauer (1979) described that in case of tension on the ward, the frequency of evaluations declines and important issues are avoided during these evaluations. Therefore, it is important to strive for agreement among participants over the frequency of the evaluations and topics to be discussed.

Planning/agenda training.

During the agenda training, division of household tasks and cooking duties, and organization of the ward is discussed.

The agenda training is conducted like a business meeting and a permanent agenda is used. The methodology behind activity planning involves the stepwise approach to a central plan and uses W-questions as its guideline.

With regard to weekend planning and evaluation, pre- and post-weekend sessions are included in the programme. Weekend planning is carried out in combination with the weekly evaluation. Evaluation of the weekend is conducted in two parts; a short, individual conversation on Sunday evening and an evaluation as part of the agenda training. The purpose of the individual conversation is to discover what important unpleasant and pleasant events have taken place during the weekend.

Central to the combined planning/agenda training is the evaluation of planning. If a plan has not been carried out, the reason for this will be discussed. If the problems are fundamental ones, clearly requiring more time than is available, they will be taken up during the weekly session with the personal attendant or during the weekly evaluation. When possible, promising ways for carrying out a plan that failed before are explored by the group.

Planning/spending group activities.

Apathy and loss of initiative may partially result from an inability to plan free time along with others. The planning and carrying out of group activities is a part of the training programme. A stepwise approach to making a plan together and the use of W-questions to identify and divide tasks are essential for this.

News orientation.

Watching the news on television is a permanent part of the programme. The purpose of this is to encourage ‘community’ orientation. Moreover, talking about world events is a part of ‘community orientation’ during the second stage.

Individual counselling.

To guarantee continuity of care, during the programme each participant is guided by a psychiatric nurse serving as a personal attendant and counsellor (PA). Every week the participant and the PA investigate whether there remain any practical problems that have not been discussed during the weekly evaluation. If so, with the aid of W-questions the PA guides the participant towards a solution. Besides practical problems, the emotional process the participant is going through, is a central topic in these weekly sessions. Supervised by a psychologist the PA guides the process of acceptance and reintegration. Therefore, the PA is also responsible for the coordination of (after-) care and serves as an agent between the participant and other disciplines, trainers and family.
6.2.2 Subdivisions at the first stage.

During the first stage of the programme, besides the seven subdivisions described above, the programme includes seven other subdivision. Consequently, during the first four months of the programme, patients participate in thirteen subdivisions, while relatives engage in psycho-education.

Besides learning to accept and deal with vulnerability for psychotic decompensation, and the step-by-step acquisition of basic skills, the establishment of executive control is also essential at the first stage. The training methodology aims to compensate for deficient cognitive functioning. Production systems are programmed with care, using manuals and tactics to organize step-by-step plans hierarchically which establish the conditions under which a skill can be applied successfully, and according to which successive steps it can be carried out.

In one condition of the programme it will be tried to remediate cognitive disturbances. The cognitive skills training (CST; van der Gaag, 1992) as described in section 4.3 and table 4.1, and extended as described in section 4.6, will be included in this condition of the programme (condition 1).

Since the CST will be applied in three weekly sessions of 20 minutes each, in the standard condition (condition 2), participants will receive a placebo training instead of the cognitive skills training. For this purpose an extra hour individual counselling will be given to subjects not receiving CST. The individual counselling is given by the CST-trainer who will discuss topics introduced by the participants. Regarding the content these topics may vary from evaluating weekends to general discussions about problem solving. In all cases the trainer does not teach new skills.

Besides cognitive skills training (condition 1) or extra counselling (condition 2), during the first stage all participants engage in six subdivisions: psychomotor skills training (3 x 20 minutes/week), vocational therapy (3 x 2.5 hours/week), menu planning and cooking (1 x 3 hours/week), household skills training (3 x 1 hour/week), grooming skills training (1 x 2 hours/week), and sports (1 x 1 hour/week).

Psychomotor skills training.

Body language, or nonverbal communication is important for competent social interaction. However, disturbances in psychomotor coordination and planning of psychomotor behaviour are typical in schizophrenic patients (Fellinger, 1992). Besides obstructing social interaction, these disturbances may also impede the learning of basic skills. Therefore, individual psychomotor skills training focuses on physical and spatial orientation and coordination and planning of psychomotor behaviours.

Basic vocational therapy.

Acquiring meaningful daily activities is a central aim of the rehabilitation programme. Basic working skills, central to the first stage of vocational training are identified as: attendance, working with others, independence, perseverance, tempo, distractibility and concentration.

Together these functions form a combination of cognitive functions related to work skills and capabilities such as those often listed by employers in job advertisements.

In order to set individual goals for training, participants rate their own level of
functioning on a 10-point Likert-type scale. The score on each of the seven skills is compared to the score assessed by the trainer. If the participant and/or the trainer agree that a particular skill can be improved, a step by step plan is devised to train this particular skill. In doing so, assignments or projects are not the goal of training, but rather a means of developing basic working skills.

In addition to optimizing skills, learning to accept the limits and finding ways to make good use of time in spite of handicaps is essential in the vocational therapy.

Also during the first stage, the participants take an extensive career choice test. The results of this test determine the starting point for the second stage which works towards acquiring a job or education.

Menu planning and cooking.

Putting together a menu, planning and doing the shopping, handling money, and learning to cook various menus, are the main aspects of this training. A special cookery-book has been assembled containing a number of dishes that are described and illustrated according to the step by step method.

Household skills training.

Planning household activities, knowledge of cleaning utensils and methods, all household skills and laundering, are taught in this training. Also a special textbook describing all necessary information and household tasks is used for this training.

Grooming skills training.

Awareness of one's appearance and its effect on social interaction are important objectives of body and clothing care that form the main aspects of the grooming skills training. An awareness of personal care and hygiene and healthy eating habits are developed with the help of a dietician and a beauty specialist. This training also includes learning to make small clothing repairs, again according to a step by step plan.

Sports.

Sport is recreational during the first stage and participants are free to choose a sport they wish to do together.

6.2.3 Subdivisions at the second stage.

The second stage focuses on learning to deal with external sources of stress, optimalizing self-care and social skills, seeking appropriate accommodation, and developing the necessary skills to live as independently as possible.

During the second stage of the programme, besides the seven subdivisions described in section 6.2.1, five other subdivisions have been included in the programme: social skills training (3 x 1 hour/week), community skills training (1 x 2 hours/week), daily activity training (3 x 3 hours/week), physical condition training (2 x 1 hour/week) and housekeeping and cooking (every day). So, during the second four months of the programme, patients participate in eleven subdivisions (and relatives participate the psycho-education).
Social skills training.

The social skills training (SST) as described in section 4.3 and table 6, and extended as described in section 4.6 is central to the programme at the second stage.

Community skills training.

This training is primarily concerned with 'living'. Various living situations are investigated and visited. Levels of functioning with regard to: getting up, tidying the room, preparing a meal, daily activities, taking drugs, social skills and finances are a basic consideration. Participants rate their own levels of independence in these functions and compare the scores with the demands of a particular living situation. The score differences determine the starting point for training, with the help from personal attendants or other trainers.

During this course specific attention is given to evaluation of the daily news, budgeting and learning rules pertaining to various systems, such as insurances, taxes, grants and social benefits.

Vocational training.

In addition to creating leisure activities, the seven central functions of vocational training are again addressed during the second stage of training. The scores are compared with the demands made by the firms that have been visited, and with demands associated with the various educational systems. Companies that work with the programme comprise a number of levels from institutional work projects to independent firms. Learning how to apply for a vacancy is also an important aspect of this course.

Physical condition training.

Phased fitness training such as that offered in every sports centre is given.

Housekeeping and cooking.

The participants do their own housekeeping on the ward and cook their own meals five times a week. This requires planning meals, shopping and budgeting. Assistance is given by psychiatric nurses, only when indicated.

6.2.4 The meaning of the programme.

The programme as it is presented here appears to be particularly intensive. On the one hand this is only an impression because training is limited to four or five hours per day. On the other hand, for most participants the programme will lead to a significant extension of activities. Although in section 3.2.4 shaping was identified as the central tactic to prevent improper enthusiasm on the side of the trainers, it should be stressed here that the programme is not the target, but the means for rehabilitation. In other words; the programme should not be used as an external structure to be imposed upon patients, but as a possible means to develop internal structure.

Participants take part voluntarily and act by their own motivation and may use the programme to work towards the goals of their choice. Including psycho-education and
working towards 'grief-resolution' implies that acceptation and activation are equally important in the process of rehabilitation. Therefore, close attention is required to the possible self protective function of avoiding participation. Depressed, restless or easily overstimulated participants may consciously avoid trainings in order to prevent increased restlessness or decompensation. In case of avoidance as self protective behaviour, patients are reinforced for doing so and if necessary, skills are trained afterwards.

6.3 Content of the control conditions.

Patients participating in the rehabilitation programme have been indicated for long stay wards. Instead of being referred to those wards they have been given the opportunity to participate in the programme aiming at resettlement in the community. To determine whether patients are 'better off' with the rehabilitation programme, the results of the present study will be compared to the effects of traditional long stay ward programmes.

Once the rehabilitation programme started, other hospitals showed interest to do the same. Because we wanted to have the (preliminary) results of the present study before introducing the programme in other institutions, this interest led in two cases to participation as control condition (Delta Ziekenhuis, Poortugaal and I.P.Z. Noord-Oost Brabant, Huize Padua). In both hospitals it was planned to reorganize the 'chronic wards'.

Before implementing the reorganizations, some patients, participating in long stay ward programmes, voluntarily participated in two assessments (interval 8 months).

In addition to treatment with antipsychotic medication, the long stay ward programmes included the well known daily routine of clinical long stay wards:

7.30 getting up
8.00 breakfast
9.00 vocational therapy
12.00 dinner
14.00 vocational therapy
17.00 coffee
18.00 supper
19.00 evening programme

Vocational therapy in most cases, included traditional work therapy such as simple manual labour, painting, doing needlework and working in the gardens. In none of the cases the therapy was focused on training basic functions or working towards a post-treatment goal. In addition, in none of the cases the evening programme included any training similar to any of the rehabilitation programme subdivisions.