

# The Come Back Programme: a rehabilitation programme for patients with brain injury with psychosocial problems despite previous rehabilitation

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In 1994 the Come Back Programme (CBP) started in the rehabilitation centre, Groot Klimmendaal, in Arnhem, The Netherlands. The CBP is a rehabilitation programme for (young) adults with brain injury (BI) having problems with their psychosocial functioning despite having undergone a rehabilitation programme previously. The main goal of the CBP is to regain maximal independence in psychosocial functioning. The objectives of the study were to assess problems experienced after BI, despite having undergone a rehabilitation programme previously, and whether the CBP can improve psychosocial functioning. The study was retrospective, through investigating medical records and via a structured questionnaire sent to patients who participated in the CBP between 1994 and 1998 (n=25). Follow-up was at least 1 year after the CBP. There was an 80% response (n=20). The mean age at BI was 22 years. The patients had severe BI (mean duration of coma 4.7 weeks) and 17 had traumatic BI. Prior to the CBP negative consequences were seen on independence of living, employability, relationships and contact with friends. No or little effect was seen on contact with family and leisure activities. After the CBP, positive effects were found on employability and independence of living but not on premorbid levels. The effect on the other aspects were absent or not clear. Most patients wanted support at follow-up. The authors concluded that the CBP had a positive effect on independence of living and employability. A 'second' rehabilitation programme can be useful if psychosocial problems are present. Long-lasting support and structural control seem necessary and are recommended.

Le Programme Come Back (CBP) a débuté en 1994 au centre de réadaptation Groot Klimmendaal d'Arnhem (Pays-Bas). Le CBP est un programme de réadaptation destiné à de jeunes adultes atteints de lésions cérébrales (LC) et présentant des troubles psychosociaux en dépit de précédentes mesures de réadaptation. Le but principal du CBP est de récupérer le maximum d'indépendance sur le plan psychosocial. Les objectifs de l'étude étaient d'évaluer les problèmes rencontrés après la LC malgré le programme de réadaptation précédent, et dans quelle mesure le CBP peut améliorer les fonctions psychosociales. Cette étude a été menée de façon rétrospective, au moyen d'un examen des dossiers médicaux et de réponses à un questionnaire structuré envoyé à des patients ayant participé au CBP de 1994 à 1998 (n=25). La période de suivi a été d'au moins 1 an après le CBP. 20 des 25 patients ont répondu au questionnaire (80%). L'âge moyen lors de l'atteinte cérébrale était de 22 ans. Les lésions ont été sévères (durée moyenne du coma : 4,7 semaines), et traumatiques dans 17 cas. Avant le CBP, les LC ont eu des conséquences néfastes sur l'indépendance de vie, l'aptitude à travailler, les contacts et les rapports avec les amis. Les contacts familiaux et les activités de loisirs n'ont pas ou peu été affectés. Le CBP a eu des effets positifs sur l'aptitude à travailler et l'indépendance de vie, mais non sur les degrés pré-morbides. Les effets sur les autres aspects ont été nuls ou peu évidents. La plupart des patients a réclamé une aide lors du suivi. Un "deuxième" programme de réadaptation peut s'avérer utile en présence de problèmes psychosociaux. Un accompagnement à long terme et un contrôle structurel semblent nécessaires et sont recommandés.

Das Come-Back-Programm (CBP) wurde 1994 im Rehabilitationszentrum Groot Klimmendaal in Arnhem, Niederlande, begonnen. Das CBP ist ein Rehabilitationsprogramm für (junge) Erwachsene mit Hirnverletzungen (BI), die trotz eines früheren Rehabilitationsprogramms psychosoziale Probleme haben. Das Hauptziel des CBP ist das Wiedererlangen einer maximalen Unabhängigkeit in psychosozialen Funktionen. Die Ziele der Studie waren die Beurteilung von Problemen nach Hirnverletzungen, die trotz früherer Teilnahme an einem Rehabilitationsprogramm aufgetreten waren, und die Klärung der Frage, ob das CBP psychosoziale Funktionen verbessern kann. Die Studie

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erfolgte retrospektiv über die Auswertung von Krankenakten und über einen strukturierten Fragebogen, der an die Patienten geschickt wurde, die zwischen 1994 und 1998 (n=25) an dem CBP teilgenommen hatten. Die Nachbeobachtung erfolgte frühestens 1 Jahr nach dem CBP. Der Rücklauf betrug 80% (n=20). Das mittlere Alter bei der Hirnverletzung betrug 22 Jahre. Die Patienten hatten schwere Hirnverletzungen (mittlere Dauer des Komas 4,7 Wochen) und 17 hatten eine traumatische Hirnverletzung. Vor dem CBP zeigten sich negative Folgen auf das unabhängige Leben, Vermittlungsfähigkeit auf dem Arbeitsmarkt, Beziehungen und Kontakt mit Freunden. Auf den Kontakt mit der Familie und Freizeitaktivitäten wurde kein oder ein geringer Effekt festgestellt. Nach dem CBP zeigten sich positive Wirkungen auf die Arbeitsvermittlungsfähigkeit und das unabhängige Leben, aber keine Rückkehr auf das Niveau vor der Erkrankung. Die Auswirkung auf die anderen Aspekte war nicht vorhanden oder unklar. Bei der Nachbeobachtung äußerten die meisten Patienten den Wunsch nach Unterstützung. Das CBP hatte eine positive Wirkung auf das unabhängige Leben und die Arbeitsvermittlungsfähigkeit. Ein 'zweites' Rehabilitationsprogramm kann nützlich sein, wenn psychosoziale Probleme vorliegen. Eine langfristige Unterstützung und eine strukturelle Kontrolle scheinen notwendig und werden empfohlen.

En 1994 se inició el Programa "Regresa" (*Come Back Programme*, CBP) en el centro de rehabilitación de Groot Klimmendaal, en Arnhem, Países Bajos. Se trata de un programa de rehabilitación para adultos (jóvenes) que han sufrido una lesión cerebral y que siguen teniendo problemas con sus funciones psicosociales pese a haber participado anteriormente en otro programa de rehabilitación. Su finalidad principal es conseguir que los participantes recuperen la máxima independencia en las funciones psicosociales. Se fijaron como objetivos evaluar los problemas experimentados tras una lesión cerebral pese a haber participado anteriormente en un programa de rehabilitación y determinar si el CBP puede mejorar las funciones psicosociales. El estudio fue retrospectivo, ya que se basó en la investigación de historias clínicas y en el envío de un cuestionario estructurado a los pacientes que habían participado en el programa entre 1994 y 1998 (n=25). Se hizo un seguimiento hasta por lo menos 1 año después de la asistencia al CBP. Respondieron el 80% (n=20) de los encuestados. La edad media en el momento de sufrir la lesión cerebral había sido de 22 años. Las lesiones sufridas habían sido en todos los casos graves (duración media del coma: 4,7 semanas) y 17 de ellas habían tenido un origen traumático. Antes del CBP, se habían observado consecuencias negativas en la capacidad de vida independiente, las posibilidades de encontrar trabajo, las relaciones y el contacto con los amigos. El efecto sobre el contacto con la familia y las actividades de tiempo libre había sido escaso o nulo. Después del CBP, se observaron efectos positivos sobre las posibilidades de encontrar trabajo y sobre la capacidad de vida independiente, pero no en los niveles premórbidos. No se apreció o no estuvo claro el efecto sobre los demás aspectos. La mayoría de los pacientes manifestaron su deseo de recibir apoyo durante el seguimiento. El CBP tuvo un efecto positivo sobre la capacidad de vida independiente y las posibilidades de encontrar trabajo. En presencia de problemas psicosociales puede que sea conveniente un 'segundo' programa de rehabilitación. En estos casos parece necesario y recomendable prestar al paciente apoyo y control estructural durante un largo período de tiempo.

**Keywords:** brain injury; employment; independent living; psychosocial functioning; rehabilitation programme

## Introduction

Besides somatic problems, acquired brain injury (BI) can lead to psychosocial problems, influencing functioning in daily life (ADL). These problems may become apparent for the first time after discharge from hospital or a rehabilitation centre as patients with BI return to society. For these patients the Come Back Programme (CBP) was developed in 1994, at the rehabilitation centre, Groot Klimmendaal, in Arnhem, The Netherlands.

With the present study we wanted to evaluate what problems patients experienced prior to the CBP in their psychosocial functioning having undergone rehabilitation previously, whether they experienced a positive effect of the CBP and whether programmes like the CBP are of additional value after earlier rehabilitation.

The incidence rate and prevalence of BI show different values depending on several factors, such as

the method of registration, the definition of BI and geographical differences. In the USA, every year 422000 patients with closed head injury are admitted to a hospital (Klonoff *et al.*, 1986; Jennet, 1996). In The Netherlands, 85000 patients are admitted to a hospital every year with the diagnosis of BI, of which 13000 patients have traumatic BI. The number of patients with traumatic BI is probably underestimated because of associated diagnoses being more prominent at the time of admission (Groet *et al.*, 1997). Eighty-nine per cent of the patients with so-called 'minor' BI and 91% of the patients with 'major' BI are discharged home directly after hospital admission. Only 1–2% are transferred to a rehabilitation clinic and the same number to a nursing home. Ten per cent still go to a rehabilitation centre later on (Balen and Knoop, 1993; Balen *et al.*, 1996; Groet *et al.*, 1997).

The commonly perceived problems concern independence of living, employment and social contacts.

The number of patients with BI living (totally) independently ranges from 24% to 94%. This wide range is due to several factors such as severity of BI, being treated in a rehabilitation centre and time since BI. Long-term results are better after a multidisciplinary rehabilitation programme compared to a monodisciplinary approach. Stress for patients' families is also shown to be diminished after multidisciplinary treatment. Most studies showed a (slow) decline in the patients' functioning after discharge from rehabilitation treatment (Rappaport *et al.*, 1989; Dikmen *et al.*, 1993; Malec *et al.*, 1993; Balen *et al.*, 1996; Mazaux and Richer, 1998; Semlyen *et al.*, 1998).

Without rehabilitation, the number of patients returning to work varies from 75% to 100% after mild BI, from 60% to 70% after moderate BI and from 10% to 92% after severe BI (Klonoff *et al.*, 1986; Nyström *et al.*, 1992; Dikmen *et al.*, 1993; Balen and Mulder, 1996; Balen *et al.*, 1996; Mazaux and Richer, 1998; Naalt *et al.*, 1999). These figures do not give a complete view of the problems concerning employability. There appears to be a direct relationship between the severity of BI and return to previous jobs and to the level of work. If patients return to their previous job, they often have to put in more effort to fulfil the requirements. Several factors influence the chance of returning to work. Negative factors are older age, severe BI, long post-traumatic amnesia, cognitive and emotional problems, problems in ADL activities, absence of vocational services and start of primary rehabilitation 1 year after BI. No significant relationship is found with sex, Glasgow Coma score and previous level of education. Rehabilitation programmes have a positive influence but the success rate diminishes after some time (Sahgal and Heine-mann, 1989; Malec and Basford, 1996; Mazaux and Richer, 1998; Naalt *et al.*, 1999). The literature is not conclusive about the influence of BI on relationships or on contact with family and friends. This may be caused by factors such as 'spontaneous' changes in contact and relationships occurring at the age of most patients with acquired BI (adolescents and young adults), differences in severity of BI and time since BI. Some authors find no clear difference in the number of patients having a relationship, others conclude that there is evidently a negative relationship with severe BI. This negative correlation is also found with regard to contact with friends. Cognitive problems are found to be an important factor, neither physical problems nor changes in personality were important. The family relationships were not worsened. Positive effects were found if patients followed a rehabilitation programme and if extensive information was given to patients and relatives (Oddy and Humphrey, 1980; Klonoff *et al.*,

1986; Aronow, 1987; Dikmen *et al.*, 1993; Balen and Mulder, 1996; Wade *et al.*, 1998; Willer *et al.*, 1999).

After BI up to 50% of patients spend less time on leisure activities and do not enjoy them as much as before. Many patients pursue passive activities such as reading and watching television. Positive effects were seen after the extensive supply of information and support by a rehabilitation programme (Oddy and Humphrey, 1980; Klonoff *et al.*, 1986; Balen and Knoop, 1993; Mazaux and Richer, 1998; Wade *et al.*, 1998).

### *The Come Back Programme*

The main goal of the CBP is to regain maximal independence and functioning in the social and domestic situation, in work and in leisure activities. Patients could be referred to the CBP by anyone (including doctors, relatives, employers or themselves). Inclusion criteria for participating in the CBP were acquired BI, an age between 18 and 35 years, perceived psychosocial problems after a previous rehabilitation programme and being able to function in a group. The patients were not included if somatic problems were the main goal of treatment.

The CBP was offered on both an in- and out-patient basis, depending on the goals (for example, domestic training) or if travel to the rehabilitation centre every day was not possible. Patients were supervised by Come Back trainers (individual trainers), social workers, a (neuro)psychologist and a Physical Medicine and Rehabilitation (PMR) physician.

The CBP had the following phases, which together lasted 1 year (in principle).

1. During the observational phase (about 3 months) individual problems and goals were investigated.
2. The second phase (practice) lasted about 6 months. Patients had an individual programme for 4 days a week (guided by the Come Back trainer) and a group programme for 1 day per week. Some objectives of this period were to make the patients more aware of how they reacted to other people, to learn compensation strategies to cope with their problems, and to receive household, leisure-activity and job training.
3. The individual training took place at the rehabilitation centre (for example, household training) as well as outside (for example, job training). When job training took place, patients were guided by the employer or a job coach and every week they consulted with the Come Back trainers about the steps to follow.
4. During the group programme patients had the opportunity to exchange what they had experienced from the previous week. Also,

several themes were discussed, for example, how to apply for a job, how to present yourself in a group and orientation on what is going on in the world by discussing newspapers and so on.

- In the last period (about 3 months) the CBP was evaluated and steps were made towards social reintegration. If necessary, part of the programme could be continued or transferred to other professionals (for example, social workers).

Parallel to the CBP, the patients' family members (and, if needed, also friends) received information about BI and how to cope and react to the new situation. Information was given by a neuropsychologist and a social worker.

## Methods

A retrospective study was carried out over the period from 1994 to 1998 (incorporating the first three groups who participated in the CBP since it started in 1994), with a follow-up at least 1 year after the CBP. All 25 patients who participated in the CBP during this timeframe were included. Information was obtained by investigating medical records and the

patients were asked to fill in a standard questionnaire. This questionnaire was made up of 'open questions' and multiple-choice questions on a five-point scale (for example, ranging from very satisfied to very unsatisfied). Because the number of patients was small, the percentages shown in the 'Results' section are clustered in three groups. For example, the top two were grouped as (very) satisfied, the middle as 'neutral' and the lower two as (very) unsatisfied.

Questions were asked about the patients' medical and social situation (also about items that were not necessarily the reason for the patients participating in the CBP) for three different periods, namely the last 3 months before BI, the last 3 months before CBP and the last 3 months before follow-up. They were also asked what objectives they had to participate in the CBP, whether they were satisfied about the results and whether they had any kind of (professional) support at the time of follow-up.

## Results

Twenty patients (Table 1) sent replies to the questionnaire (an 80% response). Four patients did not

**Table 1.** Patient characteristics

<i>Diagnosis</i>	
Cerebral concussion	16
Cerebral concussion + mesencephalic haemorrhage	1
Cerebral infarction	1
Postanoxic encephalopathy following cardiac arrest	1
Cerebral haemorrhage as a complication after resection colloid cyst	1
	} Number of patients
<i>Length of coma</i>	
Mean length of coma (n=18)	4.7 weeks (6 days–22 weeks)
No coma (patient with cerebral infarction)	1 patient
Unknown	1 patient
<i>Rehabilitation period</i>	
Mean age at time of brain injury	22 years (17–33 years)
Mean length of first rehabilitation period	12 months (1–20 months)
Mean time between first rehabilitation period and the CBP	23 months (0–92 months)
Total length of participation in the CBP	16 months (3–24 months)
Age at follow-up	29 years (24–39 years)
Follow-up after the CBP	36 months (16–52 months)
<i>Medical problems experienced at follow-up</i>	
Concentration	17
Memory	16
Motor problems upper extremities (pareses, disturbed co-ordination)	13
Motor problems lower extremities (pareses, disturbed co-ordination)	11
Vision	8
Hearing	5
Epilepsy	1
Headache	1
Fatigue	1
Smell	1
	} Number of patients

**Table 2.** Problems and help experienced in living

	<i>Before brain injury</i>	<i>Before the CBP</i>	<i>At follow-up</i>
<i>Independence in living</i>			
Dependent	1	11	7*
Lived in sheltered accommodation, 'no help'	0	0	2*
Lived in sheltered accommodation, with help	0	1	5*
In-patient rehabilitation (other than the CBP)	0	3	0
<i>Help needed because of ... (cumulative)</i>			
Smaller household activities (e.g. washing dishes)	0	8	2
Complex household activities	0	9	5
Structuring daily activities	0	4	2
Other	2	2	2
<i>Help given by</i>			
Partner	0	1	0
Family/friends	1	10	1
Professionals	0	6	7
<i>Was the amount of help sufficient?</i>			
Yes	0	11	5
No	1	2	2
Unknown	0	1	0

\*See text. CBP, Come Back Programme, values represent number of patients.

respond or refused to participate, one patient could not be traced. In the period before the CBP, three patients had followed a rehabilitation programme in the rehabilitation centre at Groot Klimmendaal, 16 patients had followed a programme elsewhere in The Netherlands and one in Belgium. Sixteen patients started the CBP on an in-patient basis, four patients started on an out-patient basis. Nine patients were treated for more than 1 year. In this period, most of them did not participate in the whole programme but had job training or were guided to find (sheltered) accommodation.

Almost everyone was able to live independently before BI (Table 2). Before starting the CBP 14 patients did not live independently. Relatives rather than professionals gave most help. At follow-up more patients (13) were able to live independently. Seven patients lived in a 'sheltered accommodation' situation. The need for help was diminished and professionals instead of relatives gave most of the help.

BI had a clear negative influence on employability (Table 3). Before BI 14 patients had a job, three of them were following education alongside their job. In the 3 months before the CBP, only four out of these 14 patients still worked but they had more problems with

**Table 3.** The situation regarding work and school

	<i>Before brain injury</i>	<i>Before the CBP</i>	<i>At follow-up</i>
Full-time job	8	1	3
Part-time job	3	3	8
Part-time job + school	3	0	3
At school, no job	4	2	0
Unemployed	2	11	6
In-patient rehabilitation	0	3	0

CBP, Come Back Programme, values represent number of patients.

fulfilling the jobs; only one of them had found another job since BI. At follow-up, 10 patients who were employed before BI had a job, seven of these were paid. Only three patients did the same kind of work as before BI, although with more effort and for fewer hours per week. One of the two patients who were unemployed before BI worked at the time of follow-up but was not paid for it. The other still does not work. The CBP seems to have a positive effect on employability (but not to the premorbid level). No conclusions can be drawn regarding education.

Before BI, 10 patients (50%) had a relationship. Eight of them had a solid, long-lasting relationship. None of them was married. Forty per cent were (very) satisfied with their relationship, 20% were (very) unsatisfied. All relationships terminated after BI. In the period before the CBP, five patients had a relationship; 60% were (very) satisfied with their relationships. At follow-up, 10 patients had a partner. These relationships were started after BI. Eighty per cent were (very) satisfied with their relationship. Although these figures seem positive, it is hard to tell whether the CBP was responsible for these changes.

In all three periods the patients had contact with their family. Two patients did not give information about this item, one of them because of amnesia. The frequency of contact showed little change. During the three periods, 12, 14 and 10 patients respectively had contact with their family (very) often. Although the frequency of contact slightly diminished, the number of patients being (very) satisfied about this contact was increased (12, 10 and 17 patients for the three different periods respectively). A better understanding of each other or better coping with the situation may have played a role.

The number of patients having friends showed little change during the three different periods (19, 17 and 19 respectively). After BI the number of patients who met their friends (very) often decreased from 10 to three. Also satisfaction diminished; before BI 55% were (very) satisfied about the contact with their friends, after BI only 25% were (very) satisfied. At follow-up 40% had contact (very) often with friends

**Table 4.** Patients' objectives for participating in the Come Back Programme and perceived success

<i>Patients' objectives</i>	<i>Total</i>	<i>Not successful</i>	<i>Successful</i>	<i>Very successful</i>
Work	15	3	9	3
Social contacts (family/friends)	3	0	1	2
Leisure activities	3	0	2	1
School	1	0	1	0
Memory problems	3	1	1	1
Coping with sequelae of brain injury	3	0	2	1
Self-awareness of functioning	6	0	3	3
Coping with different moods	1	0	1	0

Values represent number of patients.

and 45% were (very) satisfied about it. In contrast to this apparently positive result, there were also more patients who were (very) unsatisfied about the quality of this contact. During the three periods this number changed from 2 to 5 to 6 patients at follow-up (10% to 29% to 32%). It should be mentioned that most patients had different friends to those they had before BI and CBP. It can be concluded that more patients were unhappy about their contact with friends after BI. There is a partial improvement after the CBP.

During the three periods the number of patients having a hobby did not really change but the amount of time spent on it and the satisfaction decreased. The total number of patients who participated in sport showed little change after BI; seven patients stopped and six patients started participating in sport. The time spent on sport was unchanged and satisfaction was decreased. There was no clear effect of the CBP on leisure activities.

In the period after the CBP most patients were getting some kind of support (temporarily or continuously), usually from professionals. The main reasons for help were problems in the fields of living, work and social situations (12, 11 and eight patients respectively). Regarding problems in the living situation, it should be noticed that seven patients lived in 'sheltered accommodation' (see also Table 2). Although two of them said they could live independently, they were considered to need some kind of help (otherwise there would be no reason to live in a sheltered accommodation situation). Six patients were helped in finding or participating in leisure activities. Three patients were guided in their training for a job. There were a few patients who did not have support after the CBP, although they said that they had wanted it. Two patients wanted help to find a job, one patient wanted education or training to get a job and two patients wanted support for dealing with social situations. Unfortunately, it was not quite clear why these patients did not get the support they wanted. It can be concluded that after the CBP most patients had

some kind of support (or wanted it), especially with regard to living, work and social situations.

Participants of the CBP were asked what their main reasons for participating in the CBP were (Table 4). They were also asked to score (on a three-point scale) whether they found that they had reached their goals. The most important reasons for participating in the CBP were problems in living (11 patients) and work-related problems (15 patients). Regarding the first goal, 9 out of 11 patients were satisfied with the outcome after the CBP and regarding the second goal, 12 out of 15 patients were satisfied. These results resemble those of the more extensive questionnaire, where patients were asked about several items, even if these items were not their (main) reason to participate in the CBP.

## Discussion

According to the literature, acquired BI can lead to negative effects on several aspects of psychosocial functioning. The extent of this influence depends on several factors, especially severity of BI, period since BI and having followed a rehabilitation programme. Although a rehabilitation programme might have a positive influence on psychosocial functioning, the results might decline slowly in the years afterwards (Rappaport *et al.*, 1989; Dikmen *et al.*, 1993; Malec *et al.*, 1993; Balen *et al.*, 1996; Mazaux and Richer, 1998; Semlyen *et al.*, 1998).

The population in this study had severe BI (duration of altered consciousness of more than 24h (Jennet, 1996)) and had problems in one or more aspects of their psychosocial functioning, despite the fact that they had followed a rehabilitation programme before starting the CBP. In the period prior to the CBP, patients were experiencing problems especially concerning relationships, contact with friends, independence of living and employability.

At follow-up a positive effect was seen on employability and independence of living. The number of

patients able to live independently was doubled (from six to 13). The others were living in a supported living situation. The need for help was diminished for most of the patients. Before the CBP most of the help was given by relatives and at follow-up it was mainly given by professionals. This help was sufficient for most of them. Employability improved after the CBP. More patients were working but, compared to the situation before BI, mostly at a lower level and for fewer hours. Those working at the same level as before BI were required to put in more effort. It should be noted that the number of patients who had work was increased but many of them were not being paid for it. Contact with family remained good after BI. Similar effects were found in the literature. We found negative effects on leisure activities to a lesser extent than those reported in the literature. More patients had a relationship and most of them were satisfied with their relationship. It is not clear whether this was caused by the CBP or due to a 'spontaneous course'. Although the frequency of contact with family slightly diminished, more patients were satisfied with their contact. No positive effect was seen on leisure activities.

Most patients participated in the CBP because they had problems concerning independence of living and employability. The majority experienced the programme as successful. Nevertheless, many patients needed or wanted support in the period after the CBP, especially for independence of living, work and social situations. Most of the support was given by professionals and most patients found this help adequate.

One explanation for the positive effects of the CBP is that the patients who may experience problems in their social functioning were more aware of what this meant to them. Due to this raised awareness they could work in a more directed and motivated way on their problems. Leading the patients in the 'right direction' and taking care of adequate support afterwards may also have been a part of the positive results of the CBP.

Because changes in employability and independence of living were most prominent, it is relevant to discuss whether patients should always follow the complete CBP or only some parts of it (for example, job training). One argument for entering the whole programme is that there are often more reasons for problems in social functioning than one isolated problem experienced by the patient. If the programme is only focused on this 'single problem' other less prominent problems might be overlooked and become a problem later on.

It is not clear how many patients could benefit from a programme like the CBP because the precise number

of patients who experience psychosocial problems despite having undergone rehabilitation previously is also unclear. However, because routine follow-up is recommended for patients with moderate to severe BI (Wade *et al.*, 1997) and is based on clinical impressions, it might be expected that there are many potential patients.

The conclusions drawn from this study should not be taken as absolute, because this study had a retrospective design, the number of patients was small and there was a possibility of recall bias. On the other hand, there was a consistency in the answers on the standard questionnaire compared to the questions about the objectives of individual patients. In our opinion, the conclusions of this study can be seen as an indication of the problems that patients with BI can experience despite having undergone an initial rehabilitation programme. The study also indicates the need for and the possibilities of a rehabilitation programme in a later stadium.

### Conclusions and recommendations

The population investigated comprised patients with BI who experienced problems in their social functioning despite the fact that they had followed a rehabilitation programme before the CBP. The CBP started in 1994, with the intention of giving these patients a 'second chance' for trying to cope with these problems. At follow-up, at least 1 year after the CBP, a beneficial effect was seen on employability and independence of living. There was no clear effect on social contacts and leisure activities. The majority experienced the programme as successful. Nevertheless, many patients needed or wanted support in the period after the CBP, especially for independence of living, work and social situations. Most of this support is given by professionals and most patients find this help adequate.

Based on these findings we recommend regular controls in the years after BI, because problems in social functioning often become apparent when patients re-enter society and not in the first months after BI. Particularly in the first period after BI, a PMR doctor can fulfil an important role. In the 'chronic' period regular controls can be accomplished by others, such as nurse practitioners or social workers who are trained in the problems concerning BI. They can be intermediary between patients, their family and, for example, doctors, employers and schools. In case the social problems are disabling (especially concerning work and independence of living), a programme such as the CBP can be useful,

even if patients have followed a rehabilitation programme before.

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