

Environmentally Valid Rehabilitation at the Centre for Neuro Skills; Report of a Working Visit

Currently, the effectiveness of a strategy training for stroke patients with apraxia is being evaluated in a large Dutch, multi-centre research project. The Institute for Rehabilitation Research in Hoensbroek and the Brain and Behaviour Institute of the University of Maastricht are conducting this research project that is financed by the Rehabilitation Research Programme of The Netherlands Organisation of Health Research and Development. The main theme of the apraxia research project is the occurrence of transfer of treatment effects. Therefore, the goal of the study is to evaluate the occurrence of both transfer from the rehabilitation setting to the patients' home and transfer from trained to non-trained tasks.

Last September, the researcher of the apraxia study – also the writer of this report – visited the Centre for Neuro Skills (CNS) in Bakersfield, California. This rehabilitation centre is specialised in so called “environmentally valid rehabilitation”. The transfer of skills to daily life situations is the central theme of this rehabilitation treatment, and a lot of attention is being paid to the tasks that the patients are expected to be performing after discharge from the centre. During my visit, I got the opportunity to observe all therapies that are offered at the centre, to attend a large number of conferences and to meet with the staff of the centre.

Client population

The client population of CNS consists of adults with traumatic brain injury (TBI). Both subacute as well as chronic clients can be admitted to the centre. Therefore, the time post onset widely differs at admission. Most of CNSs' clients have acquired brain injury due to work related or traffic related accidents. A striking difference with the Dutch rehabilitation population is the fact that clients that abuse alcohol or drugs or clients who have serious behavioural problems are not excluded from admission. Handling these problems is integrated in the rehabilitation programme. This admission policy is not only different from the situation in the Netherlands, it is also one of the major topics that sets the centre apart from other rehabilitation centres in the U.S. Other things that stood out for me compared to the situation in the Netherlands, were that the clients at CNS often were quite young and that the number of stroke patients was relatively low. Possibly, these last two differences could be

explained by differences in health insurance systems. The rehabilitation care that CNS offers is expensive. Therefore, uninsured people generally will not be admitted to the centre. Yet, people who do have a health care insurance often turn out to be entitled to a very limited period of rehabilitation care. However, if the brain injury is acquired during work, the insurance company of the employer is obliged to pay for all health care costs that result from the accident, up to the point that the employee has regained his former level of functioning; that is, the level of functioning that the employee had at the time of the accident. It follows that costs due to chronic health care will be paid as well. A traffic accident usually results in a lawsuit, and the insurance company of the person found guilty will have to pay for the health care costs of the other party. All in all it can thus be concluded that it is very difficult to obtain good care that is paid for by insurance companies if the brain injury is acquired at home. This could explain why the number of stroke patients was relatively low compared with the number of TBI patients and why the CNS clients are relatively young compared to the rehabilitation population in the Netherlands. Traumatic brain injury can often be work related or caused by a traffic accident. In contrast, a stroke will often not be work related. Furthermore the odds of a stroke are higher as people get older.

Most of CNSs' clients are referred to CNS by their case managers of an insurance company. Besides that, clients sometimes get referred to the centre by a hospital or the clients contact CNS themselves. In cases like this too, the insurance company of the client will ultimately decide whether he or she will be eligible for rehabilitation at CNS. Before a client is admitted to CNS, a co-worker of the institute will visit the client at home, to assess the possibilities for rehabilitation. This co-worker reports his findings to the clients insurance company, and the insurance company will decide whether the client can actually start the rehabilitation treatment.

The duration of the rehabilitation treatment varies from some weeks to several months and largely depends on the financing that is available. If the rehabilitation treatment is financed by an insurance company, CNS has to report on the improvements of the client at least once a week to the case manager of the insurance company. The case managers of the company will ultimately decide whether rehabilitation treatment will be continued. In general, rehabilitation treatment will be stopped when the client shows too little improvement.

Organisation

There is a lot of competition between different institutions offering rehabilitation services in the U.S. Hence it is very important for an institution to distinguish itself from other institutions and to pursue a powerful public relations policy. Therefore, several PR agents work for CNS to inform case managers from insurance companies on the rehabilitation programme that CNS offers and to explain them in what way CNS sets itself apart from other institutions. By doing this, CNS hopes to increase the number of clients that are referred to the centre.

CNS consists of two different units: a clinic, which is the place where therapy sessions take place during work days, and the apartment buildings, where the in-patients live during their rehabilitation treatment. The clinic and the apartment buildings are located in different parts of town. In the morning and in the evening, clients are transported from and to the apartment buildings by vans. During my visit, there were approximately 25 in-patients and 20 out-patients in the rehabilitation programme. However, the centre strives to lodge clients in the apartment buildings during their rehabilitation treatment, as in this way, much training can take place in a natural, daily setting. In addition clients at CNS come from different parts of the U.S, most of the time making it impossible to travel back and forth to the centre and their homes everyday. Furthermore, CNS regularly has clients coming from different countries of the world.

At CNS, case managers of the centre have final responsibility over the treatment programme, while in the Netherlands, the rehabilitation physician has final responsibility. The case manager is the central contact for all parties involved in the rehabilitation process, namely the client and his or her family, the therapists and other co-workers, the insurance company and (if applicable) a lawyer. All case managers that are employed at CNS have first been working at the centre as a therapist. Therefore, they all have extensive experience in working with ABI clients and they are very familiar with the method of working of the centre. Approximately once every three months, the case manager arranges a conference for each individual client. This conference is attended by the client, his or her family and the CNS case manager. During the meeting, the status of the rehabilitation process is discussed and all therapists that are involved with the client come over to clarify the part of the meeting that concerns their disciplines.

Clinic

During working days, therapy sessions take place at the clinic. A very important part of the therapy programme consists of cognitive training. This training is carried out by speech and language pathologists, who focus on several specific cognitive functions, and by educational therapists, who focus on aspects like orientation, math, reading, planning and handling money. In a later phase of the rehabilitation process, educational therapists can also help the client in finding a suitable education or job. The cognitive training that is offered during therapy shows an important difference with the training that is currently offered in Dutch rehabilitation centres. Over the last couple of years, the use of strategy training in cognitive rehabilitation has become more and more common in the Netherlands. This type of therapy is based on the assumption that many cognitive deficits are resistant to treatment and that rehabilitation should therefore concentrate on teaching compensatory strategies. Cognitive strategy training is aimed at teaching patients new, general ways to compensate for problems in everyday life, resulting from a cognitive impairment. Thus, improving the cognitive function itself is not a primary goal of this treatment method. In contrast, the cognitive therapies that are offered by CNS are aimed at recovering the cognitive function itself, or in other words, improving specific cognitive functions like memory and attention. The CNS therapists explained that they try to improve the cognitive functions as much as possible, to ensure that the client can fall back on a basis that is as strong as possible while they are functioning in everyday life. This, however, does not mean that strategy training is not used at CNS. This treatment method is extensively used at the apartments, while training everyday tasks.

An other important part of the rehabilitation treatment are the counselling sessions. The counsellors take care of psychological support of the clients and they focus on possible alcohol or drug problems. Possible maladjusted behaviour of the client is another important focus of the rehabilitation programme. The managing of this behaviour forms an important part of the rehabilitation programme and holds a prominent place in all therapies at the clinic and in the apartments. Several behavioural specialists that work at CNS develop the behavioural programmes and assist the therapists and co-workers in applying these programmes.

Physical therapists working at the centre mainly focus on components of movement and on functional movements, with an emphasis on (the preparation of) walking. Two main subjects that the

occupational therapists focus on are the visual functioning of the clients and the arm-hand functioning (eg the strengthening of the upper extremities). In the Netherlands, ADL training is a very important part of occupational therapy. The occupational therapists working at CNS explained that this usually is the same in the US as well. At CNS, however, the situation is a bit different. One of the main goals of CNS is to offer environmentally valid rehabilitation, meaning that daily tasks will be trained in daily situations as much as possible. Therefore, the training of daily tasks will take place at the apartments, making it possible to train these tasks at the appropriate place and the appropriate time. If difficulties occur during ADL training at the apartments, occupational therapists can advise the staff of the apartments on handling the problems.

CNS has three physicians (a rehabilitation physician, a neurologist and a GP) working in the centre as consultants. They attend the centre several times a week, and they can be summoned to the centre in case of an emergency.

A notable difference to the Dutch rehabilitation care is the fact that therapies at CNS are rather competitive. Training modules are used, consisting of several levels that are completed one by one. At the end of each training session, the therapists tells the client his or her percentage of passed items within a level. When this percentage is above a cut-off score, the client moves on to the next level. Whereas the same level will be addressed again during the following therapy session when the percentage is too low. The clients seem to be very focused on their percentage of passed items. They are eager to know what their scores are and they will certainly ask a therapist to tell them the percentage in case the therapist forgets to provide this feedback.

Apartments

Each apartment houses two inpatients, and provides fulltime supervision by rehabilitation aids (RAs). For 24 hours a day, one or two aids will be present at the apartment. The number of aids present at an apartment depends on the extent of care that is needed by the two clients. Furthermore, CNS has several independent living apartments to its disposal, housing one client that functions independently. In this way, this client can be monitored to see whether the return to his or her own home can be realised the short term.

In the apartments, daily tasks are trained in daily situations, meaning that these tasks are trained at the appropriate place and the appropriate time of day. Clients are challenged to perform all tasks as independently as possible. When needed, the rehabilitation aids can provide assistance in task performance, using strategy training and compensatory techniques like using a day planner or checklists. When the performance of a task turns out to be too difficult for a client, the aids will try to involve him or her in the task as much as possible. In addition, the aids will try to explain to the client exactly what the aids are doing to perform a certain task, as well as why it needs to be done in this way. This method of environmentally valid training uses all daily tasks that have to be performed in the apartments to keep the household on track, like cooking, making a grocery list, grocery shopping, cleaning, doing the laundry, having breakfast, preparing lunch and managing medication etc. Each night, the client is asked to look ahead to the next day: at what time does his or her first therapy of the day start and at what time does he or she need to take the van in order to be at the clinic in time for the first therapy session? Thus, at what time should he or she get up and at what time should the alarm clock be set?

The dedication, the commitment, but above all, the patience with which the aids work with the clients made a big impression on me.

The rehabilitation aids register the functioning of the clients at the apartments. The aids report whether the clients initiate task performances and they register the sort and the amount of assistance that the clients need to perform a task. Furthermore, the aids register the way in which the clients behave themselves during their stay at the apartments. The Independent Living Scale (ILS) was specially developed by CNS to register the clients' functioning, and is used by the rehabilitation aids.

Continuity of care

Integrating the therapy sessions that take place at the clinic and the training that takes place at the apartments is very important in terms of the continuity of care. To guarantee this continuity of care, CNS makes use of a computer system that contains a lot of information on each individual client. Both at the clinic and at each apartment, PCs are available that can be used by the therapist and the co-workers to access client information on this computer system. The clients' file contains his or her medical history and prescribed medicines, as well as the clients' functioning during therapy sessions

and at the apartments. Based on this information, the file contains recommendations for therapists and co-workers on how to react to problematic behaviour the client is familiar with, on what daily tasks the client can perform independently and for what daily tasks he or she will need specific assistance. Also, recommendations are made on the best ways to support the individual client. Therapists working at the clinic can add homework assignments for the client to the file, as well as recommendations for the aids on how to assist the client with the homework.

A considerable part of CNSs' clients returns to their own homes after discharge from the rehabilitation programme. To guarantee the continuity of care after discharge, family members of the clients are encouraged to come and visit the client at the clinic for several days, in order to observe the therapies and the training sessions. In this way, the family members learn about the methods that the therapists and the co-workers use to assist the client during the performance of daily tasks, as well as the methods they use to handle behavioural problems of the client. Furthermore, these days can provide the family members with a good impression on what it will be like to take care of the client, if he would come home after discharge from the rehabilitation program. In this way, the family members will be better able to judge whether they will be able to cope with the caring for the client after discharge from the programme.

After discharge from the programme, the case managers of the clients keep in touch with the clients over the telephone. The frequency of this contact decreases over time, from once a month to once a year. In this way, therapists and co-workers can be kept up to date on the clients functioning. Moreover, case managers can advise clients in handling problems that they might encounter after discharge. During team meetings, the case manager reports on these phone calls to inform the therapists that used to work with the clients. All therapists are eager to hear how their former clients are doing, so this information is warmly welcomed.

Community outings

Clients can join a community outing several times a week. Community outings can include a visit to the library, a church, a restaurant, a movie theatre, the shopping mall, the bowling alley or a sports game. During these outings, clients are accompanied by rehabilitation aids and the outings

coordinator. Depending on the sort of outing and the specific clients that attend the outing, therapists or nurses can be mobilised to assist during the outings as well. In my opinion, the huge benefit of these activities is that the staff considers them to be part of the therapy programme, whereas the clients really consider it to be an outing: just for once they feel that they don't have to be rehabilitating and learning new things. However, during these outings, clients are learning a lot of things on how to behave themselves in specific social contexts, in an informal, natural way. Moreover, there are things that can happen or go wrong during an outing. These events are utilized by the staff to start a conversation with the clients on what has happened, creating a sort of informal group therapy session.

Group homes

In addition to the apartments, CNS has several group homes to its disposal. These homes house approximately 20 clients who were not able to return to their own home after finishing their rehabilitation treatment. When the clients' support system is not able to handle the care for the client, when the client has serious behavioural problems or when disabilities are too severe, ABI clients in the U.S are usually referred to nursing homes. However, CNSs' clients are relatively young compared to people living in nursing homes. Therefore, CNS staff believes nursing homes to be an inappropriate housing condition for their clients. Hence CNS started running several group homes to house this group of long-term clients. During daytime, the long-term client attend the Adult Activity Centre as well as community outings. In addition clients are challenged to help out with daily tasks in the group homes.

Conclusions

By means of the apraxia research project, we try to gain more insight in transfer of treatment effects of a Dutch rehabilitation programme. In this perspective, the visit to CNS has been a very valuable experience. Transfer of treatment effects to daily life situations are a very important part of CNSs' rehabilitation programme. To promote this transfer, CNS uses a special approach, namely environmentally valid rehabilitation.

Several differences between Dutch rehabilitation practice and the rehabilitation programme that is offered by CNS stood out for me. First, the rehabilitation programme seems to be largely driven by the

financial structure and by funding possibilities. The progress of every patient needs to be repeatedly reported to the insurance companies. When these companies judge the progress to be too small, rehabilitation treatment will be stopped. Second, in the clinic, CNS uses cognitive training that is aimed at improving the cognitive function itself, while in the Netherlands, this type of therapy is hardly used anymore. In the Netherlands, there has been a shift from training cognitive functions itself to training strategies to compensate for the cognitive deficits. This shift is probably based on the reports that training the cognitive function itself does improve the trained task, although transfer to other tasks or to daily life situations is problematic. Third, the competitive elements in the therapy sessions at CNS cannot be compared with the Dutch therapy programme. A final, clear difference is the way in which clients are trained to perform everyday tasks in the apartment buildings and to participate in society during community outings. In my opinion, this is the most valuable part of CNSs' rehabilitation programme.

Personally, I think it is interesting to assess to what extent some of CNSs' approaches to rehabilitation could be applied in Dutch rehabilitation care, like challenging of the clients to perform daily tasks independently as much as possible and at least trying to involve the clients in daily tasks in case they cannot perform them independently. Another aspect of the rehabilitation at CNS that is definitely worth to assess is the way in which clients, right after the start of the rehabilitation programme, are stimulated into supervised participation in society by means of community outings. Dutch rehabilitation practice can also merit from the computer database containing detailed client information that improves the continuity of rehabilitation care.

This report suggests that rehabilitation care after acquired brain injury can be designed in different ways. The difference I observed during my visit surely set me thinking. Therefore, this visit has been a very valuable experience to me.