The Adventure of Engaging Traumatic Brain Injured Patients in a Therapeutic Challenge Course Program

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Abstract

A Challenge Course Program for Traumatic Brain Injured (TBI) patients of a psychiatric hospital was organized. The authors focused on the high frequency of anosognosia, lack of awareness, as a characteristic of TBI and its different behavorial symptoms such as refusal to participate in revalidation, incapability to learn from feedback, communication problems about relevant functionality issues, and difficulties dealing with confrontation. These symptoms are evaluated in view of the patients' participation in an Experiential Outdoor Learning Program. The complex clinical picture of anosognosia is analyzed and a program that was developed to address this challenging condition is reviewed. Working principles of the program are described, and program findings are presented along with recommendations for future efforts to treat this population through experiential programming.

The Problem

In the field of mental health, motivation is a prerequisite to initiate therapeutic engagement. If a patient is not motivated towards change, the vast majority of therapists or therapeutic communities will renounce treatment. Several reasons account for the lack of motivation towards change. A patient may not recognize a behaviour or feeling as inappropriate or harmful, or may not acknowledge his or her own responsibility in the occurrence of disruptive situations. This is a problem concerning many groups of patients in need of care/cure, including our target group: patients with traumatic brain injury (TBI).

TBI patients suffer from a combination of neurological and psychological defects that often lead to a lack of awareness of their own possibilities or disabilities (Prigatano, 1991). This can lead to difficulties in recognizing a need for change. Due to the lack of awareness, the patient may verbally deny that a certain behaviour poses a problem, but his behaviour, indirect speech, and emotions may in fact be causing significant difficulties for primary caregivers and others with whom he or she interacts on a regular basis (Weinstein, 1955). Therefore, change may be necessary due to the disruptive effect of the behaviour (Wallace & Bogner, 2000). The contradiction often seen between verbal and non-verbal communication may suggest some possibilities for treatment since it demonstrates that this phenomenon is not an entirely untouchable neurological process, but instead implies psychological processes that may be amenable to treatment.

Based on observations within the structured setting of a psychiatric hospital, the authors concluded that adventure activities might function as an effective catalyst towards behavioural change with TBI patients. The observation of such patients in a five-day Challenge Course program allowed them to identify a number of important issues that have to be taken into account when working with this client group.

Traumatic Brain Injury

TBI patients suffer from a variety of problems including neuropsychological, locomotor and emotional problems including memory distortions, attention problems, hemiplegia, balance problems, disinhibition, loss of speech, aggression, depression, an unrealistic and non-adapted body image, seizures, and psychotic episodes. Other debilitating symptoms may include a reduced or vanished capability to formulate goals, solve problems, carry out a plan, and exert fine locomotor control. However, it is the lack of self-awareness that most clearly impedes the chances of successful revalidation and poses a major stress on caregivers (Wallace & Bogner, 2000).

Problem of lack of awareness

Anosognosia refers to the lack of knowledge, awareness or recognition of disease. The terms "lack of insight" or "lack of awareness" are also encountered frequently and stress the importance of reduced awareness of neuropsychological deficits. This lack of self- awareness on the part of the TBI patient is by far the most difficult symptom that families must deal with. It results in the absence of motivation to get treatment, as the patient is unaware of the inappropriate nature of their behavior (McGlynn & Schacter, 1989). There is a failure to implement compensation strategies, and difficulty maintaining realistic goals for rehabilitation. TBI patients often do not benefit from therapy, and social exclusion and breaking of family ties is common. Anosognosia also limits vocational possibilities.

The complex clinical picture of anosognosia

The diagnosis of anosognosia is the result of an interaction in which the observer compares the patient's responses to questions about his disability with his behaviour in situations in which his capacities are tested. Thus, anosognosia takes many forms and is expressed in various spheres of function (McGlynn & Schacter, 1989). A hemiplegic patient for example, may claim that he is not partially paralyzed but perfectly well; or he may admit some weakness and assign it to a trivial cause. He may not deny the paralysis explicitly but express delusions about the affected member, disowning it or referring to it as a foreign body. A patient may deny all his disabilities, part of his disabilities, or use one form of denial for one incapacity and another for some other deficit. Anosognosia is thus a concept that provides unity to phenomena that might otherwise be regarded as discrete disturbances in cognition, perception, attention or affect.

Importantly, the term anosognosia in its literal meaning of "lack of knowledge of disease" is not accurate for many anosognosia patients. Many patients display implicit knowledge of the extent of their difficitulties. They may deny a disability verbally, but not in their behaviour (Weinstein & Kahn, 1955). For example, although a patient may claim that he or she is fine, he or she does accept the role of patient. Another example might be a patient who denies symptoms, yet takes medication, submits to procedures, and does not ask or attempt to leave the hospital. For example, most hemiplegic patients who deny that they are partially paralyzed do not try to walk on their own.

Implicit awareness of disability is also indicated in the selectivity and content of delusions and confabulations. Patients may be delusional or confabulatory only about the body part whose function is impaired or they may deny one disability but not another because of the personal meaning attached to the dysfunction. This implicit awareness shows the involvement of psychological mechanisms, namely in the class of coping behaviour, denial being the most relevant coping behaviour in the context of anosognosia. Thus the symptom picture of anosognosia reflects the direct neurological and indirect psychological effects of brain injury.

Certainly, premorbid personality characteristics are considered important determinants of ways in which the individual handles the struggle. As mentioned, denial syndromes are a common way to cope with this struggle. Premorbid experiences are determinants of the existence and form of denial and other symbolic representations of incapacity, as well as the content of delusions and confabulations. The types of disability that are denied include neurological symptoms directly attributable to brain injury such as blindness, left and right hemiplegia, left and right hemianopia, aphasia, alexia, deafness, involuntary movements and paraplegia. Denial may also arise from premorbid experiences that influence the type of adaptation to a non-neurologic loss of function, such as denial of the loss of an amputated limb, the scars and contractures following severe burns with associated encephalopathy, incontinence, a craniotomy or head injury, and the illness itself. For many patients who develop explicit verbal denial, their illness is seen as a kind of personal failure or weakness involving a loss of prestige and integrity (Lewis, 1991). Thus the deficit the patient denies is not necessarily the direct result of a brain lesion, but rather premorbid experiences influence the type of adaptation to the loss of function following brain injury.

We consider the anosognosia and its resulting behaviour as a combination of neurological damage and a psychological defense mechanism. If a person is not fully aware of his possibilities after an injury or after the onset of a disease, he will experience the corrections, or feedback, of others as threatening to his sense of self. This compels him to react strongly to this feedback and to hold firmly to the distorted image he has of himself. We observed that many brain injured people hold onto the identity, goals, values, behaviours and abilities that they had before the injury. Each confrontation with their anosognosia strengthens their defensive walls.

Another aspect of this entrenchment is the threat of disintegration, which Goldstein calls ”catastrophic reaction” (cited in Prigatano, 1999). Anosognosia patients cannot accept the circumstances of their medical condition because the reality of their present condition is not acceptable since it represents a threat to their identity. Thus, the important function of denial serves as a form of protection. Therapy to treat anosognosia must take this identity issue into account.

There are important clinical considerations related to these phenomena. Patients who use denial as a coping mechanism are not conscious of this process. If the therapist tries to make the patient acknowledge the denied aspect of his illness by sheer willpower and motivated self-control, both he and the patient will be frustrated. Many proposed therapies for anosognosia provide patients with massive feedback training (Schlund, 1999; Fordyce & Roueche, 1986). The goal of this form of therapy is to teach the patient the consequences of his brain damage by repetition. Although some investigations do find some improvement of the anosognosia, this approach is considered questionable, because the confrontation technique that the therapist uses can cause patients to retreat even further into denial.

An Experiential Outdoor Learning Approach

We do not believe that anosognosia should be considered an obstruction to treatment that must be resolved before treatment can progress. It is at least partially a motivated process with an adaptive value and meaning. Through the mechanism of denial, the patient tries to avoid aspects of reality that would cause more damage than he or she can cope with. This behaviour is a meaningful reaction of a person to a meaningful situation. The specific danger that arises when denial is eliminated has to be investigated by the therapist (Lewis, 1991) and the adaptive capability of this behaviour must be understood in order to treat it effectively. This behaviour serves a goal and it is the treatment providers' task to discover its meaning for the patient and how it helps that person to avoid, solve or approach his or her problems. Therefore, the mechanism of denial is important to the patient and in the process of trying to reduce its occurrence, we should consider alternative ways of reaching the pursued goal. The approach proposed here is not only to work towards socially appropriate behaviour but also to work on the patient's new identity in a non-threatening way. While the goal of therapy could be the heightening of self-awareness, ultimately it is geared towards the promotion of socially accepted behaviour.

The Experiential Outdoor Learning Program consisted of five separate days where a group of patients were invited to participate in adventure activities. The interval between sessions was approximately one month. The only selection criterion was that the participants had to be responsive to the instructions given by the facilitator. The staff during the outing was a nurse, a neuropsychologist, an occupational therapist, and a psychomotor therapist.

The different activities were selected to provide the possibility of utilizing the strengths of each participant. This provides the opportunity to get positive feedback from the group and from the successful completion of the activities themselves. In working with physically and psychologically challenged patients, this kind of feedback is most valuable. We observed many situations where the power from these accomplishments gave participants enough strength to shed their maladaptive coping system.

When considering the choice of activites, major modifications were made to fit the broad range of physical abilities and limitations within the target group. Examples of such modified activities included: Spider's Web, Whole in Space, Mohawk Walk, High Balance Beam, Obstacle Course, Gutter Ball, Bullring, Orientation Circuit, Flying Fox, and Adapted Low Ropes Course Elements. Some of the activities were already adapted to universal (i.e., wheelchair and limited physical abilities) use. The Spider's Web, for example, was set-up to accommodate wheelchairs. The climbing wall was equipped with a counterweight system so that limited strength was needed. The Balance Beam could also be used with a wheelchair. The introductions, interventions and debriefs had to be modified to meet the special memory and speech features typical for some of the participants.

Taking the above mentioned issues into account we will summarize some principles of an approach (Bieman-Copland & Dywan, 2000) that expanded our therapeutic thinking and that were operationalized and into an outdoor setting.

”Mind the gap:” no comparison with former life

An important issue in working with TBI patients is the interaction between their life prior to and after the injury. Their existing self-conception is based on their re-TBI period. Where a lack of awareness poses difficulties in their proper assessment of the situation at hand, it is important to remember that they are viewing the situation from the perspective of their pre-TBI period.

Brain injury can damage one's capabilities to process information in an efficient and comprehensive manner. In a complex situation with many stimuli, it is a difficult task to regain control. In a situation where the whole of the stimuli and demands cannot be integrated the individual tends to return to one's pre-TBI self-image. Due to this phenomena, it might be impossible for the patient to correct his self-image, or the patient might refuse to accept the limitations encountered. Regardless, an evolution towards an awareness (implicit or explicit) of the present physical and cognitive capacities must be pursued. Therefore, a goal of the program is to not engage in a discussion of someone's abilities before the injury, but rather to encourage reflection on one's capabilities here and now; helping to build the patient's self-esteem based on his current achievements.

It is important to understand each patients pre-TBI characteristics, including how one used to be, how one reacted to stress, how one coped with difficulties, and how one related to others. However, the primary emphasis of our approach is how the client evaluates oneself today, what the persons' strengths are, weaknesses, perspectives and goals in life. We work with the abilities that the TBI patient sees in oneself and refrain from imposing our own assessment of a patient's capacities and limitations.

Specific ways to process the activities.

We choose to always frontload the activity by asking the participants how they thought that they would perform in the upcoming action and videotape this explicit statement. During the review that followed the activity, the patients were asked to compare their pre-activity statements with their actual accomplishments. By applying this structure the patients were able to bridge expectations and estimations with actual outcomes, without having to deal with his or hers own memory problem or being dependent on a caregivers memory. (It is often observed that caregivers become scapegoats for encountered failures.)

We also asked what the participants thought that they needed to perform the given task. Examples that the participants came up with included: the use of both arms; intelligence; ability to orientate and; the help of others. This helps the patients to focus on the reality of the situation and their capabilities and limitations. It is important at this point not to judge if the answers are adequate, only to facilitate the thinking about the questions. It is up to the patients to experience the adequacy. After each task or activity, we asked them if their ”toolbox” was sufficient or if there were too many “tools” in it. In order to avoid confrontation in these early developmental stages of the program, we asked them what they thought that they would need when re-engaging in the same activity if they wanted to improve their performance.

At this point we often observed that patients started to explicitly verbalize their physical disability and proposed alternative ways to deal with it. They could state the things that were difficult or impossible for them, often accompanied with some emotion. Importantly, at this point delusional thoughts may be more likely to manifest themselves in more psychotic patients. A confrontation with their abilities as well as their limitations can cause a psychotic reaction. This happened to a patient (who previously lost an arm in a car accident) when he reached the top of a 40 foot climbing wall. His eyes shifted which was a sign that his achievement was too overwhelming to integrate into his reality. The days following, back in the hospital, he was very delusional and aggressive. This reaction occurred during each of the following outdoor trips. The patient achieved something that he thought was not possible with his disability and decompensated afterwards. However, each time the strength of his reaction decreased, and eventually it disappeared.

Getting connected

Getting connected is another crucial aspect of the working alliance in two different ways. First, it is important to build a trusting therapeutic relationship. Second, we have to find an issue to work with that patients are able to acknowledge. Patients with anosognosia often propose issues unrelated to their injury or irrelevant to their problem. For example, they may suggest goals such as “ do powertraining”, “smoke more cigarettes” and so on. In order to develop trust and rapport, we engage in their proposed goals as a first step towards our goal.

Iceberg politics

Although the therapeutic actions are limited to the issues agreed upon, this does not prevent the therapists from working simultaneously on other themes. Here a comparison can be made to an iceberg, only a small part of which is visible while the main part is beneath the surface of the sea. By addressing the minor issues first, the patient is sometimes able to build a necessary trusting relationship that provides the necessary basis to challenge more difficult problems. In the meantime the therapists try to rehabilitate the other problems as well, but without making them subject of conversation. This may mean creating a stimulating environment in which other problems can be addressed, e.g., physical revalidation. A patient who does not want to engage in physical therapy to regain his ability to walk, can nonetheless be challenged to walk over a wooden girder in order to reach the group on the other side. A patient with equilibrium problems is not interested in therapy, because he does not acknowledge it is a problem. However, we can challenge him to walk the Mohawk Walk, which at the same time addresses this revalidation issue.

Opposed to the situation in the hospital where during revalidation patients have to practice certain movements as an end in itself the Outdoor activities provide attractive goals that detract from the actual behaving. The confrontation is thus decreased because the focus tends to be on succeeding in the activity. This provides a unique possibility for the patient with anosognosia to experience movements, situations, and interactions that one would normally avoid, as well as a unique learning possibility and a chance to discover one's present abilities.

Do not judge, but elicit thinking

Because of the obvious unfeasibility of many proposed goals, the therapist is often compelled to react in a restrictive or disapproving way. The repeated communication of this judgement can be experienced by the patients as a disapproval of their self-determination, personality, or values, and may push them further into a defensive state of being. Therefore, it is important that the patient's proposals are questioned with authentic interest instead of being dismissed immediately. The therapists will ask questions, some out of genuine curiosity, some within the framework of designing an action plan. They will even risk puting words in the patients' mouths if this helps the latter to uphold their existing self-image. However, in an effort to stimulate more critical thought, the therapists also challenge their choices.

A 25-year old male patient with memory problems, lack of awareness, delusions, and auto-destructive behaviour as a result of a motor vehicle accident, chose a difficult path to go up a 40 foot climbing wall. We (the therapists) knew that he was not capable of achieving this goal. We also knew that if he did not succeed, he would get angry and he would withdraw and flee into delusions or self-destructive behaviour.

Given this, we encouraged his choice but at the same time proposed to develop a step-by-step climbing program with his ambitious wall route as the final step. He refused and tried the difficult path, giving up after 9 feet. We first congratulated him for these 9 feet, acknowledging that he knew that it would be difficult and that it took courage to attempt it. Next, we encouraged him to go on with “his” first plan; take the easy wall first and then gradually move to the more difficult levels. The purpose of this intervention was to try to support his self-esteem as much as possible, avoiding embarrassment and providing him with a valid alternative. Believing that he himself was the author of that plan provided him with the necessary motivation to take it along. He first practiced at the easier levels and when he then finally tried the difficult path, hereby limiting his own goal to 20 feet, he succeeded.

The good, the bad and the ugly

Rules are necessary when people live together. TBI patients often challenge these rules. In our program set-up, the ”the good, the bad, and the ugly” paradigm was used to make a discussion of these rules possible. The ”ugly” is the caretaker who creates the rules; that person is referred to by the rest of the team as the one responsible for the existence of the rule. He or she is to be addressed by the patient who wants to change the rule. The ”bad” is the therapist who repeats the rules and implements them. This one has to confront the patient repeatedly when the rules are violated. This creates space for the “good,” who can avoid these confrontations by referring to the ”ugly” and the ”bad”, and engage in a collaborative relationship with the patient (Bieman-Copland & Dywan, 2000). He depicts himself as not being a full member of the group that makes the rules and can, together with the patient, take an objective view of the situation and look for alternative solutions.

As is common in traditional clinical settings, rules are often challenged in outdoor settings as well. At least one of the staff members in our program assumes the role of the ”bad.” He points out the restrictions and imposes them. The facilitator in charge is responsible for the collaborative relationship; he acts as the “good” guy. Together with the patients, he can look for a way to make the assignment work by discussing how to deal with the restrictions and how they can find their way between the established boundaries.

The truth lies within: no reference to brain damage

As mentioned previously, we do not confront the patients with their brain damage and the consequences of it when they show signs of a lack of awareness. The way that they see the world and the problems that they are experiencing is where we begin the work.

To refer to their brain damage has several disadvantages. The responsibility for behaviour, emotion and cognition is then no longer their own and any communication about difficulties can be discarded. Furthermore, the matter of brain damage is highly sensitive and the patient may easily lose confidence and trust in the therapeutic relationship. Only when the patient her or himself brings up the matter, should information be given.

Program Findings

The main goal of this program was to explore the possibilities and limitations of an adventure therapy approach in addressing the lack of awareness issue. It is evident that we wanted to improve the patient’s awareness, but we also wanted to provide an opportunity to give necessary therapy to patients that were not motivated because of their anosognosia. Pre- and post-test measurements of the patients’ self-awareness were taken in order to evaluate the impact of the program. However, because of the small number of participants in this program, the findings were not statistically significant and will not be reported here. Instead, we will comment on some of our observations.

Behavioural changes

We observed an astonishing change in motor activity and responsiveness of certain participants over the different sessions and even during the course of one day. For example, one of the participants was known in the hospital as an apathetic, almost mute patient. After half a day outdoors, he actively walked behind the group and helped them to reach the goal,

paid attention to everything that happened and even gave an elaborate explanation of his thinking and actions after one specific activity. The mere fact of changing the environment also seemed to provoke a change in behaviour for many of the patients. It is rather difficult to create a challenging environment in a psychiatric hospital with its daily routines. Living together with many mentally and physically challenged patients creates an environment that is sometimes too tolerant of deviant behaviour and sometimes too restrictive to permit creativity. Going outdoors can be enough to create a stimulating climate.

The issue of trust in the therapeutic relationship

It appeared that the adventue experience had a positive impact on the patient’s trust in the therapeutic relationship which transferred to other situations, even on hospital grounds. To promote this transfer even more, we videotaped each activity and we watched the tapes with the whole group on a regular basis. By reviewing the videotaped activities and referring to their accomplishments throughout the day, the positive and trusting relationships during the outdoor activities are brought into the hospital. Not only the patients’ trust was influenced, noticeable was the growing trust of caregivers in the autonomy and therapeutic abilities of their patients.

Moving towards a greater awareness

Some patients, previously denying that anything was wrong with them and therefor not wanting therapy, were now able to explicitely state their limitations. This evolution towards awareness is remarkable, but unfortunately was only witnessed during the outdoor activities and did not seem to transfer to hospital grounds

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How to motivate this client-group effectively?

The art of motivating was important in framing each activity. We achieved the best results if we vaguely addressed the day’s plan. “We go out, dress warm!” was often sufficient. If we gave them more information, patients would hesitate or even drop out. A description of the planned activities gave rise to uncertainty, fear of failure, and/or fear of confrontation. This was not verbally expressed but was clear from the patients’ refusal to engage in the program. Notably however, while this appeared to be an important element in successfully implementing the days activities, we recognize that this practice gives rise to ethical considerations regarding the issue of ”informed consent.” This is something to be considered in the future.

Important Considerations for Program Development

TBI patients have various neuropsychological problems that can affect the reflection phases of an adventure program and create a real challenge for the outdoor therapist. The therapist will have to surmount difficulties in verbiage and pronunciation, concentration and amnesia, and impulsivity and apathy. In our program we tried to approach this by repeating the same pattern of reflection throughout the total program sequence and by making these reflections immediately after the activities while the participants still remembered them. During activities we sometimes assigned a mentor to each patient, to guide them through the activities and to be able to react to events as they happened.

Another important problem was the lack of continuity over the different sessions because of memory problems. Often participants did not have an explicit recollection of the activities

of the previous session. One patient even denied having met the outdoor therapist previously, although non-verbally she was showing signs of closeness and recollection.
In our opinion outdoor trainers should be prepared to accept apperently strange behaviours and be guided more by the communicative aspect of that behaviour than by language.

We found it important to make the participants feel comfortable each time that we left for an outdoor activity. Due to memory problems the facts are often forgotten, but the emotional evaluation stays. Thus, if we wanted to motivate the patients to participate in the next session of the program, it was crucial that they felt positive about the previous activity. This was a dangerous issue, because it influenced our therapeutic attitude. We noticed that in order to have the group achieve success, we were at times too directive in our facilitation. Consequently, here is a danger of moving away from our experiential therapeutic practice and moving towards a therapists centered approach.

We are still debating whether an individual or a group approach is better for TBI patients. We have the impression that individual activities seem to be a better entre for personal development than group challenges. In an individual activity succes (and failure) can only be attributed to their own actions and thus less complex. At least at the beginning of a series of activities, an individual program can address the specific individual problematic issues and gain confidence towards more complex (group) challenges.

Conclusion

Overall, we noticed increased compliance, higher motivation, more cooperation, and sometimes an astonishing change in behaviour, Based on our observations, this type of adventure therapy program offers a well-designed intervention that avoids many of the problems encountered in standard therapies typically used to address anosognosia. In this program we only began to explore the possibilities of adventure therapy with the adaptations implemented for our target group. The next step is to design new programs to broaden our therpeutic outdoor experience with this target group, to refine our processing methods, how to introduce activities and motivate the client system in an ethical way, to integrate measurements that will allow a more objective evaluation of our present findings. We also want to provide more attention to the role and function of the primary caregivers in the rehabilitation process of the TBI patient..

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Thomas Debaenst graduated as a MD in clinical psychology with a dissertation discussing the neuropsychological and neuropsychoanalytical approach of anosognosia and he is specializing in the phenomenon of unawareness of deficits ever since. He has been working in the Psychiatric Centrum Caritas in Gent, Belgium.

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