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IDENTITY DISTURBANCES IN A PATIENT WITH SEVERE TRAUMATIC BRAIN INJURY: A CASE STUDY

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SUMMARY

Background Patients aroused from a long -term coma after severe TBI often

exhibit identity disorders, which are connected with discontinuity of the life story, and in consequence with the existence of two different autobiographies, one before and one after the

accident.

Material/ The research group included 4 women and 4 men (average age Methods: 26.7 years), aroused from a long-term coma (average 67.5

26.7 years), aroused from a long-term coma (average 67.5 days). The methods used included clinical observation, clinical interview with the patient and his family, and the

Multidimensional Identity Assessment Scale.

Results: The patients demonstrated little sense of their own identity, with

a tendency towards identity diffusion, in consequence of having acquired features of deferred or mirror identity. 7 patients demonstrated disorders of time awareness, and one patient was

fixated in the past.

Conclusions: In the case of TBI patients aroused from a long-term coma

there can be identity disturbances, including disorders of identity congruence, creating a false identity, and inadequate per-

ception of reality, leading to social isolation.

Key words: coma, brain injury, microgenetic theory

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INTRODUCTION

Although we human beings are, as is well known, social creatures, we fulfil ourselves completely only by discovering and developing that which singles us out from others, i.e. our autonomy and individuality (Obuchowski, 2000). This is possible only when there is a developed and stable identity. How should this latter construct, so fundamental from the life perspective, be understood? Depending on the chosen perspective, we can distinguish the following kinds of identity (Grochmal-Bach & Pachalska, 2004):

- physical, i.e. the possession of one, unique body, whose existence is continuous from birth to death;
- theological, i.e. the uniqueness of the soul as created or begotten by a divine power;
- legal, i.e. the identity certified by documents and provable in a court of law;
- sociological, i.e. belonging or aspiring to belong to one or more social groups, whose members share some common features held to be of some importance;
- psychological, i.e. the subjective feeling of being a person, the awareness of being oneself, and not someone else.

These categories are often not homogenous, because they contain further subcategories. For example, in the field of psychology, a distinction between personal and social identity is commonly accepted (Stephan & Stephan, 1999). At the same time the distinction between the content and the scope of the terms involved (identity, personality and awareness) is not hermetical, and so these two terms, which are distinct in qualitative terms, overlap in functional terms (Pąchalska, 2003). For the present purposes, only the last category – psychological identity – will be discussed.

Each of us, in order to develop and function efficiently, has to be able to form an answer to two fundamental questions: *Who am I?* and *Who do I want to become in the future?* Research has proved that the answers given by an individual differ among subsequent phases of ontogenesis. At the age of about two years the concept of self is being created, which is built up from concrete features connected with appearance or ownership: i.e. "I am the person who looks back at me in the mirror" and "I am the person who possesses what is mine" (Pąchalska & MacQueen, 2002). In the course of maturation, due to accumulating personal experience, we learn reflexive self – observation, and become sensitive to the relativism resulting from the situational context. The term *Self* is therefore enriched with various mental qualities, emotional, motivational, axiological and social, which include information acquired about oneself in various interpersonal relations (see Aronson et al., 1997).

Having acquired the ability to "define" ourselves (the word "define" itself implies a process of imposing limits), we face another challenge: that is, making the self construct dynamic, by locating it within time (Brown, 2005). This

is achieved by seeking answers to the second question posed above. Such an ability is indispensable in order to direct and facilitate the pace of developmental changes. At the same time, all this goes to show that human identity is of a processual nature, which involves three domains of psychological time: past, present, and future. The past self is a reservoir of personal experience, which allows us to introduce changes in the present self in order to make the desired future self real. Any dysfunctions in experiencing the complete time perspective cannot be without influence on one's sense of identity.

As Pachalska points out (2003), scientific research and clinical practice have proved that the real identity of an individual, in terms of both structural and functional aspects, meets each of the following conditions:

- is coherent, hence we are convinced that despite our inner complexity and mutability, we have a stable self that makes sense, rather than an amalgam of characteristics that belong to different selves;
- forms a unity, which means that there is one self in the body, which is nevertheless very diverse and changeable (I may "change my mind," but that does not mean that I am no longer myself);
- *maintains continuity,* which means that from birth till death the sense of the self's continuity is maintained, despite numerous "transformations".

Clinical observations suggest that identity disturbances often occur in the case of patients aroused from a prolonged coma. These are most often patients after severe traumatic brain injuries (TBI), most commonly after an automobile accident, a fall, or a physical assault. (Pąchalska, 2003; Grochmal-Bach & Pąchalska, 2004; Talar, 2002). In many cases, the patient's autobiography is divided into two distinct periods – before and after the accident (see Fig. 1). What should be stressed here is that quite often – especially at the beginning of rehabilitation – patients see no essential connection between these periods. They form, from patients' subjective point of view, two separate stories, only accidentally or not at all related to one another.

How strange and unknown their past life may seem is best illustrated by a metaphor. In the history of nations and countries some events are known

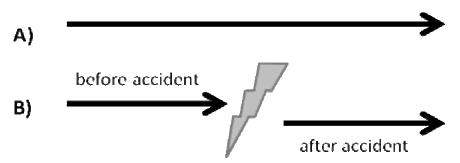


Fig. 1. Development of psychological identity in the course of life. A) the imagined course of development before the accident, B) identity "derailed" after the accident

to have altered the mentality of entire societies irreversibly, enriching the civilization with new content, or impoverishing it by destroying something irreplaceable, but in any event evoking a new phase in its collective life. In recent times, the destruction of the World Trade Center on 11 September 2001 is an example of such an event, marking a discontinuity in history. For many people the following morning belonged to a different reality. Peace and the feeling of security; the naive belief that one can live a carefree life regardless of political turmoil elsewhere in the world, the unspoken conviction that life in a complex modern society goes on with the inevitability of nature, like the changing seasons or the tides - all this was as much a casualty of this dreadful event as the thousands of people who lost their lives. This can be heard not only in commentaries in the media, but even in the daily conversations of ordinary people, who automatically divide experienced time into "before 9/11" and "after 9/11," with the assumption that what was true in the former period of time may have no importance or meaning at all in the latter. This same way of thinking in the face of dramatic discontinuity can often be observed in postcoma TBI patients. To be sure, the same thing happens after many traumatic events and serious illnesses, but in the case of brain damage the problem is intensified by cognitive and emotional changes resulting directly from dysfunctions in the central nervous system.

The purpose of our study was to document this phenomenon empirically in a concrete clinical context.

MATERIAL AND METHODS

The research group was composed of 8 patients in rehabilitation after a severe TBI with prolonged coma (defined as a Glasgow Coma Scale score of 9 or less for longer than 14 days). The average age of the subjects was 26.7 years; the average duration of coma was 67,5 days. Rehabilitation was based on the "Academy of Life" ("Akademia życia") program, designed by Pąchalska (2003), and implemented in the Rehabilitation Clinic at the Rydygier Medical Academy in Bydgoszcz, Poland.

All these patients underwent initial evaluations immediately after regaining consciousness, to diagnose their mental state and assess the impact of the injury and the coma. The neuropsychological examinations included clinical observation, clinical interview with the patient and the family, and the Multidimensional Identity Assessment Scale (Wielowymiarowa Skala Oceny Tożsamości – WSOT), designed by Grochmal-Bach and Pąchalska (2004). The examinations were not performed purely for research purposes, because the results were used to shape the rehabilitation program oriented to reintegrating identity¹.

¹ The Academy of Life program involves comprehensive, coordinated action by an interdisciplinary team of specialists,. It is run under the supervision of Professor Maria Pąchalska, simultaneously in four institutions in Poland, including the Rehabilitation Clinic at the L. Rydygier Medical Academy in Bydgoszcz.

Detailed information was gathered about the following topics:

- the mental and-physical state of the patient, which included the depth and length of the coma, the scope and extent of brain damage, and its consequences in terms of motor activity, cognitive functions, emotional and motivational functions, and mood.
- 2) the nature of the accident the circumstances and course including verifying the patient's answers whenever and however possible.

The pace of the interview process and the scope of information obtained were dependent on the state of the patients, because in the course of rehabilitation their condition was changing.

It was necessary to obtain some kind of an answer from each patient to the question: Who am I?, and then to verify whether or not the trauma had affected in any way the patient's perception or understanding of herself. The assessment tool was the Multidimensional Identity Assessment Scale (Wielowymiarowa Skala Oceny Tożsamości – WSOT), designed by Grochmal-Bach and Pąchalska (2004, see Fig. 2).

The scale, as illustrated in Fig. 2, consists of four dimensions which tend to change over time (from left to right). Taking time into account corresponds not only with the changeable nature of human identity, but also with the processual model of recovering mental and physical well-being by a patient in rehabilitation after a severe TBI. This construct is consistent with the microgenetic theory of Jason Brown (Brown, 2005, Grochmal-Bach & Pachalska,

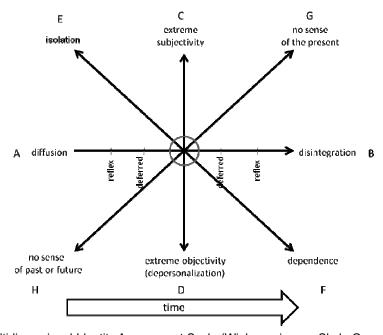


Fig. 2. Multidimensional Identity Assessment Scale (Wielowymiarowa Skala Oceny Tożsamości – WSOT). Source: Grochmal-Bach & Pąchalska, 2004

2004, Brown & Pąchalska, 2003). The optimal model would be four-dimensional, i.e. a three-dimensional object that would move through a certain segment of objective time. Since this is not mechanically possible without complex computer animation that cannot be printed, the two dimensional scale given here is an attempt to approximate such an ideal model.

The first axis, diffusion – disintegration (AB), illustrates the direction of changes in the development of identity, in respect to the unfolding of ontogenesis. According to Marcia, there first occurs the integration of identity, and later, potentially, as a consequence of aging, a secondary involution occurs. This process may be distorted – inhibited or even reversed – as a result of a trauma, which is why patients should be located at the appropriate point on the scale.

The second dimension, extreme subjectivity – extreme objectivity (CD), characterizes the attitude a person has towards surrounding reality. Two extreme situations mark the two ends of the scale: an inwardness or introversion that impedes or even prevents contact with the outer world, and a reactive attitude towards the environment, lacking any reflection or criticism. In the former case, only the inner world of the psyche seems real; in the latter, the inner, mental world does not seem real at all, and all interest and attention is focused outside the self.

The next axis, isolation – dependence (EF), describes a person in relation to the social context. Analogically, its extremes describe either a pathological negation of other people, as in the case of a sociopath, or an extreme subordination, connected with a complete surrender of autonomy.

The last dimension, no sense of the present – no sense of the past or future (GH), describes the way a person deals with time. In order to function at an optimal level, it is vital to develop a complete time line. The absence of any of the three domains of time in consciousness leads to the distortion of actions and the development of an individual. A person fixated in the present cannot learn from past mistakes and successes, cannot make plans that require thinking ahead; a person fixated in the past or the future is lost in dreams, unwilling or unable to act here and now.

The optimal situation is when a person is located near the center point of the scale, marked by a circle, at or near the crossing point of all four axes. Since the axes are each defined by pathological extremes, we expect to find a healthy, balanced, mature identity at or near the center, applying an Aristotelian "golden mean." Placement on the scale results from the clinician's best judgement, after conversations and observations with the patient, the family, and other sources of useful and reliable information. Each of the authors independently analyzed each of the eight patients on all four axes; the results, then, are the averages of the four judges.

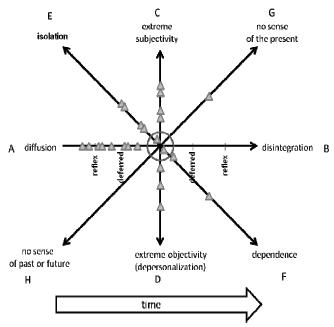


Fig. 3. Results obtained by all eight patients on the WSOT

RESULTS

The results for all eight patients are presented in Fig. 3.

These results indicate that all our patients displayed a disturbed sense of their own identity. Analysing the distribution of the results on each of the four dimensions, the following conclusions were drawn:

The results of the patients were grouped on the left hand side of the axis in case of the first dimension (AB), which means they were shifted towards identity diffusion, acquiring features of deferred identity ("I'll be someone when...") or reflex identity (features of identity absorbed from others). In the sphere of consciousness (axis CD), five patients revealed lack of empathy, and three of them exhibited a tendency to objectify feelings. In respect to the social context (EF) – two persons demonstrated dependence, four isolated themselves from the environment, and only two revealed no disorders. Seven out of eight patients demonstrated disturbances connected with the time axis (GH). They lacked the continuity of the timeline, and one person was fixated on the past.

DISCUSSION

The results reported above support the hypothesis that there are identity disturbances in patients aroused from prolonged coma after a severe TBI. These patients were alienated from their own autobiography, assuming that the past did not belong to them, even when there was no amnesia in the clas-

sic sense. In conversation the patients usually remembered important facts, events, and persons from their past, but with a remarkable detachment, as though they were taking a history test in school. Therefore, having lost the continuity and completeness of psychological time perspective, their potential for recovery was seriously blocked. A person who has lost touch with her own past rejects her own resources of experience, distorts the cause-and-effect relationships between events, and at the same time deprives herself of the possibility to even imagine, let alone shape, a personal "tomorrow." The second source of identity disturbance we observed during our research was a tendency to escape into the world of dreams and fantasies, negating the difficult present (anosognosia).

In order to understand the problem of disturbance of identity, it is necessary to look closely at the qualitative data gathered during the interviews we conducted with patients. It is not possible to quote everything that was said. Therefore only one example will be given in detail, selected on the basis of the author's assessment as the most vivid exemplification of the problem (see also Pąchalska, 2003).

Case study of a patient with anosognosia

The patient is a 37-year-old man, married, two children. In 2000, after being seriously beaten, he had a severe TBI. After emergency trepanation to relieve life-threatening intracranial pressure, he remained in a profound coma (3 points in the GCS scale) for 42 days. After awakening, he was diagnosed with a left-sided paresis, frontal syndrome, and anosognosia.

Comprehensive rehabilitation was started with this patient, which also included interventions aimed at helping the patient regain a sense of his own identity. This process was not easy, but as a result of consistent specialized therapy provided within the framework of the Academy of Life, it was possible to obtain positive results. Currently the patient is functioning normally in his family, although his life is of much lower quality, objectively and subjectively, than the one he led before the accident.

In one of our conversations with this patient, we attempted to obtain information about his sense of identity. A fragment of that conversation is presented in Table 1.

It seems clear that the task of coming up with one of many possible "self-definitions" was not only a difficult and rather distressing experience for the patient, but also – at that stage of rehabilitation – too difficult to be completed. It also turned out that the patient compensated for the lack of self-knowledge with florid confabulations, which became apparent in the further course of the conversation.

The next utterance shows how the perception of reality by severe TBI patients can be extremely inadequate. Autobiographic memory distortions cause an inadequate structuring of the chaos of events in the real world, and therefore result in identity disturbances (see Pachalska, 2003). An incidental

Table 1. Transcript of a fragment of conversation with a TBI patient

Speaker*	Text	Commentary
OB1	Who are you?	OB1 tries to help YY in getting to the key issues, to activate selectivity.
YY	Well, certainly it is about me being a beer drinker [8s.]. I don't know	The patient starts to answer, but stops in the middle of the sentence.
OB2	Well, OK, but who are you, where did you work, what school did you graduate from?	OB2 will not let YY avoid OB1's question.
YY	I simply don't know [11s.]. I don't know who I am. [has tears in his eyes, his voice trembles]	By giving justification YY signals indirectly that he does not know who he is, and does not wants to seek an answer to this question.
OB1	All right, please do not bother about it. Can you recall where you used to work?	Due to the negative emotional reaction OB1 decides not to ask the question again and tries to shift YY's attention to the next problem.

^{*} OB1 - researcher no. 1

encounter with the owner of the pub, just before the assault that injured his brain, constituted the basis for creating a false identity in the period after awakening, when, in consequence of memory disturbances, it turned out to be impossible to rediscover the "pre-accident" self.

What is more, the patient did not remember anything about the circumstances in which he had been admitted to the hospital. He felt suspicious towards the doctors, whom he accused of insidiously keeping him in the hospital for too long and conducting bizarre medical experiments on him.

YY	Oh yes! Well, I spend my time in a pub I am a beer drinker and old beer drinker yes but a homeless one that's it, I am an old, homeless beer drinker! I sit in bars and pubs It's just that the white coats were stalking me	
	and locked me up in the hospital. They were digging around in my grey matter [he knocks at his head with his finger!] But nothing hurts me only the doctors are picking on me and don't want to let me go home, but I'm going back to the pub anyway Oh, yes that's where I belong.	

It is known from the family interview that the patient drank beer very rarely before the injury. However, at the time of this interview he was always saying about himself that he was a beer drinker, and brought that subject into every conversation. After subsequent interviews – especially with family members – it was revealed that before the injury YY made friends with the owner of a local pub, whose name, oddly enough, happened to be Piwosz - Beerdrinker.

In the further course of rehabilitation, the patient began to take into account two periods in his identity; however, it was vital to exclude the possibility of his suffering from amnesia, which was done on the basis of an interview. Below the key moment of that conversation is presented.

OB2 - researcher no. 2

YY - patient

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OB.	How old are you?	OB. attempts to make the personal data precise, in order to decide whether amnesia can be diagnosed.
YY	What? Three, I am three years old. I am a clone, you know, well, they cloned me three years ago, when they were digging around in my grey matter.	In this way YY demonstrates his conviction there is a huge discrepancy between his presence and his past.
ОВ.	So, which year you were born in?	OB. Once more verifies the autobiographic knowledge of YY.
YY	1962. It is only according to the calendar that someone like me is 42 years old, but I'm really three, you know, three, because I was cloned.	This answer proves that YY has a disruption of identity continuity, not amnesia. He knows the year of his birth but has "disowned" that fact.

It is stressed in the literature that, regardless of the realities, patients have a tendency to idealize the period when "they were healthy and everything was perfect", in contrast to "now, when I am ill, and everything is horrible" (Grochmal-Bach & Pąchalska, 2004). During rehabilitation, patients get acquainted with the "metamorphosis" they have undergone. It is not an easy process, because apart from the necessity to provide psychological help to make it easier for the patients to bear the bitterness, or often grief, after losing their "pre-accident" selves, it is vital to mobilize them to get involved in the creation of the new, "post-accidental" self. Nevertheless, if this process is successful, patients often declare they are better people then, in comparison to the ones they were before (which means, before the accident and the coma) (Pąchalska, 2003; Grochmal-Bach & Pąchalska, 2004).

The loss of the "pre-accident" identity distorts the communication of the person with the environment, and may well lead to isolation. Families often state that the accident took away forever their loved one nearly as completely as if they had died. Therefore it is vital to first of all introduce a systemic family therapy, aimed at helping both the patient and his family to accept the new identity. Secondly, a bridge of sorts needs to be built between the past and current selves. It is important, as previously stated, to start and continue self-development. Despite the long disability, a patient aroused from a prolonged coma may begin a productive, creative and satisfying life. Hence it is highly recommended to undertake all possible steps to reduce identity disturbances.

CONCLUSIONS

On the basis of our research it may be concluded that patients aroused from a long-term coma display:

- disruption in the continuity of identity, which is connected with a leap along the psychological timeline, due to which the personal past is not perceived as linked with the present moment,
- 2. disruption of identity coherence, especially in terms of the congruity of each of the elements of the self;

- inadequate perception of reality, due to the fact that distortions of autobiographic memory trigger inadequate structuring of events in the real world;
- 4. social isolation, as a consequence of losing former social roles, which usually leads to poverty, diminishing one's social status, increased dependence, etc.
- 5. fracture within other identity spheres, connected with difficulties in analysing one's own self before and after the accident, and in consequence with creating a false identity.

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