

Abstracts

correlation between 'sense of self' measures and the development of PTSD. Conclusion: There was significant data to support a follow-up study to continue evaluating links between a strong or weak 'sense of self' and the development of PTSD in individuals with TBIs. A longitudinal study following mild and moderate TBI cases has been proposed and should be underway by the date of this conference.

O.25

Risk factors for suicidal ideation after mild traumatic brain injury

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Introduction: Traumatic brain injury (TBI) has known association with depression and increased risk of suicidal ideation (SI). The prevalence and risk factors for SI following TBI were examined prospectively in mild and moderate TBI presenting to a large trauma hospital.

Methods: Prospective data was collected over 14 years. Radiological and clinical features were collected at admission; psychiatric and social assessment took place at 3 and 6 months. Over 50 demographic, outcome, and psychometric measures were evaluated. Chi-square analyses were used to determine correlates of SI. Logistic regression analysis was performed to model the predictors.

Results: Between 1998 and 2012, 2296 TBI patients presented to ER (64% male, mean age = 34.7 years), 82% of cases were mild (mTBI). The overall frequency of SI at 3 months was 24% and increased to 53% by 6 months, regardless of severity.

From presentation in ER, altered level of consciousness ($p=.008$), female sex ($p=.01$), and mechanism of injury (car driver, passenger or pedestrian, $p=0.025$) were correlated with higher SI. Radiological and clinical variables (GCS, amnesia length) were not. Follow-up psychiatric assessment revealed sociodemographic predictors of SI: English as a second language ($p=.0001$), marital status ($p=.002$), professional ($p=.003$), previously diagnosed schizophrenia or depression ($p=.0001$). Unique predictors of SI at 6 months included unemployment ($p=.024$) and no past history TBI ($p=0.0008$).

Conclusion: Suicidal intent following mTBI is frequent and risk does not decrease with time from injury. Current methods for ER assessment of patients with mTBI fail to identify patients at highest risk. The identification of demographic predictors of SI can guide improvements for identifying patients at risk. Our observation of a delayed increase in SI indicates a time window for therapeutic intervention.

O.26

Self-perceived quality of life in TBI patients and its plausible correlation with cognitive impairment and psychological disorders

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Introduction: Designed to explore self-perception of quality of life, and inspired by WHO definition of QoL (1994), this clinical study has adopted a phenomenological perspective based on subjective perception (patients' experience and expectations) and objective measurement (neuropsychological/psychological assessment).

Objective: Aim of this study is to search for a plausible correlation of patient's self-perceived quality of life with severity of cognitive impairment and psychological disorders.

Patients: The sample is composed of 29 TBI patients (age 23 to 56), all having gone through the process of filing civil law suits.

Materials and Methods: Data was compiled through two 4h00 length semi-directive interviews with patients and family (NRS, Levin, 1991) with open questions inspired from the WHO definition of quality of life (physical health, appearance, level of autonomy, self-esteem, family/social relations, personal/spiritual beliefs, environment, future

expectations) and neuropsychological and psychological assessment (Wechsler Wais III, Grober et Buschke RL-RI-16, Rey-Osterrieth Complex Figure Test (ROCF), Trail Making Test, Cardebat Semantic and phonemic verbal fluencies, Beck Depression Inventory, Hirschfeld Mood Disorder Questionnaire, Coopersmith Self-Esteem Inventory, Rorschach).

Results: No correlation has been found between self-perceived quality of life with level of impairment or presence of psychological disorders but between awareness of cognitive impairment and self-perceived quality of life. Euphoric frontal syndrome and anosognosia result as improving self-perception of quality of life and giving normative self-esteem even if patients show slight signs of depression, while awareness of cognitive impairment is paired with a negative perception of QoL, low self-esteem and more severe depression.

Conclusion: A further longitudinal study with a larger sample of patients must be pursued to better understand the potential impact of awareness of neurological and psychological disorders after TBI in self-perception of quality of life in order to improve therapeutic care and information to families.

O.27

Environmental factors and their impact on the long term rehabilitation of a person with traumatic brain injury

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Introduction: Traumatic brain injury (TBI) affects millions of people worldwide and causes significant physical, emotional, and cognitive disabilities among those affected. Advances in life-saving measures have increased survival from TBI, leading to more individuals living with the consequences of these injuries. Many factors influence the rehabilitation outcome, using International Classification of Functioning (ICF) occupational therapists recognize those factors and plan treatment program. The ICF Core Sets are tools that assess various health conditions and the functioning of an individual.

Objective: In the study a Brief Core Set for TBI has been used, with emphasis on the environmental factors, to determine which environmental factors have the greatest impact on a person with TBI in the long term rehabilitation.

Methods: Review of the case history of a 42 year old male patient after TBI was performed; data from the beginning of the rehabilitation program and also data from discharge into his home environment were entered into the Brief Core Set for TBI. Alongside a review of domestic and foreign literature was conducted.

Results: The Brief Core Set for TBI showed that occupational therapists can influence some aspects of the environmental factors (family, products and technology), and that healthcare system takes care of the costs of rehabilitation. However, there is still a gap in the social aspects of the environmental factors (stigmatization, social isolation, high costs of home adaptation).

Conclusions: Using the Brief Core Set for TBI, occupational therapists can determine what kind of facilitators or barriers patient after TBI will experience when returning to his home environment. Using our knowledge as occupational therapists we can educate family members or caregivers, we can advise how to adapt home environment in a way that person will be able to live a full life despite his limitations.

07. Neurological Rehabilitation in TBI and Ethics

O.28

Ethics in neurorehabilitation

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The moral and social principles of the modern Western community were initiated with the onset of the Judeo-Christian Ideology, based

on the 10 commandments of Moses, establishing the guidance of ethical and moral rules. In the antique phase of the Western world the philosophy of the Greco-Roman culture and its founders, Socrates, Plato and Aristoteles, was the basis of ethical rules. They were refined by the philosophical work of Saint Augustinus, critically analyzed by Thomas Aquinas.

Immanuel Kant's Categorical Imperative summarized the European ethical demands: "Every human being has to act that his action could be an eternal law".

Biomedical ethics are bound on Hippocratic principles and fundamentally based on the Western ethical rules with their historical roots. In modern medicine the Declaration of Human Rights (1948) in its practical use as well as in research the Helsinki Declaration (1965) and as a next step the Unesco Declaration of Paris (2005) are the actual directives. They are including social, legal and environmental dimensions in requiring patient's autonomy and patient's responsibility. Article 12 of the Paris Declaration requires respect for cultural diversity and pluralism. The development of modern medicine, especially in the field of neuroscience with all the new technical possibilities and the social considerations needs a harmonization to include the different cultural and religious requirements to be accepted.

The ethical based demand is that neurorehabilitation in all acute neurological diseases has to be continued as long as improvement can be expected - even for years. A temporary neurorehabilitation program has to be accepted in chronic conditions. For ending a neurorehabilitation program all prognostic possibilities have to be proven.

O.29

Games and arts fun ways to develop capabilities

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Before the accident I was a common teacher of arts. Now, I am still doing that but it doesn't make sense for me anymore, because I've learned a lot after the TBI and now I want to work on confronting its sequels. In my experience as a TBI person, I learned one can be stimulated to improve their own rehabilitation.

The brain is a mystery, and it can surprise us by doing improbable things.

Through plastic arts one can stimulate their own brain to work the movement of the hand, to look for their own inner-self and happiness, to improve communication, to stand for a longer time.

I created art classes for TBI persons. Students will come to these classes paying extra money (for material) after a course of neurorehabilitation in a very famous center in my country, Portugal. Plus, the result is a piece of art you can exhibit, offer and talk about with others. The result is not only the art, but also the social experience. In my speech at the TBI Challenge I would like to serve as an example to other TBI survivors as a living proof that we should always look for and find our best solutions for rehabilitation and for life. I want to stand before the scientific society and present myself as a person who could have been killed in a car accident, who lost all her friends, fiancé and hopes in life, and yet here I am fighting, talking, walking and surprising the medical society with my improvements. I would like to remember TBI families and care givers to give TBI persons a chance to prove they can do more than just rehabilitation treatments. I would like to present a multimedia exhibition throughout my intervention

O.30

Experienced Disablement in the Narration of People with Traumatic Brain Injury - Anthropological Perspective

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TBI affects often significantly person's abilities as well as her personality, behaviour and emotionality. Her self/subjectivity fractures, which causes often feelings of confusion. Own reactions and action can be surprising. The self no longer works as it used to work.

Objective: to search from cultural viewpoint the strategy of TBI-people to cope with their injury as well as to adapt the contradiction in self caused by the injury.

Material: informal interviews of 24 Finnish TBI-people (16 male, 8 female) and written narratives of 23 Finnish TBI-people (12 female, 11 male). Nine of the writers (6 male, 3 female) are also interviewees. The interviews has been executed 3-4 times per person within about one year period (altogether 74 interviews). Interviewees are 22-62 years old and have been injured at the age of 14-53.

Results: TBI causes disappearance of cultural knowledge and automation of function (when physical and cognitive functions (etc. memory) become injured), which leads to feelings of confusion and produces a fracture of experienced self as well as a need to reconstruct subjectivity according to a cultural norm/expectations. In addition, TBI-person's experience of her subjectivity is becoming layered, which can be described as the dynamics between 1) pre-injured, 2) post-injured, 3) rehabilitating and 4) norm selves. These layers appear partly overlapping and contradictory in the experience of an injured person and complicate the construction of coherent subjectivity.

In rehabilitation there is a need to use the knowledge from studies searching the experiences of the injured people. How an injured person is experiencing herself affects crucially to her motivation in rehabilitation. The lost self is connected to information loss in cultural environment of a person, who does not have anymore sufficient control of her life because of inability to function successfully. Research is a PhD. study in cultural anthropology.

O.31

Ethics in neurorehabilitation

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In this study ethics means to be again able to take decisions to solve problems in a conscious way; that is: the objective/therapist does not overcome the subjective/patient.

On the basis of : 1) the discovery of the passage from objective to the subjective and vice versa, 2) the new theory of the Cognitive Process, 3) the unicity of the Cognitive Process and consistently the unicity of its recovery, this study aims to demonstrate the recovery of the synchronism of information coming from internal/subjective and external/objective space leads to decisions awareness. Two subjects (Autistic and DSA) have been undergone, for six months to my rehabilitative method. The Autistic subject highlighted deficits caused by a perception based mainly on visual and auditive information due to genetic causes. The DSA subject had a very high IQ, but, besides, he was unable to solve problems. As a consequence of our investigation, this was due to an exposure in early age and for long time to prevalent visual and auditive information by video-game, TV and play-station. In both cases, the information of the internal space was unconscious. The results reached by autistic subject were very interesting regarding the goals of the tailored rehabilitative program. The results showed by DSA subject were swinging: the parents were unable to deny their son to play with the games above named. If the information coming from the external space does not synchronize with the one of the internal space on the reference system



BIF European Confederation

SELBST
HILFE
GRUPPE



SCHÄDEL
HIRN
TRAUMA

Trauma

Österreichische Gesellschaft
für Schädel-Hirn-Trauma

2nd TBI-Challenge.eu 2013



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September 19th to 20th, 2013 in Vienna

Biennial Interdisciplinary Conference
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Karl Landsteiner Institute
for Neurorehabilitation
and Space Neurology

Ethics in Neurorehabilitation

F. Gerstenbrand, Ch. Kurzmann

2nd TBI-Challenge.eu 2013
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Ethics

- Altruism
- Sense of Honour
- Justness
- Respect for others
- Solidarity
- Ability to forgive

Definition of ethics

- **Ethics:** Part of philosophy dealing with morality
- **Moral** is search for an inner standard
- **Kant's Categorical Imperative:**
The individual shall act in a way that his action can be regarded as general law

Occidental Ethics Western ethical thinking

- Founders:
 - Socrates, Plato, Aristoteles
Greek philosophy: moral virtue
values are natural rather than conventional ethics as science
 - Saint Augustinus, Thomas Aquinas
Incorporation of Greek ethics
Attainment of happiness
God given natural order
 - Immanuel Kant
Categorical imperative: the individual shall act in a way, that this action can be regarded as general law
 - Modern ethics
Different schools:
Value ethics, existentialistic ethics, American bioethics, Marxian ethics, theological ethics

Bioethical principles

Medical conduct, physicians obligations
(Belmont Criteria, 1979)

- Autonomy of the patient
- Beneficence
- Non-maleficency
- Justice
- Trust

Hippocratic oath

Obligation to heal
Not do anything to harm the patient
No continuation of therapy in untreatable disease
No therapy in advanced physical and mental destruction
No continuation of life prolongation for hours or days
No prolongation of suffering during dying
Not to tell anyone the details of patients
No admitting of lethal poison, even as advice

Will to respect the teacher like own parents, sharing one's life support with teacher or his successors, treated as own brothers
Medical teaching to own sons and the sons of the teacher or to pupils bound by physician's rules and oath

Hippocratic oath

Obligation for modern physicians

- Curative element: Main demand of physician is to do everything for the benefit of a patient to the best of his knowledge and ability, to keep away damages, injustice and risks.
- Obligation to minimize suffering of a patient
- Strict prohibition to apply lethal poison or to give advise to use deadly poison
- A prolongation of suffering has to be prevented
- The basic obligation of a physician is to preserve life.
- The decision about life and death of a patient is not in the hands of a physician

Human Rights

- **1948: Universal Declaration of Human Rights (UDHR)**
 - International reaction after the 2nd World War and medical experiments with human beings
 - Adopted by the United Nations General Assembly
 - Right of everybody to live independently
 - Right for health

World Medical Association, Helsinki Declaration, 1964

Medical Research Involving Human Subjects

Ethical Principles

- Medical progress is based on research which ultimately must rest in part on experimentation involving human subjects
- In medical research on human subject, considerations related to the well-being of the human subject should take precedence over the interest of science and society
- International Code of Medical Ethics : A physician shall act only in patient interest when providing medical care which might have the effect of weakening the physical and mental condition of the patient
- Ethical Principles to provide guidance for physicians and other participants in medical research involving human subjects Including identifiable material or identifiable data

UNESCO Bioethics Declaration on

Human Rights

Paris, September 2005

Aims – Article 2

- Universal framework of principles and procedures to guide States in bioethics
- to guide the actions from individuals as well as communities, public and private
- to promote respect for human dignity and protect human rights
- to recognize the importance of freedom in scientific research
- to foster multidisciplinary and pluralistic dialogue
- to promote equitable access to medical, scientific and technological development
- to safeguard and promote the interest of the present and future generations
- to underline the importance of biodiversity

UNESCO Bioethics Declaration on

Human Rights

Paris, September 2005

- Art. 3: Human dignity and human rights
 - Fundamental freedoms: fully respect
- Art. 4: Benefit and harm
 - Applying and advancing scientific knowledge, medical practice and associated technologies, direct and indirect benefits to patients including research participants
- Art. 5: Autonomy and individual responsibility
 - Persons to make decisions while taking responsibility for those decisions and respecting the autonomy of others
- Art. 6: Consent

Patients unable to consent

Decision making on behalf of patients

- Presumed consent in emergency situations
- Proxy consent by an authorised person (legal representative)
- Living will
 - Advanced directives
 - Previously expressed wishes

Patient-Doctor Relationship

- Expectation of personal attention
- Trust
- Individualized treatment
- Best available and best care
- Best benefit to risk/ratio

Rights and responsibilities Physician and patient

- The treating physician has the individual responsibility for his patient. Highest level of his education and training is essential and necessary.
- The treating physician is guided by ethical principles, medical guidelines, declaration, domestic and international law and human rights law.
- The personal responsibility of the physician to his patient can't be replaced.
- Patient's right is to accept or to refuse the recommendation of a treatment program.
- Patient's right is to interrupt a running treatment program
- The physician's obligation is to inform the patient about the danger for his health in case of refusal or interruption of a treatment program.

Decisions during treatment program of neurorehabilitation

- Decision to start rehabilitation program or to refuse
- Start of rehabilitation program as soon as possible
- Decision to continue or to reduce special medical treatment
- Decision to continue the active rehabilitation program in a special center or to transfer the patient to a nursing home with long-term activating program, or at home care

Evidenced Based Medicine Ethical position

- A cultural and methodological approach to clinical practice helping to make decisions based on clinical expertise and an intimate knowledge of the individual patient's situations, beliefs, and priorities.
- Considered to be the scientifically based art of medicine.
- It de-emphasizes intuition and unsystematic clinical experience as the background for medical decision-making.

Evidence Based Medicine (EBM) Critics I

- Among internal bias, economic-based interest may influence the development and diffusion of research and its results.
- Difficulty to convert EBM into clinical practice recommendations- it is nearly impossible to make recommendations that are appropriate in every situation.
- EBM cannot be evaluated as the scientific "totem" of the third millennium, neither as the clinical digest of medical literature.

Evidence Based Medicine (EBM) Critics II

- "Evidence" in EBM must be of high quality in order to be useful but is not always the case
 - "Real world" trials often do not give the same results as these highly artificial controlled clinical studies.
 - EBM may be unreliable, sometimes giving different results to subsequent large randomized trials
 - Bias in the hypotheses tested in large trials usually covered by commercially interested companies
 - Process of journal review and publication is capricious, slow, may have a selection bias towards positive studies (communication channels for evidence are often unsatisfactory)
 - For many rarer conditions there is no "high level" evidence (pediatrics, subspecialty surgery, etc.)
 - Usual no trials of old people who are on many pills
- DS Celermajer, 2001
S Butterworth, 2004

Ethics in neurology Special conditions

- Primarily in neurology and psychiatry ethical rules to accept
- Bioethical guidelines fully to transfer and to apply in neurology
- Informed consent in all details to transfer in daily practice and research
- Special guidelines and medico-legal laws for patients unable to consent in daily practice and research
- Special protection of patients with neurological and psychiatric diseases
- Consideration of patient's capability following informed consent

Summarizing I

- Every human being has the right to live (Paris Declaration, 2005).
- Every human being has the right to most modern medical treatment, modern neuro-rehabilitation adjusted to the special condition and best nursing care.
- A patient has to be cared according to the basic human rights and the medical principles.

Summarizing II

- Economic consideration are not acceptable in treatment and life decision (Hippocratic principles and Universal Declaration on Human Rights (December 10th, 1948).
- According to Hippocratic principles patients have to be treated in dignity but not to be "over-treated" by all modern possibilities.

Summarizing III

- Every patient with an acute brain damage of different etiology needs a neurorehabilitation treatment.
- Every neurorehabilitation has to be organized with an individual program, depending on existing neurological deficits.
- A neurorehabilitation program has to be continued as long as improvement can be expected, even for years.
- After acute brain damage, but also under chronically confirmed conditions, temporary phases of neurorehabilitation can be repeated;
Repeated Form of Neurorehabilitation.
- Before ending a neurorehabilitation program, remaining rehabilitation potentials have to be proofed.