Reclaiming Self after Brain Injury:

Hope for a New, “New Self”


NEW YEAR
NEW YOU

“Self” is a HOT TOPIC

Can COVID-19 alter your personality? Here's what brain research shows.
National Geographic PUBLISHED DECEMBER 29, 2021
https://www.nationalgeographic.com/science/article/can-covid-19-alter-your-personality-heres-what-brain-research-shows

HOW THE BRAIN PRESERVES SELF Scientific American December 21, 2021
https://www.scientificamerican.com/article/how-our-brain-preserves-our-sense-of-self/

A SENSE OF SELF SCIENCE 11 Jun 2021
https://www.science.org/doi/abs/10.1126/science.372.6547.1142

Brain Scientists Probe the Mechanisms Behind Self-Identity Discover Magazine Jan 3, 2022
https://www.discovermagazine.com/mind/brain-scientists-probe-the-mechanisms-behind-self-identity

I Miss Me. Do You Miss You? Psychology Today August 5, 2020
https://www.psychologytoday.com/gb/blog/wander-woman/202008/i-miss-me-do-you-miss-your-old-self

The Tragedy of long-Covid Harvard Heath Publishing March 1, 2021
s://www.health.harvard.edu/blog/the-tragedy-of-the-post-covid-long-haulers-202010152479_“


Silent epidemic*
Est 69 M/yr TBIs globally
30 M CNS infections/yr globally
16.9 M strokes /yr Globally
*Global Neurosurgery Initiative Estimating the global incidence of traumatic brain injury 2019

“Potentially the **most enduring change after brain injury** relates to the *subjective experience* of who someone is and is seen to be.” (Coetzer ’08)

“[Loss of sense of self] is so common in fact that the it has been described as being "almost the ***sine qua non***” of brain injury.”

Coetzer R. “Holistic neuro-rehabilitation in the community: is identity a key issue? “ *Neuropsychol Rehabil*. 2008 Oct-Dec;18(5-6):766-83. doi: 10.1080/09602010701860266. PMID: 18654932 at 767.

Myles, Stephen M. “”Understanding and Treating Loss of Sense of Self Following Brain Injury: A Behavior Analytic Approach.” 2004 Int J of Psych and Psych Theory. Vol 4. No 3, 487-504 at 488

Roadmap

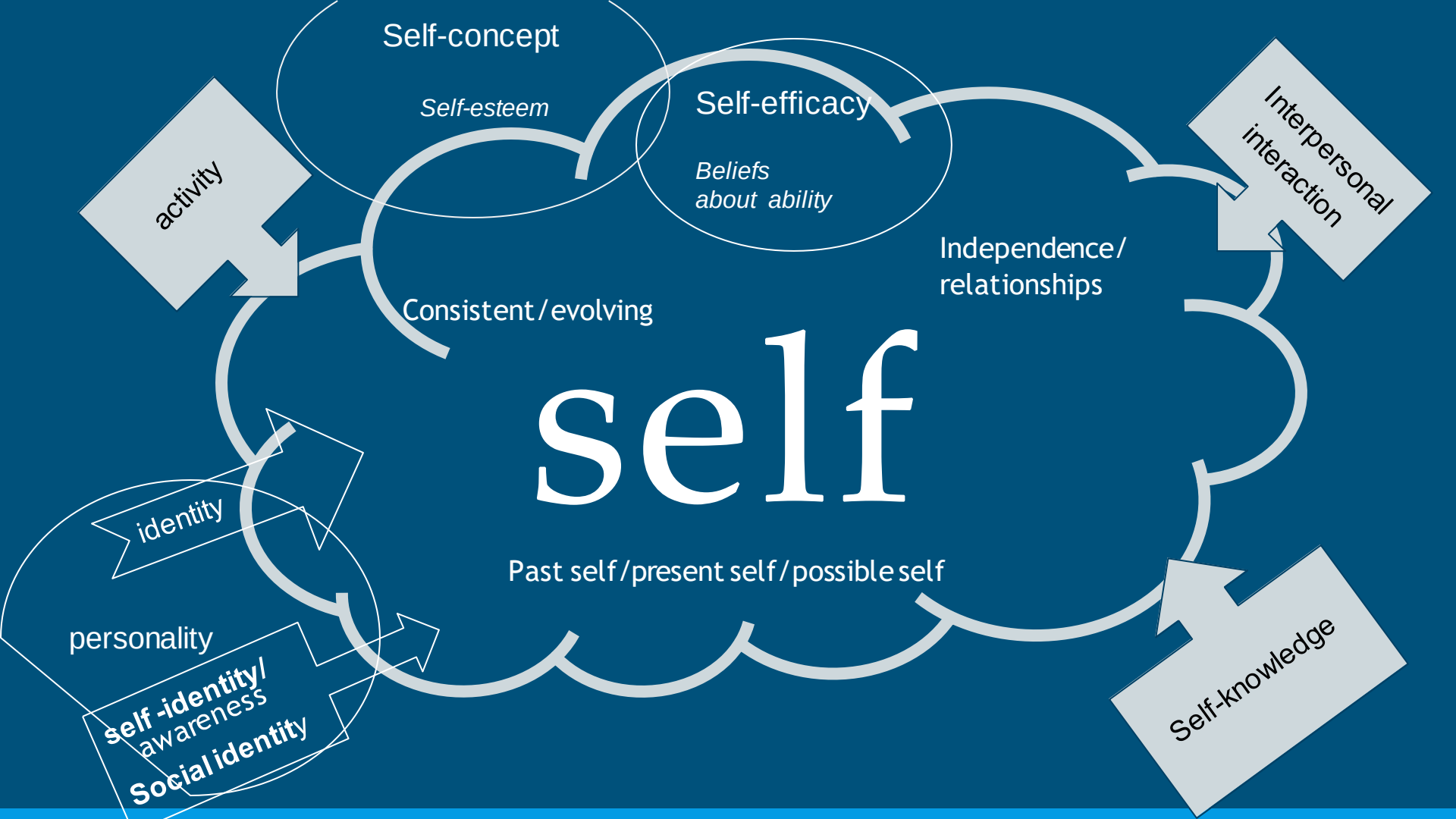
1) “SCIENCE”
    a) Self
    b) Loss of Sense of Self
        i) Importance of patient voice
    c) Impaired self-awareness
        i) Importance of Patient Voice
2) My recovery Story evidence of Importance of Patient voice and Advances Returning Self
3) Advances
4) Questions

CONDITIONS: THE ACTION "DISTRIBUTION OF SURPLUS PROFITS" OF FINKELSTEIN & PARTNER IS PART OF THE DIFFERENT GAMES WITH WINNINGS ORGANIZED IN 2014 BY FINKELSTEIN & PARTNER TO PUBLICIZE ESOTERIC METHODS WHICH CAN BE PRESENTED UNDER DIFFERENT ASPECTS AND NAMES AND WHICH CONSIST IN ONE MAIN WINNER AND OTHER MINOR WINNERS. THE RIGHT TO PARTICIPATE IS RESERVED TO THOSE HAVING RECEIVED THE DOCUMENT "REQUEST FORM", WHICH IS USED AS A PARTICIPATION FORM AND WHO ARE AT LEAST 18 YEARS OLD AND WHO HAVE SCRUPULOUSLY COMPLETED THE DOCUMENT AND WHO HAVE RETURNED THE SAID DOCUMENT WITHIN THE FIXED TIME LIMITS TO THE INDICATED ADDRESS. THE DATE LIMIT TO SEND IS 12/31/2014 FOR SO LONG AS THE PRESENT DOCUMENTS DON'T INDICATE A DIFFERENT DATE. PARTICIPATION IS FREE WITH NO OBLIGATION TO BUY. THOSE WHO ARE NOT AUTHORIZED TO PARTICIPATE ARE: STAFF OF THE COMPANY FINKELSTEIN & PARTNER INCLUDING THEIR FAMILIES, ALONG WITH THE AGENCIES, SERVICE COMPANIES OR OTHER PROVIDERS CONCERNED BY THE PUBLICITY ACTIONS. AT THE END OF THE ACTION WHICH IS FIXED ON 12/31/2014, THERE WILL BE A DRAW AMONG ALL THE FORMS HAVING BEEN CORRECTLY COMPLETED AND RECEIVED WITHIN THE TIME LIMITS, MADE BY A NEUTRAL PERSON AT RANDOM, OF A WINNING NUMBER, WHICH IS DESIGNATED IN THE PRESENT CASE BY "NUMBER OF PERSONAL FILE" AS BEING THE WINNING NUMBER. THE WINNINGS OF $ 51,164.40 WILL BE PAID TO THE RECIPIENT OF THIS WINNING NUMBER. THE WINNER WILL BE INFORMED OF HIS WINNINGS AT THE END OF THE ACTION. HE WILL THEN HAVE TWO WEEKS TO CLAIM HIS WINNINGS IN WRITING TO FINKELSTEIN & PARTNER. THE PAYMENT OF THE SUM WILL BE MADE WITHIN THE FOUR FOLLOWING WEEKS. ON TOP OF THIS, A CONSOLATION PRIZE WILL BE GIVEN TO ALL PARTICIPANTS. THIS PRIZE CAN ALSO BE A REDUCTION VOUCHER ON PRODUCTS OF ANOTHER OFFER OF FINKELSTEIN & PARTNER. CASH PAYMENTS ARE NOT POSSIBLE. IF THE UNIQUE WINNER OF THE MAIN PRIZE DOES NOT MAKE HIMSELF KNOWN, THE ORGANIZER OF THE GAME IS NOT OBLIGED TO ADVISE HIM ONCE AGAIN OF HIS WINNINGS. WINNINGS THAT REMAIN UNCLAIMED OR WHICH ARE CLAIMED OUTSIDE OF THE TIME LIMITS REMAIN THE PROPERTY OF FINKELSTEIN & PARTNER. IN THIS CASE, THE ORGANIZER CAN DRAW A NEW WINNER IN REPLACEMENT, AMONG ALL THE OTHER PARTICIPANTS WHO HAVE RETURNED WITHIN THE TIME LIMITS AND COMPLETED THEIR PARTICIPATION FORM CORRECTLY. $ 5,000.00 WILL BE MADE AVAILABLE AS A SPECIAL AMOUNT. THIS MEASURE IS NOT COMPULSORY AND CANNOT BE CLAIMED LEGALLY. BY ACCEPTING HIS PRIZE, THE WINNER OF THE MAIN PRIZE OF THE ACTION ACCEPTS TO MAKE AVAILABLE HIS NAME AND HIS PHOTO FOR ULTERIOR PUBLICITIES. THE ORGANIZING COMPANY PROMISES NOT TO USE HIS NAME AND PHOTO IN A DISCRIMINATORY MANNER AND TO ALWAYS RESPECT THE RIGHTS OF THE GREAT WINNER. FOR REASONS OF ORGANIZATION, NO INFORMATION WILL BE GIVEN BY TELEPHONE. THE GAME WITH WINNINGS IS FREE AND ENTIRELY INDEPENDENT OF AN ORDER. IT IS HIGHLY RECOMMENDED TO READ CAREFULLY THE PRESENT CONDITIONS. TO HAVE THE RIGHT TO WINNINGS, THE WINNER MUST ABIDE BY THE PRESENT CONDITIONS. AT THE END OF THE GAME, STAMP FEES ON THE PARTICIPATION ENVELOPE CAN BE REIMBURSED UPON SIMPLE WRITTEN REQUEST. ANY RECOURSE TO JUSTICE IS EXCLUDED. THE GAME WITH WINNINGS IS ORGANIZED ON AN INTERNATIONAL LEVEL. THE CHANCE OF WINNING THE MAIN PRIZE IS 1:117,000. IF YOUR CHECK IS RETURNED NSF OR FOR INSUFFICIENT FUNDS BY YOUR BANK YOU HEREBY AUTHORIZE US TO ELECTRONICALLY DEBIT THE FACE AMOUNT OF THE CHECK AND DEBIT ALL APPLICABLE STATE ALLOWABLE FEES.

X102 4 USA

OT | Pt received asleep on mat c verbal outbursts or restlessness noted. Pt awoken after 10 minutes, SPT mat→w/c c mod (A)

NSG. | - Alert, restless when pt. was working c OT therapist. Pt. fearful and keep stating that she doesn't have her memory
- Observed increased anxiety - reassurance done; allowed to rest in bed via two person assist -
- Observed sleeping (eyes closed) c "Sale" music turned on.
- Attended all a.m. therapies c occasional restlessness & verbal outburst
- Toileted @ short intervals & voided g.s.
- Bed rest maintained while in w/c


Self-concept
Self-esteem
Self-efficacy
Beliefs about ability
activity
Interpersonal interaction
Independence/ relationships
Consistent/evolving
self
identity
personality
self-identity/ awareness
Social identity
Past self/present self/possible self
Self-knowledge

“SELF” according to neuroscience

- “A major weakness”*/ “ENIGMA”* for cognitive science.
- “self emerges from brain as a product of biology and culture.”*

Johnstone B, Cohen D, Dennison A. The integration of sensations and mental experiences into a unified experience: A neuropsychological model for the "sense of self". Neuropsychologia. 2021 Aug 20;159:107939.

Ownsworth, T (2014) Self-identity after Brain Injury. London and New York: Psychology Press. at 26 and 27.

“SENSE OF SELF”

“The mental processes that provide one with feelings of singularity, coherence, individuality and unity that defines one as a unique and particular human being.” *

Banerjee, Meenakshi et al. ‘In Search of the “self”: Holistic Rehabilitation in Restoring Cognition and Recovering the “self” Following Traumatic Brain Injury: A Case Report’. 1 Jan. 2021 : 231 – 242.

SELF CHANGES

EVENTS IN LIFE WHEN CHANGE HAPPENS:

- *Neurological event (brain injury)*
- Major life transitions and stressful events- becoming a parent
- Social evaluation- feedback
- Psychotherapy targeting self -schema

Beadle EJ, Ownsworth T, Fleming J, Shum D. "The Impact of Traumatic Brain Injury on Self-Identity: A Systematic Review of the Evidence for Self-Concept Changes." *J Head Trauma Rehabil.* 2016 Mar-Apr;31(2):E12-25. d

How is the self lost after brain injury?

Loss of clear knowledge of self-* AMNESIA of past self to understand present self

Opaqueness of present self*- not understanding of cognitive/emtional impairments, “WHAT AM I?”

Loss of sense of self by comparison- past self-image/present self image -or- pre-injury future/post injury future**

Loss of self in the eyes of others- survivor is receiving messages from others that she is not the same person she used to be.

Nochi ’98 to Villa D, Causer H, Riley GA. Experiences that challenge self-identity following traumatic brain injury: a meta-synthesis of qualitative research. *Disabil Rehabil.* 2021 Nov;43(23):3298-3314.

“Loss of sense of self”

(characteristic features in lieu of def.)

1. "**Self estrangement**”-“conscious **AWARENESS** on the part of the survivor that they are **“not the same person.”**
2. Survivor makes a negative evaluation of post-injury self
3. Emotional distress- anger anxiety, depression, grief
4. **Denial***- "Protctive response in the face of **increasing recognition** of disability and emotional distress.” (avoidance)

Myles, Stephen M. “”Understanding and treating Loss of Sense of Self Following Brain Injury: A Behavior Analytic Approach.” 2004 Int J of Psych and Psych Theory. Vol 4. No 3, 487-504 at 489.

IMPLICATIONS of LSS / LSS with Denial

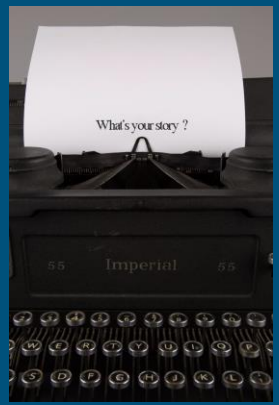
- Disengagement in rehabilitation*
- Disengagement ⟹ deterioration in functioning over time
- Poorer psychological adjustment (depression) in long term
- Greater risk of psychological distress upon exposure of impairment.
- Avoidance-> survivor becomes unable to even use in tact ability
- Overall diminished Qual of Life.

POSITIVE SELF-IDENTITY AFTER BRAIN INJURY

i. Focus on **revising self-narratives**

- The better than others self- "Things could be worse."
- The protesting self- Recognized impairment, but said other factors added to unhappiness.
- The grown self- past self was negative and TBI, though it left them with impairment, it gv them momentum for growth for the better in the future.
- The self living here and now- look at themselves without comparison to past selves or to anyone else.
- The recovering self (HOPE)]

Nochi, H. Reconstructing self-narratives in coping with traumatic brain injury. Soc Sci & Med 51 (2000) 1795-1804.

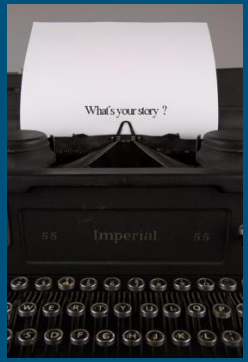


Treatment-how?

challenges:

- psych/neuro “turf war”
- Cognitive abilities are measured in quant terms.
- difficult to measure- loss of sense of self is a subjective experience**

How to capture the “subjective experience” of brain injury?



“Narrative enables entry into the **insider** experience, as the 'lifeworld’ or innerworld of meaning.”

D'Cruz K, Douglas J, Serry T. Narrative storytelling as both an advocacy tool and a therapeutic process: Perspectives of adult storytellers with acquired brain injury. Neuropsychol Rehabil. 2020 Sep;30(8):1409-1429.

Unawareness of Change in Self

Anosognosia- "The clinical phenomena in which a brain dysfunctional patient does not appear to be aware of their impaired neurological or neuropsychological function, which is obvious to the clinician and other reasonably attentive individual."

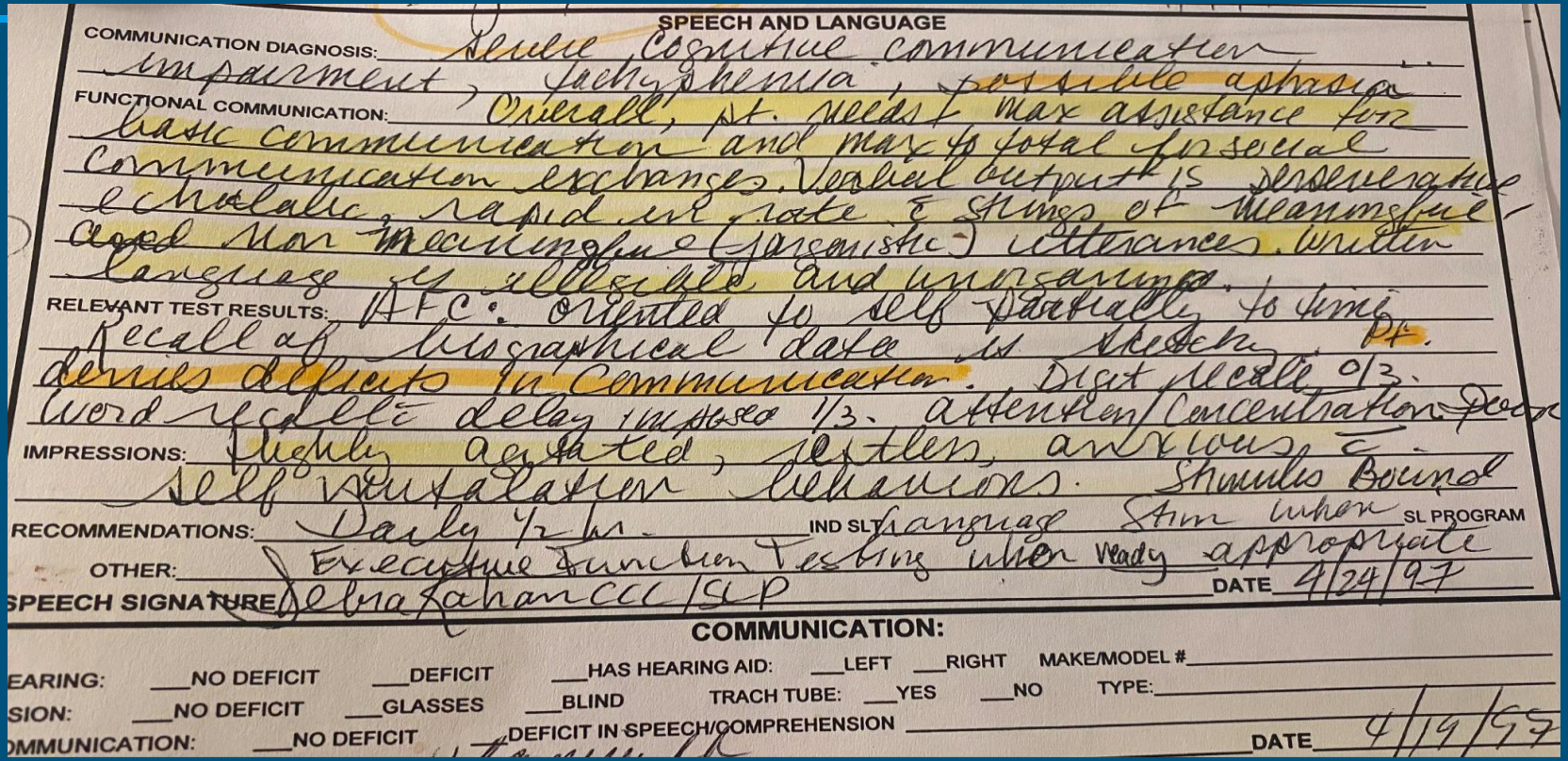
- "We use the term Impaired self awareness (ISA) to describe a partial syndrome of unawareness of the diturbed function."

Prigatano, George P. "Disturbances of self-awareness and rehabilitation of patients with traumatic brain injury: a 20-year perspective." *The Journal of head trauma rehabilitation* vol. 20,1 (2005): 19-29 at 20.

Prigatano, George P. "Anosognosia, denial, and other disorders of phenomenological experience" (202).

Prigatano, G.P *The* Study of Anosognosia (2011) Oxford New York at 495..

Impaired self-awareness of Aphasia



SPEECH AND LANGUAGE

COMMUNICATION DIAGNOSIS: Severe Cognitive communication impairment, Jachyphemia, possible aphasia

FUNCTIONAL COMMUNICATION: Overall, pt. needs + max assistance for basic communication and max to total for social communication exchanges. Verbal output is perseverative echolalic, rapid int. rate & stems of meaningful and non meaningful (jargonistic) utterances. Written language is illegible and unorganized.

RELEVANT TEST RESULTS: AFC: oriented to self partially to time Pt. Recall of biographical data is deficit. denies deficits in communication. Digit recall 0/3. word recall delay impaired 1/3. attention/concentration poor

IMPRESSIONS: Highly agitated, restless, anxious & self destructive behaviors. Stimulus Bound

RECOMMENDATIONS: Daily 1/2 hr. IND SL/language Stim when SL PROGRAM

OTHER: Executive function Testing when ready appropriate

SPEECH SIGNATURE Debra Kahan CCC/SLP DATE 4/24/97

COMMUNICATION:

HEARING: ___NO DEFICIT ___DEFICIT ___HAS HEARING AID: ___LEFT ___RIGHT MAKE/MODEL #_____

VISION: ___NO DEFICIT ___GLASSES ___BLIND TRACH TUBE: ___YES ___NO TYPE:_____

COMMUNICATION: ___NO DEFICIT ___DEFICIT IN SPEECH/COMPREHENSION _____ DATE 4/19/97

PROBLEM	DISCIPLINE	ACTION/OUTCOME
med.	Nsg.	given for sleep. Incontinent of urine kept clean and dry. Taking off her clothes and wandering around. Assistant sitting at the bedside to give pt. support and calm her down. Remains restless and yelling at times. Wisecare
med.	Nsg.	c/o stomach ache mylanta 30cc given. Pt. requested the Spanish station to be turned on. Pt. became very calm and quiet

Impaired self-awareness following TBI

IMPLICATIONS of impaired self-awareness

Decreased motivation to engage in rehabilitation-

Decreased safety from overestimation of ablity

Depression- if patient with impaired self-awareness attempt unrealistic goals and fail.

Caregiver distress

INITIAL EVALUATION

Ms. Perna is a 21-year-old single, white woman with three years of college education who was attending Colgate University as a senior. On March 21, 1997, she was involved as a passenger in a motor vehicle accident where she suffered multiple traumatic injuries including a head injury. She incurred basilar and left temporal bone fractures and a left subdural hematoma. Her past medical history was noncontributory.

COGNITIVE/BEHAVIORAL STATUS: On evaluation, Ms. Perna was alert, very restless, somewhat agitated, and complaining of pain. She attempted to cooperate and provided some accurate personal information. On mental status examination, she appeared mildly confused and moderate to severely impaired cognitively. She was oriented to person and partially oriented to place and time. She said she was a "nurses place" in Newark. Temporally, she was oriented to the correct month, saying that it was "1991." At first she said she was here because of pulling a muscle playing soccer.

Her primary memory span was somewhat impaired, and her ability to retrieve remotely stored data and her short-term memory were severely impaired. Higher order cognitive functions were at least moderately impaired, related to attention-concentration difficulties.

COMMUNICATION SKILLS: She correctly repeated utterances. Object naming was moderately impaired, and she provided perseverative and neologistic paraphasic substitutions. Her spontaneous utterances often were repetitive and stereotyped; she was unable to perform the 'automatic' process of counting from 1 to 30 correctly, even with considerable assistance. She followed a few simple commands correctly, but perseveration and right/left disorientation interfered with her executing commands.

PSYCHOSOCIAL STATUS: She said that she felt "fine." She appeared confused and distracted by pain.

PSYCHOLOGY GOALS: During her hospitalization, we will monitor her status. Prior to discharge, we will test her neuropsychologically in order to make outpatient treatment recommendations.

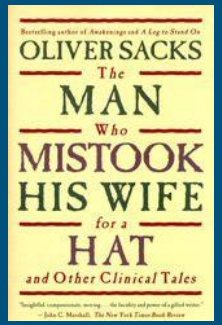
ASSMENT

Impaired self-awareness v2020

"a failure to experience (as assessed via subjective reports) a disturbance in higher integrative brain functions due to a disruption or damage to regions of the brain that are important for the normal performance of those higher integrative brain functions"

Prigatano, George P, and Mark Sherer. "Impaired Self-Awareness and Denial During the Postacute Phases After Moderate to Severe Traumatic Brain Injury." *Frontiers in psychology* vol. 11 1569. 16 Jul. 2020

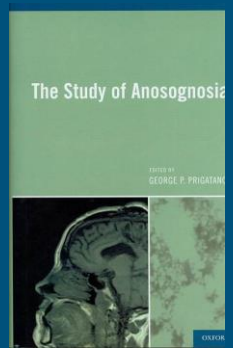
1985



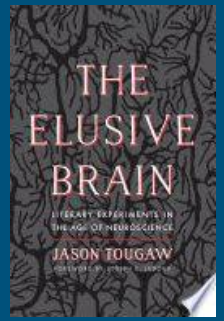
2004

Morris

2011



2018



2020

Denial of Disability

COGNITIVE REMEDIATION PROGRAM II
INITIAL EVALUATION
PERNA, TARA

reduced motor strength (left--upper/lower extremity)
reduced range of motion (left--upper/lower extremity)
impaired eye-hand coordination

Executive Functions
decreased flexibility of thought
decreased awareness of self
reduced integration of feedback
impaired sequencing ability
impaired conceptualization
impaired organization skills
impaired planning skills
reduced problem solving (identification, generation)
reduced abstract reasoning

Behavior/Psychosocial
decreased awareness of deficits
apathy
decreased insight/denial

Physical/Medical
medications
physical disabilities
impaired ambulation

Vocational/Educational
uncertainty regarding ability to return to previous educational pursuits
decreased basic skills (reading, spelling, math, writing)

TREATMENT PLAN
In order to address these deficit areas, Ms. Perna will participate in the following groups and individual sessions.

GROUPS: Psychosocial Group, Visual/Perceptual Group, Memory/New Learning Group, Brain Education Group, Language Group, Executive Functions Group, Basic Skills Group, Social Skills/Community Integration Group, Stress Management Group, Substance Awareness Group, Communications Group, Current Events Group and Vocational Awareness Group.

INDIVIDUAL: Case Management, Cognitive Therapy, Counseling, Executive Functions, Occupational Therapy, Physical Therapy, Speech and Language Therapy, Physical and Vocatio Therapy.

assignments and exams that support these claims. In viewing her long term goals, Mr. Perna contends that she will return to Law School in the fall of 1998. Related to this, Ms. Perna was counseled on the value of starting her law program part time and building up to a full time status. While Mrs. Perna states that she understands the logic of this strategy, she indicates that she will assess her academic abilities at the time of her enrollment.

Related to work, Ms. Perna reports that she has adjusted well to her part time position with a local law firm. It is noted that her duties will include filing, typing of memos, monitoring incoming telephone calls, and assisting in the organization of the office. Further, Ms. Perna indicates that her boss is pleased with her performance and would like to extend her hours once the current semester has ended. Additionally, Ms. Perna views the prospects of working full time as a way that she can build experience in the field develop her autonomy.

Given the prospect of expanding her position at the law firm and the progress she has made in her program and at school, Mrs. Perna has asked that her Cognitive Remediation Program be concluded at this time. It is noted that Ms. Perna's last day of attendance was 12/11/98. Should you have any further questions or concerns, please do not hesitate to contact us at 201-414-4700.

“A NEW ERA”

a. Fmri watched the brain in action in early 1990s
b. 2002 Neuroimaging found “self-awareness” in numerous parts of brain
c. “personhood thought in ’99 to be located in the brainstem, basal forebrain, paralimbic cortices and parietal cortical structures. (Damasio, 1999).
d. 2003 neuroimaging data saw that self-other processes happened in the right hemisphere.
e. 2007 “self-knowledge” located by FMRi in medial prefrontal cortex and the medial posterior parietal cortex.
f. 2009 - paralimbic region more active in depressed pop - often self-focus.
g. 2010 self-referential processing seen in anterior cingulate cortex showed activity inpatients in persistent veg state when name called. - consciousness not required.
h. 12/21/21- A new study explores how a brain region ties together memories of past and present self. The study surmises that this is the region, the ventral medial prefrontal cortex, may produce a model of self.

NEUROPLASTICITY/GENERATION

- 1998- HAPPENS IN THE ADULT BRAIN- supported and refuted by later studies.
- 1999- Learning promotes neurogenesis.*
- 1999- Voluntary exercise, specifically running promotes new cell growth. *
- 2007- New cell growth happens when exposed to learning in challenging new environments.*
- 2008- New challenging experiences stimulate new cell growth. *
- 2013- **Traumatic brain injury increases new cell production 3- 4 x.***

“Neuropsychology rehabilitation is entering a new era.”

“…potential evidence that more than compensatory training may occur as a result of different rehabilitation activities.”

Prigatano GP, Braga LW, Johnson SF, Souza LMN. Neuropsychological rehabilitation, neuroimaging and neuroplasticity: A clinical commentary. NeuroRehabilitation. 2021;49(2):255-265.