OSPEDALE PRIVATO SANTA VIOLA

18th International Neuropsychoanalysis Congress, “COMPULSION TO PREDICT”, London, 13-15 July 2017

THE IMPACT OF CAREGIVERS' INTERNAL WORKING MODELS ON CAREGIVING: A CASE STUDY ABOUT DISORDERS OF CONSCIOUSNESS

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INTRODUCTION AND BACKGROUND

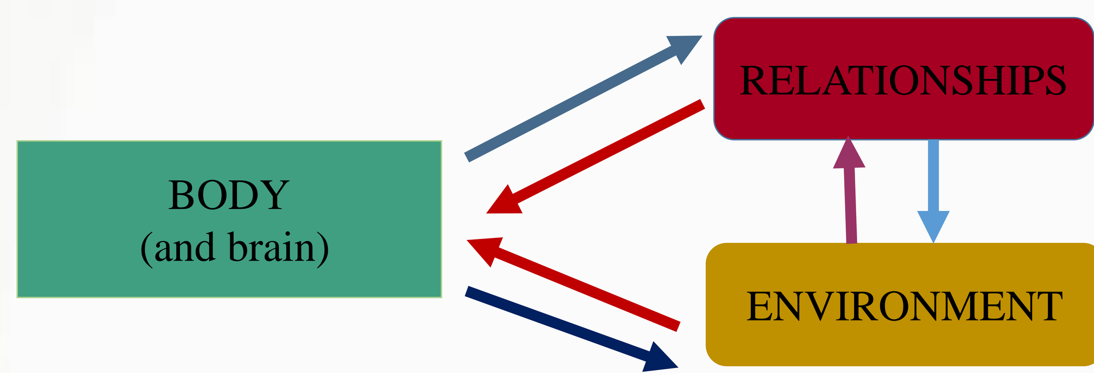
-**Consciousness** can be defined by two components: arousal and awareness. Disorders of consciousness (DOCs) are characterized by a disrupted relationship between these two components.

-**Vegetative state**: defined by recovery of arousal without signs of awareness. It is characterized by:

- Wakefulness
- No awareness of self or environment
- No sustained, reproducible, purposeful behavioral responses to external stimuli
- No language comprehension or expression
- Relatively preserved hypothalamic and brain stem autonomic functions
- Bowel and bladder incontinence
- Variably preserved cranial-nerve and spinal reflexes

(Gosseries et al., 2014)

Due to the severe compromising of autonomies, caregivers are crucial in both home and hospital settings.



In a vision in which the body (and the brain) perceives and simultaneously shapes environment and relationships, the caregiver may be considered as the relational context of the patient.

CAREGIVING AND ATTACHMENT

-Despite the severe impairment of consciousness, **the patient still represents a component of the attachment relationship** because he keeps on being present in caregivers' mind.

-**ATTACHMENT SYSTEM**: psychobiological system that motivates to build emotional bonds with significant others to protect themselves from threats and alleviate distress.
When the attachment figure is threatened (e.g. by an illness), caregiving behavior will be engaged to preserve the attachment bond.

-**Caregiving and attachment**: deeply inter-related (Bowbly, 1969; Simpson et al. 2010), both associated with specific neural circuitries (Panksepp, 1998; Coan, 2010). Caregiving behaviours are influenced by attachment styles (Romaniello et al., 2015) and Internal Working Models (Bowbly,1969)

INTERNAL WORKING MODELS IN CAREGIVING

-Products of repetitive relational experiences from which individuals builds unconscious mental representations and expectations about the self, significant others and the relationship between the two.

-Despite substantial changes DOCs cause, these caregiver's old intrapsychic and interpersonal dynamics keep on influence expectations, affective and behavioural interactions with the patient and the hospital professionals.

-To investigate the role of IWM and expectations about self and others in caregiving and to explore the relationships between IWM and other psychological features, a clinical case will be discussed.

CLINICAL CASE

-**Clinical Context**: a dedicated ward in S. Viola Hospital (Bologna, Italy), with a multidisciplinary staff, in which the caregiver is considered part of the care environment

SUBJECTS

THE CAREGIVER	THE PATIENT
-Middle aged woman -High school graduate -Secretary of her husband in a family-run business -After the event, totally devoted to the care of her husband -Detached, alexithymic, neglected appearance, sceptical and wary with others -Heavy smoker, Diabetes II type -Recent bereavement in the family (brother)	-Middle aged man -High school graduate -Medical salesman in a family-run business -In a Vegetative State since 2007 after a heart attack -Described as solitary, detached, usually far away from home -Severe hypertonia

INSTRUMENTS AND PROCEDURES

Beck Anxiety Inventory (BAI; Beck et al., 1988; Sica et al., 2005), a self-report measure of anxiety symptoms.

Semi-structured interview to collect caregiver and patient life history and features of their relationship

Affective Neuroscience Personality Scale (ANPS; Davis et al., 2003; Davis & Panksepp, 2011), a self-report measure of basic emotions (Panksepp, 1998): three positive (PLAY, SEEK, CARE), three negative (FEAR, ANGER, SADNESS).

Caregiver Burden Inventory (CBI; Novak & Guest, 1989; Marvardi et al.,2005) a self-report measure of burden

Defense Style Questionnaire (DSQ; Bond et al., 1995, San Martini et al., 2004), self-report measure of conscious derivatives of defense mechanisms grouped in immature and mature styles.

Beck Depression Inventory-II (BDI-2; Beck et al., 1996; Ghisi et al., 2006) a self- report measure of depressive symptoms.

Attachment Style questionnaire (Feeney et al., 1994; Fossati et al., 2003) a self-report measure of attachment through 5 dimensions: confidence, need for approval, discomfort with closeness, relationships as secondary, preoccupation with relationships

Toronto Alexithymia Scale (TAS-20; Taylor et al., 1990, Bressi et al., 1996), a self-report measure of alexithymia through 3 scales: difficulty identifying and describing feelings, operational thinking.

Coping orientations problems experienced (COPE; Sica et al., 2008), a self-report measure of behavioural strategies in stressful situations.

-Observation of interactions in daily life within the hospital setting

-Observation of structured multisensorial stimulation of the patient with self-related stimuli don by the caregiver

-Assessment of patient's basic interactions through the Wessex Head Injury Matrix (WHIM, Shiel et al., 2002; Di Stefano et al., 2012), a behavioural scale for monitoring active behaviours in DOCs.

RESULTS

SELF-REPORT	SCORES	AVERAGES/ CUT-OFF	RESULTS
BDI-II	31	13	Severe depression
BAI	17	13	Moderate Anxiety
COPE	32 19	M=23 SD=5 M=27 SD=8.4	-High Avoiding -Low social support
CBI	20	M=10,4 SD=5.4	-High time-dependent burden
TAS-20	65	61	-Alexithymia
ASQ	50	M=37 SD=7	-Avoidant Attachment
DSQ			-Immature defence profile (Splitting, Projection)
ANPS	33 24	M=28.25 SD=4.44 M=29.28 SD=4.44	-Low SEEKING -Low PLAY

OBSERVATION RESULTS

-Caregiver present in the hospital 9 hours per day every day, without vacations

-The interactions caregiver-patient is detached (third person speaking, patient called by his surname);

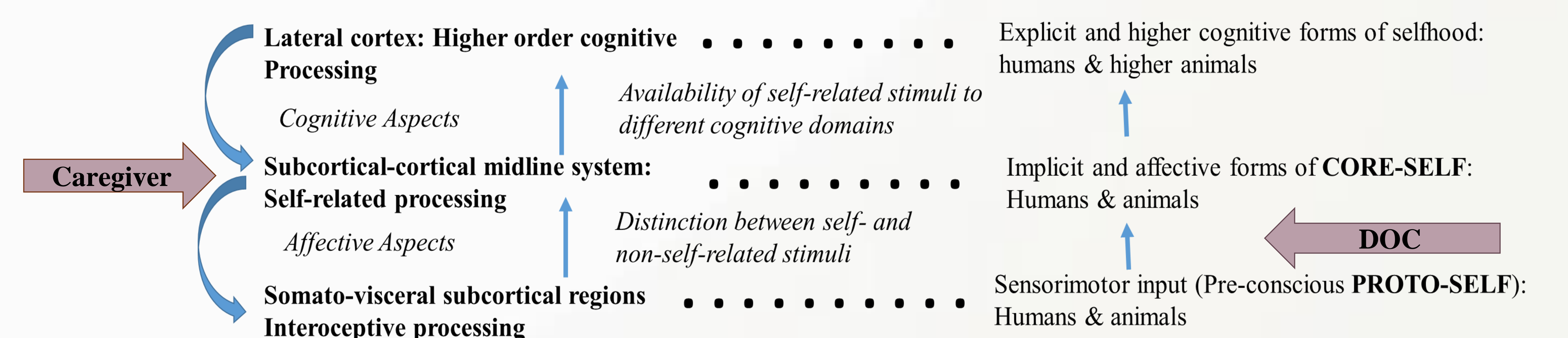
-Strenuous collaboration with hospital professionals

-Caregiver personally takes care of his hygiene and posture and she is the unique to deal with her husband hypertonia

DISCUSSION

Caregiver shows a IWM typical of avoidant style attachment:
-**POSITIVE MODEL OF SELF** (“*I will deal with threats alone*”) → high burden, difficult collaboration with hospital professionals
-**NEGATIVE MODEL OF OTHERS** (“*Others are unreachable and unresponsive*”)→ no seeking social support, low PLAY, DEACTIVATING STRATEGIES (avoiding coping strategy, alexithymia, external regulator of distress, psychosomatic pathologies).

BRAIN FUNCTIONING IN RELATIONSHIPS



A summary of the different levels of processing of the slef in association with possible neural and psychological substrates in relation to different concepts of self. Also highlighted is the level of organization that may be shared between animals and humans (PROTO-SELF is preconscious) (Panksepp & Northoff, 2009)

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