ATRACTO Onlus
Associazione Traumi Cranici

CONVEGNO Nazionale: 1997/2017

20 ANNI D'IMPEGNO

"LE PERSONE E LE FAMIGLIE
AL CENTRO"

Sabato 18 novembre 2017
dalle 9.30 alle 23.00

Casa dell'Energia Arezzo
Via Leone Leoni, 1

I Centri di neuroriabilitazione: una Rete costruita per le Famiglie?

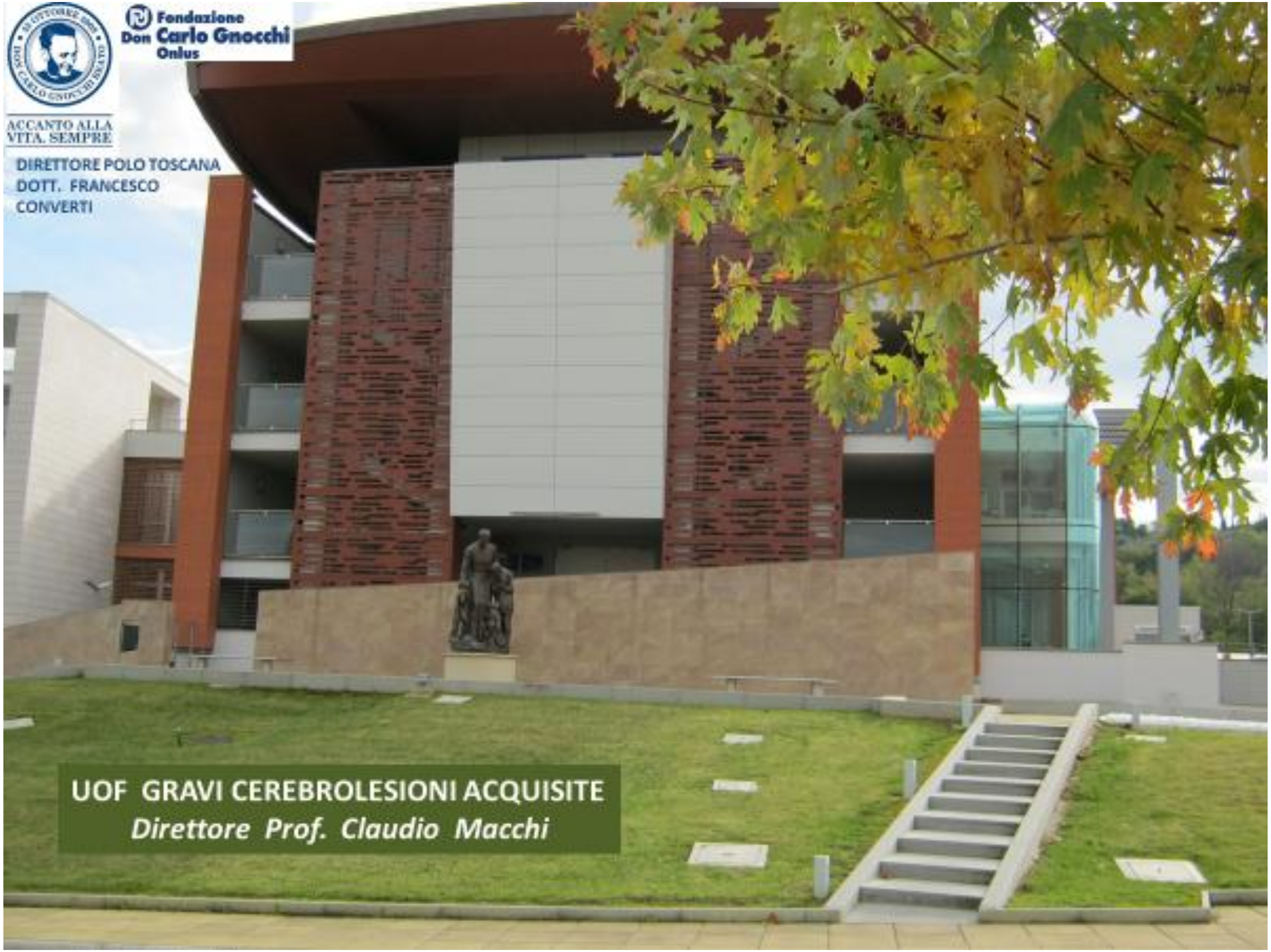
Emilio Portaccio
UGCA Fondazione Don Gnocchi
Firenze

Caregiver burden

- Colpisce 90% dei caregiver
    - Isolamento sociale
    - Depressione, ansia, altri disturbi psicologici
    - Beneficio da adeguate strategie di coping

- Alterazione del funzionamento familiare nel 25-74% delle famiglie
    - Problemi comunicativi
    - Alterazione della relazione di coppia (separazione/divorzio nel 15-78%)

Hanks RA, 2007; Livingston LA 2010; Ergh TC, 2003; Ponsford J, 2003; Kreutzer JS, 2009; Wood RL, 2006



Fondazione Don Carlo Gnocchi Onlus

ACCANTO ALLA VITA. SEMPRE

DIRETTORE POLO TOSCANA
DOTT. FRANCESCO
CONVERTI

UOF GRAVI CEREBROLESIONI ACQUISITE

Direttore Prof. Claudio Macchi

STAFF MEDICO SPECIALISTICO

5	Neurologi
3	Pneumologi
2	Geriatri
1	Cardiologo
2	Psicologi Clinici
1	Neurofisiologo
1	Internista
1	Endocrinologo Nutrizionista

STAFF
TERAPISTI E LOGO TERAPISTI

1	Coordinatore
12	Terapisti
4	Logoterapisti

NEUROPSICOLOGI
1

ASSISTENTI SOCIALI EDUCATORI
1

SERVIZI
Neurofisiopatologia
(EEG, PES,SM,EMG,ENG)
PNEUMOLOGIA
Fibrobroncoscopia
CARDIO ANGIOLOGIA
ECG,
ECD,HOLTER,MONIT.PRESS:
RADIOLOGIA

UGCA Fondazione Don Gnocchi Firenze

- Pazienti ricoverati (periodo agosto 2012 – dicembre 2016)
  - #218 (77-35,3% donne, 141-64.7% uomini)

- Eziologia
  - Post-traumatico 70 (32.1%)
  - Post-anossico 44 (20.2%)
  - Vascolare 104 (47.7%)

- Durata media del ricovero: 4.8 ± 2.8 mesi

- Tipologia dimissione
  - Domicilio 37.2%
  - RSA/lungodegenza 28.7%
  - Riduzione intensità assistenziale (Cod 56, ex articolo 26…) 16.5%

UGCA Fondazione Don Gnocchi Firenze coinvolgimento delle famiglie

- Tre momenti/periodi fondamentali
  - Ammissione/presa in carico
  - Ricovero
  - Dimissione/post-dimissione

UGCA Fondazione Don Gnocchi Firenze coinvolgimento delle famiglie

- Ammissione/presa in carico
  - Identificazione dei caregiver – familiari di riferimento (in genere 2 persone)
  - Presentazione del team di reparto
  - Informazione sull’organizzazione del reparto
    - Consegna libretto informativo
    - Orario visita (lun-ven 16-19; sab-dom 13,30-19)
  - Raccolta dell’anamnesi
  - Identificazione eventuali problematiche familiari
  - Avvio procedure invalidità, nomina amministratore di sostegno
  - Colloquio conoscitivo con lo Specialista psichiatra/psicologo

UGCA Fondazione Don Gnocchi Firenze coinvolgimento delle famiglie

- Ricovero
  - Comunicazione con il personale medico
    - Due colloqui settimanali (facoltativi) con i Medici di Reparto
    - Colloquio ogni 15 gg con Neurologo di riferimento
      - Comunicazione degli obiettivi riabilitativi
      - Prognosi
      - Avanzamento del percorso riabilitativo
  - Coinvolgimento diretto nel trattamento riabilitativo
    - Logopedico
    - Neuromotorio
    - Neuropsicologico
  - Percorso psicoterapeutico per il/i caregiver

UGCA Fondazione Don Gnocchi Firenze coinvolgimento delle famiglie

- Dimissione
  - Programmazione condivisa della dimissione
  - Comunicazione dell’outcome/esiti
  - Consegna documenti dimissione e indicazioni terapeutiche
  - Assistenza per l’organizzazione del domicilio (consulenza per eliminazione barriere architettoniche, prescrizione e assistenza consegna ausili)
  - Impostazione del trattamento riabilitativo post-dimissione

Criticità – Direzioni future

- Assistenza per aspetti burocratici
  - Invalidità
  - Nomina amministratore di sostegno
- Organizzazione del domicilio
  - Modifiche strutturali
  - Ausili
- Comunicazione/Accettazione della prognosi e degli outcome
- Situazioni particolari
  - Isolamento
  - Abuso sostanze
  - Problematiche sociali

Criticità – Direzioni future

- Necessità approccio «family and patient-centered»
  - In particolare per gli aspetti emozionali

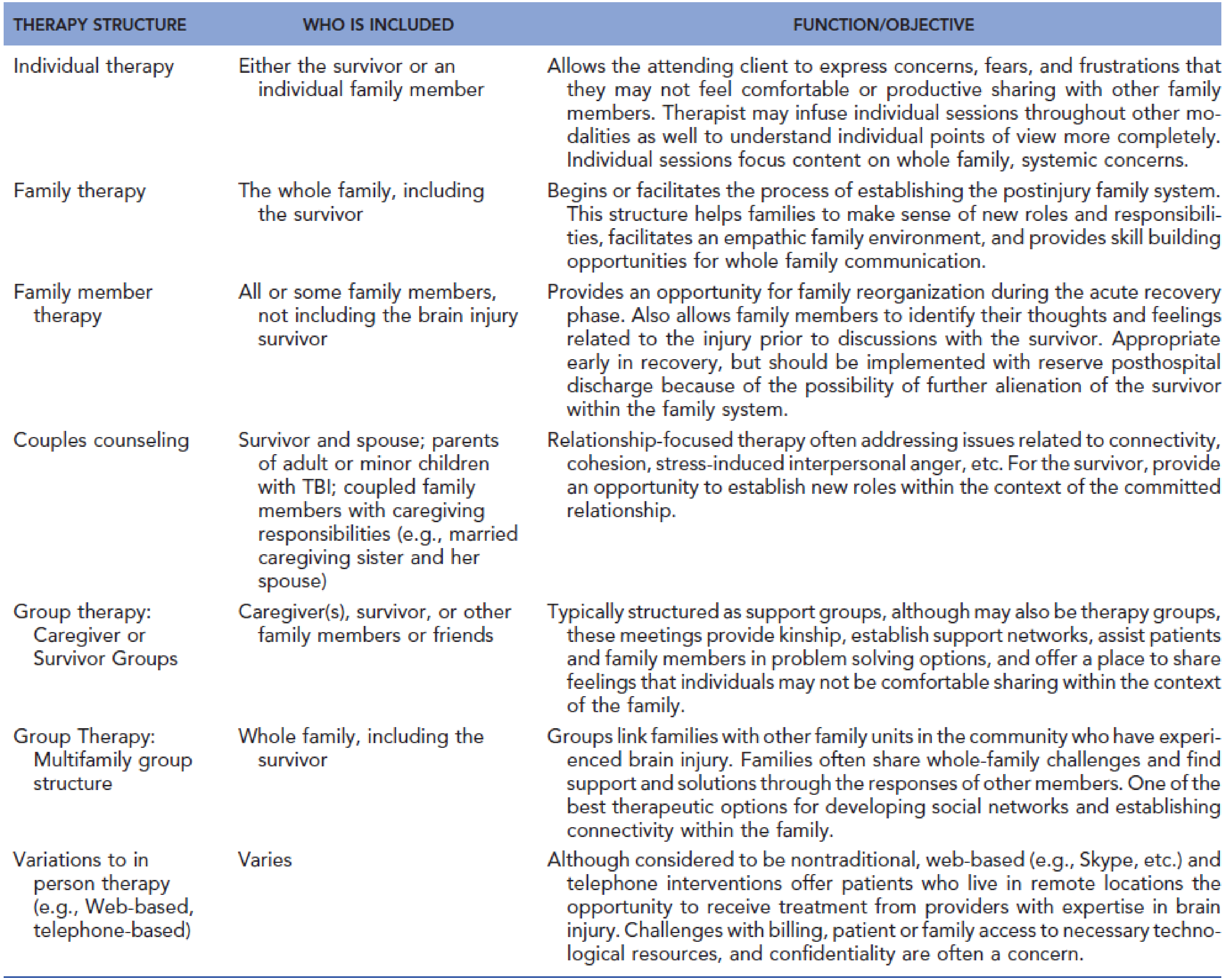
- Dall'ingresso in reparto il/i familiari coinvolti determinano la rapidità, l'efficacia e la sostenibilità del trattamento riabilitativo (Sherer M, 2007)

- Teorie di riferimento
  - Family System Theory (Goldenberg H, 2007)
  - Cognitive Behavioral Family Therapy (Schwebel A, 1992)
  - Resilience Theory (Walsh F, 2006)

Bisogni delle famiglie: Scale di Valutazione

MEASURE	BRIEF DESCRIPTION
Dyadic Adjustment Scale (DAS)	The DAS is a 32-item measure assessing relationship satisfaction (69). The scale provides a total adjustment score and 4 subscales scores: dyadic consensus, dyadic satisfaction, dyadic cohesion, and affectional expression. Several studies have supported the measure's internal consistency, concurrent and predictive validity, and reliability (70). Although not initially developed for a rehabilitation population, the DAS has been used with brain injury populations to examine couple functioning (71,72).
Family Adaptability and Cohesion Evaluation Scale (FACES IV)	The FACES IV is a self-report measure designed to assess family cohesion and flexibility based on the circumplex model of marital and family systems. The measure includes 42 items belonging to 6 subscales (cohesion, flexibility, chaotic, disengaged, enmeshed, and rigid) and can be completed by any family member older than than the age of 12 years (73). The FACES IV is a recently redeveloped version and has been tested with limited samples. However, previous iterations of the measure have been used with families in rehabilitation settings (74). The author's preliminary study indicates acceptable reliability and validity, but was tested on a convenience sample of nonclinical families (73).
Family Assessment Device (FAD)	The FAD is used to assess family functioning from the perspective of the caregiver. This 60-item self-report measure is based on the McMaster model of family functioning and has 6 subscales: problem solving, communication, roles, affective responsiveness, affective involvement, and behavior control. In addition, there is a general functioning subscale based on all items (75). The FAD has been used with families after TBI and has been shown to be sensitive to changes experienced after injury (14).
Family Needs Questionnaire (FNQ)	The FNQ is a frequently used 40-item self-report instrument intended to describe family members' perceived needs after brain injury (13,18,31,76). Items address commonly identified psychosocial and informational needs apparent after injury. Previous research indicates good content and construct validity as well as internal consistency (13). The measure contains 6 factor analytically derived scales: health information, emotional support, instrumental support, professional support, community support network, and involvement with care (63).
Neurobehavioral Functioning Inventory (NFI)	Developed for use with a TBI population, the NFI is an 83-item measure designed to examine the frequency of neurobehavioral difficulties postinjury (77). The measure can be administered in a self-report format or orally. Patient and family versions are available, allowing for comparison of responses. Normative data, based on age and injury severity, is available. Information is gathered about functioning in 6 domains: depression, somatic symptoms, memory or attention, communication, aggression, and motor abilities.
Service Obstacles Scale (SOS)	The SOS is a 6-item scale designed to solicit information regarding availability of and satisfaction with brain injury services. Items also address obstacles that might interfere with use of resources. Research has provided evidence for criterion-related validity and internal consistency of the measure when used with persons with brain injury and their caregivers (78).
Zarit Burden Interview (ZBI)	The ZBI is a self-administered scale consisting of 22 items regarding how the caregiver feels about their relationship with the patient, their health condition, finances, psychological well-being, and social life (79,80). The scale was originally developed for use with caregivers or family members of patients with dementia or elderly patients (80), but has also been used with brain injury samples (12). Despite criticism that the ZBI implicitly assumes the caregiver is stressed, reliability and validity of the scale are adequate (80).

Bisogni delle famiglie: Approcci terapeutici



THERAPY STRUCTURE	WHO IS INCLUDED	FUNCTION/OBJECTIVE
Individual therapy	Either the survivor or an individual family member	Allows the attending client to express concerns, fears, and frustrations that they may not feel comfortable or productive sharing with other family members. Therapist may infuse individual sessions throughout other modalities as well to understand individual points of view more completely. Individual sessions focus content on whole family, systemic concerns.
Family therapy	The whole family, including the survivor	Begins or facilitates the process of establishing the postinjury family system. This structure helps families to make sense of new roles and responsibilities, facilitates an empathic family environment, and provides skill building opportunities for whole family communication.
Family member therapy	All or some family members, not including the brain injury survivor	Provides an opportunity for family reorganization during the acute recovery phase. Also allows family members to identify their thoughts and feelings related to the injury prior to discussions with the survivor. Appropriate early in recovery, but should be implemented with reserve posthospital discharge because of the possibility of further alienation of the survivor within the family system.
Couples counseling	Survivor and spouse; parents of adult or minor children with TBI; coupled family members with caregiving responsibilities (e.g., married caregiving sister and her spouse)	Relationship-focused therapy often addressing issues related to connectivity, cohesion, stress-induced interpersonal anger, etc. For the survivor, provide an opportunity to establish new roles within the context of the committed relationship.
Group therapy: Caregiver or Survivor Groups	Caregiver(s), survivor, or other family members or friends	Typically structured as support groups, although may also be therapy groups, these meetings provide kinship, establish support networks, assist patients and family members in problem solving options, and offer a place to share feelings that individuals may not be comfortable sharing within the context of the family.
Group Therapy: Multifamily group structure	Whole family, including the survivor	Groups link families with other family units in the community who have experienced brain injury. Families often share whole-family challenges and find support and solutions through the responses of other members. One of the best therapeutic options for developing social networks and establishing connectivity within the family.
Variations to in person therapy (e.g., Web-based, telephone-based)	Varies	Although considered to be nontraditional, web-based (e.g., Skype, etc.) and telephone interventions offer patients who live in remote locations the opportunity to receive treatment from providers with expertise in brain injury. Challenges with billing, patient or family access to necessary technological resources, and confidentiality are often a concern.

Grazie per l’attenzione