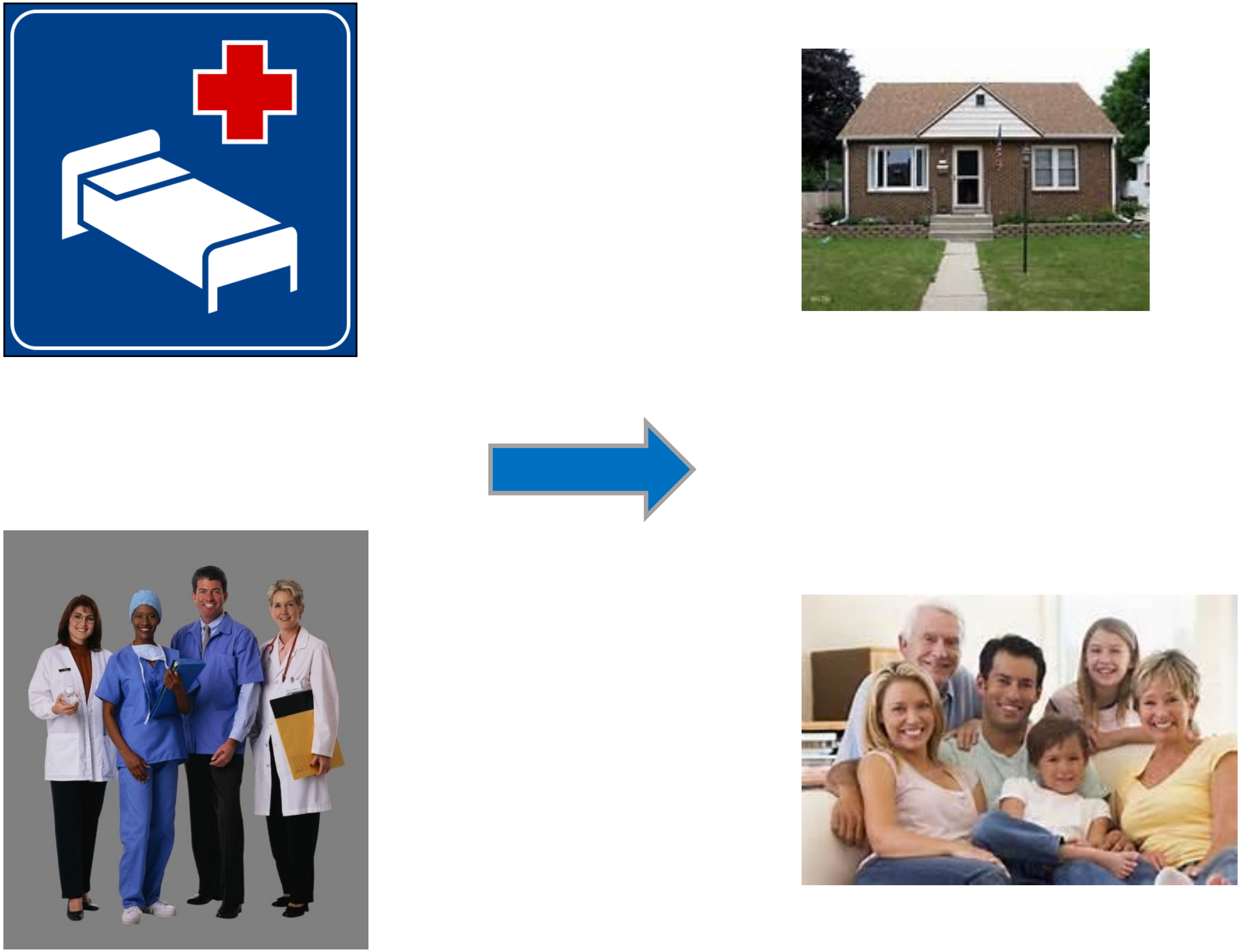
# PSICOLOGIA CLINICA

dott.ssa Paoletta Florio
psicologa-psicoterapeuta



# CAREGIVER E CAREGIVER BURDEN

- il caregiver può essere chiamato a rispondere a bisogni fisici, sociali, emotivi ed economici
- l’attività di caregiving può essere a tempo pieno se la persona necessita di supervisione e assistenza h24
- il caregiver spesso trascura la soddisfazione dei propri bisogni
- «caregiver burden» = condizione di stress fisico, psicologico, emotivo, sociale ed economico che deriva dal caregiving

# RECIPROCITÀ E CAREGIVER BURDEN

- relazione «reciproca» = i benefici di ciascuno dei protagonisti della relazione è approssimativamente proporzionale al contributo dato
- mancanza di reciprocità → disagio emozionale
- relazione caregiver–familiare = relazione a reciprocità potenzialmente molto limitata

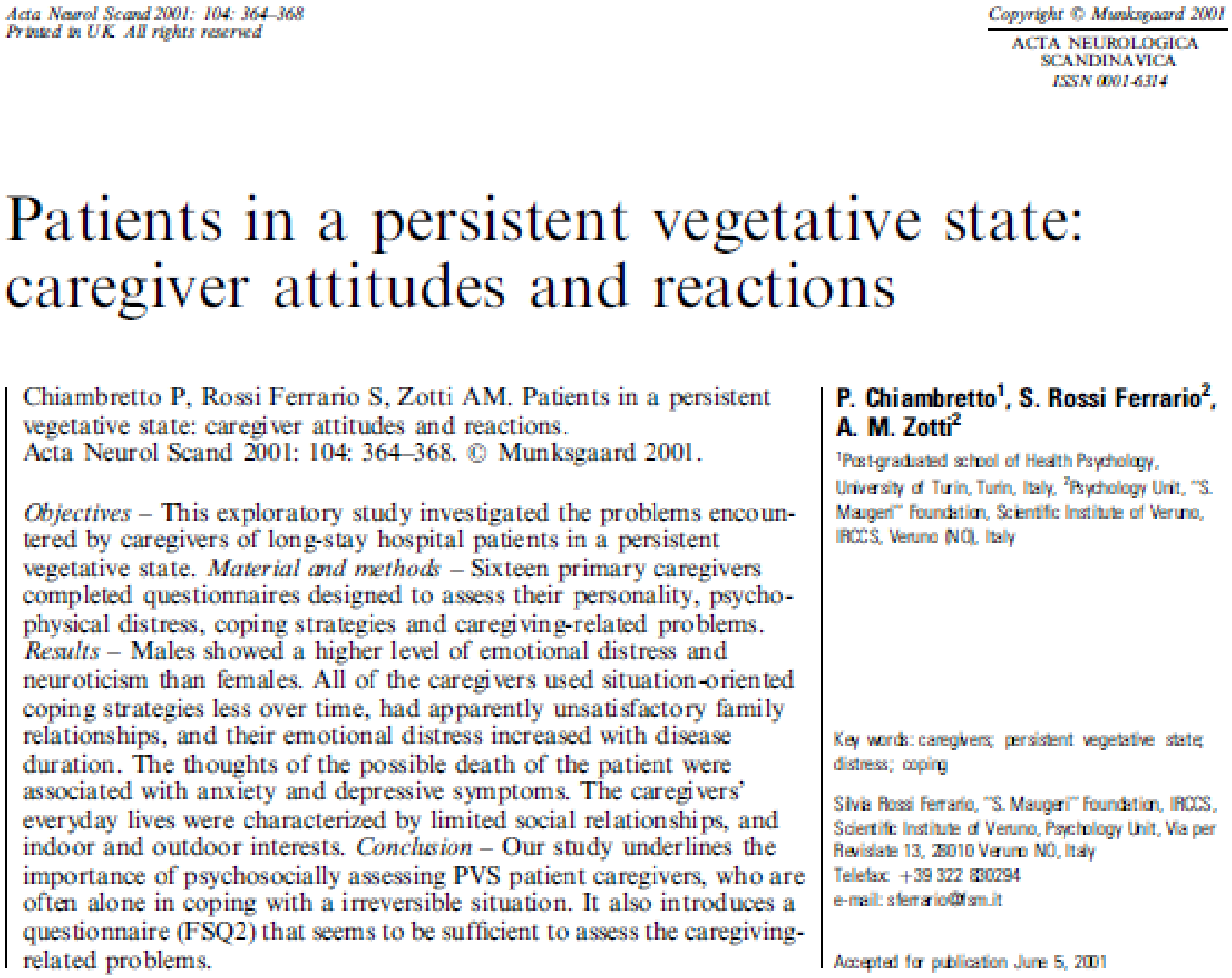
# RECIPROCITÀ E CAREGIVER BURDEN

- Hirschfeld (1983): la percezione di reciprocità consente al caregiver di affrontare le richieste del proprio ruolo
- Dwyer et al. (1990, 1994): il caregiver sperimenta livelli inferiori di stress e di carico emotivo quando la persona assistita è in grado di garantire reciprocità
- Carruth et al. (1997): la mancanza di reciprocità influenza il carico emotivo del caregiver più del tempo effettivamente speso per assistere il familiare

# IL CAREGIVER
# DELLA PERSONA IN STATO VEGETATIVO

- lo stato vegetativo può essere considerato come un «paradosso emotivo» per il caregiver (Stern et al., 1988)
- il caregiver può negare la realtà o sviluppare speranze irrealistiche di un recupero
- il perdurare di questa condizione di incertezza determina la comparsa di disturbi psicosomatici, insonnia e perdita dell’appetito (Tzidkiahu et al., 1994)

# IL CAREGIVER
# DELLA PERSONA IN STATO VEGETATIVO



*Acta Neurol Scand 2001: 104: 364–368*
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ACTA NEUROLOGICA
SCANDINAVICA
*ISSN 0001-6314*

## Patients in a persistent vegetative state: caregiver attitudes and reactions

Chiambretto P, Rossi Ferrario S, Zotti AM. Patients in a persistent vegetative state: caregiver attitudes and reactions.
Acta Neurol Scand 2001: 104: 364–368. © Munksgaard 2001.

*Objectives* – This exploratory study investigated the problems encountered by caregivers of long-stay hospital patients in a persistent vegetative state. *Material and methods* – Sixteen primary caregivers completed questionnaires designed to assess their personality, psychophysical distress, coping strategies and caregiving-related problems. *Results* – Males showed a higher level of emotional distress and neuroticism than females. All of the caregivers used situation-oriented coping strategies less over time, had apparently unsatisfactory family relationships, and their emotional distress increased with disease duration. The thoughts of the possible death of the patient were associated with anxiety and depressive symptoms. The caregivers' everyday lives were characterized by limited social relationships, and indoor and outdoor interests. *Conclusion* – Our study underlines the importance of psychosocially assessing PVS patient caregivers, who are often alone in coping with a irreversible situation. It also introduces a questionnaire (FSQ2) that seems to be sufficient to assess the caregiving-related problems.

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Key words: caregivers; persistent vegetative state; distress; coping

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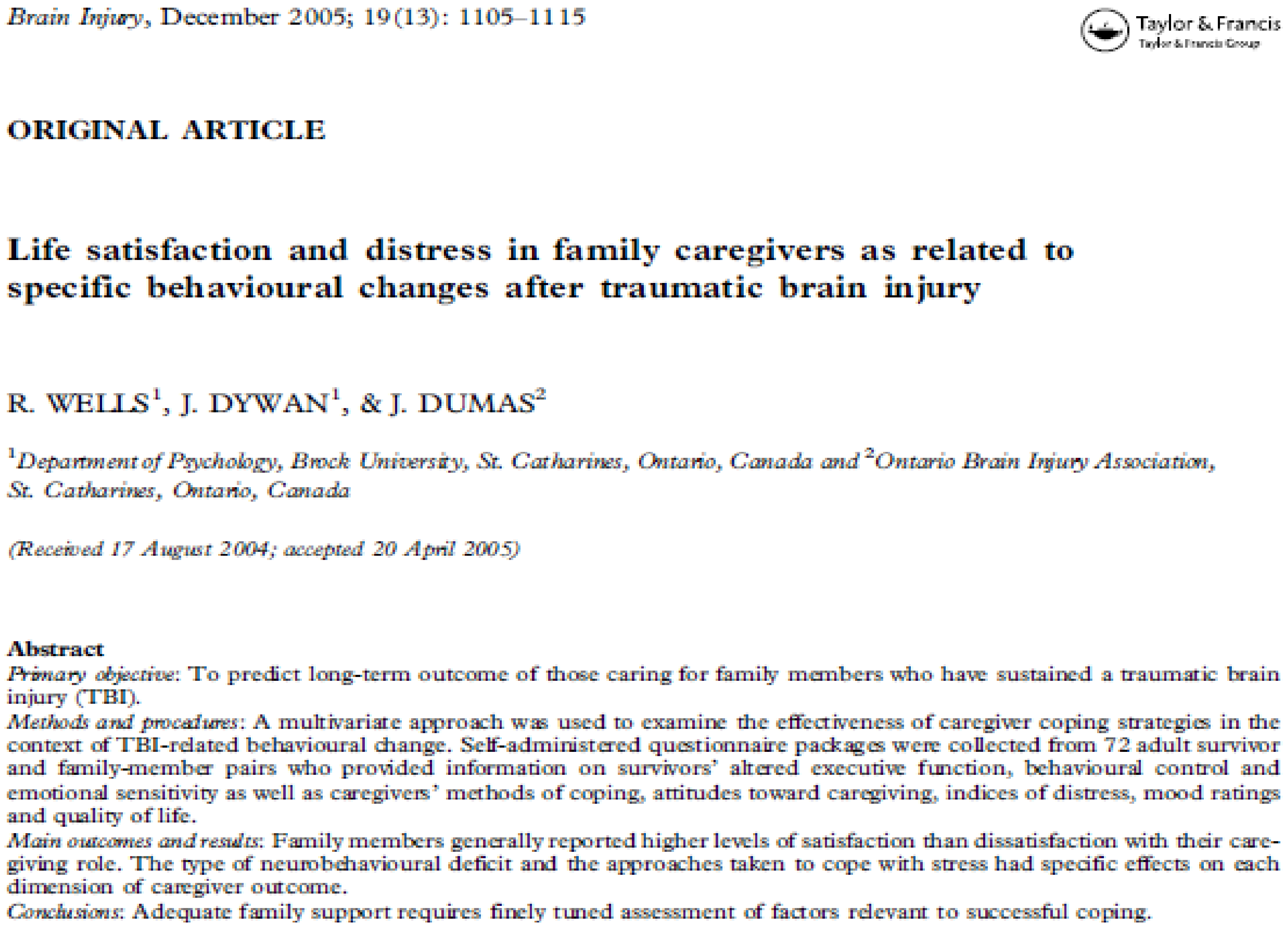
# IL CAREGIVER
# DELLA PERSONA IN STATO VEGETATIVO

Risultati:

- i maschi presentano livelli più elevati di distress emotivo rispetto alle femmine
- tutti i caregiver tendono a «mantenere le distanze» da una realtà che considerano inaccettabile (non chiedono informazioni, non pensano alla possibilità che il paziente possa morire)
- frequenti importanti restrizioni alla partecipazione sociale e limitazioni alle attività piacevoli
- frequenti i problemi pratici ed economici

# TRAUMA CRANIOENCEFALICO



*Brain Injury*, December 2005; 19(13): 1105–1115

Taylor & Francis
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**ORIGINAL ARTICLE**

## Life satisfaction and distress in family caregivers as related to specific behavioural changes after traumatic brain injury

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*(Received 17 August 2004; accepted 20 April 2005)*

**Abstract**

*Primary objective*: To predict long-term outcome of those caring for family members who have sustained a traumatic brain injury (TBI).

*Methods and procedures*: A multivariate approach was used to examine the effectiveness of caregiver coping strategies in the context of TBI-related behavioural change. Self-administered questionnaire packages were collected from 72 adult survivor and family-member pairs who provided information on survivors' altered executive function, behavioural control and emotional sensitivity as well as caregivers' methods of coping, attitudes toward caregiving, indices of distress, mood ratings and quality of life.

*Main outcomes and results*: Family members generally reported higher levels of satisfaction than dissatisfaction with their care-giving role. The type of neurobehavioural deficit and the approaches taken to cope with stress had specific effects on each dimension of caregiver outcome.

*Conclusions*: Adequate family support requires finely tuned assessment of factors relevant to successful coping.

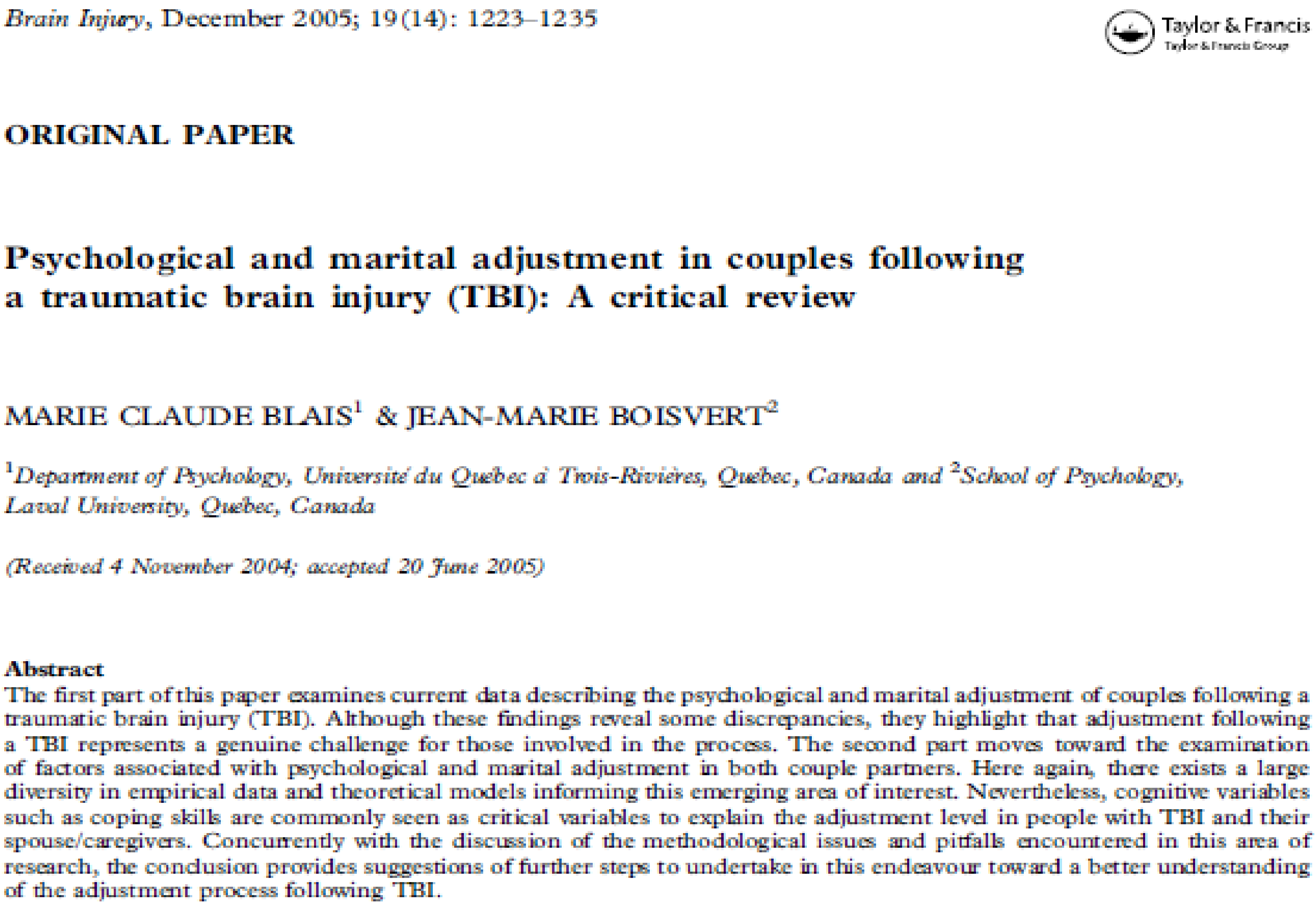
# TRAUMA CRANIOENCEFALICO

Quali fattori sono maggiormente predittivi del benessere psicologico?

- i familiari esprimono più emozioni positive che negative (bias di desiderabilità sociale?)
- elevato senso di autoefficacia rispetto al ruolo di caregiver
- adozione di efficaci strategie di coping
- presenza di una rete sociale

I disturbi comportamentali (impulsività, scarsa pianificazione, scarsa empatia) riducono il benessere del caregiver

# TRAUMA CRANIOENCEFALICO



*Brain Injury*, December 2005; 19(14): 1223–1235

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**ORIGINAL PAPER**

## Psychological and marital adjustment in couples following a traumatic brain injury (TBI): A critical review

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*(Received 4 November 2004; accepted 20 June 2005)*

**Abstract**
The first part of this paper examines current data describing the psychological and marital adjustment of couples following a traumatic brain injury (TBI). Although these findings reveal some discrepancies, they highlight that adjustment following a TBI represents a genuine challenge for those involved in the process. The second part moves toward the examination of factors associated with psychological and marital adjustment in both couple partners. Here again, there exists a large diversity in empirical data and theoretical models informing this emerging area of interest. Nevertheless, cognitive variables such as coping skills are commonly seen as critical variables to explain the adjustment level in people with TBI and their spouse/caregivers. Concurrently with the discussion of the methodological issues and pitfalls encountered in this area of research, the conclusion provides suggestions of further steps to undertake in this endeavour toward a better understanding of the adjustment process following TBI.

# TRAUMA CRANIOENCEFALICO

Effetti del TCE sulla relazione di coppia

- ansia e depressione con % molto variabili
- riduzioni delle interazioni sociali e isolamento
- differenze nella natura del carico per genitore e coniuge (→ perdita del ruolo supportivo/affettivo, dell'intimità sessuale, della comunicazione empatica)
- favoriscono un miglior adattamento strategie di coping orientate sul problema (problem-solving e reinterpretazione) piuttosto che strategie di coping di evitamento

# TRAUMA CRANIOENCEFALICO

*Brain Injury*, October 2005; 19(11): 909–923

Taylor & Francis
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**ORIGINAL PAPER**

## Exploring the impact of traumatic brain injury on the older couple: 'Yes, but how much of it is age, I can't tell you …'

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*(Received 2 January 2004; accepted 14 February 2005)*

**Abstract**

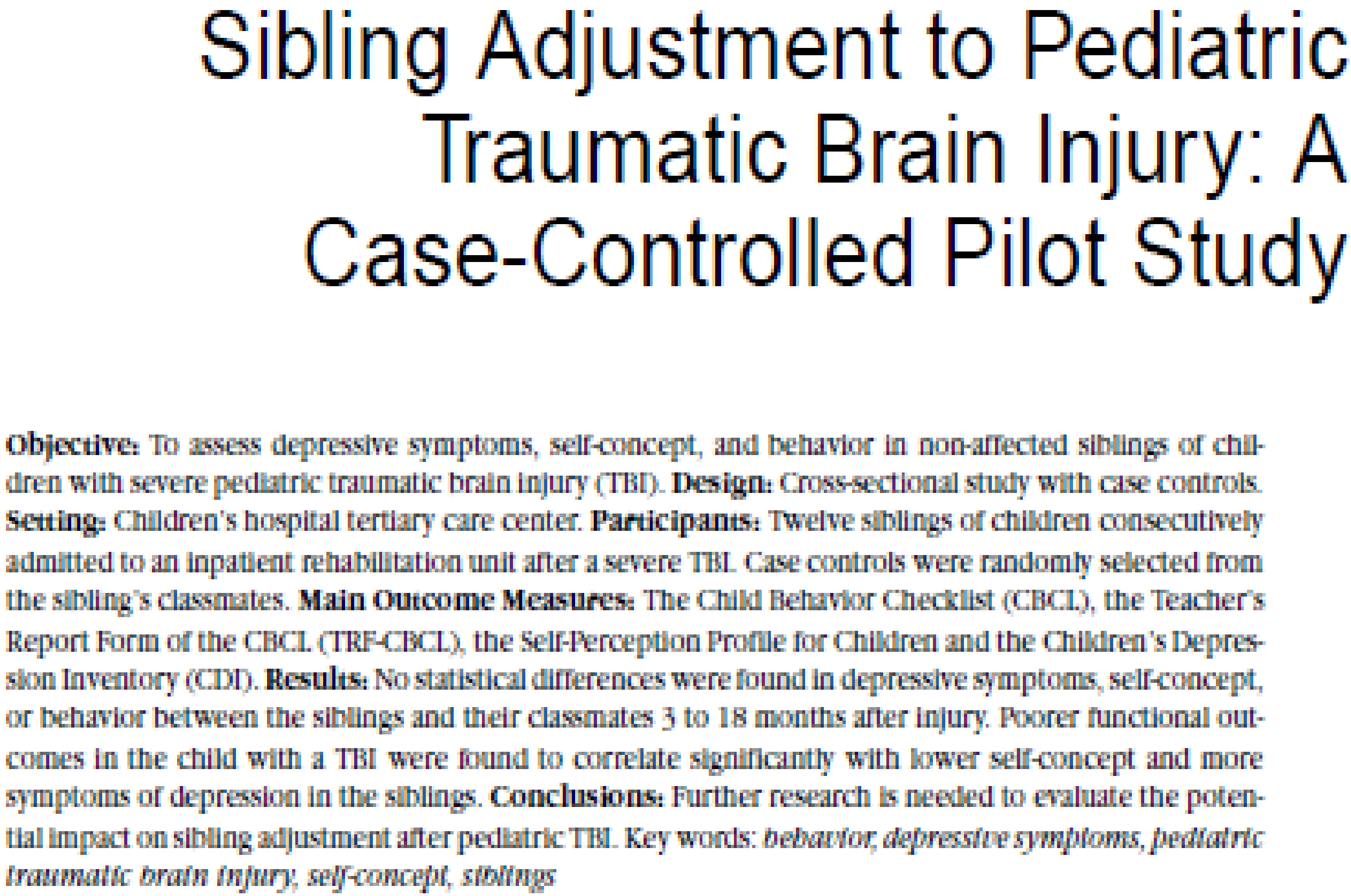
*Primary objective*: To qualitatively explore the partner relationships of older couples faced with traumatic brain injury (TBI).
*Research design*: Qualitative analysis comparing individuals with TBI and a comparison group.
*Methods and procedures*: Twenty-one individuals were interviewed using a semi-structured format focusing on various aspects of their partner relationship. A qualitative analysis of transcripts identified general themes.
*Main outcomes and results*: Variability of relationship experiences (relationship relatedness and persistence of the partnership) was shown across groups. Aspects of relationship commitment to the partnership were revealed. Many individuals with TBI and their partners attributed various relationship changes to ageing and age-related issues and not to the TBI.
*Conclusions*: These findings suggest that the effects of TBI are not clearly distinguished from age-related causes for change in the partners and their relationship. Older couples' experiences may be different from those of younger couples impacted by TBI, in the areas of sexuality, inter-personal support and role functions.

# TRAUMA CRANIOENCEFALICO

Effetti del TCE sulla coppia anziana

- maggiore tendenza ad attribuire i cambiamenti nella relazione all’età piuttosto che al TCE
- gli uomini anziani «funzionano» meglio nel ruolo di caregiver rispetto a quelli più giovani

# TRAUMA CRANIOENCEFALICO



## Sibling Adjustment to Pediatric Traumatic Brain Injury: A Case-Controlled Pilot Study

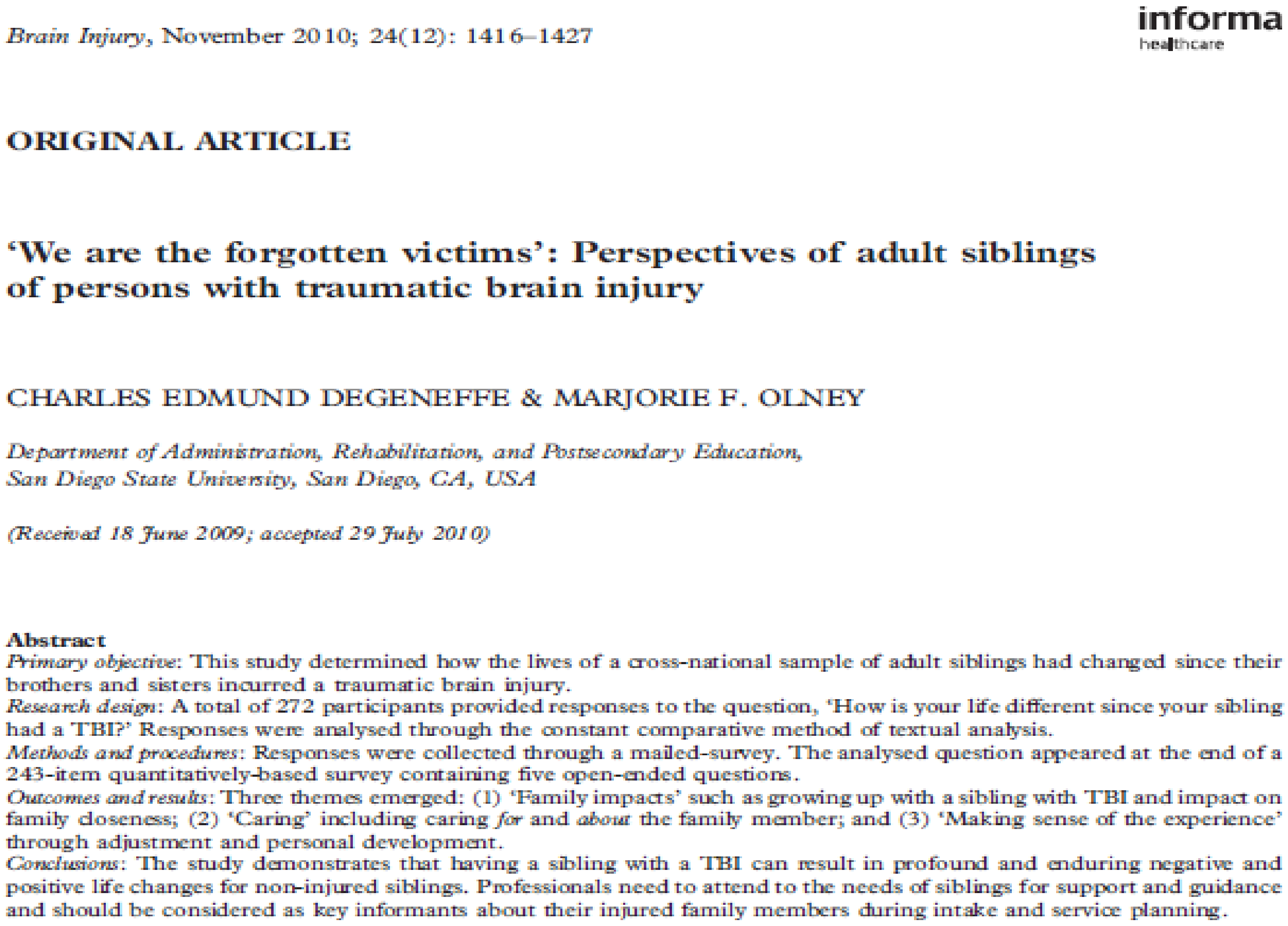
**Objective:** To assess depressive symptoms, self-concept, and behavior in non-affected siblings of children with severe pediatric traumatic brain injury (TBI). **Design:** Cross-sectional study with case controls. **Setting:** Children's hospital tertiary care center. **Participants:** Twelve siblings of children consecutively admitted to an inpatient rehabilitation unit after a severe TBI. Case controls were randomly selected from the sibling's classmates. **Main Outcome Measures:** The Child Behavior Checklist (CBCL), the Teacher's Report Form of the CBCL (TRF-CBCL), the Self-Perception Profile for Children and the Children's Depression Inventory (CDI). **Results:** No statistical differences were found in depressive symptoms, self-concept, or behavior between the siblings and their classmates 3 to 18 months after injury. Poorer functional outcomes in the child with a TBI were found to correlate significantly with lower self-concept and more symptoms of depression in the siblings. **Conclusions:** Further research is needed to evaluate the potential impact on sibling adjustment after pediatric TBI. Key words: *behavior, depressive symptoms, pediatric traumatic brain injury, self-concept, siblings*

# TRAUMA CRANIOENCEFALICO

Funzionamento psicologico dei fratelli

- in genere, stato emozionale paragonabile a quello dei coetanei
- in caso di gravi deficit funzionali alla dimissione, maggiori difficoltà di adattamento emozionale per diverse ragioni:
    1. maggiore stress genitoriale
    2. più tempo speso ad occuparsi del figlio con TCE
    3. attribuzione di maggiori responsabilità al figlio «sano»
    4. modificazioni della relazione tra fratelli

# TRAUMA CRANIOENCEFALICO



*Brain Injury*, November 2010; 24(12): 1416–1427

informa
healthcare

ORIGINAL ARTICLE

## 'We are the forgotten victims': Perspectives of adult siblings of persons with traumatic brain injury

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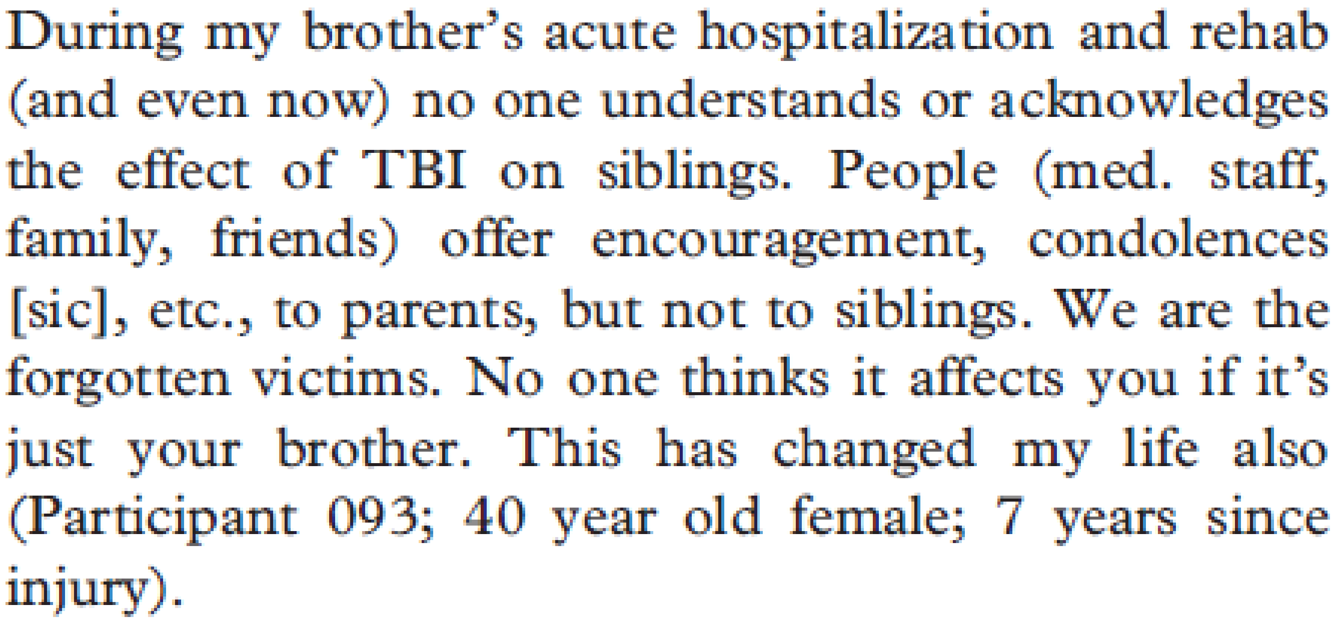
*(Received 18 June 2009; accepted 29 July 2010)*

**Abstract**
*Primary objective*: This study determined how the lives of a cross-national sample of adult siblings had changed since their brothers and sisters incurred a traumatic brain injury.
*Research design*: A total of 272 participants provided responses to the question, 'How is your life different since your sibling had a TBI?' Responses were analysed through the constant comparative method of textual analysis.
*Methods and procedures*: Responses were collected through a mailed-survey. The analysed question appeared at the end of a 243-item quantitatively-based survey containing five open-ended questions.
*Outcomes and results*: Three themes emerged: (1) 'Family impacts' such as growing up with a sibling with TBI and impact on family closeness; (2) 'Caring' including caring *for* and *about* the family member; and (3) 'Making sense of the experience' through adjustment and personal development.
*Conclusions*: The study demonstrates that having a sibling with a TBI can result in profound and enduring negative and positive life changes for non-injured siblings. Professionals need to attend to the needs of siblings for support and guidance and should be considered as key informants about their injured family members during intake and service planning.

# TRAUMA CRANIOENCEFALICO



During my brother's acute hospitalization and rehab (and even now) no one understands or acknowledges the effect of TBI on siblings. People (med. staff, family, friends) offer encouragement, condolences [sic], etc., to parents, but not to siblings. We are the forgotten victims. No one thinks it affects you if it's just your brother. This has changed my life also (Participant 093; 40 year old female; 7 years since injury).

# TRAUMA CRANIOENCEFALICO

Funzionamento psicologico dei fratelli adulti

«com'è cambiata la tua vita da quando tuo fratello ha avuto un TCE?»

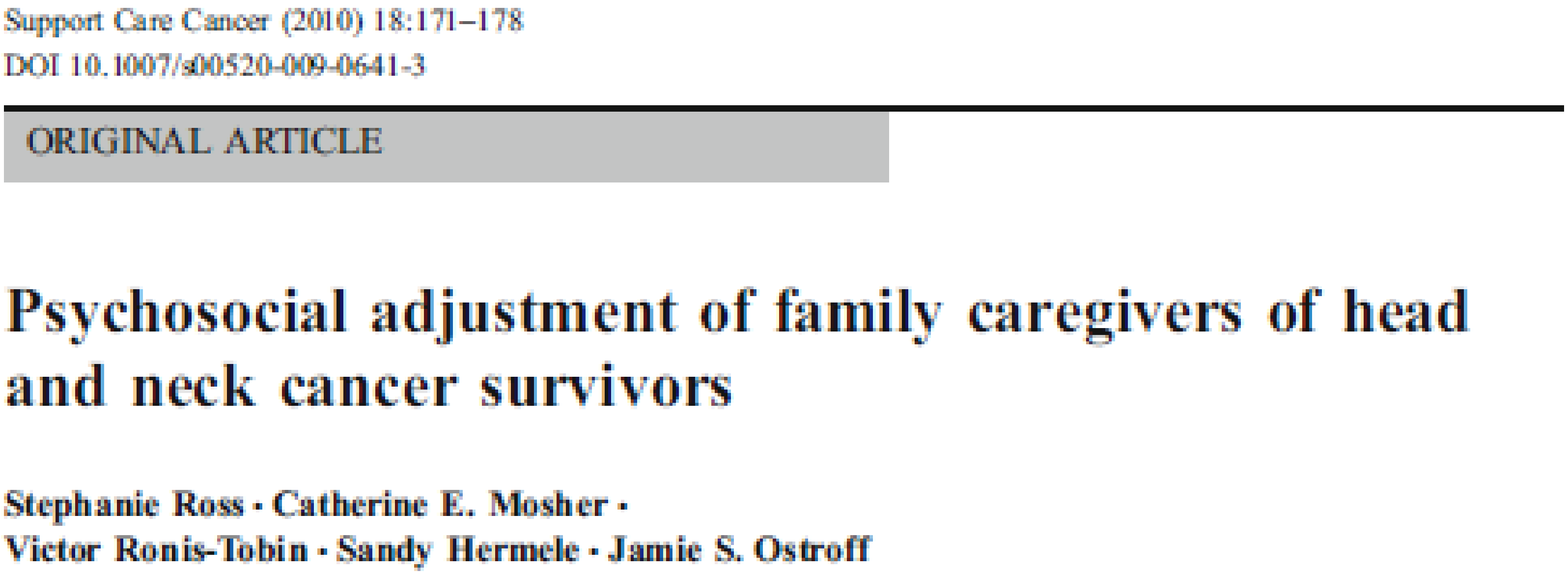
- emozioni negative: rabbia, senso di colpa, lutto
- paura per comportamenti aggressivi
- anticipazioni del carico di future responsabilità
- mantenere il ruolo di «bravo figlio»
- emozioni contrastanti nei confronti dei genitori (rabbia, risentimento, empatia, preoccupazione, tristezza)

# CANCRO DEL DISTRETTO TESTA-COLLO

Impatto del cancro sul nucleo familiare

- cambiamento delle routine domestiche
- difficoltà di tipo economico
- difficoltà di tipo emotivo
- cambiamento dei ruoli all’interno della famiglia
- riduzione della qualità di vita paragonabile o superiore
- livelli di distress clinicamente significativi nel 20/30% dei caregiver (soprattutto in caso di giovane età, sesso femminile e status socioeconomico inferiore)

# CANCRO DEL DISTRETTO TESTA-COLLO



Support Care Cancer (2010) 18:171–178
DOI 10.1007/s00520-009-0641-3

ORIGINAL ARTICLE

## Psychosocial adjustment of family caregivers of head and neck cancer survivors

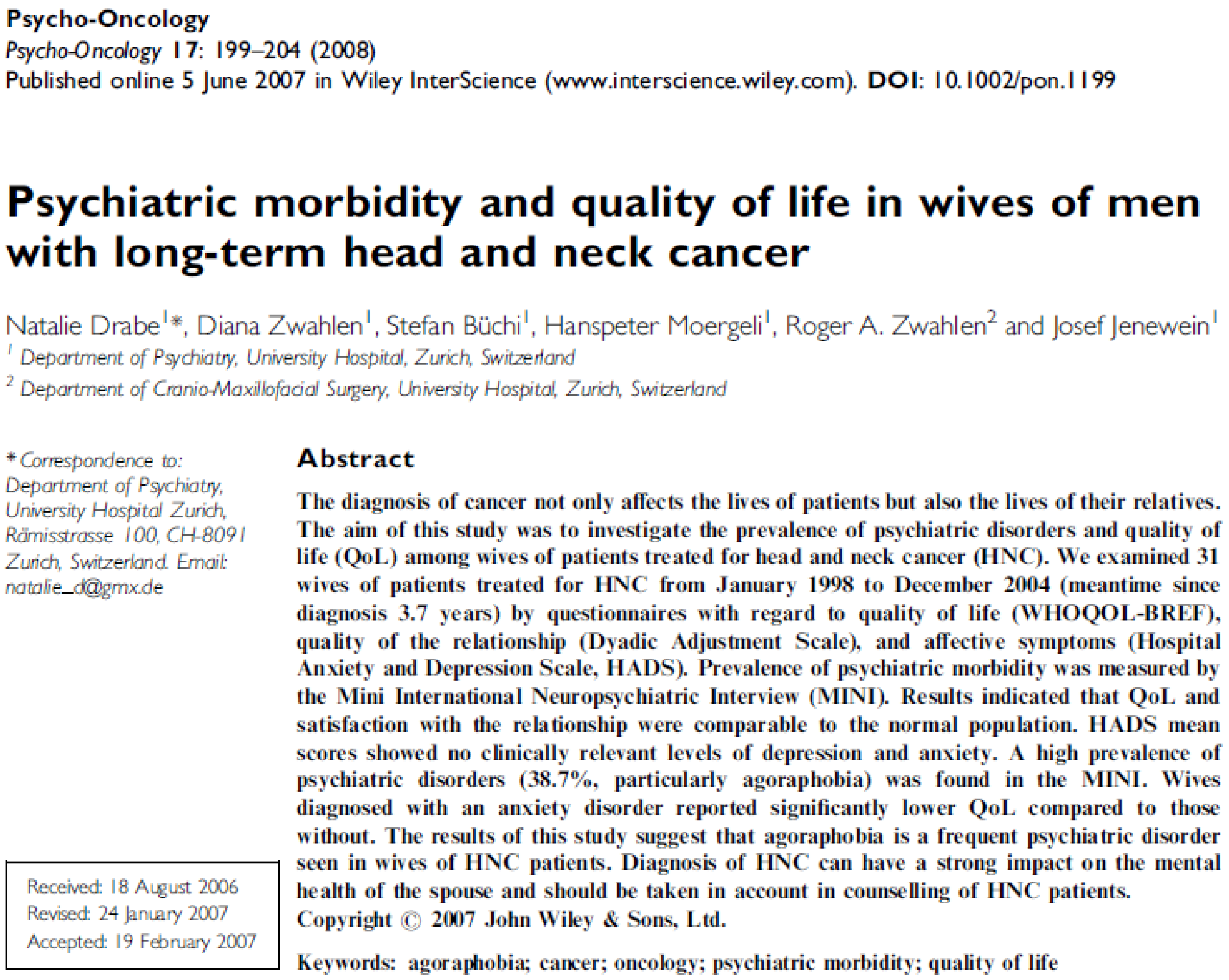
Stephanie Ross · Catherine E. Mosher ·
Victor Ronis-Tobin · Sandy Hermele · Jamie S. Ostroff

# CANCRO DEL DISTRETTO TESTA-COLLO

- il 38% dei caregiver riporta livelli di distress che variano da moderato ad alto
- maggiore numero di ore di caregiving correla con maggiore livello di distress
- solo il 39% dei partecipanti riferisce la soddisfazione di tutti i propri bisogni pratici e di informazione
- qualità di vita migliore in fase cronica rispetto alla fase acuta del trattamento

LA FAMIGLIA

# CANCRO DEL DISTRETTO TESTA-COLLO



**Psycho-Oncology**
*Psycho-Oncology* **17**: 199–204 (2008)

**DOI**: 10.1002/pon.1199

## Psychiatric morbidity and quality of life in wives of men with long-term head and neck cancer

Natalie Drabe[1]*, Diana Zwahlen[1], Stefan Büchi[1], Hanspeter Moergeli[1], Roger A. Zwahlen[2] and Josef Jenewein[1]
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Revised: 24 January 2007
Accepted: 19 February 2007

### Abstract

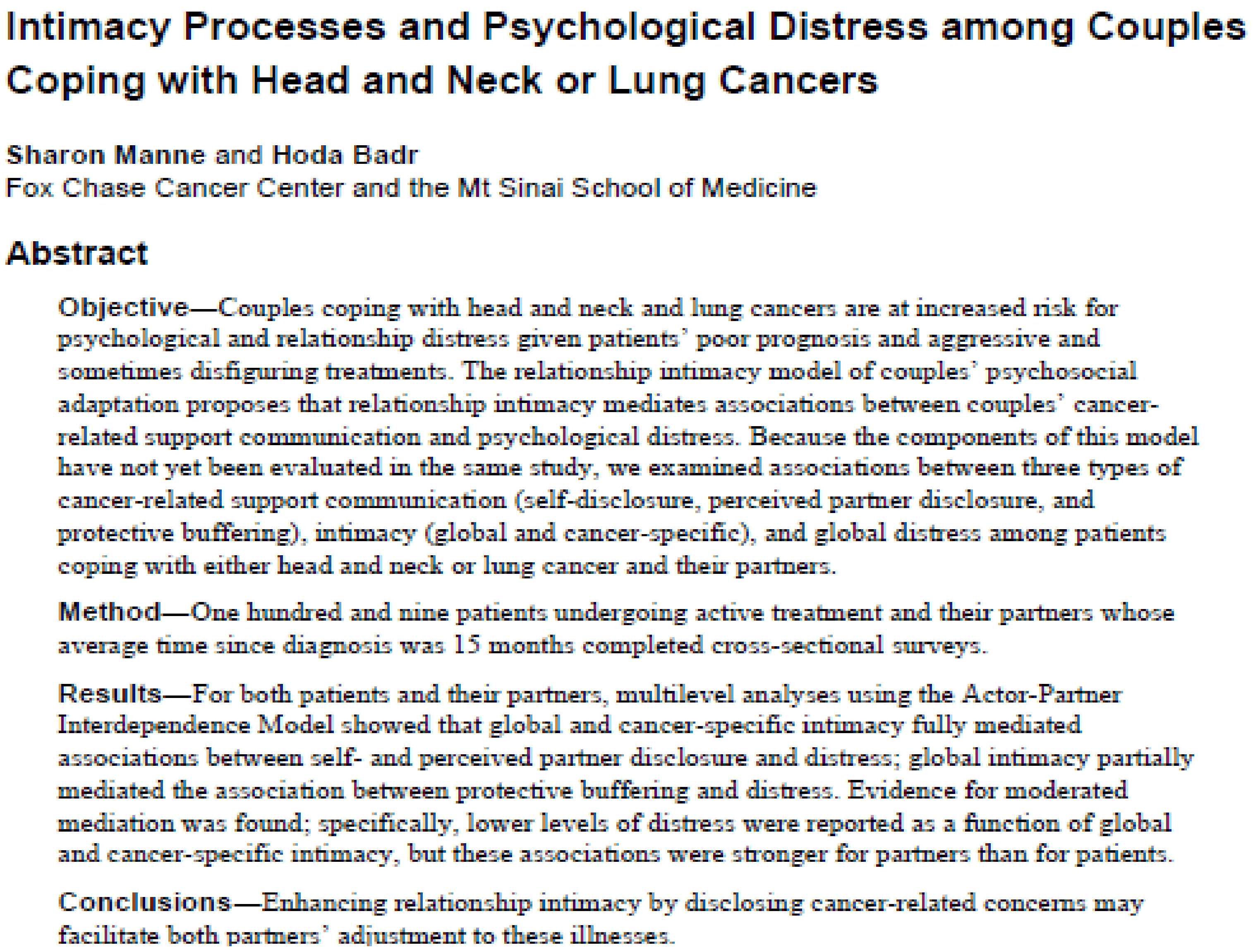
The diagnosis of cancer not only affects the lives of patients but also the lives of their relatives. The aim of this study was to investigate the prevalence of psychiatric disorders and quality of life (QoL) among wives of patients treated for head and neck cancer (HNC). We examined 31 wives of patients treated for HNC from January 1998 to December 2004 (meantime since diagnosis 3.7 years) by questionnaires with regard to quality of life (WHOQOL-BREF), quality of the relationship (Dyadic Adjustment Scale), and affective symptoms (Hospital Anxiety and Depression Scale, HADS). Prevalence of psychiatric morbidity was measured by the Mini International Neuropsychiatric Interview (MINI). Results indicated that QoL and satisfaction with the relationship were comparable to the normal population. HADS mean scores showed no clinically relevant levels of depression and anxiety. A high prevalence of psychiatric disorders (38.7%, particularly agoraphobia) was found in the MINI. Wives diagnosed with an anxiety disorder reported significantly lower QoL compared to those without. The results of this study suggest that agoraphobia is a frequent psychiatric disorder seen in wives of HNC patients. Diagnosis of HNC can have a strong impact on the mental health of the spouse and should be taken in account in counselling of HNC patients.

Keywords: agoraphobia; cancer; oncology; psychiatric morbidity; quality of life

# CANCRO DEL DISTRETTO TESTA-COLLO

- il 23% delle mogli di pazienti con cancro testa-collo soffre di disturbi d’ansia (soprattutto agorafobia) con ripercussioni sulla qualità di vita, ma non sulla soddisfazione nella relazione coniugale
- % di disturbi dell’umore relativamente bassa

# CANCRO DEL DISTRETTO TESTA-COLLO



## Intimacy Processes and Psychological Distress among Couples Coping with Head and Neck or Lung Cancers

**Sharon Manne and Hoda Badr**
Fox Chase Cancer Center and the Mt Sinai School of Medicine

### Abstract

**Objective**—Couples coping with head and neck and lung cancers are at increased risk for psychological and relationship distress given patients' poor prognosis and aggressive and sometimes disfiguring treatments. The relationship intimacy model of couples' psychosocial adaptation proposes that relationship intimacy mediates associations between couples' cancer-related support communication and psychological distress. Because the components of this model have not yet been evaluated in the same study, we examined associations between three types of cancer-related support communication (self-disclosure, perceived partner disclosure, and protective buffering), intimacy (global and cancer-specific), and global distress among patients coping with either head and neck or lung cancer and their partners.

**Method**—One hundred and nine patients undergoing active treatment and their partners whose average time since diagnosis was 15 months completed cross-sectional surveys.

**Results**—For both patients and their partners, multilevel analyses using the Actor-Partner Interdependence Model showed that global and cancer-specific intimacy fully mediated associations between self- and perceived partner disclosure and distress; global intimacy partially mediated the association between protective buffering and distress. Evidence for moderated mediation was found; specifically, lower levels of distress were reported as a function of global and cancer-specific intimacy, but these associations were stronger for partners than for patients.

**Conclusions**—Enhancing relationship intimacy by disclosing cancer-related concerns may facilitate both partners' adjustment to these illnesses.

# CANCRO DEL DISTRETTO TESTA-COLLO

- intimacy: processo nel quale una persona esprime importanti sentimenti e informazioni ad un’altra persona e, in seguito alla risposta che ottiene, si sente compreso, validato e accudito
- l’autoapertura, la percezione di un’apertura da parte del partner e la percezione di responsività da parte del partner alla propria autoapertura favoriscono l’adattamento della coppia al cancro

# PSICOPATOLOGIA

- deistituzionalizzazione
- riduzione del benessere del caregiver → riduzione del benessere del paziente
- lo stigma porta a isolamento della famiglia, difficoltà lavorative ed economiche, frustrazione, ansia, riduzione dell'autostima, percezione di inaiutabilità, diminuzione del tempo libero, effetti negativi sulle relazioni sociali, esperienze di discriminazione e preoccupazione per il futuro

# PSICOPATOLOGIA

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## Effects on Resilience of Women Family Caregivers of Adults With Serious Mental Illness: The Role of Positive Cognitions

Jaclene A. Zauszniewski, Abir K. Bekhet, and M. Jane Suresky

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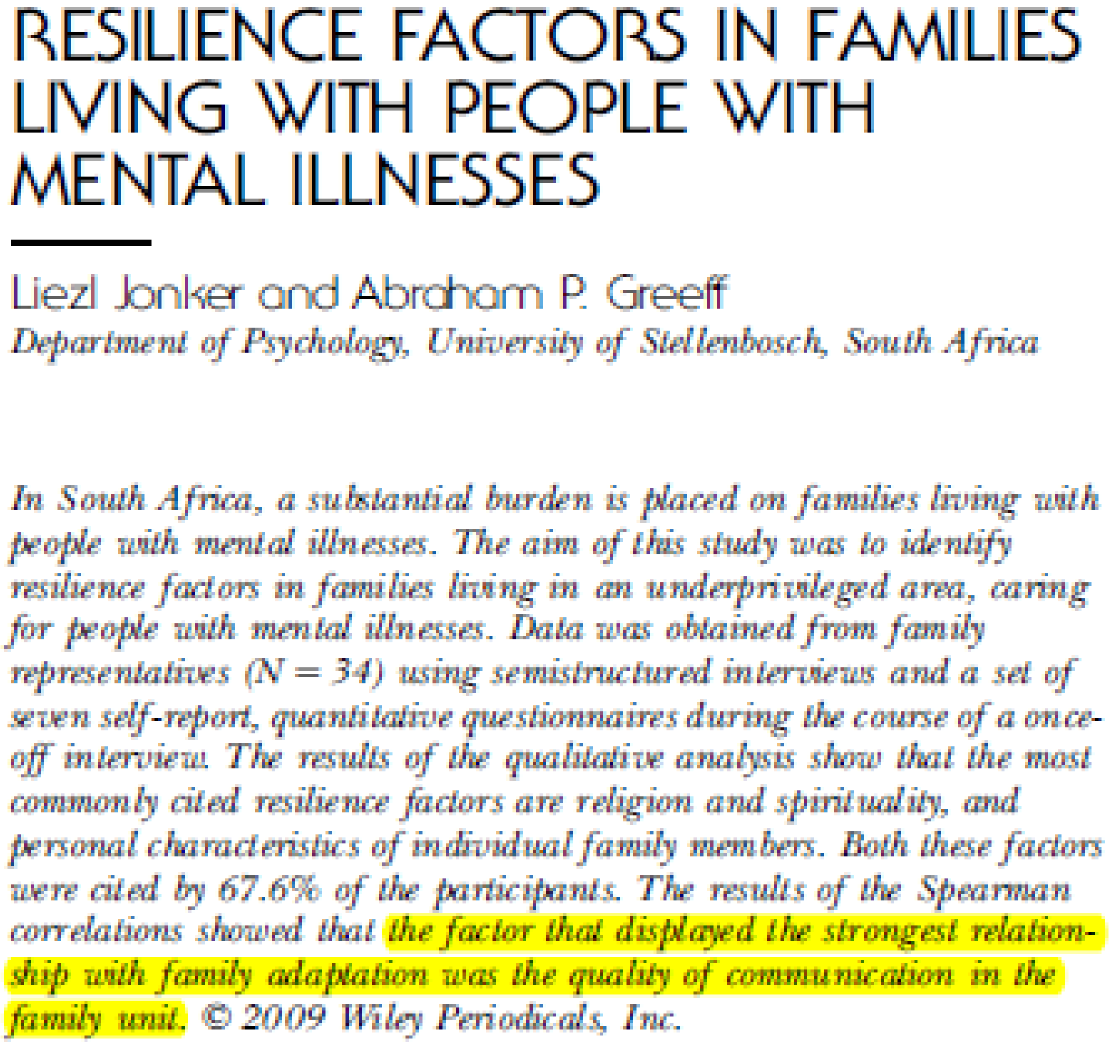
This study examined the effects of risk and protective factors on resilience in 60 women family members of adults with serious mental illness. Both the risk factors constituting caregiver burden (strain, stigma, client dependence, and family disruption) and protective factors, including eight positive cognitions were found to predict two indicators of resilience: resourcefulness and sense of coherence. The effects of caregiver burden on resourcefulness and sense of coherence were mediated by positive cognitions, lending support to resilience theory and suggesting the need to develop interventions to encourage positive thinking among women caregivers of adults with mental illness.

# PSICOPATOLOGIA

- resilienza: capacità di far fronte alle avversità
- dipende dall’interazione tra fattori di rischio e fattori protettivi
- indicatori di resilienza: senso di coerenza (orientamento complessivo nei confronti della vita che comprende elementi cognitivi, comportamentali e motivazionali e che è espresso nella convinzione che il mondo sia un posto comprensibile, gestibile e dotato di significato) e presenza di risorse (insieme di abilità cognitivo-comportamentali per gestire le avversità continuando a funzionare al proprio livello ottimale nelle attività di vita quotidiana)

# PSICOPATOLOGIA



## RESILIENCE FACTORS IN FAMILIES LIVING WITH PEOPLE WITH MENTAL ILLNESSES

Liezl Jonker and Abraham P. Greeff
*Department of Psychology, University of Stellenbosch, South Africa*

*In South Africa, a substantial burden is placed on families living with people with mental illnesses. The aim of this study was to identify resilience factors in families living in an underprivileged area, caring for people with mental illnesses. Data was obtained from family representatives (N = 34) using semistructured interviews and a set of seven self-report, quantitative questionnaires during the course of a once-off interview. The results of the qualitative analysis show that the most commonly cited resilience factors are religion and spirituality, and personal characteristics of individual family members. Both these factors were cited by 67.6% of the participants. The results of the Spearman correlations showed that the factor that displayed the strongest relationship with family adaptation was the quality of communication in the family unit.* © 2009 Wiley Periodicals, Inc.