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## A Critical Analysis of Measures of Caregiver and Family Functioning following Traumatic Brain Injury

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### Abstract

More than 5.3 Million Americans are living with long-term disability following TBI and approximately 40% of TBI survivors report at least one unmet need at 1 year post-injury. The totality of the problem of TBI may therefore put increased responsibilities on the significant other and family. The purpose of this work was to conduct an integrative review of the literature to identify available instruments that might be useful to researchers and clinicians interested in the effects of TBI on family functioning. A review of the literature was undertaken using CINAHL Plus, Family Systems Abstracts, and Pubmed from 1998–2008. 35 articles were identified the initial search and 8 were excluded leaving 27 articles for full review and analysis. Conceptual and methodological issues identified across the studies resulted in an inability to recommend any of the instruments used in the present studies for use without further study. These issues identified included: a lack of conceptual framework for construct validity, variability in injury characteristics, issues with sampling methodology, a lack of longitudinal designs, comparison group issues and an inability to compare instruments across studies.

### Introduction

More than 1.4 Million people sustain a traumatic brain injury (TBI) in the US each year and more than 5.3 Million Americans are living with long-term disability following TBI (*Injury Fact Book*, 2002). Traumatic brain injury may result in persistent cognitive and communication problems that vary depending on the location and severity of the injury. Symptoms commonly include: difficulty concentrating, impaired judgment, impaired memory, problems with decision making and problem solving, word-finding difficulties and inappropriate social behavior. Approximately 40% of TBI survivors report at least one unmet service need at 1 year post injury (Heinemann, Sokol, Garvin, & Bode, 2002). In order to attempt to meet unmet needs following injury in TBI patients, increased responsibilities may be placed on the significant other/family than prior to injury.

Head trauma can affect anyone at any age but older adults are particularly vulnerable to injuries from falls and traffic accidents. In persons 65 years of age and older, traumatic brain injury (TBI) is responsible for over 80,000 emergency department visits each year and adults age 75 years or older have the highest rates of TBI-related hospitalization, thus they are a large and growing population within the TBI community (Langlois, Rutland-Brown, & Thomas, 2004; Department of Health and Human Services., 2000).

When one partner in an intimate relationship experiences a sudden injury resulting in temporary or permanent disability, such as a TBI, the relationship is stressed by the events. In some cases; however, these stressors strain the couple's relationship to the breaking point, and may result

in higher rates of separation and divorce among TBI survivors (Wood & Yurdakul, 1997). Research to date has primarily focused on younger and middle aged adults and little is known about older adults following TBI. A single qualitative study was identified from the literature about the experience of using the multiple case study approach Layman and colleagues (2005) focused on the experience of older partners of persons with TBI. The authors identified Relatedness and Relationship Persistence as the two primary themes of interest and noted that there was an inability of couples to discern normal aging changes versus TBI-related changes (Layman, Dijkers, & Ashman, 2005).

Thus, given the paucity of available research for caregivers/family member functioning of older adult TBI survivors, it is clearly an area warranting further attention. Well-validated instruments of caregiver role functioning are available from the geriatric literatures and include the Kingston Caregiver Stress Scale (Hopkins, Killik, & Day, 2007) the Modified Caregiver Strain Index (Thornton & Travis, 2003) the Zarit Caregiver Burden Scale (Zarit, Reever, & Bach-Peterson, 1980). However, these were originally developed for use in caregivers of persons with dementia, not TBI. As to date there is only a single article available specific to older adults TBI survivors and family functioning, a review of the literature was consequently undertaken to identify available instruments used to assess caregiver/family member functioning of TBI survivors of all ages.

### Questions of Interest

Is there an optimal measure of family functioning identified from the TBI literature for use in future studies of TBI survivor family member/caregivers? Is this identified measure appropriate for use with older adult TBI survivor family member/caregivers?

### Method

To answer the research questions of interest, a review of the literature was undertaken using the following databases: CINAHL Plus, Family Systems Abstracts, and Pubmed. The databases were searched from 1998–2008 using the MeSH terms: Brain Injuries; caregivers; questionnaires and the following restrictions: English; Research Articles; Full Text Available.

### Results of Literature Review

From the initial search, 35 full-text articles were identified. Following a review of the article abstracts, 8 were excluded from the initial search because they were a) qualitative interviews and/or b) studies that used caregiver factors to predict of TBI survivor outcome and this was not the focus of research question. 27 articles remained for full review and analysis (See Table 1).

The unit of analysis in the majority of studies (n=21) was the individual caregiver or family member. Very few studies of caregivers have focused on a particular type of individual eg. spouse in these studies. Thus there is a high degree of variability in the type of family members represented within studies. Some studies have focused on the dyad (n=4) of the TBI survivor and the caregiver/family member (Carnevale, Anselmi, Busichio, & Millis, 2002; Ergh, Rapport, Coleman, & Hanks, 2002; Ponsford, Olver, Ponsford, & Nelms, 2003; Wells, Dywan, & Dumas, 2005); but only a single group (Gan, Campbell, Gemeinhardt, & McFadden, 2006; Gan & Schuller, 2002) has focused on the family system, which is a framework that centers on the family as a whole and the interactions within the family, rather than an individual member. Using a theoretical approach that views the family holistically, is logical as the sequelae of TBI can be far reaching beyond any individual (Gan & Schuller, 2002).

From this review, there were conceptual and methodological issues identified across the studies. This resulted in the inability to recommend any of the instruments used in the present studies for use without further study. These identified issues included: a lack of conceptual framework for construct validity, variability in injury characteristics, issues with sampling methodology, a lack of longitudinal designs, comparison group issues and an inability to compare instruments across studies.

## Discussion

### Lack of conceptual framework for construct validity

There was a lack of an explicit conceptual framework present in the majority of studies (Table 1 and Table 2). This absence of a clear framework was then manifested in a wide range of concepts of family functioning presented by various authors (See Table 2) across studies as outcomes of interest. The concepts presented in the various papers could be classified as having positive, negative, or neutral connotations for functioning. This lack of conceptual clarity likely influenced other issues such as design, comparison and interpretation (Hutchison, 1999; O'Reilly, 1988).

### Variability in Injury Characteristics

Many issues frequently encountered in the cross-sectional studies centered around the sampling methods (e.g. multiple injury severities, the wide range of time since injury in many cross sectional studies, and inclusion of child/parent/siblings in single studies). Injury severity may play a large role in the type of sequelae that result following TBI and thus influence the caregiver/family's function over time. The studies reviewed in this paper often included wide ranges in brain injury severity indicators such as post-traumatic amnesia and length of unconsciousness (e.g. Wells et al., 2005) which may have influenced these but were not used as covariates in the analyses. Time since injury also varied widely in the majority of the cross-sectional designs; in some cases from a few months to up to 30 or 40 years post-injury (Katz, Kravetz, & Grynbaum, 2005); Wells et al., 2005). While this may have allowed for larger sample sizes, it is not representative of a population, thus the ability to draw any real inference or to identify an effective intervention is significantly reduced. In only a few studies was the cross-sectional study designed to assure sampling a temporally similar group of caregivers (Kolakowsky-Hayner, Miner, & Kreutzer, 2001; Marsh, Kersel, Havill, & Sleigh, 1998a, 1998b; McPherson, Pentland, & McNaughton, 2000). Lastly, for several of the studies (e.g. Marwit & Kaye, 2006; McPherson, Pentland, & McNaughton, 2000), the inclusion criteria were family members or caregivers of persons with acquired brain injury which is not exclusive to TBI, but also includes chronic or pathological injury such as stroke. The use of these broad inclusion criteria was stated by the authors to be deliberate to increase sample size (Murray, Maslany, & Jeffery, 2006). For most analyses; however, this actually represents multiple perspectives of multiple types of recovery experiences, rather than a single uniform analysis.

### Issues with sampling methodology

Often the samples selected were not an optimal match for the research question of interest; frequently the samples were convenience samples from secondary sources (See Table 1-Study Design; Sample) or from patients presenting in clinic. While the stated purpose of many studies was to elucidate family members' or caregiver's experiences, they did not approach this from multiple persons within a single family, so the study could only really attempt to describe the experience of a single family member's experience. Also, in using a convenience sample often the defining characteristics were ill-defined, e.g. in many samples "Frequent close contact" was required, but this was not explicitly defined and could vary widely based on the subjects' interpretation; this differed from other studies in which the subjects were required to reside in

the same household to define “family”. This could have greatly influenced the types of responses.

In many of the studies, despite the use of a cross-sectional design and the use of convenience sampling, the numbers obtained were relatively small. The sample sizes varied from 28 to 249. In the larger sample sizes, these were generally mixed populations of various types of family members, with wide age ranges, various types of injury (mild and severe in same group), so again the issue of multiple perspectives of multiple types of recovery experiences pooled together is raised as study limitations.

### **Relative lack of longitudinal designs**

The majority of studies (n=23) available were cross-sectional designs. A single study (Marsh, Kersel, Havill, & Sleight, 2002) has examined the individual experience of individual primary caregivers of adults discharged from rehabilitation services participating in the TBI model systems program. The authors reported that there was an adaptation of the caregiver in the period from 6 months to one year post-injury. They also found that social isolation and behavioral problems of the TBI patient were predictive of burden. Limitations in the cross-sectional designs again include the times chosen to report outcomes of family members/caregivers varied widely based again primarily on convenience and included unusual timepoints e.g. 40 years post-injury (See Table 1).

### **Comparison group issues**

In several studies the comparison group selected included rehabilitation professionals (Man, 2002) or professional caregivers (Godfrey et al., 2003). The selection or inclusion of these groups is not particularly informative in describing caregiver functioning as defined by the investigators. Frequently, the comparison group selected was convenient, but not concordant with the research question of interest. An additional issue was that researchers made temporal assertions based on comparisons of differing times since injury of various families/caregivers in cross-sectional studies. These are not valid comparisons to make.

### **Inability to compare instruments across studies**

Many researchers sought to develop or validate their own family/caregiver functioning instrument for use in TBI and specifically developed the instrument for the study reported. Seven of the 27 studies reviewed were testing new instruments, often with insufficient data provided on reliability and validity. Across the 27 studies more than 50 different instruments (See Table 1-Instruments) were used to measure family/caregiver functioning and only rarely (e.g. Beck Depression Scale, Family Needs Questionnaire, Caregiver Appraisal Scale) was an instrument used in more than one study, thus there is an inability to compare instruments across studies of family functioning in TBI.

**Recommendations for Future Studies**—In future cross-sectional studies, it will be particularly useful to evaluate a particular family member’s/caregiver’s perspective of the recovery experience of the same level of TBI severity at a similar time-point post-injury. In designing or reporting future studies, when data is obtained from intake assessments, more information would be particularly useful in interpreting findings in relationship to generalizability to those persons who do not seek treatment for TBI or qualify for rehabilitation services. This work would be better done with a clear time of assessment post-injury defined (e.g. 2 years post injury when most plasticity and recovery has occurred or within 1 year of injury when the adjustment and service use is really the greatest). In particular, a prospective longitudinal study that enroll families near the time of injury and includes an assessment of pre-injury functioning as a baseline measure would be especially useful.

**Limitations of this Review**—This review is limited in that only published articles available on-line in English were reviewed from particular databases and gray literature (e.g. dissertations) were not included, thus some bias may have been introduced. Attempts to reduce bias in this review were maintained via the use of clear questions to guide the literature review, a threshold for inclusion of studies and systematic methods evaluate the research literature.

## Summary

The lack of conceptual clarity within the field of family functioning in TBI has resulted in a lack of consistent use of terminology and has led to the use of more than 50 instruments across various studies and the continual development of additional, yet poorly justified tools. There is a clear need to conduct an evolutionary concept analysis of family functioning in TBI and to gain a lucid, comprehensible definition of the idea prior to continuing additional work in this area. Based upon this review, the author was unable to answer the second research question since there was insufficient data to be able to recommend any TBI-specific instrument for use with caregivers/family members, let alone recommend its' with use of older populations. The use of well-validated family function and caregiving instruments from other fields, such as geriatrics, is recommended in the interim for ongoing and planned family TBI research with older adults. These studies should focus on longitudinal analyses of a family functioning within the context of a focused TBI population (e.g. mild brain injury). Additionally, these studies should account for differences in family development in their sampling structures (e.g. children of parents with TBI should be examined separately from spousal issues) until there is a clear understanding of these issues. Once a better understanding of family functioning within the family system has been obtained, comparison across these populations can occur.

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## References

- Anderson MI, Parmenter TR, Mok M. The relationship between neurobehavioural problems of severe traumatic brain injury (TBI), family functioning and the psychological well-being of the spouse/caregiver: path model analysis. *Brain Injury* 2002;16(9):743–757. [PubMed: 12217201]
- Brown R, Pain K, Berwald C, Hirschi P, Delehanty R, Miller H. Distance education and caregiver support groups: comparison of traditional and telephone groups. *Journal of Head Trauma Rehabilitation* 1999;14(3):257–268. [PubMed: 10381978]
- Carnevale GJ, Anselmi V, Busichio K, Millis SR. Changes in ratings of caregiver burden following a community-based behavior management program for persons with traumatic brain injury. *Journal of Head Trauma Rehabilitation* 2002;17(2):83–95. [PubMed: 11909508]
- Department of Health and Human Services. Centers for Disease Control and Prevention. *Healthy People 2010*. Vol. 2nd ed.. Vol. 2. Atlanta, GA: 2000. Chapter 15: Injury and Violence Prevention.
- Ergh TC, Rapport LJ, Coleman RD, Hanks RA. Predictors of caregiver and family functioning following traumatic brain injury: social support moderates caregiver distress. *Journal of Head Trauma Rehabilitation* 2002;17(2):155–174. [PubMed: 11909512]
- Gan C, Campbell KA, Gemeinhardt M, McFadden GT. Predictors of family system functioning after brain injury. *Brain Injury* 2006;20(6):587–600. [PubMed: 16754284]
- Gan C, Schuller R. Family system outcome following acquired brain injury: clinical and research perspectives. *Brain Injury* 2002;16(4):311–322. [PubMed: 11953002]
- Godfrey HPD, Harnett MA, Knight RG, Marsh NV, Kesel DA, Partridge FM, et al. Assessing distress in caregivers of people with a traumatic brain injury (TBI): a psychometric study of the Head Injury Behaviour Scale. *Brain Injury* 2003;17(5):427–435. [PubMed: 12745714]

- Hanks RA, Rapport LJ, Vangel S. Caregiving appraisal after traumatic brain injury: The effects of functional status, coping style, social support and family functioning. *NeuroRehabilitation* 2007;22(1):43–52. [PubMed: 17379947]
- Harris JKJ, Godfrey HPD, Partridge FM, Knight RG. Caregiver depression following traumatic brain injury (TBI): a consequence of adverse effects on family members? *Brain Injury* 2001;15(3):223–238. [PubMed: 11260771]
- Heinemann AW, Sokol K, Garvin L, Bode RK. Measuring unmet needs and services among persons with traumatic brain injury. *Arch Phys Med Rehabil* 2002;83(8):1052–1059. [PubMed: 12161825]
- Hopkins, RW.; Killik, L.; Day, D. Kingston Caregiver Stress Scale Administration and Interpretation Manual. 2007. Retrieved 12/1/2007, 2007, from [http://www.providencecare.ca/cms/sitem.cfm/clinical\\_services/geriatric\\_psychiatry/kingston\\_scales/kcss\\_\(stress\)/](http://www.providencecare.ca/cms/sitem.cfm/clinical_services/geriatric_psychiatry/kingston_scales/kcss_(stress)/)
- Hutchison C. Social support: factors to consider when designing studies that measure social support. *J Adv Nurs* 1999;29(6):1520–1526. [PubMed: 10354249]
- Injury Fact Book. Atlanta: National Center for Injury Prevention and Control, Centers for Disease Control and Prevention; 2002.
- Katz S, Kravetz S, Grynbaum F. Wives' coping flexibility, time since husbands' injury and the perceived burden of wives of men with traumatic brain injury. *Brain Injury* 2005;19(1):59–66. [PubMed: 15762101]
- Kolakowsky-Hayner SA, Miner KD, Kreutzer JS. Long-term life quality and family needs after traumatic brain injury. *Journal of Head Trauma Rehabilitation* 2001;16(4):374–385. [PubMed: 11461659]
- Langlois, JA.; Rutland-Brown, W.; Thomas, KE. Traumatic Brain Injury in the United States: Emergency Department Visits, Hospitalizations, and Deaths. Atlanta, GA: National Center for Injury Prevention and Control; 2004.
- Layman DE, Dijkers MP, Ashman TA. Exploring the impact of traumatic brain injury on the older couple: 'yes, but how much of it is age, I can't tell you ...'. *Brain Inj* 2005;19(11):909–923. [PubMed: 16243747]
- Man DWK. Family caregivers' reactions and coping for persons with brain injury. *Brain Injury* 2002;16(12):1025–1037. [PubMed: 12487717]
- Marsh NV, Kersel DA, Havill JA, Sleigh JW. Caregiver burden during the year following severe traumatic brain injury. *J Clin Exp Neuropsychol* 2002;24(4):434–447. [PubMed: 12187457]
- Marsh NV, Kersel DA, Havill JH, Sleigh JW. Caregiver burden at 1 year following severe traumatic brain injury. *Brain Inj* 1998a;12(12):1045–1059. [PubMed: 9876864]
- Marsh NV, Kersel DA, Havill JH, Sleigh JW. Caregiver burden at 6 months following severe traumatic brain injury. *Brain Inj* 1998b;12(3):225–238. [PubMed: 9547953]
- Marwit SJ, Kaye PN. Measuring grief in caregivers of persons with acquired brain injury. *Brain Injury* 2006;20(13–14):1419–1429. [PubMed: 17378234]
- McPherson KM, Pentland B, McNaughton HK. Brain injury - the perceived health of carers. *Disabil Rehabil* 2000;22(15):683–689. [PubMed: 11087064]
- Morris KC. Psychological distress in carers of head injured individuals: the provision of written information. *Brain Injury* 2001;15(3):239–254. [PubMed: 11260772]
- Murray HM, Maslany GW, Jeffery B. Assessment of family needs following acquired brain injury in Saskatchewan. *Brain Inj* 2006;20(6):575–585. [PubMed: 16754283]
- Nabors N, Seacat J, Rosenthal M. Predictors of caregiver burden following traumatic brain injury. *Brain Injury* 2002;16(12):1039–1050. [PubMed: 12487718]
- O'Reilly P. Methodological issues in social support and social network research. *Soc Sci Med* 1988;26(8):863–873. [PubMed: 3287636]
- Perlesz A, Kinsella G, Crowe S. Psychological distress and family satisfaction following traumatic brain injury: injured individuals and their primary, secondary, and tertiary carers. *Journal of Head Trauma Rehabilitation* 2000;15(3):909–929. [PubMed: 10785622]
- Ponsford J, Olver J, Ponsford M, Nelms R. Long-term adjustment of families following traumatic brain injury where comprehensive rehabilitation has been provided. *Brain Injury* 2003;17(6):453–468. [PubMed: 12745702]



- Rappoport LJ, Kreutzer JS, Hart T, Marwitz JH. Traumatic brain injury caregiver distress and use of support services. *Journal of Head Trauma Rehabilitation* 2006;21(5):432–433.
- Sander AM, Davis LC, Struchen MA, Atchison T, Sherer M, Malec JF, et al. Relationship of race/ethnicity to caregivers' coping, appraisals, and distress after traumatic brain injury. *NeuroRehabilitation* 2007;22(1):9–17. [PubMed: 17379945]
- Struchen MA, Atchison TB, Roebuck TM, Caroselli JS, Sander AM. A multidimensional measure of caregiving appraisal: validation of the caregiver appraisal scale in traumatic brain injury. *Journal of Head Trauma Rehabilitation* 2002;17(2):132–154. [PubMed: 11909511]
- Thornton M, Travis SS. Analysis of the reliability of the modified caregiver strain index. *J Gerontol B Psychol Sci Soc Sci* 2003;58(2):S127–S132. [PubMed: 12646602]
- Watanabe Y, Shiel A, McLellan DL, Kurihara M, Hayashi K. The impact of traumatic brain injury on family members living with patients: a preliminary study in Japan and the UK. *Disability & Rehabilitation* 2001;23(9):370–378. [PubMed: 11394587]
- Wells R, Dywan J, Dumas J. Life satisfaction and distress in family caregivers as related to specific behavioural changes after traumatic brain injury. *Brain Injury* 2005;19(13):1105–1115. [PubMed: 16286324]
- Wood RL, Yurdakul LK. Change in relationship status following traumatic brain injury. *Brain Inj* 1997;11(7):491–501. [PubMed: 9210986]
- Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist* 1980;20(6):649–655. [PubMed: 7203086]

**Table 1**  
A Comparison of Studies of Caregiver and Family Functioning in Traumatic Brain Injury

Reference	Unit of Analysis	Conceptual Framework	Study Design	Sample	Instrument(s) Used to measure Caregiver/Family Function	Findings/Comments
(Anderson et al. 2002)	Spouse/Partner of TBI survivor	Hobfoll and Spielberger's COR theory of psychological distress and Epstein's McMaster Model of Family Functioning	Path Analysis	N=74 Spouse/partners of TBI survivors (age range of TBI patient 27-75; time since injury 5-184 months)	Problem Checklist of General Health and History Questionnaire; Family Assessment Device; Global Severity Index; Brief Symptom Inventory (BSI)	TBI survivor behavioral problems were strongest predictor of caregiver psychological distress. Communication and social problems have linear relationship with symptoms of psychological distress.
(Brown et al. 1999)	Individual caregivers	None	Quasi-experimental pre/post-test design; evaluate effectiveness of face-to-face vs. phone caregiver support groups	Caregivers (family member or s.o.) living within 40km (n=169) vs. those living >40km (n=146)	POMS; Caregiver Burden Inventory; McMaster Model Family Assessment Device	Similar results seen with both methods. Rural phone support group participants reported fewer difficulties on most scales so may be good option for this population.
(Carnevale et al. 2002)	Dyad	Stress-Appraisal-Coping Model	RCT of Educational program and education plus behavior management vs. control	n=27 TBI survivors and their caregivers (n=27)	Questionnaire on Resources and Stress for Families with Chronically Ill or Handicapped Members; Maslach Burnout Inventory	Initial levels of caregivers' burden and distress were highly predictive of those at 14 weeks (outcome). Low sample size per group
Ergh et al. (2003)	Dyad	Well-being	Cross-sectional (range post-injury 4 months to 10 years)	N=120 (60 pairs of TBI survivors and caregivers)	Neuropsychology Behavior and Affect Profile-Significant Other Form; Social Provision Scale; Satisfaction with Living Scale	Social support found to be positive mediator; however, TBI survivor neurobehavioral issues were associated with lower caregiver life satisfaction regardless of social support.
Gan & Schuller (2002)	Family (also reported BI vs. family)	Family Systems Framework	Cross sectional; instrument development	N=92	FAM-III	Family defined as those living in same household. See Gan et al. (2006) as includes greater differences in functioning than BI person.
(Gan et al. 2006)	Family System (also reported individual)	Family Systems Framework	Cross sectional; At time seeking rehab services; instrument validation	N=214 from registry; 66 BI persons and 148 family members; (Mean time since injury 5.7	FAM-III	Family defined as those living in same household. Pooling effect seen when family unit of analysis; however fathers reported less stress when analyzed individually. BI families statistically different from



Reference	Unit of Analysis	Conceptual Framework	Study Design	Sample	Instrument(s) Used to measure Caregiver/Family Function	Findings/Comments
(Godfrey et al. 2003)	Individual caregiver	None	Cross sectional; Instrument validation (factor analysis)	years; ages of FM ranged 14–55). N=242 88 parents, 81 spouses, 11 siblings, 34 other relatives, 14 friends and 13 other acquaintances (e.g. professional caregivers)	Head Injury Behavior Scale	normative; but unclear if clinically significant as still in “normal range”. 2 factor solution Emotional and Behavioral Regulation.
(Hanks et al., 2007)	Individual caregiver	Stress-Appraisal-Coping Model	Cross-sectional (6 months-15 years post-injury)	N=60 primary caregivers of persons with TBI	Caregiver Appraisal Scale; Coping Inventory for Stressful Situations; Family Assessment Device; Social Provisional Scale	Perception of social support is highly related to perceived burden, caregiving mastery and satisfaction. Coping style was related to caregiving satisfaction: better among those who use task-oriented coping and less emotion-focused coping.
(Harris et al. 2001)	Individual caregivers	Stress-Appraisal-Coping Model	Cross sectional (between 6 months and 3 years following injury)	N=58 Caregivers identified by persons with TBI (age of TBI survivor ranged 15–64; 47% parents; PTA 24h–10 weeks)	Social Behaviour Assessment Schedule; Zung Depression Scal	23% of caregivers were experiencing clinically significant levels of depression. Caregiver reports of behavioral problems, social role problems, and adverse effects were correlated to depression scores. Perceived support was also predictive of depression in this model.
(Katz et al. 2005)	Wife	Brooks and Aughton’s subjective vs. objective caregiver burden	Cross sectional	N=40 wives of persons with TBI (range of time since injury 1–32 years)	Perceived Burden Questionnaire; Lester’s ways of Coping Questionnaire	Wives with low coping flexibility were perceived to have higher burden at earlier times after injury; however, if analysis done correctly as df incorrect for interaction term.
(Kolakowsky-Hayner et al. 2001)	Individual caregiver	None	Cross sectional at least 4 years post injury	N=57 caregivers of persons with TBI (age range 19–82; 72% lived with person; 35% spent q day with)	Virginia Traumatic Brain Injury Family Needs Assessment Survey	Study demonstrated a decline in family members’ quality of life after injury relative to preinjury (but 58% were at least somewhat satisfied); percentage of needs rated as unmet/partially met ranged from 48% to 60%
(Man et al., 2002)	Individual Family Member	None	Cross sectional; instrument development	Group 1: 221 mixed group of family members of persons with TBI; Group 2:	Family Empowerment Questionnaire	Differences noted between rehab professionals and Hong Kong Chinese family members on 4 empowerment factors may have clinical implications for care

Reference	Unit of Analysis	Conceptual Framework	Study Design	Sample	Instrument(s) Used to measure Caregiver/Family Function	Findings/Comments
(Marsh et al., 1998a)	Individual caregiver	None	Cross-sectional at 6-months post-injury	65 rehab professionals N=69 primary caregiver of adult with TBI	Beck Depression Inventory; Trait Anxiety Inventory; Head Injury Behavior Rating Scale; Caregiving Questionnaire	provision. Anxiety, depression, and social adjustment problems present in 1/3 of caregivers at 6 months. Social isolation and negative emotions of TBI survivor associated with most distress while behavioral problems have most impact overall on caregiver function at 6 months.
(Marsh et al., 1998b)	Individual caregiver	None	Cross-sectional at 1-year post injury	N=69 primary caregiver of adult with TBI	See (Marsh 1998a) for instruments	Number of behavioral problems and physical impairment of the TBI survivor as well as social isolation were strongest predictors of burden. Caregiver distress resulted from TBI survivor emotional difficulties such as anger. Most impact was loss of personal time on part of caregiver.
(Marsh et al., 2002)	Individual caregiver	None	Longitudinal (combined prior data 6 mo/1 yr)	N=52 primary caregiver of adult with TBI	See (Marsh 1998a) for instruments	Evidence of adaptation over time.
(Marwit et al. 2006)	Primary caregiver	None	Cross sectional; instrument validation	N=28 caregivers of persons with acquired BI; (spouse/partner, adult child, relative or friend)	Marwit-Meuser Caregiver Grief Inventory; Caregiver well-being scale-basic needs; Caregiver Strain Index; Perceived Social Support Questionnaire; Beck Depression Inventory	No relationship found between ABI level of function, years since injury, and measures of caregiver grief, depression, wellbeing, strain or perceived social support. Small sample size did not allow factor analysis of tool in this new population.
(McPherson et al. 2000)	Individual caregiver	None	Cross-sectional (15-18 months post-discharge from inpatient rehabilitation)	N=70 caregivers of survivors of acquired brain injury (TBI 60%). Mixed population of spouses, parents, others. Age range of respondents 14-76 years.	Short Form-36; Caregiver Strain Index	Strain levels of TBI caregivers higher than for other types of acquired BI, but this not significant. Spouses reported worse perceived health on the SF-36 in comparison to parent caregivers.
Morris (2001)	Primary caregiver	None	Pre/post test design; evaluate effectiveness of informational	N=34 primary caregivers of TBI survivors grouped into	General Health Questionnaire; Symptom Checklist; Hospital	Booklet would have been most useful if provided at discharge. No significant change in anxiety, depression or symptom scores.

Reference	Unit of Analysis	Conceptual Framework	Study Design	Sample	Instrument(s) Used to measure Caregiver/Family Function	Findings/Comments
(Murray et al., 2006)	Individual Family members/caregivers	None	booklet on TBI to caregivers	early (2-9 mo) or late (>1 yr) following injury	Anxiety and Depression Scale; Questionnaire about booklet	Acquired brain injury includes traumatic, chronic or pathological injury. About one half of caregivers reported partially or unmet needs.
(Nabors et al. 2001)	Individual caregiver	None	Cross-sectional (range 5 months-14.5 years post-injury)	N=66 caregivers of person with acquired brain injury; mix of parents, spouse, others	Family Needs Questionnaire; Content analysis of open-ended questions	The younger the caregiver the fewer the needs that were met. African American and White caregivers exhibited similar patterns of adjustment after TBI.
(Rapport et al. 2006)	Individual caregiver	None	Cross sectional at least 1 year post-injury (range 12-52 months)	(N=45) 24 African American and 21 White caregivers of TBI survivors at least 1-year post-injury. Age range 21-73; defined as FM directly involved in care upon d/c from rehab	Head Injury Family Interview; Family Needs Questionnaire (FNQ); Family Assessment Device; Personality Assessment Inventory	Prevalence of depression 17%, anxiety 16%, somatization 21%, and low satisfaction with life 23%; but more than 40% of caregivers who exceeded clinical cutoffs did not receive treatment. House of worship was primary source of support.
(Perlesz et al. 2000)	Individual with TBI and primary, secondary and tertiary caregivers	None	Cross sectional at 1, 2 or 5 years post-injury	N=249 caregivers of TBI survivors; mix of parents, spouses, others ranged	Family Satisfaction Scale; Beck Depression Inventory; State Anxiety Inventory; POMS; Head Injury Family Interview	Gender differences seen among primary caregivers; wives are at greatest risk of poor psychological risk and report much more responsibility than prior to injury.
(Ponsford et al. 2003)	Dyad (TBI survivor and a close family member)	None	Cross sectional at 2, 3 or 5 years post-injury	79 Families (65 TBI survivors; 72 primary caregivers; 43 secondary carers; 22 tertiary) (age at time of injury ranged 16 to >66 yoa)	Family Assessment Device (FAD); Leeds Scales for Self-Assessment of Anxiety and Depression; Structured Outcome Questionnaire; Sickness Impact	Level of family adjustment in those participating was reasonably healthy. Stepwise regression analysis examining strongest predictors of functioning were the number of cognitive, behavioural and emotional changes reported in the injured relative

Reference	Unit of Analysis	Conceptual Framework	Study Design	Sample	Instrument(s) Used to measure Caregiver/Family Function	Findings/Comments
(Sander et al., 2007)	Individual Caregiver	None	Nested Cross-sectional 1 year post-injury	N=195 caregivers. Blacks and Hispanics grouped together due to small sample size for comparison to Whites.	Profile Ways of Coping Questionnaire; Caregiver Appraisal Scale; Brief Symptom Inventory	Implied model: cultural context of care. Blacks/Hispanic caregivers reported more distress than whites in contrast to prior studies. Limited generalizability due to grouping of racial and ethnic categories acknowledged.
(Struchen et al. 2002)	Individual Caregivers	Stress (Lazarus & Folkman)-Appraisal	Cross sectional; instrument validation	N=241 (149 in TBI model systems; 92 in rehab)	Caregiver Appraisal Scale; Subjective Burden Scale; Objective Burden Questionnaire; General Health Questionnaire	Factor analysis yielded similar structure to that for caregivers of frail older adults (Lawton et al., 1989). Caregiving mastery had poor internal consistency. Physical burden, caregiver relationship satisfaction and caregiver ideology performed well.
(Watanabe et al. 2001)	Individual Family Member	None	Cross sectional	(N=30) 18 British family members and 12 Japanese Family Members of TBI Survivors living in same household and providing most care in Japan	Family experience and attitudes questionnaire; Japanese FM were significantly worried about opinions of non-household relatives and others. British FM who reported social embarrassment appeared to experience higher levels of mental and physical stress	Implied model: Cultural context of care. Needs not different between the 2 groups. to some extent, Japanese FM were significantly worried about opinions of non-household relatives and others. British FM who reported social embarrassment appeared to experience higher levels of mental and physical stress
(Wells et al. 2005)	Dyad (TBI survivor and primary caregiver)	None	Cross sectional (mean time since injury 1-40 years)	72 pairs of adults; (caregivers were 52 spouses, 17 parents, 1 grandparent, 1 cousin)	Brock Adaptive Functioning Questionnaire ; Zari Caregiving Stress Questionnaire Short Form; Questionnaire on Resources and Stress; Symptom Checklist (SCL-90); Satisfaction with Life; Family Coping Strategies (F-Copes)	Wide variation in PTA; length of unconsciousness. Positive caregiving feelings>Negative. Loss of income following injury related to more negative feelings. No behavioral change on part of TBI patient added to predicting positive care feelings. Recruited 351; so sample bias possible.

**Table 2**  
Concepts of Family Functioning Identified in Reviewed Articles

Positive Valued Concepts	Negative Valued Concepts	Neutral Concepts
Quality of Life	Caregiver Distress	Caregiver Functioning
Caregiver Adjustment	Psychological Distress	Caregiver Appraisal
Life Satisfaction	Caregiver Depression	Family Needs
Psychological Well-being	Caregiver Stress	Perceived Health
Family Empowerment	Caregiver Burden	
Caregiver Coping	Carer Strain	