

## **Depression and anxiety in parent versus spouse caregivers of adult patients with traumatic brain injury: A systematic review**

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A systematic review of studies which evaluated depression and anxiety in parent versus spouse caregivers of adults with traumatic brain injury (TBI) was conducted. Demographic variables of the TBI patients and caregivers, study design, measurement tools used, and outcomes reported were collected. Twenty-four studies met the inclusion criteria and were evaluated for methodological quality. While the majority of studies revealed no significant differences between caregiver types on measures of depression and/or anxiety, there was a great deal of variation in methodology and quality between the studies. Overall, high levels of caregiver distress were exposed, regardless of caregiver type (parent versus spouse). There is a need for qualitative and quantitative research designs in order to elucidate the factors that put caregivers at risk for depression and anxiety.

**Keywords:** Depression; Anxiety; Traumatic brain injury; Systematic review; Caregivers.

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## INTRODUCTION

Globally, it is estimated that 10 million people will be affected by a traumatic brain injury (TBI) each year (Hyder, Wunderlich, Puvanachandra, Gururaj, & Kobusingye, 2007). While survivors can make a relatively good physical recovery within the first few months (Marsh, Kersel, Havill, & Sleigh, 2002; McKinlay, Brooks, Bond, Martinage, & Marshall, 1981) the psychological and cognitive deficits, including personality and behavioural changes that follow TBI tend to be enduring and persist throughout their lifetime (Lezak, 1988; Marsh et al., 2002; McKinlay et al., 1981; Thomsen, 1984). These changes include difficulties with self-confidence, coping with cognitive and interpersonal failures, negative affect (Brooks, Campsie, Symington, Beattie, & McKinlay, 1986; Hibbard et al., 2000; Layman, Dijkers, & Ashman, 2005), increased mood swings, irritability (Knight, Devereux, & Godfrey, 1998; Layman et al., 2005; Weddell, Oddy, & Jenkins, 1980), childish behaviour (Rosenbaum & Najenson, 1976), and decreased motivation (Anderson et al., 2009).

A high percentage of individuals with TBI are young and have a normal life expectancy (Morton & Wehman, 1995) and as such, their deficits warrant long-term support (Thomsen, 1984). However, ongoing rehabilitation is seldom available, leaving family members, usually parents or spouses, to assume the role of de facto "healthcare providers" (Kreutzer, Gervasio, & Camplair, 1994a; Serio, Kreutzer, & Gervasio, 1995; Thomsen, 1984). Unfortunately, relatives generally do not adjust well to the novel role of caregiver (Knight et al., 1998; Leathem, Heath, & Woolley, 1996; Lezak, 1988; Marsh et al., 2002). Caring for survivors of TBI is particularly distressing because of the personality changes associated with TBI and, as a result, their caregivers report higher levels of subjective burden, psychological distress, and marital breakdown as compared with those providing care for survivors of other traumatic injuries such as spinal cord injury (Peters et al., 1992; Rosenbaum & Najenson, 1976) or for persons with non-traumatic brain injury (McPherson, Pentland, & McNaughton, 2000). Unfortunately, this situation does not appear to get easier over time (Brooks et al., 1986): high levels of caregiver burden and psychological distress have been found to persist for as long as 15 years after the TBI (Thomsen, 1984).

When treating patients with TBI, healthcare professionals should be concerned with the family caregivers' health and well-being, as well as the functioning of the nuclear family due to the profound impact families have on successful rehabilitation and social integration of the patient (Anderson, Parmenter, & Mok, 2002; Douglas & Spellacy, 1996; Rivara et al., 1996; Rotondi, Sinkule, Balzer, Harris, & Moldovan, 2007). Studies have demonstrated that the length and degree of recovery for individuals following TBI is closely associated with their family functioning (Rotondi et al., 2007;

Sander et al., 2002) and the health, stress level, and psychological burden of their primary caregiver (Serio et al., 1995).

While a caregiver can be related to the individual with TBI in many ways, most adult survivors of TBI are cared for by either spouses or parents (Perlesz, Kinsella, & Crowe, 2000). Several researchers and review authors assert that healthcare professionals must take into account the relationship primary family caregivers have to the patient when planning rehabilitation (Blais & Boisvert, 2005; Kreutzer et al., 1994a; Kreutzer, Gervasio, & Camplair, 1994b; Perlesz et al., 2000; Serio et al., 1995). For example, Serio and colleagues (1995) highlight that family intervention should begin by acknowledging the different roles played by a spouse versus a parent caregiver. Serio et al. describe how the needs of these two caregivers are likely to differ in that a spouse whose partner sustains a brain injury may lose his or her confidant, sexual partner, economic support, household co-manager and child-rearing assistant. While spouses may have the option to divorce their brain injured partner, parents of brain injured adult offspring may be responsible for caring for a child-like dependent adult for the rest of their lives. These parents may never be able to enjoy the independence they had anticipated in later life. As well, older parents who may be accustomed to an empty nest or child-free lifestyle may have to return to a parenting role that they had not been emotionally or financially prepared for (Florian & Katz, 1991; Lezak, 1988).

There remains disparity in the literature as to whether spouses experience more psychological disturbance caring for traumatically brain injured partners as compared to parents caring for their adult child with TBI. Some authors (Kreutzer et al., 1994b) have reported clinical observations that spouses acting as primary caregivers to partners with TBI become more depressed than parents providing primary care to an injured adult child, and further studies have suggested that TBI has a more negative impact on spouses as compared with other caregivers (Blais & Boisvert, 2005; Florian, Katz, & Lahav, 1989; Verhaeghe, Defloor, & Grypdonck, 2005; Zeigler, 1999).

In order to assist healthcare providers with identifying which caregivers are at greatest risk of anxiety and depression, the primary aim of this systematic literature review was to answer the question: are there differences in the levels of anxiety and depression between spouses versus parents acting as primary caregivers to adult individuals following TBI? The secondary aims were to examine the methodological differences between the studies and to assess their level of quality.

## METHODS

A literature search was conducted using keywords in CINAHL (1983–2012), MEDLINE/ PubMed (1966–2012), and PsycINFO (1887–2012). The key

search terms used were: (1) (“TBI” OR “Traumatic brain injury”) AND (“Spouse\$” OR “Caregiver\$”) AND (“depression” OR “anxiety” OR “psychological outcomes”); and (2) (“TBI” OR “Traumatic brain injury”) AND (“Spouse\$” OR “Caregiver\$”) AND (“Caregiver diff\$”). In addition to the computer search, manual searches were performed using reference lists from reviews and relevant papers.

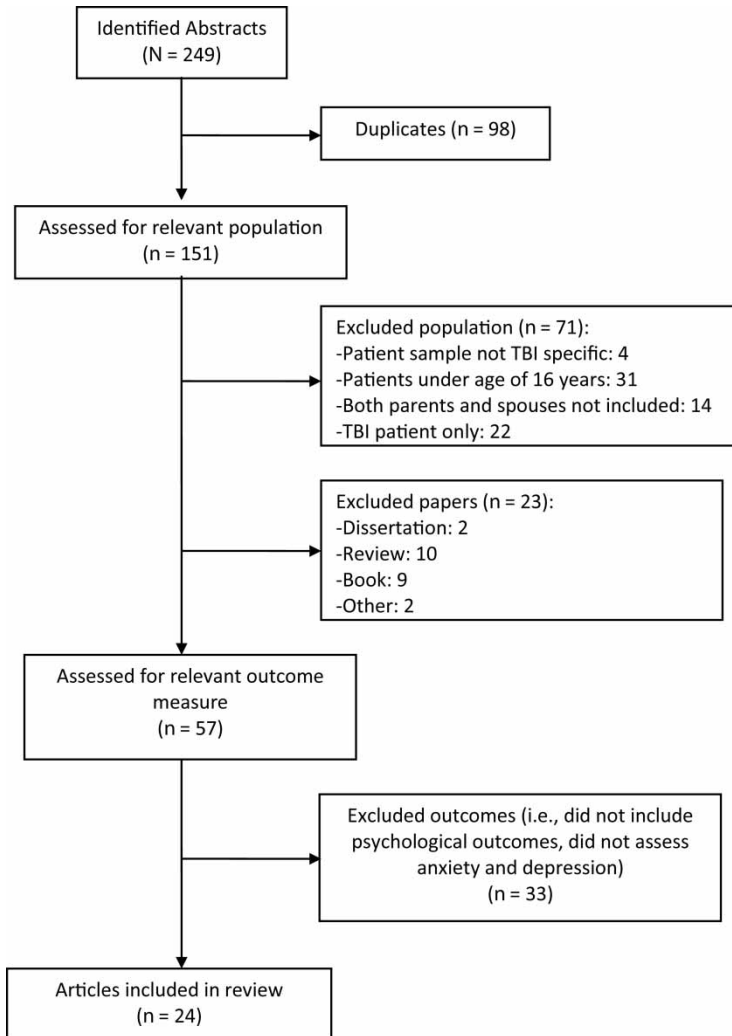
Two reviewers (B.R., N.E.) screened all identified titles and abstracts for relevance and assessed potentially relevant studies for inclusion. Based on abstract review, articles were included if: (1) the study included a sample of caregivers of TBI patients; (2) the study reported outcomes for spouse and parent caregivers either separately or collectively; and (3) the study included a measure of anxiety and/or depression in the caregivers of the TBI patients. Studies were excluded if: (1) the TBI patient sample included patients under the age of 16 years; or (2) either of the caregiver groups (spouse or parent) comprised  $\geq 80\%$  of the study sample, which would have rendered statistical comparisons between the two groups unbalanced (see Figure 1). If abstracts did not contain enough information to evaluate inclusion or exclusion, full articles were examined by both reviewers. Level of agreement between the two reviewers (B.R., N.E.) was 98% and any disagreements were resolved by discussion with a third reviewer (J.T.V.).

### Methodological quality of studies

The Downs and Black checklist (1998) was used to evaluate the overall methodological quality of the included studies. This checklist measures quality of both randomised clinical trials and nonrandomised studies using several items distributed across the following subscales: reporting, external validity, internal validity (bias and confounding), and power. The test–retest reliability ( $r = .88$ ), inter-rater reliability ( $r = .75$ ), and internal consistency (Kruider-Richardson formula  $20 = .89$ ) of the checklist are good (Downs & Black, 1998). The total possible score an article can achieve is 18 and the higher the score, the better the methodological quality of the study. Two raters (B.R., N.E.) applied this checklist to all studies. Inter-rater reliability ranged from 85% to 100% on each article reviewed. The raters met to discuss any discrepancies in the scores of each checklist item and consensus was achieved for each item discrepancy.

## RESULTS

A total of 249 abstracts was identified and screened for inclusion based on study criteria (Figure 1) and a total of 24 studies was included for analysis



**Figure 1.** Flow diagram of articles included.

in this review. Three categories of studies emerged: (1) studies that included both spouse and parent caregivers but did not conduct a direct statistical comparison between the two groups (e.g., collapsed the data across the groups;  $n = 8$ ; Table 1); (2) studies that compared spouses to parents on measures of anxiety and/or depression with statistical analyses and found no differences

TABLE 1  
 Studies that made no statistical comparisons between caregiver groups

<i>Author (year)</i>	<i>QR</i>	<i>Patient characteristics</i> <sup>1</sup>	<i>Caregiver characteristics</i> <sup>1</sup>	<i>Outcome measures</i>
Douglas & Spellacy (1996)	12	<i>N</i> = 30 (18 male) Age: 36.8 (12.3) Injury severity: Severe Assessed: 84.0 (21.5)	<i>N</i> = 17 spouses, 13 parents (25 female) Age: 46.9 (11.9)	SRDS
Flanagan (1998)	7	<i>N</i> = 28 (24 male) Age: 29.8 (10.2) Injury severity: Severe Assessed: 45.3 (41.6) <sup>2</sup>	<i>N</i> = 8 spouses, 18 parents (25 female) Age: 44.5 (9.8)	Leeds Scales for Anxiety and Depression
Marsh et al. (1998b)	16	<i>N</i> = 69 (53 male) Age: 28 (11) Injury severity: Mild–Severe Assessed: 6.8 (0.8) <sup>3</sup>	<i>N</i> = 11 spouses, 43 parents (59 female) Age: 43 (11)	Short Form BDI; TAI
Marsh et al. (1998a)	16	<i>N</i> = 69 (52 male) Age: 28 (11) Injury severity: Mild–Severe Assessed: 12.93 (1.1) <sup>4</sup>	<i>N</i> = 17 spouses, 44 parents (59 female) Age: 44 (11)	Short Form BDI; TAI
Kolakowsky-Hayner & Kishore (1999)	4	<i>N</i> = 14 (11 male) Age: 29.7(12.1) <sup>4</sup> Injury severity: NR Assessed: NR	<i>N</i> = 14 (caregiver type NR; Sex NR) Age: NR	BSI
Douglas & Spellacy (2000)	14	<i>N</i> = 30 (21 male) Age: 36.7 (12.0) Injury severity: Severe Assessed: 84.3 (20.6)	<i>N</i> = 20 spouses, 15 parents (28 females) Age: 47.7 (11.7)	SRDS
Morris (2001)	10	<i>N</i> = 33 (Sex NR) Age: 16–65 Injury severity: Mild–Severe Assessed: 9–22; 12 or more <sup>5</sup>	<i>N</i> = 33 (caregiver type NR; 27 female) Age: NR	HADS Anxiety Scale; GHQ-28
Marsh et al. (2002)	16	<i>N</i> = 52 (42 male) Age: 28 (11) Injury severity: Mild–Severe Assessed: 6.6 (0.8), 12.8 (1.1) <sup>6</sup>	<i>N</i> = 15 spouses, 36 parents (46 female) Age: 43 (9)	Short Form BDI; TAI

BDI, Beck Depression Inventory; BSI, Brief Symptom Inventory; QR, Quality Rating; SRDS, Self-Rating Depression Scale; GHQ, General Health Questionnaire; HADS, Hospital Anxiety and Depression Scale; TAI, Trait Anxiety Inventory from Form Y of the State–Trait Anxiety inventory.

<sup>1</sup>Age reported in years (standard deviation); Time assessed post-injury reported in months (standard deviation).

<sup>2</sup>Mean amount of time that patient had been cared for in family home. Mean time post-injury not specified.

<sup>3</sup>Mean time to assessment was reported in days and calculated to months for this review.

<sup>4</sup>Mean age at time of injury. Mean age at interview not recorded.

<sup>5</sup>Two groups of participants examined, those between 9 and 22 months post-injury and those 12 months or more.

<sup>6</sup>Repeated measures study.

between the two types of caregivers ( $n = 13$ ; Table 2); and (3) studies which compared spouses to parents on measures of anxiety and/or depression with statistical analysis and identified differences between two types of caregivers ( $n = 3$ ; Table 3).

## Studies without caregiver comparisons

*Study demographics.* Eight studies were identified which included both parents and spouses in the study sample and reported outcomes on validated anxiety and/or depression outcome measures, but did not conduct a direct statistical comparison on these measures between the two groups of caregivers (Table 1). These studies were published between 1996 and 2002. The median sample size of caregivers across these eight studies was 44 (range 14–61) participants. The mean time between assessment and TBI occurrence across these studies was 46.65 months (range 6.8–84.3 months). However, three studies were excluded from this calculation: Kolakowsky-Hayner & Kishore (1999) did not report time since injury; and both Marsh et al. (2002) and Morris (2001) included multiple time-points post-injury in their study designs.

*Methodological quality.* The median quality rating utilising the Downs and Black Quality Checklist score for these eight studies was 13 (range 4–16).

*Outcome measures.* Three studies used the Beck Short Form Depression Scale and Trait Anxiety Inventory from form Y of the State–Trait Anxiety Scale (Marsh, Kersel, Havill, & Sleight, 1998a, b; Marsh et al., 2002). Two studies used the Self-Rating Depression Scale and did not measure anxiety (Douglas & Spellacy, 1996, 2000). The Leeds scale for Anxiety and Depression (Flanagan, 1998), the Brief Symptom Inventory (BSI; Kolakowsky-Hayner & Kishore, 1999), the General Health Questionnaire–28 and the Hospital Anxiety and Depression Scale (Morris, 2001) were used in three respective studies. While the studies did not present data separately for each group they did indicate that the caregivers in general demonstrated high levels of anxiety and depression with all eight studies reporting significantly elevated scores on the outcome measures used. Specifically, four studies (Douglas & Spellacy, 1996, 2000; Flanagan, 1998; Kolakowsky-Hayner & Kishore, 1999) found elevated scores of depression and anxiety in over half of their samples, and three studies (Marsh et al., 1998a,b; Marsh et al., 2002) observed elevated scores of depression and anxiety in over one-third of their sample.

TABLE 2  
 Studies that used statistical analyses and found no differences between caregiver groups

<i>Authors (year)</i>	<i>QR</i>	<i>TBI Patient characteristics<sup>1</sup></i>	<i>Spouse characteristics<sup>1</sup></i>	<i>Parent characteristics<sup>1</sup></i>	<i>Outcome measures</i>
Livingston et al. (1985b)	12	<i>N</i> = 83 (83 male) Age: mild TBI, 32.8; severe TBI, 36.4 Severity: Mild–Severe Assessed: 3	<i>N</i> = 55 (55 female) Age: NR	<i>N</i> = 31 (31 female) Age: NR	Leeds Scale for Anxiety and Depression
Livingston et al. (1985a)	14	<i>N</i> = 50 (50 male) Age: at least 50% of patients aged ≥ 39 <sup>2</sup> Severity: Severe Assessed: 3, 6, 12 <sup>3</sup>	<i>N</i> = 25 (25 female) Age: NR	<i>N</i> = 20 (20 female) Age: NR	Leeds Scale for Anxiety and Depression
Livingston (1987)	9	<i>N</i> = 98 (98 male) Age: NR Severity: Minor–Severe Assessed: 3, 6, 12	NR	NR	Leeds Scale for Anxiety and Depression
Gillen et al. (1998)	14	<i>N</i> = 59 (51 male) Age: 27.5 (NR) Severity: Moderate–Severe Assessed: 18.5 (NR)	<i>N</i> = 20 (Sex NR) Age: NR	<i>N</i> = 39 (39 female) Age: NR <i>All caregivers</i> Age: 44.1	Diagnostic Interview Schedule Revised; SCL-90
Knight et al. (1998)	10	<i>N</i> = 52 (28 male) Age: 30.6 (13.2) Severity: Severe Assessed: 65.3 (58.6)	<i>N</i> = 17 (Sex NR) Age: 39.8 (9.7)	<i>N</i> = 29 (Sex NR) Age: 51.6 (10.6)	CES-D
Perlesz et al. (2000)	16	<i>N</i> = 65 (43 male) Age: 33.8 (15.0) <sup>4</sup> Severity: Moderate–Severe Assessed: 9.3 (6.2)	<i>N</i> = 24 (20 female) Age: NR	<i>N</i> = 42 (38 female) Age: NR <i>All caregivers</i> Age: 44.8 (10.9)	BDI, State Anxiety Inventory
Stebbins & Pakenham (2001)	8	<i>N</i> = 116 (Sex NR) Age: NR Severity: Moderate–Severe Assessed: 99.9 (103.7)	<i>N</i> = 42 (Sex NR) Age: NR	<i>N</i> = 59 (Sex NR) Age: NR <i>All caregivers</i> Age: 52.3 (12.5)	BSI, Irrational Beliefs Inventory

(Continued)



TABLE 2  
Continued

<i>Authors (year)</i>	<i>QR</i>	<i>TBI Patient characteristics<sup>1</sup></i>	<i>Spouse characteristics<sup>1</sup></i>	<i>Parent characteristics<sup>1</sup></i>	<i>Outcome measures</i>
Ponsford et al. (2003)	18	<i>N</i> = 143 (100 male) Age: 33.6 (13.8) Severity: Severe Assessed: 39.6 (NR)	<i>N</i> = 49 (37 female) Age: NR	<i>N</i> = 70 (56 female) Age: NR	Leeds Scales: Anxiety; Depression
Wells et al. (2005)	12	<i>N</i> = 72 (51 male) Age: 48.5 (12.9) Severity: NR Assessed: 115.7 (93.1)	<i>N</i> = 52 (Sex NR) Age: NR	<i>N</i> = 17 (Sex NR) Age: NR <i>All caregivers</i> Sex: 53 female Age: 54.3 (11.9)	Symptoms Checklist (Anxiety and Depression scales)
Anderson et al. (2009)	16	<i>N</i> = 93 (Sex NR) Age: 34 (NR) Severity: Severe Assessed: 41 (NR)	<i>N</i> = 64 (Sex NR) Age: 45 (NR)	<i>N</i> = 58 (Sex NR) Age: 52 (NR)	BSI- Depression, BSI-Anxiety
Kreutzer et al. (2009)	12	<i>N</i> = 273 (197 male) Age: 36.6 (16.7) Severity: Moderate–Severe Assessed: 12, 24, 60 <sup>3</sup>	<i>N</i> = 92 (Sex NR) Age: NR	<i>N</i> = 128 (Sex NR) Age: NR <i>All caregivers</i> Age: 51.6 (14.2)	BSI- Depression, BSI- Anxiety
Sady et al. (2010)	18	<i>N</i> = 141 (103 male) Age: 34.5 (17.0) <sup>4</sup> ; Severity: Mild– Severe Assessed: 1 (NR)	<i>N</i> = 56 (Sex NR) Age: NR	<i>N</i> = 70 (Sex NR) Age: NR <i>All caregivers</i> Sex: 116 female Age: 34.5 (17.0)	BSI
Phelan et al. (2011)	15	<i>N</i> = 70 (65 male) Age: 40.9 (6.5) Severity: Moderate–Severe Assessed: NR	<i>N</i> = 22 (Sex NR) Age: NR	<i>N</i> = 29 (Sex NR) Age: NR <i>All caregivers</i> Age: 53.3 (13.2)	PROMIS Depression and Anxiety Short Form Scales

BDI, Beck Depression Inventory; BSI, Brief Symptom Inventory; CES-D, Center for Epidemiological Studies Depression Scale; NR, not reported; QR, Quality Rating; SCL-90, Symptom Checklist 90 revised.

<sup>1</sup>Age reported in years (standard deviation); Time assessed post-injury reported in months (standard deviation).

<sup>2</sup>Age reported in publication by decade, unable to determine mean age.

<sup>3</sup>Time assessed post injury for cross sectional or repeated measures designs.

<sup>4</sup>Age at injury, age at assessment not reported.

*Statistical analyses.* Statistical comparisons between the groups were not conducted in these studies.

### Studies that found no differences between spouses and parent caregivers

*Study demographics.* There were 13 studies that by means of statistical comparisons found no difference between spouses and parent caregivers on measures of depression and/or anxiety (Table 2). These 13 studies were published between 1985 and 2011. Specifically, three studies were published between 1985 and 1995, six studies were published between 1996 and 2005 and four studies were published between 2006 and 2011.

The sample size of caregivers (the number of spouse and parent caregivers combined) in these studies ranged from 45–220 (Median = 86). While some studies included other caregiver types (siblings, grandparents, etc.), our review and the data presented in Table 2 focuses on spouse and parent caregivers. All but one of these studies (Phelan et al., 2011) reported time since TBI. On average, caregivers of TBI patients were studied 43.7 months post-injury ( $SD = 42.0$ , range 1–115.7). However, three of the studies used either a cross-sectional design assessing caregivers who were 1, 2, or 5 years post-TBI (Kreutzer et al., 2009) or repeated measures design assessing caregivers at 3, 6, or 12 months post-TBI (Livingston, Brooks, & Bond, 1985a; Livingston, 1987) and therefore were excluded from the calculation of time post-injury.

*Methodological quality.* The median Downs and Black quality checklist rating for these studies was 14 (range 8–18).

*Outcome measures.* All 13 studies measured caregiver depression with self-report questionnaires; however one study (Gillen, Tennen, Affleck, & Steinpreis, 1998) also used the Diagnostic Interview Assessment. Twelve of the 13 studies assessed anxiety using self-report measures. The self-report measures consisted of the Brief Symptom Inventory Anxiety and Depression Scales in four studies (Anderson et al., 2009; Kreutzer et al., 2009; Sady et al., 2010; Stebbins & Pakenham, 2001), the Leeds Anxiety and Depression scale in four studies (Livingston, 1987; Ponsford, Olver, Ponsford, & Nelms, 2003; Livingston et al., 1985a; Livingston, Brooks, & Bond, 1985b), and the Symptoms Checklist in two studies (Gillen et al., 1998; Wells, Dywan, & Dumas, 2005). The Beck Depression Inventory (Perlesz et al., 2000), the Centre for Epidemiologic Studies – Depression scale (Knight et al., 1998), and the PROMIS Depression and Anxiety short-form scales (Phelan et al., 2011) were used in three respective studies. In a majority ( $n = 9$ ) of these 13 studies (Anderson et al., 2009; Gillen et al.,

1998; Knight et al., 1998; Kreutzer et al., 2009; Livingston, 1987; Livingston et al., 1985a,b; Ponsford et al., 2003; Stebbins & Pakenham, 2001), both parents and spouses demonstrated clinically significant levels of depression and anxiety.

*Statistical analyses.* The main statistical methods used for comparing spouses to parents on measures of anxiety and depression were means analyses (ANOVAs and *t*-tests) in nine studies (Anderson et al., 2009; Gillen et al., 1998; Knight et al., 1998; Kreutzer et al., 2009; Livingston et al., 1985a, b; Perlesz et al., 2000; Ponsford et al., 2003; Wells et al., 2005) and regression analyses in four studies (Livingston, 1987; Phelan et al., 2011; Sady et al., 2010; Stebbins & Pakenham, 2001).

### Studies that found significant differences between spouses and parent caregivers

*Study demographics.* In three studies, statistical differences between spouses and other caregivers on measures of depression and/or anxiety were reported (Table 3). Two studies (Kreutzer et al., 1994a, b) were based on the same sample of 62 patients assessed on average 16 months post-injury ( $SD = 8.4$  months, range 1.5–60 months) and were published in 1994. The third study, conducted by the same research team (Gervasio & Kreutzer, 1997), employed a cross-sectional design to study caregivers of 116 patients with TBI who were 10–24 months, 25–48 months, and 49 months post-injury.

*Methodological quality.* The median quality rating on the Downs and Black Checklist for these three studies was 13 (range 13–15).

*Outcome measures.* All three studies utilised the Brief Symptom Inventory to assess anxiety and depression. Two studies demonstrated that spouses had higher mean anxiety scores (Gervasio & Kreutzer, 1997; Kreutzer et al., 1994b). All three studies demonstrated elevated mean depression scores in spouses as compared to parents. No studies found parents to have statistically higher scores than spouses.

*Statistical analyses.* One of the three studies examined the difference using both means analysis and a Chi square (Gervasio & Kreutzer, 1997). Of the two remaining studies, one utilised a regression analysis (Kreutzer et al., 1994a) while the other utilised a means analysis (Kreutzer et al., 1994b).

## DISCUSSION

This review aimed to assess the literature on depression and anxiety in caregivers of adult persons with TBI in order to determine whether there is a differential impact upon spouses versus parents acting in this role. Using a systematic approach, 247 abstracts were found using the specified search criteria and of these 223 were excluded from analysis. The reference lists from identified articles were hand-searched to ensure that all relevant articles were included in the review. Each included article was assessed for methodological rigor using a validated quality checklist.

Of the 16 studies that statistically compared caregivers who were spouses to caregivers who were parents on measures of depression and/or anxiety, only three articles identified a difference, with spouses rating higher on levels of depression and anxiety. While previous reviews have suggested that TBI has a more negative impact on spouses than other caregivers (Blais & Boisvert, 2005; Florian & Katz, 1991; Verhaeghe et al., 2005; Zeigler, 1999), the results of this review indicate that few studies have reported this association using validated measures of anxiety and depression. It is important to note however that the meaning of “negative impact” referred to in previous reviews is unclear and may be related to other types of distress, such as burden, rather than psychological distress, such as depression and anxiety.

There was a great deal of variation in the methodological quality, as assessed by the Downs and Black (1998) checklist, of the studies analysed for this review (rating ranged from 3–18 across the studies). The most commonly identified limitation of the studies was limited reporting or missing information. Specifically, information was frequently missing to enable the reader to determine whether the subject sample was representative of the study population (primarily self-selection bias), how patients and caregivers lost to follow-up were handled in the analyses, and whether or not the study was sufficiently powered to detect differences in scores between the spouses and other caregivers. The studies that ranked poorly in this subset of the tool were amongst the lowest scoring studies in this review. As the methodological rigor can influence the representativeness of the sample and the results, additional studies, powered appropriately could yield different results.

Despite aiming to examine differences between spouses and parents, most of the reviewed studies did not report key confounding demographic variables between the groups. For example, many studies did not indicate the age of the individual with TBI independent from the age of the caregiver. Across the studies included in this review, the term “spouse” was not clearly defined. There was a lack of clarity as to whether “spouses” encompassed cohabiting couples or legally married partners. Duration of the relationship was also

TABLE 3  
Studies that used statistical analyses to compare caregivers and found significant differences

<i>Authors (year)</i>	<i>QR</i>	<i>TBI Patient characteristics<sup>1</sup></i>	<i>Spouse characteristics<sup>1</sup></i>	<i>Parent characteristics<sup>1</sup></i>	<i>Outcome measures</i>	<i>Mean score-spouses</i>	<i>Mean score-parents</i>	<i>p-values</i>
Kruetzer et al. (1994a)	13	<i>N</i> = 62 (50 male) Age: 30.5 Severity: Mild–Severe Assessed: 16 (8.4)	<i>N</i> = 28 (25 female) Age: NR	<i>N</i> = 34 (28 female) Age: NR	BSI- Depression BSI- Anxiety	NR NR	NR NR	< .05 n.s.
Kruetzer et al. (1994b)	13	<i>N</i> = 62 (50 male) Age: 30.5 Severity: Mild–Severe Assessed: 16 (8.4)	<i>N</i> = 28 (25 female) Age: NR	<i>N</i> = 34 (28 female) Age: NR	BSI- Depression BSI- Anxiety	59 58.5	52 52.2	< .01 ≤ .05
Gervasio & Kruetzer (1997)	15	<i>N</i> = 116 (82 male) Age: 32.6 (11.2) <sup>2</sup> Severity: NR Assessed: Various <sup>3</sup>	<i>N</i> = 69 (51 female) Age: NR	<i>N</i> = 44 (37 female) Age: NR	BSI- Depression BSI- Anxiety	55.95 57.21	50.44 51.12	.03 .001

BSI, Brief Symptom Inventory; NR not reported; n.s., not statistically significant; QR, Quality Rating.

<sup>1</sup>Age reported in years (standard deviation); Time assessed post-injury reported in months (standard deviation).

<sup>2</sup>Age at injury, age at assessment not reported.

<sup>3</sup>Time assessed post-injury for cross-sectional or repeated measures designs.

rarely examined as a variable. In addition, no studies reviewed included same-sex couples. Similarly, data regarding gender of caregivers and TBI patients was typically collapsed across groups. Across the studies reviewed, the TBI survivors were more often males, whereas their primary caregivers were females, which is a pattern consistently found in the TBI literature (Zeigler, 1999). However, most studies reviewed did not account for the differences in caring for a female versus male patient or the gender of the caregiver. It can be construed that if the samples were not well matched on demographics in relation to these confounding variables the study results may have been distorted. Future studies using cohort designs should more thoroughly report on the demographic variables of the participants.

It is important to note that not all of the studies included in this review set out to examine differences between caregiver types as their primary objective. In three of the 16 studies for which a statistical comparison was conducted between spouses and parents (Knight et al., 1998; Perlesz et al., 2000; Sady et al., 2010), the analyses were conducted in a post-hoc manner. In each of the three studies where post-hoc analyses were conducted, no differences between spouses and parents on measures of anxiety and depression emerged. As well, only four of the studies that found no differences between caregiver types (Anderson et al., 2009; Ponsford et al., 2003; Sady et al., 2010; Stebbins & Pakenham, 2001) indicated that a power analysis had been conducted to evaluate accurately potential differences between spouse and parent caregivers. Even in the 12 studies for which a comparison between the two groups was a primary aim, the samples were often not matched on key demographic factors and not adequately powered. For example, Sady et al. (2010), in their post-hoc analysis, noted that spouses in their study more often cared for patients with mild to moderate injury whereas parents were more likely to care for severely injured patients. Moreover, they noted that the time from injury to assessment differed significantly between these two groups. Wells et al. (2005) also did not find kinship to be a significant predictor of caregiver depression and anxiety but did also declare that the results of their study may have been affected by inequality across the sample sizes: there were more than twice as many spouses as parents assessed in the study. Gillen et al (1998) noted that in their sample parent caregivers were assessed at a significantly longer time point since the TBI than spouse caregivers. Unlike these studies, Kreutzer et al. (1994b), who did report higher levels of anxiety and depression in spouses, aimed to compare the two groups as a primary objective and as such equally matched the two groups on key demographic variables.

Fifteen of the 16 studies that compared spouse versus parent caregivers reported clinically significant levels of depression and anxiety in both groups as compared to the general population, raising the possibility of ceiling effects. With both groups demonstrating high levels of distress on

the quantitative outcome measures used, the ability to detect a difference between the groups may have been diminished. The inclusion of qualitative measures in future studies may bolster identification of more subtle, yet significant differences between caregiver groups that quantitative measures alone cannot capture. The lack of qualitative research in this area may be due to the dual challenge of the time required to conduct full psychological assessments, and the difficulty of analysing qualitative data such as diagnostic interviews or other qualitative tools. It is also noteworthy that some of the reviewed studies did find differences in scores between spouses and parents on other measures, such as family functioning (Anderson et al., 2009; Perlesz et al., 2000). While, as a whole, the literature in this area does not suggest a difference between parent versus spouse caregivers on measures of anxiety and depression, this review has demonstrated that caregivers do experience depression and anxiety and a better understanding of these affects is necessary.

## CONCLUSIONS

This systematic review highlighted the immense methodological variation across studies in this field. Future studies could be strengthened by ensuring samples which are adequately powered and matched on key demographic variables (gender, patient injury severity, duration of relationship, duration of caregiving). Randomised enrolment procedures, and accounting for missing data (e.g., lost to follow-up) could help in reducing potential biases. Moreover, the use of qualitative as well as quantitative approaches, structured or semi-structured interviews, and additional longitudinal designs and longer-term follow-up assessments would contribute significantly to this field of research.

Despite the methodological variation, the studies consistently demonstrated the significant amount of psychological distress that the primary caregivers of adults with TBI experience. Family caregiver needs are complex and this review offers a narrowed view of the impact of being a primary family caregiver. This review did not address other important constructs related to care giving such as burden, quality of life, or isolation. Every person providing care for a significant other with a TBI does so within a distinct environment with unique challenges and consequences. The many factors that make each care-giving situation different, such as the kinship between the injured person and the caregivers, caregiver age and gender as well as the age, gender and injury severity of the TBI patient makes this research field complex. However, it is imperative that researchers continue to examine the factors that contribute to psychological distress in representative samples of caregivers and the potential differences that exist across caregiver types. Findings from such research will help to provide more tailored supports

for family caregivers that target specific problems and challenges associated with each caregiver situation.

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