

ORIGINAL REPORT

## HEALTH-RELATED QUALITY OF LIFE IN CAREGIVERS OF INDIVIDUALS WITH TRAUMATIC BRAIN INJURY FROM GUADALAJARA, MEXICO

Juan Carlos Arango-Lasprilla, PhD<sup>1</sup>, Elizabeth Nicholls, MT<sup>1</sup>, Teresita Villaseñor Cabrera, PhD<sup>2</sup>, Alison Drew, MS<sup>1</sup>, Miriam Jimenez-Maldonado, MS<sup>2,3</sup> and Maria Luisa Martinez-Cortes, MS<sup>2</sup>

From the <sup>1</sup>Department of Physical Medicine and Rehabilitation, Virginia Commonwealth University, Richmond, VA, USA, <sup>2</sup>Department of Neurosciences Guadalajara University, Guadalajara and <sup>3</sup>Hospital Civil Fray Antonio Alcalde, Guadalajara, Mexico

**Objective:** The goal of the present study was to assess the health-related quality of life of a group of family caregivers of individuals with traumatic brain injury from Guadalajara, Mexico.

**Patients and methods:** Ninety family caregivers of individuals with traumatic brain injury and 83 healthy controls completed the Short-Form 36, a self-report health-related quality of life measure composed of 8 component areas: physical functioning, role-physical, bodily pain, general health, vitality, social functioning, mental health, and role-emotional. The samples were statistically similar with respect to age, gender, marital status, and education. However, caregivers had significantly lower household income than controls.

**Results:** After controlling for income, results showed significantly lower scores for traumatic brain injury caregivers compared with healthy controls on 6 Short-Form 36 subscales: role-emotional, vitality, mental health, social functioning, bodily pain, and general health.

**Conclusion:** Caregivers of individuals with traumatic brain injury living in Guadalajara, Mexico report having poorer health-related quality of life across various domains including mental and general health. Future studies should be conducted to determine which specific factors (e.g. lack of services, physical strain of providing care) are responsible for reduced health-related quality of life in these areas. It is likely that resources, such as respite services, adult day-care, aides, outpatient rehabilitation, psycho-educational programs, and support groups would increase health-related quality of life for these individuals.

**Key words:** quality of life; traumatic brain injury; caregivers.

J Rehabil Med 2011; 43: 983–986

*Correspondence address:* Juan Carlos Arango-Lasprilla, Department of Physical Medicine and Rehabilitation, Virginia Commonwealth University, Rehabilitation Psychology and Neuropsychology School of Medicine, Theater Row Building, 730 E Broad Street, Richmond, VA 23219, USA. E-mail: jcarangolasp@vcu.edu

Submitted May 20, 2011; accepted August 11, 2011

### INTRODUCTION

Every year, more than 10 million people around the world experience a traumatic brain injury (TBI) (1). In the USA alone, it is

estimated that 1.7 million people sustain a TBI each year (2). As a region, Latin America has the highest incidence of intracranial injury worldwide, with most injuries due to road traffic accidents and acts of violence (3). TBI is predicted to be one of the leading global causes of morbidity and mortality by the year 2020 (4).

TBI often causes deficits in cognitive (5–7), psychosocial (8–10), behavioral/emotional, and physical functioning (11). The course of rehabilitation after TBI can last from several years to a lifetime and impacts not only the individual with TBI, but their family members as well (12). Due to the wide-ranging difficulties associated with TBI, individuals often require constant care and support from informal caregivers, usually family members (12). Such caregivers often bear the burden of providing a significant level of physical care and assistance with activities of daily living, which can result in stress, depression, anger, anxiety, psychosomatic disorders, irritability, increased use of prescription and non-prescription drugs, financial problems, family role changes, poor social adjustment, and increased isolation (12–16). Over time, these symptoms can create poor quality of life (QoL) for caregivers of individuals with TBI.

QoL generally refers to an individual's perception of their physical, emotional, or social well-being that is shaped by experiences, expectations and beliefs (17). Health-related quality of life (HRQoL) more specifically refers to the impact of health conditions on daily functioning (18). Only five known studies have examined HRQoL in caregivers of individuals with TBI (19–23). Sample sizes ranged from 22 caregivers (22) to 222 caregivers (20). The majority of the studies were cross-sectional, with one longitudinal design (19) and one prospective study (21). These studies varied in how they measured HRQoL; one utilized the World Health Organization Quality of Life - short version (20), two utilized the Short-Form 36 (SF-36) (21, 23), two utilized the Schedule of Evaluation of Individual Quality of Life-Direct Weighting (19, 22). Hickey et al. (19) additionally included the Psychosocial Adjustment to Illness Scale as a measure of QoL. In general, these studies concluded that caregivers of individuals with TBI exhibit poorer QoL than individuals in normal reference populations (19, 21–23). TBI caregivers also exhibit poorer quality of life than caregivers of individuals with dementia (20) and other chronic diseases (19).

These few studies examining HRQoL of caregivers of individuals with TBI all utilized caregivers from either the UK (19–22) or Denmark (23). There is a clear need to examine HRQoL in

underdeveloped regions of the world, such as in Latin America, where incidence rates of TBI are very high (1), but caretaking resources such as nursing homes, adult day-care, healthcare facilities, education, and support groups are scarce. This lack of resources may contribute to lower reported HRQoL in TBI caregivers, which in turn may affect the family system, the individual with TBI, and the community. The purpose of the current study was to compare the HRQoL of a group of Mexican caregivers of family members with TBI with that of healthy controls.

## METHODS

### Participants

In the present study, 90 family caregivers of individuals with TBI were recruited from the Hospital Civil Fray Antonio Alcade in Guadalajara, Mexico, as well as 83 healthy controls from the community. Caregivers were defined as family members actively providing day-to-day-care for a person with TBI and who were familiar with the patient's medical and social status. The inclusion and exclusion criteria stated that participants must: (i) be the primary caregiver of a patient with a diagnosis of TBI; (ii) have been providing care to the patient for a minimum of 3 months; and (iii) have no personal history of physical, psychological, or neurological problems. Healthy controls also had no history of physical, psychological, or neurological problems and did not serve as caregivers for an individual with any type of disability. Demographic information for the caregivers and healthy controls is provided in Table I.

### Instruments

The SF-36 (24), a self-report health questionnaire, is one of the most widely used instruments to assess HRQoL. The instrument consists

of 36 items that focus on eight different health dimensions: physical functioning, role-physical (role limitations due to physical problems), bodily pain, general health, vitality, social functioning, mental health, and role-emotional (role limitations due to emotional problems). Responses are scored on a 0–100 scale, with higher scores representing higher HRQoL. The SF-36 is a commonly used measure of HRQoL in brain injury caregivers (25) and has been translated into many languages. The Spanish version of the SF-36 has well-established reliability and validity (26).

### Procedure

Ninety family caregivers of individuals with TBI were recruited from the Hospital Civil Fray Antonio Alcade in Guadalajara, Mexico. Eighty-three healthy controls were recruited from the same community using fliers and word-of-mouth. Individuals who expressed interest in participating were told about the purpose of the study. All these individuals consented to participate in the study in accordance with the research protocol approved by the hospital's ethics committee. Subsequently, all caregivers and healthy controls completed a 30- to 45-min interview during which a psychologist collected sociodemographic information and administered the SF-36. Caregivers who were able to leave the home for this period of time were interviewed at the hospital, and those who were unable to attend the appointment were visited in their homes.

### Statistical analysis

The sociodemographic characteristics (gender, age, education, and household income) of the TBI caregivers and healthy controls were compared using *t*-tests for continuous variables and  $\chi^2$  tests for nominal variables. Multivariate analysis of covariance (MANCOVA) analysis was then conducted to compare the means of each individual SF-36 subscale between the two groups.

## RESULTS

The groups did not differ significantly with regard to age, gender, marital status, and education, but the caregiver group had a lower household income than healthy controls ( $p < 0.01$ ). MANCOVA analysis revealed that after adjusting for household income, significant differences existed between healthy controls and TBI caregivers on six out of the eight SF-36 subscales. Specifically, the caregivers of individuals with TBI had lower means on the role-emotional ( $p < 0.001$ ), vitality ( $p < 0.001$ ), mental health ( $p < 0.001$ ), social function ( $p < 0.001$ ), bodily pain ( $p < 0.01$ ), and general health ( $p < 0.01$ ) subscales (see Table II).

## DISCUSSION

The goal of the present study was to compare the HRQoL of a group of Mexican caregivers of family members with TBI with that of healthy controls. The results showed significantly lower scores for TBI caregivers vs healthy controls on six SF-36 subscales: role-emotional, vitality, mental health, social functioning, bodily pain, and general health. It is not surprising that caretakers of individuals with TBI would score lower than healthy controls in these areas; caring for an individual with TBI is a time-consuming process that can create significant burden for the caregiver and interfere considerably with everyday life (16). The day-in, day-out responsibilities of providing for a person with TBI could reasonably be expected to produce interruptions in emotional well-being, physical health, energy levels, and ability to participate in social activities.

Table I. Demographic characteristics

Variables	Caregivers ( <i>n</i> =90)	Healthy controls ( <i>n</i> =83)	<i>p</i>
Age, years, mean (SD)	47.12 (12.67)	46.18 (12.86)	NS
Sex, %			NS
Male	7.80	14.50	
Female	92.20	85.50	
Marital status, %			NS
Single	10.00	18.10	
Married	65.60	60.20	
Divorced	0.00	2.40	
Separated	6.70	1.20	
Widowed	10.00	9.60	
Cohabiting	7.80	8.40	
Relationship to patient, %			
Spouse	23.30	N/A	
Parent	66.70	N/A	
Sibling	8.90	N/A	
Other	1.10	N/A	
Education, years, mean (SD)	5.71 (3.53)	5.67 (3.51)	NS
Household income, %			$p < 0.01$
< minimum wage	12.20	30.10	
Minimum wage	43.30	18.10	
1–2 × minimum wage	32.20	25.30	
2–3 × minimum wage	5.60	13.30	
3–4 × minimum wage	1.10	3.60	
4–5 × minimum wage	3.30	6.00	
> 5 × minimum wage	2.20	3.60	
Weekly time caregiving, h, mean	60.73	N/A	
Total time caregiving, month, mean	28.06	N/A	

SD: standard deviation; NS: not significant.

Table II. Short-Form 36 (SF-36) scores for caregivers of individuals with traumatic brain injury and healthy controls

SF-36 subscale	Adjusted mean		95% confidence limits for LS Mean
	(LS Mean)	<i>p</i>	
<b>Physical Functioning</b>			
Caregivers	85.88	NS	82.48–89.28
Healthy controls	82.97		79.43–86.50
<b>Role–Physical</b>			
Caregivers	54.33	NS	46.17–62.50
Healthy controls	63.68		55.17–72.18
<b>Role–Emotional</b>			
Caregivers	40.93	<0.001	32.61–49.25
Healthy controls	74.09		65.43–82.76
<b>Vitality</b>			
Caregivers	43.56	<0.001	40.32–46.80
Healthy controls	58.85		55.48–62.23
<b>Mental Health</b>			
Caregivers	49.93	<0.001	46.35–53.52
Healthy controls	69.37		65.64–73.11
<b>Social Functioning</b>			
Caregivers	63.69	<0.001	59.35–68.03
Healthy controls	82.45		77.93–86.97
<b>Bodily Pain</b>			
Caregivers	64.04	<0.01	59.27–68.80
Healthy controls	75.60		70.63–80.56
<b>General Health</b>			
Caregivers	45.40	<0.01	41.33–49.46
Healthy controls	54.99		50.76–59.23

NS: not significant.

Current results are generally in agreement with previous research. In studies that did not use the SF-36 to measure HRQoL (19, 20, 22), poorer HRQoL was identified in TBI caregivers as opposed to healthy controls and caregivers of individuals with other diseases. Studies that did use the SF-36 (21, 23) also found caregivers of individuals with brain injury to have lower scores on subscales of the SF-36 than normative reference populations and caretakers of individuals with other illnesses. However, contrasts with these previous studies can be seen in that current participants fared poorly in the area of bodily pain and general health, whereas McPherson et al. (21) and Norup et al. (23) did not find significant differences between brain injury caregivers and comparison groups on these subscales.

It is interesting to find that this group of Mexican TBI caregivers fared significantly worse than controls in areas of bodily pain and general health, a finding not previously reported in studies of caregivers of brain-injured individuals using the SF-36. There are several possible causes for this discrepancy. First, these previous studies (21, 23) were performed in Denmark and the UK, respectively. Both Denmark and the UK are countries with comprehensive rehabilitation systems that provide substantial assistance to the families of individuals with TBI. In contrast, Mexican resources for TBI caregivers (e.g. nursing homes, adult day-care, healthcare facilities) are scarce or non-existent, a disparity that could directly impact the physical health of TBI caregivers. For example, access to aides, adult day-care, and rehabilitation programs in Western Europe may make it less likely that those caregivers would be solely responsible for activities such as washing, dressing, and

helping the patient move around the home; factors that, over time, could well impact the physical health of a caregiver.

Next, it may be that the TBI caregivers in the present sample were simply in worse physical health to begin with than their Western European counterparts. In Mexico, poverty is rampant and more than half of the citizens are uninsured (27). Because it may well be more difficult for caregivers in the current sample to obtain care for their own health needs, they may be less equipped physically to deal with the long-term physical and mental strain associated with caregiving (16), resulting in poorer health overall. And finally, TBI caregivers in the present sample had been providing a substantial amount of care in terms of time spent caring; on average, over 60 h per week of care for more than two years. In contrast, 81% of caregivers in the study by Norup et al. (23) reported being employed full-time and were interviewed on average only 36 days post-discharge of the patient, making it highly unlikely that they were providing 60 h of care per week and limiting the amount of time they could have spent caring. One study (28) has found the amount of time spent caring for a critically ill spouse to be negatively associated with health outcomes; in short, it is possible that this sample of Mexican TBI caregivers has experienced more physical problems secondary to the significant and ongoing burden they have experienced.

It is striking that in the present study, caregivers did not report significantly worse functioning on the physical functioning (measuring the degree to which health problems inhibit daily activities) and role-physical subscales (specifically related to health problems interfering with the types of roles an individual is able to perform) than healthy controls. Several explanations may account for these findings. With respect to the physical functioning subscale, it is possible that caregivers' general health problems have not reached a level where they were unable to perform daily activities such as self-care, driving, shopping, and so on. In terms of the role physical subscale, it may be that due to limited resources, caregivers have been forced to maintain physical roles despite feeling that they are in poor health. Essentially, because they are responsible for full-time or greater than full-time care of an individual with a disability, these caregivers may not be reporting changes in physical functioning and roles simply because they are not able to make changes while maintaining their responsibilities.

It should also be noted that, in comparison with previous studies conducted using the SF-36 among TBI caregivers (21, 23), individuals in the present sample scored considerably lower on several subscales. For example, although McPherson et al. (21) reported worse subscale scores between caregivers of individuals with brain injury and a comparison group, the present Mexican sample scored significantly lower than McPherson's sample on subscales including role-physical (mean 54.33 vs 71.79), social functioning (mean 63.69 vs 81.75), role-emotional (mean 40.93 vs 71.01), and mental health (mean 49.93 vs 68.80). Similarly, the Mexican sample scored lower than subjects in the study by Norup et al. (23) on the role-emotional subscale (mean 40.93 vs 64.03). It has been noted that caregivers with higher levels of unmet needs report

lower QoL (22), and it seems likely that the lack of resources specific to Mexican TBI caregivers create unique challenges and therefore worse outcomes among caregivers. It is therefore notable, but not surprising, that this group of TBI caregivers report worse HRQoL than caregivers in countries with greater access to instrumental and professional support.

The results of the current study should be interpreted in the light of several limitations. First, participants were drawn from an urban area (Guadalajara, Mexico), and findings should not be generalized to those living in remote or rural areas, which may have even fewer resources for individuals with disabilities and their caregivers. Second, in the present study, it was not possible to determine caretakers' pre-injury HRQoL scores, and therefore not possible to determine whether pre-existing problems with HRQoL could have impacted findings. Third, the present study was cross-sectional, and findings may not account for changes in HRQoL than can occur over time. Finally, because the current study used the SF-36, findings should not be taken as a complete inventory of HRQoL among caretakers of individuals with TBI in Guadalajara, Mexico. Caring for an individual with TBI involves many challenges that may not be included as specific items on this instrument, and it is therefore possible that some issues could have gone unreported.

In conclusion, caretakers of individuals with TBI from Guadalajara, Mexico report having poorer HRQoL across various domains than controls, indicating the need for rehabilitation health professionals to develop and implement interventions to improve HRQoL. Because subjects in the current study reported lower HRQoL in both physical and emotional domains, future studies should be conducted to determine which specific factors (e.g. lack of emotional support, physical strain of providing care) are responsible for reduced HRQoL in these areas. It is likely that resources such as respite services, adult day-care, aides, outpatient rehabilitation, psycho-educational programs, and support groups would increase HRQoL for these individuals.

*Conflict of interest.* The authors report no financial or other conflicts of interest.

## REFERENCES

- Hyder AA, Wunderlich CA, Puvanachandra P, Gururaj G, Kobusingye OC. The impact of traumatic brain injuries: a global perspective. *NeuroRehabilitation* 2007; 22: 341–353.
- Centers for Disease Control and Prevention. Washington, DC: CDC. CDC Office of Injury Prevention & Control. [updated 2011 May 5; cited 2011 May 20]. Available from: <http://www.cdc.gov/traumaticbraininjury/statistics.html>.
- Murray CJ, López AD. The Global burden of disease: a comprehensive assessment of mortality and disability from diseases, injuries, and risk factors in 1990 and projected in 2020. Boston: Harvard School of Public Health: Harvard University Press; 1996.
- Zitnay GA. Lessons from national and international TBI societies and funds like NBIRTT. *Acta Neurochir Suppl* 2005; 93: 131–133.
- Brooks DN. Cognitive deficits after head injury. In: Brooks DN, editor. *Closed head injury: Psychological, social, and family consequences*. Oxford: Oxford University Press; 1984, p. 148–178.
- Molloy M. New perspectives in cognitive rehabilitation. *Aust Rehab Rev* 1983; 7: 34–37.
- Tate RL, Fenelon B, Manning ML. Patterns of neuropsychological impairment after severe blunt injury. *J of Nerv Ment Dis* 1991; 179: 117–126.
- Cunningham JM, Chan F, Jones J. Brain injury rehabilitation: a primer for case managers. In: Chan F, Leahy MJ, editors. *Health care and disability case management*. Illinois: Vocational Consultants Press; 1999, p. 475–526.
- Prigatano GP. Personality disturbances associated with traumatic brain injury. *J Consult Clin Psych* 1992; 60: 360–368.
- Smith LM, Godfrey HPD. Family support programmes and rehabilitation: a cognitive-behavioural approach to traumatic brain injury. New York: Plenum Press; 1995.
- Lynch RT. Traumatic brain injury: Implications for rehabilitation counseling. In: Riggat TF, Maki DR, Wolf AW, editors. *Applied rehabilitation counseling*. New York: Springer; 1986, p. 262–270.
- Knight RG, Devereux R, Godfrey HPD. Caring for a family member with a traumatic brain injury. *Brain Inj* 1998; 12: 467–481.
- Rotondi AJ, Sinkule J, Balzer K, Harris J, Moldovan R. A qualitative needs assessment of persons who have experienced traumatic brain injury and their primary family caregivers. *J Head Trauma Rehabil* 2007; 22: 14–25.
- Hart T, Millis S, Novack T, Englander J, Fidler-Sheppard R, Bell KR. The relationship between neuropsychologic function and level of caregiver supervision at 1 year after traumatic brain injury. *Arch Phys Med Rehabil* 2003; 84: 221–230.
- Arango-Lasprilla JC, Ketchum JM, Dezfulian T, Kreutzer JS, O'Neil-Pirozzi TM, Hammond F, et al. Predictors of marital stability 2 years following traumatic brain injury. *Brain Inj* 2008; 22: 565–574.
- Marsh NV, Kersel DA, Havill JH, Sleigh JW. Caregiver burden at 1 year following severe traumatic brain injury. *Brain Inj* 1998; 12: 1045–1059.
- Testa MA, Simonson DC. Assessment of quality-of-life outcomes. *New Engl J Med* 1996; 334: 835–840.
- Nanda U, Andresen EM. Health-related quality of life: a guide for the health professional. *Eval Health Prof* 1998; 21: 179–215.
- Hickey AM, O'Boyle CA, McGee HM, McDonald NJ. The relationship between post-trauma problem reporting and carer quality of life after severe head injury. *Psychol Health* 1997; 12: 827–838.
- Jackson D, Turner-Stokes L, Murray J, Leese M, McPherson KM. Acquired brain injury and dementia: a comparison of carer experiences. *Brain Inj* 2009; 23: 433–444.
- McPherson KM, Pentland B, McNaughton HK. Brain injury – the perceived health of carers. *Disabil Rehabil* 2000; 22: 683–689.
- Moules S, Chandler BJ. A study of the health and social needs of carers of traumatically brain injured individuals served by one community rehabilitation team. *Brain Inj* 1999; 13: 983–993.
- Norup A, Siert L, Mortensen EL. Emotional distress and quality of life in relatives of patients with severe brain injury: the first month after injury. *Brain Inj* 2010; 24: 81–88.
- Ware JE, Sherbourne CD. The MOS 36-item Short-Form Health Survey (SF-36): I. Conceptual framework and item selection. *Med Care* 1992; 30: 473–483.
- Grant JS, Bratolucci AA, Eliot TR, Giger JN. Sociodemographic, physical, and psychosocial characteristics of depressed and non-depressed family caregivers of stroke survivors. *Brain Inj* 2000; 14: 1089–1100.
- Alonso J, Prieto L, Anto JM. The Spanish version of the SF-36 Health Survey (the SF-36 health questionnaire): an instrument for measuring clinical results. *Med Clin (Barc)* 1995; 104: 771–776.
- Barraza-Lloréns M, Bertozzi S, González-Pier E, Gutiérrez P. Addressing inequity in health and health care in Mexico. *Health Affairs* 2002; 21: 47–56.
- Beery LC, Prigerson HG, Bierhals AJ, Santucci LM, Newson JT, Maciejewski PK, Rapp SR, Fasiczka A, Reynolds CF. Traumatic grief, depression and caregiving in elderly spouses of the terminally ill. *J Death Dying* 1997; 35: 261–279.