

## **Quality of Life (QoL) in patients with Traumatic Brain Injury (TBI): A Literature Review**

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**Purpose:** To describe the definition of quality of life (QoL) and identify the most appropriate tool for QoL assessment used in patients with TBI.

**Method:** Searching was conducted from PubMed, CINAHL, EBSCO, and ProQuest during 2000-2011. A total of 33 studies were analyzed for this review consisting of 9 review studies, 2 intervention studies, and 22 descriptive studies.

**Result:** Two important definitions of QoL were used in studies related to TBI namely achievement and subjective well-being. Although varieties of generic measurements have been used to measure QoL in TBI patients, there was a lack of TBI-specific Health-related Quality of Life (HRQoL) instrument. Despite the different approach and time measured either short or long outcomes, appropriate domains of QoL tool seem essential particularly among those with moderate and severe TBI.

**Conclusion:** QoL is a wide concept which can be defined in several dimensions. The QOLIBRI as a new disease-specific QoL measurement in TBI seems a feasible and valid approach for the assessment of QoL in TBI. However, the application across cultural remains a challenge and needs a validation.

**Key words:** quality of life, traumatic brain injury, assessment tool

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## **Introduction**

Traumatic brain injury (TBI) is a leading cause of death and disability worldwide. The World Health Organization (WHO) projected that road traffic injuries will rise from currently being the ninth leading cause of death globally to become the fifth by 2030 (WHO, 2008). The increase in road traffic injuries are also projected to become the third leading cause of global disease and the second leading cause of disease for low- and middle-income countries by 2020 (WHO, 2004). The incident of TBI in the United States was found to be between 180 and 250 per 100,000 of the population per year (Bruns, & Hauser, 2003). In Indonesia, based on the Indonesian Health Profile by the Ministry of Health Republic of Indonesia (MoHRI) (2012), TBI is currently included in the top ten diseases in hospitalized patients.

The effects of TBI can significantly disrupt the lives of those who are injured and survive. Long-term physical, cognitive, psychological and emotional outcomes following TBI have been documented (Dikmen et al., 2003; Hawthorne, Gruen, & Kaye, 2009; Huebner et al., 2003). Researchers and clinicians working in the TBI rehabilitation field have acknowledged the importance of an individual's quality of life (QoL) as a critical indicator of the outcome following TBI. A study by Kalpakjian and colleagues (2004) showed that subjects with TBI had significantly lower QoL and social support, higher negative effect, and similar positive effect and spirituality. TBI not only impact to QoL of person with it, but also impact another thing. It showed in a study conducted by Mar and colleagues (2011), the result concluded that TBI has a high impact in both epidemiological and economic terms as well as loss in quality of life.

Studies about QoL as outcome in TBI patients were found differently in conception about QoL and partially the domain for measurement QoL. For example, a review by Dijkers (2004) who assessed existing knowledge of QoL of people with TBI, reported that QoL was oriented in 3 different conceptualizations: QoL as achievement, QoL as utility and QoL as

SWB (Subjective Well Being). Another issue that need to concern was the differences in term of study design, sampling strategy, time to approach, and also a tool for measurement of QoL. Therefore the differences in those studies of QoL in TBI patients make the result hamper when comparisons between thus studies.

This major research recommends that further study in QoL in TBI is needed. Therefore, this study is exploring the QoL in patient with TBI. The objective of this study is to describe the definition of QoL and identify the most appropriate tool for QoL assessment used in patients with TBI.

## **Method**

Searches were conducted from PubMed, CINAHL, EBSCO, and ProQuest. The specific search terms used were “quality of life”, “traumatic brain injury”, and “brain injury”. The criteria used to search for published studies for this study included : (1) QoL in adult Traumatic Brain Injury (TBI); (2) written in English; (3) studies during 2000-2011. For the initial search all study types such as review papers and clinical trial were included. A total 122 studies were identified. After reading the full text of the articles, the studies which related to QoL in TBI was included. Finally 33 studies were collected and analyzed for this review. The 33 studies consist of 9 review studies, 2 intervention studies, and 22 descriptive studies.

## **Result**

### *Concept and definition of QoL in patients with TBI*

The term QoL historically has mainly been used in politics. The term QoL has also been introduced to medicine, some authors relate the introduction to early work from 1967, others, refer it to the increase of publications relating to QoL (Spilker as cited in Bullinger, 2002). The term health-related quality of life has been coined differentiating the medical from the

more sociological oriented QoL concepts, since in medicine specifically health aspects of well-being and function were to be represented (Patrick & Erickson as cited in Bullinger, 2002). The term health-related quality of life reflects the way in which patient's view their health state and has gained recognition as an evaluation criterion for medical treatments (Bullinger, 2002). Later, in this study the term HRQoL will be used to refer to QoL.

While research efforts and empirical results are available in several areas of medicine, QoL investigations in patients with traumatic brain injury has only just extensively been explored (Bullinger, 2002). The WHO defines QoL as "an individual's perception of their position in the life in the context of the culture and value systems in which they live and in relation to their goal, expectations, standards and consent". It is a broad concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, and their relationship to salient features of their environment" (WHOQoL Group, 1993 p. 153).

A review by Bullinger in 2002 in health-related quality of life in medicine determined the concept of QoL that consists of three concepts. First, QoL is individually centered and implies that QoL is principally not measurable across persons because it varies from person to person in its dimensionality. Secondly, the definition QoL is viewed as evaluable using a defined number of different dimensions which are relevant for all people. These dimensions pertain in accordance with earlier definitions of the WHO to physical, psychological and social well-being. A third concept maintains that QoL cannot be measured directly neither intra individually nor inter individually. In contrast, QoL is viewed as an implicit construct in which the implicit measurement of patient preference rather than direct questions oriented towards well-being. That is the approach of so called health economical or cost utility approaches to the quality of life assessment.

These concepts of quality of life by Bullinger (2002) are in accordance with the conception by Dijkers (2004) in his review of QoL after TBI. The concept of QoL was determined in 3 aspects, as subjective well being, as achievement, and as utility. Firstly, the conceptualization of QoL is that of the psychologists and social scientists who study life satisfaction and affect: QoL is equivalent to subjective well-being (SWB), the cognitive and emotional reactions to the balance of achievements and expectations. SWB includes such phenomena as life satisfaction, morale, happiness, and (nonpathologic) negative affect. The term QoL, meaning feeling of “well-being as influenced by the good things in life,” is so commonplace that investigators can even ask subjects for a direct rating of their QoL. Second, if Bullinger (2002) viewed that QoL as individually centered, Dijkers (2004) determined that from the individual center or individual expectations can be assumed in that there is so much commonality in people’s expectations and priorities that it is superfluous to investigate idiosyncratic needs and wishes or individual reactions. They reason that once achievements are known, reactions can be virtually predicted; therefore, a careful inventory of achievements in the major domains of life is all that is needed to assess QoL. Thus, the conceptualization of QoL is one’s share of those characteristics that many people consider essential to “the good life” and that can be determined with a large degree of objectivity. This conceptualization concludes QoL as achievements. The third conceptualization of QoL is the preference for, or utility of, a health status or even a life as a whole. This QoL stems from the applications of economic and management decision-making theories. To evaluate the expenses and benefits of one health care program or medical intervention relative to another, common metrics for costs and outcomes are needed.

Another component in the QoL conceptualization is approaching to the assessment of QoL. Johnston & Miklos’s review study (2002) determined 3 approaches to the assessment of QoL. First, the objective approach uses functional outcome as a scale for assessment of QoL.

Second is the subjective approach which is based on global QoL that has been defined as the individual's judgment of his/her life experience as a whole along a positive to negative continuum. SWB, life satisfaction, and subjective QoL all involve an appraisal of the affective tenor of live with the person. The third approach is the mixed approach. There are approaches to the assessment of QoL and experience that allow a degree of objectivity into their largely subjective items. These approaches query specific aspects of life experience as specific aspects of health or the experience of illness or need fulfillment that are more objective than global life satisfaction or general feelings.

The studies that are included in this review can be defined as three groups of conceptual framework based on Dijkers's conception (2004). Regarding the approaches for assessing QoL, most of the studies in this review use a mixed approach. The group of mixed approach studies used HRQoL as the domain for measure QoL.

A summary of the conceptualization of QoL and its domains for measurement from other studies in this review is described in table 1.

Table 1 Conceptualization of QoL in TBI

Authors	Definition of QoL	Tools for Measurement QoL	Tipe of Approach
Andersson et al. (2011)	Achievement SWB	SF-36, LiSat-11	Mixed Subjective
Bedard et al. (2003)	Achievement	SF - 36	Mixed
Breed et al. (2004)	Achievement	LLATBI, SF - 36	Subjective, mixed
Brown et al. (2000)	SWB	QoL Interview	Mixed
Chiu et al. (2006)	Achievement	WHOQOL-BREF	Mixed
Dikmen et al. (2003)	Achievement SWB	SF-36, PQOL	Mixed Subjective
Emanuelson et al. (2003)	Achievement	SF - 36	Mixed
Eriksson et al. (2009)	SWB	LiSat (life satisfaction)	Subjective
Guilfoyle et al. (2010)	Achievement	SF-36	Mixed
Hawthorne et al. (2009)	Utility	SF-36V2, AQoL, SF6D	Mixed
Huebner et al. (2003)	SWB	QOLR	Subjective
Johnston et al. (2005)	SWB	SWLS, CIQ-2	Subjective Objective
Kalpakjian et al. (2004)	SWB	QOL Inventory	Subjective
Lin et al. (2010)	Achievement	WHOQOL-BREF	Mixed
Mailhan et al. (2005)	SWB	SQL Profile	Subjective
Mar et al. (2011)	Utility	SF-36, EQ-5D	Mixed

Authors	Definition of QoL	Tools for Measurement QoL	Type of Approach
Nestvold & Stavem (2009)	Achievement	SF-36, GHQ-30	Mixed Objective
Pagulayan et al. (2006)	Achievement	SIP	Objective
Steadman-Pare et al. (2001)	Achievement SWB	SF-36, Self-rated Quality of Life Scale	Mixed Weighted
Teasdale & Engberg (2005)	Achievement	EBIQ	Objective
Thomas et al. (2009)	SWB	QOLI	Subjective
Truelle et al. (2010)	Achievement	QOLIBRI	Mixed
Upadhyay (2007)	Achievement	WHOQOL-BREF	Mixed
von Steinbuechel et al. (2010a)	SWB	QOLIBRI	Mixed
von Steinbuechel et al. (2010b)	SWB	QOLIBRI	Mixed

*Note.* SWB = Subjective Well-Being; SF-36 = Short Form-36 health survey; LiSat-11 = Life Satisfaction-11; LLATBI = Living Life After TBI; WHOQOL-BREF = World Health Organization Quality of Life-BREF; PQOL = Perceived Quality of Life; AQoL = Assessment of Quality of Life; QOLR = Quality of Life Rating; SWLS = Satisfaction with Life Scale; CIQ = Community Integration Questionnaire; SQL Profile = Subjective Quality of Life Profile; EQ-5D = Euro Quality of Life-5D; GHQ-30 = General Health Questionnaire-30; SIP = Sickness Impact Profile; EBIQ = European Brain Injury Questionnaire; QOLI = Quality of Life Inventory; QOLIBRI = Quality of Life after Brain Injury.

From Table 1 above, it is shown that 12 studies equated QoL with subjective well-being, another 14 studies defined QoL as achievement involving an external rater forming a judgement about the quality the person of interest enjoys on key aspects of life such as their health, work, leisure activities, place of residence, financial status and relationships. Only two studies (Hawthorne et al., 2009; Mar et al., 2011) use the utility as a conception of QoL. Truelle et al. (2010) and von Steinbuechel et al. (2010a; 2010b) studies which used QOLIBRI as the measurement tool for QoL also used the concept of SWB to define the QoL.

Von Steinbuechel, Petersen et al. (2005) proposed a conceptual model of a HRQoL assessment. In that model, HRQoL needs to be assessed in four areas; physis (physical), psyche (psychological), social life and daily life. In the psychological domain emotional and cognitive aspects have to be assessed explicitly. Relevant predictor variables should be measured along with the self-rated core HRQoL variables. Only in cognitively severely impaired persons after TBI, observers (proxies) should serve as raters (von Steinbuechel, Petersen, et al., 2005). This HRQoL assessment model guided the development of QOLIBRI by an international multi-disciplinary group (the TBI Consensus Group, later the QOLIBRI Task Force) which formed in 1999. The domain in the QOLIBRI consists of 5 domains from

von Steinbuechel, Petersen, et al. (2005) HRQoL conceptual model added with the self domain. The final QOLIBRI instrument consists of 6 domains which include (1) cognition, (2) self, (3) daily life and autonomy, (4) social relationships, (5) emotions, and (6) physical problem (von Steinbuechel et al., 2010a, 2010b).

*QoL after discharge in patients with TBI*

QoL has become a priority outcome in research and clinical practice. QoL is a useful frame of reference to measure outcome after TBI. Among 24 studies reviewed, it showed that the majority of patients with TBI have lows of QoL (Table 2). Although the results of QoL were similar in showing low QoL in TBI patients, it seems difficult to compare because of the differences in term of study design, sampling strategy, conceptualization to approach QoL, the tool for measurement of QoL, and the inclusion criteria when approached. The summary of studies in this review is in Table 2.

Table 2 shows that most of the studies related to QoL of patients with TBI used cross-sectional design. Regarding the outcome measured, it can be divided into two groups. First, the short-term outcome that measured the QoL was less than one year (ranged from discharge at 1 month) (Johnston, Goverover, & Dijkers, 2005; Lin et al., 2010; Pagulayan et al., 2006) until 12 months after injury (Bedard et al., 2003). Second, the long-term outcome of approaches to QoL in patients with TBI is accounted of more than 1 year after injury.



Table 2 Study on QoL after discharge in patients with TBI

Authors	Inclusion Criteria	Data Collection Method	Subjects and Sample Size	Study Design	Result of QoL
Bedard et al. (2003)	≥ 1 year post injury	Home interview	All (mild, moderate & severe TBI), 13	Intervention, pre-post study	Moderate
Breed et al. (2004)	4 years post injury	Telephone interview	All, 191	Descriptive survey	Low
Dikmen et al. (2003)	> 3 years after injury	Not state	All, 210	Descriptive	Slightly worse
Emanuelson et al. (2003)	> 3 weeks after injury	Postal questionnaire	All, 173	Longitudinal	3 months and 1 year were significantly lower and no significant different between 3 months and 1 year
Eriksson et al. (2009)	1 – 4 years after injury	A postal survey	All, 116	Cross-sectional	Low
Hawthorne et al. (2009)	> 3 months post injury	Interview ; at home or another nominates location, telephone	All, 66	Cross-sectional	Low
Huebner et al. (2003)	> 1 year post injury	Telephone interview	All, 25	Cross-sectional	Low
Johnston et al. (2005)	> 1 month after rehabilitation discharge	Telephone interview	All, 162	Longitudinal	Low at 1 month and not improve at 12 months
Kalpakjian et al. (2004)	< 1 year	Telephone interview	All, 50	Cross-sectional	Low
Lin et al. (2010)	After discharge	Telephone interview	All, 158	Longitudinal	Decline at discharge, followed at 6 months slightly increase at 12 months.
Mailhan et al. (2005)	> 2 year after injury	Home or hospital interview	Severe TBI, 75	Cross-sectional	Low
Mar et al. (2011)	> 12 months after hospital admission	Interview	All, 68	Cross-sectional	Low
Nestvold & Stavem (2008)	22 years after injury	Postal survey	All, 259	Cohort study	Low
Pagulayan et al. (2006)	> 1 month after TBI	Not state	All, 133	Longitudinal cohort	Pattern of endorsed difficulties at 6 months, 1 year, and 3 to 5 years nearly the same
Steadman-Pare et al. (2001)	8 - 24 years after injury	Home interview	Moderate to severe TBI, 275	Cross-sectional	High
Teasdale & Engberg (2005)	> 5 year post injury	Postal questionnaire	All, 257	Cross-sectional	Low
Truelle et al. (2010)	> 3 months after injury	Postal questionnaire/ face-to face interview/ telephone interview	All, 795	Cross-sectional	Low
Upadhyay (2007)	> 3 months post injury	Not stated	All, 30	Cross sectional	Low

Note. All = mild, moderate, and severe TBI

*Assessment of QoL in patients with TBI*

To assess trauma severity and clinical outcome after TBI, there are now well-established and widely-used TBI-specific instruments available. On the contrary, for outcomes after TBI-related QoL such condition-specific tools do not exist, clinicians and researcher are still developing such tools (Bullinger, 2002; Dijkers, 2004; Truelle 2010). There are two main types of QoL instruments: generic and disease-specific. Generic instruments do not take a particular condition into account and therefore, allow comparisons with healthy individuals along with comparisons across various disease states. Disease-specific instruments take into account a patient's specific health condition and therefore, may be more sensitive to the consequences of the condition and more relevant to patients (Bullinger 2002; Nichol et al., 2011). The tools that have been used in studies of this review were shown in Table 3.

Based on Table 3, it shows that 19 out of 26 studies in this review measure QoL using a generic instrument. Four studies used a version of generic medical outcome study-short form 36 (SF-36) health survey (Bedard et al., 2003; Emanuelson et al., 2003; Guilfoyle et al., 2010; Nestvold & Stavem, 2009). Other studies used a variety of other global QoL measures, such as WHOQOL-BREF (Chiu et al., 2006; Lin et al., 2010; Upadhyay, 2007), LiSat-11 (Andersson et al., 2011; Eriksson et al., 2009), and other QoL measurement (SIP, PQOL, Self Rated Quality of Life Scale, AQOL, QOLR, SWLS, QOL Inventory, QOL Interview, QOLI, and EQ-5D). Only a few studies used a disease-specific instrument such as LLTBI (Breed et al., 2004), EBIQ (Teasdale & Engberg, 2005), SQL Profile (Mailhan et al., 2005), and QOLIBRI (Truelle et al., 2008; 2010; von Steinbuechel et al., 2010a; 2010b). For the last one, QOLIBRI, is the specific QoL measurement in TBI which has been recently developed.

Table 3 Overview for measurement of QoL in patients with TBI

Tool	TBI references	Number of studies	Type of tool
SF - 36	Bedard et al., 2003; Emanuelson et al., 2003; Guilfoyle et al., 2010; Nestvold & Stavem, 2009	4	Generic
LLATBI	Breed et al., 2004	1	TBI-specific
SIP	Pagulayan et al., 2006	1	Generic
WHOQOL-BREF	Lin et al., 2010; Upadhyay, 2007; Chiu et al., 2006	3	Generic
PQOL (perceived quality of life)	Dikmen et al., 2003	1	Generic
Self Rated Quality of Life Scale	Steadman-Pare et al., 2001	1	Generic
AQoL	Hawthorne et al., 2009	1	Generic
LiSat-11	Andersson et al., 2011; Eriksson et al., 2009	2	Generic
QOLR	Huebner et al., 2003	1	Generic
SWLS	Johnston et al., 2005	1	Generic
QOL Inventory	Kalpajian et al., 2004	1	Generic
EBIQ	Teasdale & Engberg, 2005	1	TBI-specific
QOL Interview	Brown et al., 2000	1	Generic
SQL Profile	Mailhan et al., 2005	1	TBI-specific
QOLI	Thomas et al., 2009	1	Generic
EQ-5D	Mar et al., 2011	1	Generic
QOLIBRI	Truelle et al., 2008; Truelle et al., 2010; von Steinbuechel et al., 2010a; von Steinbuechel et al., 2010b	4	TBI-specific

*Note.* SF-36 = Short Form-36 health survey; LLATBI = Living Life After TBI; SIP = Sickness Impact Profile; WHOQOL-BREF = World Health Organization Quality of Life-BREF; PQOL = Perceived Quality of Life; AQoL = Assessment of Quality of Life; ; LiSat-11 = Life Satisfaction-11; QOLR = Quality of Life Rating; SWLS = Satisfaction with Life Scale; SQL Profile = Subjective Quality of Life Profile; EQ-5D = Euro Quality of Life-5D; GHQ-30 = General Health Questionnaire-30; EBIQ = European Brain Injury Questionnaire; QOLI = Quality of Life Inventory; QOLIBRI = Quality of Life after Brain Injury.

It's also shown that most of the studies used the HRQoL instrument to assess QoL in TBI patients (Andersson et al., 2011; Bedard et al., 2003; Chiu et al., 2006; Dikmen et al., 2003; Emanuelson et al., 2003; Guilfoyle et al., 2010; Hawthorne et al., 2009; Lin et al., 2010; Nestvold & Stavem, 2009; Pagulayan et al., 2006; Steadman-Pare et al., 2001; Upadhyay, 2007). HRQoL is a concept that reflects a patient's subjective view of their disease, treatment and the impact these have on their life. HRQoL covers numerous dimensions, including physical, social, psychological, and daily life. Whilst HRQoL as an

outcome measure in medicine has been used for over 30 years, its use in TBI patients has only commenced in the past decade.

*Generic instruments*

*Short Form 36 Health Status Questionnaire (SF-36) and Short Form 12 Health Status Questionnaire (SF-12).* The SF-36 is a 36-item questionnaire (as the name suggests) that covers eight dimensions of health related quality of life (HRQoL): physical functioning, social functioning, physical role, emotional role, mental health, vitality, bodily pain and general health. Each dimension yields a score ranging from 0 to 100 (where 100 represent best health). The eight dimensions can be further summarized into two summary scales – mental health and physical health (Guilfoyle et al., 2010). The reliability and validity of the SF-36 have been established in a TBI population (Guilfoyle et al., 2010) and it has been widely used in TBI research. In their study, Findler, Cantor, Haddad, Gordon, and Ashman (2001) noted that the SF-36 may be a more sensitive measure of health-related problems in patients with mild TBI than in those with moderate-severe TBI, as the correlations between the SF-36 scales and measures of health problems associated with TBI were weaker and more uniform in the moderate–severe TBI group (compared to the correlations in the mild TBI group). The SF-12 is a shorter version of the SF-36 containing 12 items. It covers the summary of physical health and mental health scales, but does not provide information about each of the eight dimensions of the SF-36. The SF-12 has begun to be more commonly used in the TBI population. However, its psychometric properties in this population have not been specifically assessed (Nichol et al., 2011).

*World Health Organization Quality of Life Brief Questionnaire (WHOQOL-BREF).* The WHOQOL-BREF is a 26-item questionnaire that is a short version of the 100-item WHOQOL developed by focus groups in numerous countries. It is available in over 20 different languages. Each item uses a scale from 1 to 5, where a higher score indicates a

higher HRQoL. It covers four domains of HRQoL: physical health, psychological health, social relationships, and environment (WHOQoL Group, 1998).

*European Quality of Life-5 Dimensions (EQ-5D)*. The EQ-5D (previously known as the EuroQoL questionnaire) is five dimensions, five item questionnaire developed in Europe in 1990. The dimensions measured are mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each item represents a single dimension with three levels: no problems, some problems, and unable or extreme. The EQ-5D can be used to generate a single health index (a utility), and is therefore useful in economic evaluations as it can be used to calculate quality adjusted life years (QALYs). It is available in many languages and there is usually no fee for its use for non-commercial purposes. A criticism of the EQ-5D for use in TBI patients is that it does not contain a cognitive dimension (Nichol et al., 2011). A systematic review of studies using the EQ-5D after injury, found that all studies that included TBI patients added a cognitive question or cognitive specific measure to the questions they asked of participants (Derrett, Black, & Herbison, 2009).

#### *TBI-specific instruments*

*The Subjective Quality of Life Profile (SQLP)*. The SQLP is a patient's self assessment and relative assessment form to be included in rehabilitation and long-term cases. It has been constructed for TBI patients, and has been tested for psychometric criteria, it contains 38 items, it needs 20 minutes to fill out, and is available in English and French. The questionnaire has a generic part which contains a life satisfaction questionnaire with 10 specific questions added for TBI patients. In its core form, it resembles a more generic life satisfaction questionnaire (Bullinger et al., 2002).

*The Living Life with Traumatic Brain Injury (LLTBI)*. The LLTBI questionnaire is a structured interview system concerning five areas of the impact of TBI on patients. It contains one QoL part with several items on cognition, physical well-being and social

function, and has been applied in over 1000 patients. However, the psychometric criteria are not available yet. It is available in English and has been constructed for descriptive purposes (Bullinger et al., 2002).

*European Brain Injury Questionnaire (EBIQ)*. The EBIQ was developed in 1997 as a measure of the subjective experience of cognitive, emotional and social difficulties experienced by people with brain injury. There are two parallel versions of the EBIQ available: one to be completed by the patient and another to be completed by a close relative/proxy. It is a 63-item questionnaire that is reported to take around 15 min to complete. Each item has three response categories: not at all, a little, and a lot. The questionnaire covers a global scale and eight subscales: somatics, cognition, motivation, impulsivity, depression, social isolation, physical activities of daily living (ADL) complaints, and communication. It has not been widely used since it was first developed, but its reliability and validity in a TBI population have been established. However, a recent study to assess the construct validity of the self-rating version of the EBIQ found that some items and overall scales did not meet expectations (using Rasch analysis) (Nichol et al., 2011).

*Quality of Life in Brain Injury (QOLIBRI)*. The QOLIBRI has been recently developed by an international collaboration, and has been evaluated in its psychometric properties. The results of the psychometric evaluation indicate favorable psychometric properties of the QOLIBRI. In spite of the variation in demographic and clinical characteristics, internal consistency and test-retest reliability are acceptable to good, both in the total sample and in different language groups. Although there is one strong HRQoL factor, a six-scale structure explaining additional variance was validated by exploratory and confirmatory factor analyses, and with Rasch modeling. The QOLIBRI is a new cross-culturally developed instrument for assessing HRQoL after TBI that fulfills the standard psychometric criteria. It is potentially useful for clinicians and researchers conducting clinical trials, for assessing the impact of

rehabilitation or other interventions, and for carrying out epidemiological surveys (von Steinbuechel et al., 2010a). It also has been evaluated in clinical use.

The QOLIBRI final version comprises of 2 parts with a total of 37 items across six subscales. The first part assesses the level of satisfaction within four domains: cognition (seven items), self (seven items), daily life and autonomy (seven items), and social relationships (six items). The second part asks respondents how 'bothered' they are in relation to two domains: emotions (five items) and physical problems (five items). The completion mean time was reported at 11 minutes for self-completion and 20 minutes for face-to-face interview, although this is likely to vary by disability level. The QOLIBRI total scores was obtained from a sum of 37 item scores (graded 1–5), after reverse of 10 'bothered' items in order to have a 'satisfaction global score'. Then, the maximum score is  $37 \times 5 = 185$ . Afterwards, the QOLIBRI scores are presented on a 0 (worst possible score on the QOLIBRI) to 100 (best possible score) scale (although this is a percentage scale it is more common among HRQoL instruments to describe this as a 0–100 point scale) (Truelle et al., 2010).

The QOLIBRI was first validated in German, Finnish, Italian, French, English and Dutch. The development of QOLIBRI in Asia already starts with meeting of the researchers to perform the first steps toward languages harmonization with researchers. The QOLIBRI also has been translated into 14 languages: Chinese (Mandarin and Cantonese), Danish, Dutch, English, Finnish, French, German, Italian, Japanese, Polish, Spanish, Norwegian, and Malayan (Truelle et al., 2008). Currently, validation of QOLIBRI in Australian population has been documented (Hawthorne et al., 2011).

## **Discussion**

QoL is a wide concept that can be defined through many dimensions. Two important definitions of QoL were used in the studies related to TBI namely achievement and subjective well being. Despite the different approach, appropriate domains of QoL seem essential particularly the cognitive domain in TBI patients which is generally accompanied by cognitive impairment.

Most of the studies used cross-sectional design. Congruent with Pagulayan et al. (2006), there are relatively few studies that have evaluated outcome at multiple points over an extended period of time after injury. Perceived health-related functioning in both physical and psychosocial domains may change over time because recovery from TBI is a complex and lengthy process. The rate of recovery may vary because of a number of factors, including the severity of the brain injury, time since the injury, the domain of functioning that is being assessed, and measures used for their assessment. Given the multiplicity of contributing factors and the difficulties in performing longitudinal studies, particularly in the TBI population, the literature is limited on the trajectory of HRQoL over time after a TBI (Pagulayan et al., 2006). Even so, there are recommendations for a longitudinal study on QoL after TBI to see the changes over time regarding QoL (Bullinger & TBI Consensus Group, 2002; Dijkers, 2004). However, a cross-sectional study with an appropriate QoL assessment using a valid specific instrument for patients with TBI can overcome the shortcoming of a longitudinal study.

Measurement of QoL in patients with TBI is conceptually difficult due to the need to obtain the patient's viewpoint for a condition which often leaves patients with impaired cognition and an inability to communicate effectively. To assess QoL a patient must be conscious, able to express them-selves, and have sufficient cognitive functioning to be able to understand and respond to questions. As some or many TBI patients may not fulfill these



requirements, the perceptions of others such as family members or caregivers are often used (proxy respondents). These responses however, cannot fully substitute for a patient's own report (Nichol et al., 2011).

Bullinger et al. (2002) also discuss that issue. They are stating that only some of the instruments measure perceived health status by the patient, and lack an additional evaluation of the importance of health status information from the patients' perspective. Therefore, a distinction between patients' perceived health and family perceived health was made, which was relevant also for the question whether or not proxy assessment should be used. They consented that the proxy assessments are not suited to assess the patients' QoL.

There are specific criteria which should be met when developing QoL instruments. They should be specific, feasible, brief, and should take less than 20 min to complete (better 10–15 min.). They should be comprehensive, include the four main dimensions of QoL (physical, social, functioning, psychological) and also include cognitive and existential dimensions (for existential dimensions items needed to be formulated). They should be usable for the patient and for significant other (i.e., not to use the significant other's information as proxy but as the family perceived patient's health). They should have acceptable psychometric quality, that is reliability, validity and sensitivity, and they should tap the "quality" of the QoL and not just consist of the recollection of behavior or function. Instruments should be easily scorable, they preferably should be accompanied by a profile sheet in which an individual patient as well as patient groups can be depicted. They should cover both, rehabilitation phases (T2) and long term (T3) (at least T3), and they should assess the relative importance of the questions for each patient. They should have room for qualitative data, that is open answers to open questions, which gives the patient a possibility to express his or her view of QoL in his or her own words (this can be done in a structured way by leaving a space for the patient to complete and rate subjectively relevant dimensions).

They should be available in several languages and should be accompanied by generic questionnaires for comparison (with other disease states, other representative populations) and they should also include information about the patients' previous life. Since the latter is difficult to achieve in terms of premorbid personality or previous life assessment, it's thought that devising or developing an existential dimension to assess QoL could incorporate the perceived change in comparison of now to the prior state, the feeling of loss, mourning, and future outlook (Bullinger et al., 2002).

Moreover, Riemsma, Forbes, Glanville, Eastwood, and Kleijnen (2001) evaluated the degree to which general health status measures have been evaluated for use with people with cognitive impairments, including TBI. It was reported that of the 34 measures used in samples with cognitive impairments, only 6 have been validated in these groups. Riemsma et al. (2001) concluded that there are no validated instruments available for use in cognitively impaired respondents and existing measures for use in general populations, should be used cautiously in studies of persons with cognitive impairment (Riemsma et al., 2001). A review by von Steinbuechel, Richter, Morawetz, & Riemsma (2005) on the assessment of HRQoL in acquired or degenerative brain injury also confirm that there are only a few measures that have been developed and validated for respondents with cognitive impairment. HRQoL assessment should therefore be validated in the specific disease and if necessary, combined with a neuropsychological evaluation and a disease-specific HRQoL measure (von Steinbuechel, Richter, et al., 2005). As noted in prior studies (Bullinger et al., 2002; Daggett, Bakas, & Habermann, 2009; Petchprapai & Winkelman, 2007) various generic measurements have been used to measure HRQOL in TBI patients, and there is lack of TBI-specific HRQOL instruments. QOLIBRI as a new HRQoL instrument, is an assessment model from von Steinbuechel, Petersen, et al. (2005) integrates disease-specific issues of TBI patients such as cognition in the assessment.

Cultural influences on determinants and outcomes related to TBI in adults have not been explored. The data in this review are limited to reports in English language. International studies may have unique perspectives but were not included in this appraisal. The majority of data about TBI in this review, focused in the USA, Australia, and Europe countries, only few studies from Asia (Chiu et al., 2006; Lin et al., 2010; Upadhyay, 2007). Therefore it makes limitation in applicability of finding in countries where the causes of trauma. Mechanism of injury and medical treatment vary in different regions of the world. Another else that may be different is about the sociocultural outcomes, and also the importance and satisfaction with the domains in QoL may be varied across the country.

## **Conclusion**

QoL in individuals of patients with TBI is recognized as a critical indicator of outcome following TBI. Two important definitions of QOL have been used in studies related to TBI namely achievement and subjective well being. The majority of studies in this review used generic measurements to measure QoL in patients with TBI, and there is lack of a TBI-specific QoL instrument. The QOLIBRI as a new disease-specific QoL measurement in TBI seems a feasible and valid approach for the assessment of QoL in TBI. The QOLIBRI includes the cognitive domain which is a specific condition in patients with TBI and it is thorough in its conceptual and psychometric analysis. However, the application across cultural remains a challenge and needs a validation.

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