

## ARTÍCULO I: DESARROLLO DE LA VERSIÓN PILOTO DEL INSTRUMENTO

Fernández, M., Verdugo, M. A., Gómez, L. E., Aguayo, V. y Arias, B. (2018). Core indicators to assess quality of life in population with brain injury. *Social Indicators Research*, 137(2), 813-828. doi:10.1007/s11205-017-1612-6




### Resumen

**Antecedentes.** La evaluación de la calidad de vida de las personas con daño cerebral adquirido tiene un papel relevante en el desarrollo de estrategias centradas en los resultados personales que nos permiten guiar las buenas prácticas y la rehabilitación. Hasta ahora, la evaluación de la calidad de vida de esta población se ha restringido a una evaluación de resultados personales desde una perspectiva de calidad de vida relacionada con la salud. Este enfoque se centra en la salud física; sin embargo, la calidad de vida debe abordarse desde una perspectiva holística y multidimensional. **Objetivos específicos.** El objetivo de este estudio es identificar los indicadores centrales de la calidad de vida en el daño cerebral adquirido basándose en un modelo teórico integral centrado en los aspectos más relevantes del funcionamiento de esta población. **Método.** Se realizó un estudio Delphi para obtener los indicadores específicos de calidad de vida para esta población. La metodología utilizada para llegar a un consenso sobre los mejores indicadores e ítems para medir la calidad de vida incluyó cuatro rondas y 14 expertos en rehabilitación de personas con daño cerebral adquirido. **Discusión.** El estudio Delphi proporcionó evidencias de la validez del contenido para la versión piloto de una nueva escala que se aplicará a una amplia muestra para verificar empíricamente su idoneidad para esta población.

**Palabras clave.** Calidad de vida, daño cerebral, adquirido estudio Delphi, validez de contenido, indicadores centrales, evaluación.



# Core Indicators to Assess Quality of Life in Population with Brain Injury

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Accepted: 13 March 2017 / Published online: 21 March 2017  
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**Abstract** Assessing quality of life of people with brain injury has a relevant role for developing strategies focused on personal outcomes that allow us to guide good practices and rehabilitation. So far, assessment of quality of life for this population has been restricted to an evaluation of personal outcomes from a health-related quality of life perspective. This approach it is mostly centered on physical health, however, quality of life needs to be addressed from a holistic and multidimensional perspective. The goal of this study is to identify core indicators of quality of life in brain injury based on a comprehensive theoretical model focused on the most relevant aspects of this population functioning. A Delphi study was carried out to obtain the specific core indicators of quality of life for this population. The methodology used to reach a consensus about the best indicators and items to measure quality of life involved four rounds and 14 experts on rehabilitation of people with brain injury. The Delphi study provided evidence of content validity for the field-test version of a new scale that will be applied to a wide sample in order to empirically check its suitability for this population.

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**Keywords** Quality of life · Brain injury · Delphi study · Content validity · Core indicators · Assessment

## 1 Introduction

In the majority of cases, acquired brain injury (ABI) is the result of sudden injury to brain structures and gives rise to a very diverse range of problems (Gómez Pastor 2008). It happens when the brain's operation is altered by an external agent (e.g. an object) or an internal agent (e.g. a haemorrhage) more or less suddenly (Bilbao and Díaz 2008). According to survey data (*Encuesta de Discapacidad, Autonomía personal y situaciones de Dependencia*—Survey of Disability, Personal Autonomy and Dependency—*Instituto Nacional de Estadística*—Spanish Statistics Institute, 2008), around 420,064 people with ABI live in Spain (Quezada 2011). These data are a reflection of the major health problem posed by ABI in contemporary society. Not only is it not decreasing, it is rising over time. One of the factors that is mainly contributing to the high incidence is the increase in the number of cases of survivors of a brain injury in recent years, mainly due to medical progress and technological advances (Rubial-Álvarez and Veiga-Suárez 2012).

ABI can take various forms and manifest in different ways depending on its etiology. The etiology of the injury may have various causes. Traumatic brain injury (TBI) and stroke are the most common, followed by anoxia, infections and brain tumours. TBI is the main cause of death or disability worldwide, mainly affecting adolescents and young adults (Hu et al. 2012; Sasse et al. 2014; Scholten et al. 2015).

ABI causes a series of cognitive, communicative, physical, emotional, behavioural and personality changes and damage in the brain, which may vary by the location of the injury and the degree of severity. As a consequence of these deficits, the quality of life of people who have suffered a brain injury, as well as that of their relatives and those close to them may diminish when areas that are of vital importance to people's lives are affected (Andelic et al. 2010; Arango-Lasprilla et al. 2012; Dijkers 2004; Jacobsson et al. 2010; Nestvold and Stavem 2009).

Taking into account the major impact ABI has on people's lives, there can be no doubt about the importance of the concept of quality of life in this population. In fact, a great deal of scientific literature focuses specifically on assessing quality of life from the viewpoint of health-related quality of life (HRQOL), which is the most used in the literature (Carlozzi et al. 2011; Forslund et al. 2013; Grauwmeijer et al. 2014; Hawthorne et al. 2009; Machamer et al. 2013; Soberg et al. 2013; Ulfarsson et al. 2014). The use of HRQOL has focused mainly on aspects related to physical wellbeing and health. It has stressed the medical characteristics of the disease, its treatment, and how these affect everyday life. In spite of the relevance of these aspects, this point of view is limited by not taking into account other areas that are also important in people's lives, such as aspects more closely related to social inclusion, personal development, self-determination and rights.

In order to overcome the limitations of an approach that focuses mainly on physical and mental health, this study is aimed at assessing the quality of life of people with ABI from a broader viewpoint, one not circumscribed to the field of health. Several quality of life models have been proposed and are used in the field of disability (e.g., Cummins 2005; Felce and Perry 1995; Petry et al. 2005; Schalock and Verdugo 2002). These quality of life models arose in the 1980s to raise awareness of what is truly important in people's lives

and as a social construct to guide policy, professional practice and social intervention (Gómez et al. 2012, 2013; Schalock et al. 2008, 2011; van Loon et al. 2013). Since then, these models have become established as an optimal framework for both the development and provision of services and for the assessment of personal results related to quality of life (Schalock and Verdugo 2002).

In this study we have adopted Schalock and Verdugo's quality of life model (2002, 2007, 2008, 2012) because in our country it has become a framework of reference for the provision of services, it provides a basis for implementing evidence-based policies, and it serves as a vehicle for developing quality of life improvement strategies. This model has also met with widespread acceptance in the scientific community (Balboni et al. 2013; Carbó-Carreté et al. 2015; Gómez et al. 2010; Schalock et al. 2005; Wang et al. 2010) and it is currently applied in the field of disability and other groups at risk of social exclusion (Alcedo Rodríguez et al. 2008; Arias et al. 2010; Gómez et al. 2014, 2015; Verdugo et al. 2010, 2014).

According to Schalock and Verdugo (2002), quality of life refers to a desirable condition of personal well-being and life satisfaction, which is multidimensional in nature, has universal properties linked to culture, is influenced by personal characteristics and environmental factors, and is made up of objective and subjective aspects. However, like any social construct, quality of life cannot be directly measured; it has to be implemented through domains, indicators and personal results.

The concept of a domain refers to the factors that comprise well-being (Schalock et al. 2016). Eight domains are proposed in this model: material well-being, physical well-being, emotional well-being, social inclusion, personal relationships, self-determination, personal development, and rights. The relative importance given to each of these domains may vary from one person to another and even at different moments in the life of the same individual (Schalock et al. 2007). These domains are implemented through core indicators, which refer to specific quality of life perceptions, behaviours and conditions that reflect personal or family well-being (Schalock et al. 2016). These indicators are culture-sensitive, therefore, it may be necessary to develop specific indicators depending on the target population. Finally, personal results refer to a person's aspirations, as well as assessment of her or his personal situation.

In the field of people with ABI, specific tools have not yet been developed to assess their quality of life from a holistic and multidimensional perspective that is not circumscribed to HRQOL. The lack of research in this field makes necessary, firstly, to identify the most relevant indicators that influence the well-being of people with ABI, and subsequently to develop assessment instruments that help plan and guide intervention to improve quality of life. With this in mind, the general objective of this study is to obtain a sufficient and adequate pool of items to implement the quality of life construct in the group of people with ABI based on the eight-domain model (Schalock and Verdugo 2002). This will be a necessary first step for the subsequent validation of a specific instrument, allowing the assessment of the quality of life in people who have suffered brain injury, taking into account their particular needs and peculiarities. Moreover, this instrument might be used to improve the provision of services through evidence-based practices.

In order to achieve this objective, in this study, as in other similar ones (e.g., Gómez et al. 2014, 2015), a Delphi method is used. This is one of the best-known expert techniques with the greatest proven effectiveness (Christie and Barela 2005; Okoli and Pawlowski 2004). The technique is widely used in education, technology, health and psychology (Barroso and Cabero 2010; Gil-Gómez de Liaño and Pascual-Ezama 2012; Lakeman 2010) for different purposes, such as drawing up questionnaires, making

decisions, identifying research themes and questions, selecting variables of interest, planning programmes, assessing needs, determining policies and using resources (Delbecq et al. 1975; Gómez et al. 2015; Hasson et al. 2000; Hsu and Sandford 2007; Okoli and Pawlowski 2004).

The Delphi method is used to obtain a consensus among a group of people, considered to be experts, regarding a particular research goal (León and Montero 2003). Unlike other expert consultation techniques traditionally used, the Delphi method ensures that there is a dynamic feedback and decision-making process through a series of structured rounds (Dalkey and Helmer 1963; Gil-Gómez de Liaño and Pascual-Ezama 2012; Hasson et al. 2000). Landeta (2006) highlights four main characteristics that define the Delphi technique: (1) *anonymity*: the experts are unaware of the identity of the other members of the panel; (2) *iteration* and *controlled feedback*: by accessing the same questionnaire and expert opinions several times, experts can modify their opinions based on the arguments presented; (3) *knowledge of the group's responses*: the information presented to the experts includes all of the opinions, not just those of the majority, indicating the extent of the agreement reached; and (4) *heterogeneous sample*: the participants may come from different areas of activity and knowledge.

The increasing use of the Delphi method in recent years has resulted in many different modifications of the technique (Keeney 2009). As we will describe below, and because we are framing the process within a widely-known model, in this research we have used a modified Delphi, as we are starting with an established questionnaire and not with open questions (as it is customary in the traditional Delphi method), avoiding in this way responses that are potentially too ambiguous.

## 2 Method

### 2.1 Participants

This study included a total of 14 participants, all of whom were professionals who worked with people with ABI and who had extensive experience in theoretical and practical areas. The participants were selected for their great knowledge of and extensive experience with this population. We sought to ensure that there was sufficient heterogeneity in terms of their profession, gender, educational level, and the types of centres where they worked.

The sample thus consisted of eight women (57%) and six men (43%) aged between 28 and 53 ( $M = 37$  years;  $DT = 7.24$ ). The professionals worked in organisations and centres that specifically focus on rehabilitation or support for people with ABI in various Spanish autonomous communities: Madrid ( $n = 6$ ), Valencian Region ( $n = 4$ ), Castile-Leon ( $n = 2$ ), Catalonia ( $n = 1$ ) and Galicia ( $n = 1$ ). 43% of them ( $n = 6$ ) were professionals who worked at *Centro de Referencia Estatal de Atención al Daño Cerebral* (National Reference Centre for Brain Injury Care—CEADAC) and 36% ( $n = 5$ ) worked at *Federación Española de Daño Cerebral* (Spanish Brain Injury Federation—FEDACE). The remaining professionals worked at ASPRODES ( $n = 1$ ), SAUVIA ( $n = 1$ ) and *Instituto Guttman* ( $n = 1$ ). Although these centres are not specifically for people with brain injury, they each have a specific unit for people with this etiology.

As far as the educational level attained by the experts is concerned, four held 3-year college diplomas, two had B. A. degrees, five had completed master-level postgraduate studies, and three held a Ph.D. The average employment experience in the field of

disability, specifically with people with ABI, was 10.35 years ( $DT = 6$ ), and the range of years in this type of work ranged from 3 to 22. The sample of participants formed a multidisciplinary team consisting mainly of psychologists ( $n = 7$ , five of these specialised in neuropsychology), plus two physiotherapists ( $n = 2$ ), one occupational therapist ( $n = 1$ ), one rehabilitation physician ( $n = 1$ ), one speech therapist ( $n = 1$ ), one social worker ( $n = 1$ ) and one nurse ( $n = 1$ ).

The response rate achieved throughout the four rounds of the study was high. Thirteen of the fourteen experts who initially agreed to take part in the study completed the first three rounds. Only one of the experts did not reply to the questions in the last round, so data from thirteen experts was collected in the final round.

## 2.2 Instrument: Items Pool

The process used to create the initial pool of items, which the Delphi study experts were later asked to consider, comprised two stages. Firstly, a systematic review of the most relevant scientific literature related to the concepts of quality of life and ABI, as well as the assessment tools used to measure them, was carried out. That gave rise to a set of specific indicators relevant for this population (see Table 1). In addition, an initial pool of items was obtained that included 275 items from various scales, both specific to a population with brain injury (Teasdale et al. 1997; Teasdale and Engberg 2005; Truelle et al. 2010) and general for people with disability (Verdugo et al. 2010, 2013, 2014). Through a refinement process aimed at reducing their number, the items were first organised into the eight quality of life model domains and then, within these domains, around the core indicators found in the review of the literature. Repeated or overlapping items were then eliminated, reducing the initial item pool to 191 items. Finally, the 20 items considered to be the most representative of each of the 8 domains were selected, a step that led to a final pool of 160 items.

Secondly, a group discussion was conducted with professionals who worked with people with ABI. Discussion groups have the advantage of actively including professionals

**Table 1** Quality of life domains and indicators specific to brain injury

Domain	Indicators
Self-determination	Goals; Choices; Decisions; Opinions and preferences; Autonomy
Emotional well-being	Satisfaction with life; Self-concept; Absence of stress and negative feelings; Basic security; Emotional expression
Physical well-being	Hygiene; Healthcare; Diet; Physical health; Sleep; Physical exercise; Mobility; Medication; Sexuality
Material well-being	Income; Conditions of housing/workplace/centre or service; Access to information; Possessions; Support Products
Rights	Respect; Awareness of rights; Defence of rights; Exercising rights; Privacy
Personal development	Problem-solving; Skills and abilities; Learning and personal enrichment; Everyday activities
Social inclusion	Integration; Participation; Support
Interpersonal relations	Family relationships; External social relationships; Sexual/emotional relationships; Communication

in the process of producing the instrument, thus making possible to contrast the results, and they involve decision-making of great practical use for producing the assessment instrument. The group was made up of 13 professionals who worked in organisations specifically dealing with people with ABI and who were trained in different fields (i.e. psychology, neuropsychology, speech therapy, physiotherapy, rehabilitation medicine, social work, social education, occupational therapy and nursing). The purpose of this group was to arrive at a consensus on the items and indicators with regard to: (1) their importance for people with ABI; (2) their adequacy to different situations experienced by people with ABI; and (3) the representativeness of the domain in which they have been classified. In addition, the professionals who took part were encouraged to propose new items and indicators that they considered to be missing from the initial item pool. They thus reformulated and clarified some items and proposed 13 new items (see Table 2), which gave rise to a final pool of 173 items.

### 2.3 Procedure

The Delphi method was applied to the pool of 173 items. It was implemented through a virtual environment, Moodle (Modular Object-Oriented Dynamic Learning Environment), which is a software package used to create internet-based courses and websites and is distributed free of charge as open source software. Since participants' anonymity is one of the main characteristics of the Delphi method, throughout the process the experts used pseudonyms unknown to the rest of the participants to access this platform and carry out the required tasks.

The virtual environment on which the Delphi method was carried out was structured into five main modules. The first module was made up of a letter of introduction, telling the participants about the study's goal and the procedural instructions. It also included a section to report any important alerts related to any aspect of the research. The remaining four modules were for each of the four rounds of which the Delphi study was made up. Each of these included the materials required to carry out the requested tasks, the instructions for carrying them out adequately and, at the end of each round, a report with the results obtained in the previous round. In addition, each of the modules had a forum in which the participants discussed various matters mainly related to the round they were in at that time but also about other aspects related to the study. Lastly, various tasks or mailboxes were set up to send in the assessments once they had been completed.

**Table 2** Examples of new items proposed by the experts in the discussion group

Indicator	Domain	Items
Family relationships	Interpersonal relations	His/her loved ones provide support and security
Autonomy	Self-determination	He/she drives his/her car without supervision
Physical health	Physical well-being	The person can control his/her bowels
Absence of stress	Emotional well-being	He/she has been provided with sufficient information about his disease and its sequelae



The experts' task consisted of assessing, in four rounds, the 173 items resulting from the previous stages based on four criteria: (1) suitability (i.e. whether the items belonged in each domain); (2) importance (i.e. relevance of the items in assessing the domain); (3) sensitivity (i.e. the extent to which the contents of an item can be modified by changes to contextual variables); and (4) observability (i.e. the degree to which the item's contents can be reported by a third party). The experts also assessed the suitability of the items' wording, the instructions and the response format.

## 2.4 Data Analysis

Data analysis and processing was carried out by using the open source statistical analysis software R, version 3.2.1 for Windows. Descriptive analyses ( $M$ ,  $DT$ ) were carried out and, for the four criteria (i.e. suitability, importance, sensitivity and observability) and the domains, agreement between judges was calculated using weighted agreement coefficients ( $B_N^W$ ) (Bangdiwala 1987). Unlike the initial agreement ( $B_N$ ), which provides information about the strict agreement between judges (i.e. the judges give the same score to the item), it shows partial agreements (i.e. when judges give more or less similar scores off the diagonal). These coefficients range "0" to "1", where scores around "0" signify no agreement and scores near "1" signify perfect agreement.

## 3 Results

### 3.1 Round 1

In the first round, the experts assessed the pool comprising 173 items, based on four previously established criteria (i.e. suitability, importance, sensitivity and observability). The items were assessed on a Likert scale with a format of four response options, in which a score of "1" signifies not at all suitable, important, sensitive or observable and a score of "4" signifies that the item was totally ideal, important, sensitive or observable.

The criteria used to select the items with the best scores was: (1) having an average score  $\geq 3$  and, (2) a standard deviation  $< 1$  (Gómez et al. 2014, 2015). Hence, 97 items (56%) were kept and 76 (44%) were rejected. Table 3 shows the mean, median and standard deviation of the scores for the 173 items for the four criteria, as well as the number and percentage of items kept (valid) and rejected (non-valid). Sensitivity was the lowest scoring criterion and had the highest number of items rejected. In contrast, importance was the highest scoring criterion and had the lowest number of items rejected.

**Table 3** Descriptive analyses for round 1 by criteria

	Me	$M$	DT	Valid items	% Valid	Non-valid items	% Non-valid
Suitability	4	3.58	0.31	150	86.70	23	12.29
Importance	4	3.62	0.23	165	95.37	8	4.62
Sensitivity	3	3.21	0.14	126	72.83	47	27.16
Observability	3	3.32	0.20	140	80.92	33	19.07

In this round the experts were also encouraged to propose a maximum of five new items and indicators that they considered relevant for each of the eight domains in the quality of life model. As a result, the experts proposed a total of 137 new items (between 11 and 25 items per domain). The domain with the highest number of new items proposed was physical well-being. Table 4 shows the number and percentage of the 173 items kept or rejected and the number of new items proposed by the experts for each of the eight domains. One can see in the table that the highest number of items rejected were in the domains of emotional well-being, social inclusion and interpersonal relations.

### 3.2 Round 2

The second round focused on assessing the new items that the experts had proposed in the first round ( $N = 137$ ). Prior to this assessment, the research team carried out a review of them in order to unify the proposals, reformulate the items for their compliance with the methodological recommendations (Popham 2003) and eliminate repeated or redundant items. The pool was thus reduced to 76 items. The experts' task consisted of assessing whether it would be appropriate to include them in the scale in a questionnaire with a dichotomous (i.e. yes/no) response format. So, if the experts considered the item to be valid and that it ought to be kept as part of the scale, they replied with the option, "Yes, the item is valid". Conversely, if they considered the item not to be suitable and that it ought not to be part of the scale, they replied with the option, "No, the item is not valid". Replies to all of the items were compulsory, so there were no responses left blank.

The item selection criterion was that it had to be considered appropriate by at least 12 of the 14 experts. Only 35 (46.5%) items met this criterion. Table 5 shows the results of the descriptive analyses in this round and the distribution of the 35 valid items finally selected.

### 3.3 Round 3

The third round consisted of reviewing the items considered non-valid in the first round ( $n = 76$  items). Specifically, items belonging to 3 of the eight domains in the quality of life model were assessed, as they were the domains with the lowest number of valid items: emotional well-being ( $n = 16$ ), interpersonal relations ( $n = 14$ ) and social inclusion ( $n = 12$ ). The experts' task consisted of discussing the suitability of the 42 items, taking

**Table 4** Descriptive analyses for round 1 by domain

	Valid	% Valid	Non-valid	% Non-valid	New items
Emotional well-being	11	11.34	16	21.05	19
Interpersonal relationship	6	6.18	14	18.42	19
Material well-being	14	14.43	6	7.89	11
Personal development	16	16.49	5	6.57	18
Physical well-being	13	13.40	9	11.84	25
Self-determination	13	13.40	9	11.84	13
Social inclusion	9	9.27	12	15.78	18
Rights	15	15.46	5	6.57	14
Total	97	100	76	100	137

**Table 5** Descriptive analyses for round 2 by domain

	New items round 1	New items selected round 2	Valid items round 2
Emotional well-being	19	7	2
Interpersonal relationship	19	14	5
Material well-being	11	6	4
Personal development	18	7	3
Physical well-being	25	13	6
Self-determination	13	13	7
Social inclusion	18	11	4
Rights	14	5	4
Total	137	76	35

into account the four aforementioned criteria (i.e. suitability, importance, sensitivity and observability), in a discussion forum, anonymously putting forward arguments for whether or not they should be included in the scale, and seeking to convince the rest of the experts in order to reach a consensus.

The research team analysed and assessed the conclusions reached by the group of experts and obtained 26 valid items. 3 items (7.14%) were relocated in another domain: 2 items initially included in the emotional well-being domain became part of the personal development and social inclusion domains, while the third item, which had been in social inclusion, became part of the personal development domain. Moreover, 13 items (30.95%) were kept in the same domain as they had initially been assigned to. Ten items (23.80%) were reformulated in order to specify and clarify their contents. Finally, 16 items were rejected (38.1%) as the majority of the experts considered them to have little validity, suitability and importance in their reformulated state, but consensus was not reached on how to improve them in order to possibly keep them in the scale.

### 3.4 Round 4

The fourth round consisted of assessing the items that were considered valid in round 2 (i.e. the new items proposed by the experts;  $n = 35$ ) and in round 3 (i.e. the valid items obtained in round 3;  $n = 26$ ). The judges' task consisted of assessing the 61 items based on the four criteria used in the previous rounds (i.e. suitability, importance, sensitivity and observability), using a Likert scale with a response format from 1 to 4 (as in the first round). The research team subsequently analysed the results, following the two criteria used in the first round to keep the best items ( $M \geq 3$  and  $DT < 1$ ).

The result of this analysis was a pool made up of 24 items. The lowest-scoring results were for sensitivity and the highest scores were in importance. The result of the descriptive analyses is shown in Table 6. Twenty-four of the 61 items (39.29%) met these criteria and were kept as valid (Table 7). We thus arrived at a final pool made up of 121 items (i.e. 97 valid items obtained in the first round and 24 valid items obtained in the next three rounds).

### 3.5 Agreement between Judges Regarding the Final Item Pool

In order to implement the concept of quality of life in people with brain injury and find a usable pool of items that could be proposed for a pilot version of the quality of life

**Table 6** Descriptive analyses for round 4 by criteria

	Me	<i>M</i>	DT	Valid items	% Valid	Non-valid items	% Non-valid
Suitability	4	3.51	0.15	60	98.36	1	1.64
Importance	4	3.50	0.15	61	100	0	0
Sensitivity	3	2.93	0.13	27	44.26	34	55.74
Observability	3	3.13	0.11	46	75.40	15	24.6

**Table 7** Descriptive analyses for round 4 by domain

	Valid	% Valid	Non-valid	% Non-valid
Emotional well-being	6	9.83	3	4.91
Interpersonal relationship	1	1.63	12	19.67
Material well-being	0	0	4	6.55
Personal development	4	6.55	1	1.63
Physical well-being	2	3.27	4	6.55
Self-determination	5	8.19	2	3.27
Social inclusion	4	6.55	9	14.75
Rights	2	3.27	2	3.27
Total	24	39.29	37	60.60

assessment scale for people with brain injury, the appropriate number of items to represent the indicators in each domain was set at 15 (i.e., taking into account that the final instrument should not have fewer than 8 items per domain and that the validation process would result in less reliable items being eliminated). In order to do this, the research team conducted an exhaustive review of the resulting item pool in order to select the best items for each domain based on their descriptive statistics (*M*, *DT*). Domains with more than 15 items thus had items eliminated: those with scores furthest from 3 points, for the average, and those closest to 1, for the standard deviation. In the case of domains with an insufficient number of items, the criterion used to retrieve items was to select the ones that only breached a single criterion: sensitivity. The pool was thus made up of 120 items distributed among the eight quality of life domains (i.e., 15 items per domain).

For these 120 items, assessment was carried out by agreement between the judges. Table 8 shows the data for the weighted agreement coefficients ( $B_N^W$ ) for the four criteria (suitability, importance, sensitivity and observability) by domains. As one can see, they varied between .72 and .91 and were thus considered good (.60–.80) and very good (>.80–1). The criterion on which the greatest average agreement was reached was importance ( $M = .85$ ) and sensitivity was the one with the least agreement ( $M = .80$ ). More specifically, the domains that obtained the highest scores were rights and material well-being ( $M = .85$ ), followed by interpersonal relations ( $M = .84$ ). The lowest scores were in personal development ( $M = .80$ ). The degree of agreement observed was generally very high ( $M = .82$ ).

**Table 8** Coefficients of concordance for agreement among experts

	Suitability $B_N^W$	Importance $B_N^W$	Sensitivity $B_N^W$	Observability $B_N^W$	$M$	
	EW	.76	.85	.82	.82	.81
	IR	.86	.82	.88	.80	.84
	MW	.84	.86	.82	.87	.85
$B_N^W$ weighted concordance coefficient, <i>EW</i> emotional well-being, <i>IR</i> interpersonal relationships, <i>MW</i> material well-being, <i>PD</i> personal development, <i>PW</i> physical well-being, <i>SD</i> self-determination, <i>SI</i> social inclusion, <i>RI</i> rights, <i>M</i> = mean	PD	.79	.84	.80	.75	.80
	PW	.85	.84	.75	.87	.83
	SD	.82	.91	.72	.77	.81
	SI	.83	.82	.77	.83	.81
	RI	.88	.86	.88	.76	.85
	<i>M</i>	.83	.85	.80	.81	.82

## 4 Discussion

The goal of this research was to obtain a valid and appropriate pool of items to assess the quality of life of people with ABI through a procedure based on the Delphi method. This method was used to provide evidence based on the contents of the scale and to ensure they were suited to this group from the viewpoint of the professionals themselves. As a result, we have obtained a pool made up of 120 items considered suitable, important, sensitive and observable, and which may be considered a valid implementation of the eight-domain quality of life model for this population. The 120 items will subsequently be put to the test empirically by applying them to a broad sample of people with ABI in order to verify their reliability and validity.

The assessment criteria used in this Delphi study have been previously used successfully to develop and construct other quality of life assessment scales in various populations (Gómez et al. 2012, 2014, 2016; Verdugo et al. 2010, 2013, 2014). In particular, the results found here closely correspond to those obtained in the Delphi study for the San Martín scale (Gómez et al. 2015), which was also developed using Schalock and Verdugo's model. Just like the San Martín scale, the criterion for which it was most difficult to reach a consensus and which scored the worst was the sensitivity of items, which gave rise to a large number of rejected items. The criterion for which the greatest consensus was achieved and which obtained the highest scores was the importance of the items and, therefore, it ended up with a larger number of accepted items.

As far as the Delphi method used in this study is concerned, a series of relevant aspects should be highlighted. First of all, one fundamental aspect of this method is selecting the number of participants who are going to be part of the panel of experts, which will directly affect the quality of the results generated (Balasubramanian and Agarwal 2013). Although there is no consensus regarding the appropriate number of participants on the panel of experts, various authors suggest that 10–18 would be sufficient (Delbecq et al. 1975; Okoli and Pawlowski 2004), as a large number of experts would generate too many items and ideas, which would hinder the decision-making process and result in a potentially low response rate (De Villiers et al. 2005; Ludwig 1997). In our case, the sample was made up of 14 participants and it was assumed that it was a sufficiently heterogeneous sample, as the participants came from different knowledge and activity areas. In addition, the use of information technology throughout the entire Delphi process (i.e. online) enabled the participants to take part in the study from different locations, while helping to maintain the

privacy of their responses. This was an advantage over other more traditional Delphi methods.

In addition, in order to make the Delphi employed sufficiently rigorous and measure its efficiency and suitability, as well as its quality, we continued the verification with the trustworthiness assumption (Guba and Lincoln 1989). Some authors suggest that this approach is useful, and even consider it more appropriate to assess efficiency and suitability than the concepts of reliability and validity (Gray and Truesdale 2015; Hasson et al. 2000; Kennedy 2004; Powell 2003). This assumption is made up of four main characteristics: credibility, dependability, confirmability and transferability. Our study complied with all of the criteria of which this assumption is made up: (1) *credibility* was achieved through both constant iteration throughout the study and through the feedback provided by the experts at the end of each round; (2) *dependability* was achieved through a heterogeneous sample of experts, which lent stability to the data; (3) *confirmability* was achieved by providing the experts with a detailed description of the data gathering and analysis process at all times; and (4) *transferability* was achieved by using the findings obtained in this study to build a quality of life assessment tool specifically for people with ABI.

However, we also came across a series of limitations while carrying out our Delphi study. One of the main disadvantages of the Delphi method is that it is a very costly technique for the participants in terms of time and fatigue. So although a Delphi study should be carried out in a short period of time of between two and four months (Delbecq et al. 1975), our study lasted nine months. That means that each of the rounds involved a minimum work period of two months and it was a long and exhausting task for the experts. The number of rounds also created a limitation. Our study was made up of a total of four, in spite of the fact that having more than three rounds could be problematic due to the time, cost and fatigue of panel members (Hasson et al. 2000). However, due to the large number of items assessed in our study, we considered it necessary to hold four rounds to achieve greater consensus among the expert judges. And it should be noted that, in spite of the lengthy process, the majority of experts completed the four rounds of the study and that only one dropped out in the final round.

To sum up, the implementation of the quality of life concept provided in this study is a means, with sufficient evidence validating its contents, to enable quality of life assessment of people with ABI. Since there is not yet a specific instrument for this population that is truly suited to their possible peculiarities and needs, this process is a necessary initial step to start applying the quality of life concept in this group. Based on the results obtained, future research will be channelled into developing the pilot version of the instrument, made up of the 120 items obtained in this Delphi study, which will be applied to a broad sample in order to empirically verify its suitability for this population. This instrument will be key in assessing the quality of life of people with brain injury and in making possible to plan and guide interventions based on the obtained results, improving the provision of services and the development of good person-focused and evidence-based professional practices.

**Acknowledgements** We gratefully acknowledge the support of the Spanish Ministry of Economy and Competitiveness (Grant PSI2015-65193-P [MINECO/FEDER, UE]), and of two predoctoral's fellowships (BES-2013-065113; FPU14/01468 – Spanish Ministry of Economy and Competitiveness and Ministry of Education, Culture and Sport respectively). We also gratefully acknowledge the support of the Centro de Referencia Estatal de Atención al Daño Cerebral Adquirido (CEADAC, Spain), who have partially funded the research, and the Federación Española de Daño Cerebral (FEDACE, Spain). Finally, the authors would especially like to thank the organizations, professionals, people with brain injury, and families for completing the questionnaires and for their support on this project.

## Compliance with ethical standards

**Conflicts of interest** There are not financial or any other conflicts of interest for the authors of this manuscript. The funding bodies of this research have not imposed any restrictions on free access to or publication of these research data.

**Ethical approval** Ethics procedures have been followed and research procedures have been approved by the Bioethics Committee at the University of Salamanca.

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