Comparison of Content and Psychometric Properties for Assessment Tools Used for Brain Tumor Patients: a Systemic Literature Review

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Research

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Abstract

Aims: To determine the most frequently utilized functional status assessment instruments for patients with brain tumors, compare their contents, using the International Classification of Functioning, Disability and Health (ICF), and their psychometric properties.

Methods: a systematic literature search was performed for identification of the frequently used functional assessment tool in clinical trials in PubMed, ScienceDirect and ProQuest databases. The content of most used instruments was linked to the ICF categories. Psychometric qualities of these assessment tools were systematically searched and analyzed.

Results: Nine most used assessment tools in clinical trials were identified. The Karnofsky Performance Scale was the only generic tool for oncologic patients. Out of four self-assessment tools, three were disease-specific (EORTC QLQ-C30, EORTC QLQ-BN20 and FACT-Br) and one used for different diagnosis (SF-36). The Functional Independence Measure and the Barthel Index were two objective assessment tools that described functioning, but two were neuropsychological tests (MMSE and Trial Making Test). Two hundred eighty-three meaningful concepts were identified and linked to 102 most relevant second-level categories covering all components of the ICF. Forty-nine studies reporting psychometric properties of those nine assessment tools were identified, indicating good reliability and validity for all the instruments.

Conclusion: Nine most frequently utilized functional status assessment instruments for patients with brain tumors represent all components of the ICF and have good psychometric properties. However, the choice of the tool depends on the clinical question posed and the aim of its use.

Introduction

Based on 2015 statistics, patients with brain tumors make up a total of 5% of all oncology patients in Latvia.(1) As the medical industry, diagnostic capabilities, and technologies for treating primary tumors evolve, the survival rates for individuals diagnosed with primary brain tumors has increased significantly.(1, 2) Tumor localization, anatomical distribution, and volume are determinants before and after primary treatment. The most common symptoms for brain tumors usually include headache, nausea, vomiting, partial and generalized seizures, cognitive impairment, and ataxia. These symptoms may also arise from common treatment strategies used for brain tumor patients such as chemotherapy, radiation therapy and surgery. It is estimated that in 75% of all patients with brain tumors show symptoms of focal neurological deficiency (3), which greatly affects one's level of functioning, as well as quality of life.

Numerous articles discuss the role of rehabilitation in tumor cases, while others discuss the positive effects of rehabilitation for patients with brain tumors compared to patients with stroke or after a traumatic brain injury. (4, 5) All of these articles demonstrate positive outcomes in restoring functioning (6, 7) Bartolo M. et al. have demonstrated that rehabilitation is very effective if it is initiated as early as possible after primary treatment for brain tumor patients. (5)

To assess the rehabilitation needs and outcomes for this population, a specific functional disability assessment tool is necessary. (8) The use of appropriate assessment tools could improve rehabilitation planning that in turn would lead to better outcomes, including patients' quality of life. Currently no standardized protocols are provided for evaluation of persons with brain tumors. The International Classification of Functioning, Disability and Health (ICF) provides a framework for coding large-scale health information, a common standardized language for identifying and comparing functional assessment tools and provides valuable information to develop an evidence-based standardized evaluation protocol for patients with brain tumor. (9)

The aim of this study was to determine the most frequently utilized functional assessment instruments for patients with brain tumors, compare their contents, using the International Classification of Functioning, Disability and Health, and analyze their psychometric properties.

Methods

Identification of assessment tools

A systematic literature review was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta- analyses statement.(10) PubMed, ScienceDirect and ProQuest databases were searched (last updated August 2020) for publications since 2000 using the following keywords: "brain neoplasm" or "meningioma" or "glioblastoma" or "intracranial neoplasm" or "brain cancer" or "outcome assessment" or "treatment outcome" or functional outcome mentioned in the title/abstract. Studies referring in the title or abstract to assessment tools used to assess people diagnosed with brain tumors older than 18 years were included. Original research studies randomized controlled clinical trials, observational studies, cross-sectional studies, qualitative studies using functional outcome measures were included. Studies were excluded if they addressed genetic, laboratory and animal research. Other systematic reviews, secondary analyses of published data, validity studies, protocols, letters, were also excluded from this report. All searches were limited to journal articles written in English; the search results were compiled in the reference management system EndNote where duplicates were removed. A summary of the search procedure is shown in Fig. 1.

Data collection was based on Cochrane Handbook for Systematic Reviews of Interventions.(11) General study data (year of publication, country, study design), available data on participants (number, diagnosis) and assessment tools used in the study were recorded. Assessment tools that were used in more than 10% of all studies were included in the systematic review using frequency analysis.

Linking to the ICF

All assessment instruments identified in the study meeting selection criteria were classified using the ICF linking guidelines. The ICF linking guidelines state that before starting the process of linking health-status measures to the ICF categories, identification of all meaningful concepts within each item of the health status measure needs to be performed. According to the rules, the interval of time cannot be linked to the ICF, also, if a meaningful concept of an item is explained by examples, both the concept and the examples are to be linked, while technical measures can be linked by defining the purpose and then linking it with the ICF category.(12, 13). Two independent medical professionals (authors LG and SS) separately identified the meaningful concepts within the analyzed instruments and linked them to the ICF concepts. The raters met and discussed any discrepancies to achieve a consensus classification for the instruments and GB served as a third rater, in case the consensus could not be reached. Perspective adopted in health information and categorization of response for self-assessment tools were also reported. (12)

Psychometric properties

Following the search methodology developed by PubMed(14), the electronic database MEDLINE (PubMed) was searched for studies that reflect the psychometric properties of a particular assessment tool. First, a search was performed using a diagnosis specific MeSH terms and key words identified in the search methodology, and the names of assessment tools. Headline screening identified studies that reflected one of the psychometric properties of a given instrument (reliability: internal coherence; test/retest method, evaluator reliability. Validity: content validity; criterion validity; construct validity) specific to patients with brain tumor. If specific psychometric properties for chosen assessment tools were not identified, the search was repeated excluding diagnosis specific MeSH terms, thus conducting a search for studies covering different diagnoses. Headline screening then identified studies that reflected one of the psychometric properties of a given instrument for various diagnoses. The interpretation of the psychometric properties is given in Table 1.

Table 1
The interpretation of the psychometric properties

Reliability		
Internal reliability	+	Cronbach`s α or ICC ≥ 0.70
	-	Cronbach`s α or ICC < 0.70
Test/retest method	+	ICC ≥ 0.70 or Pearson correlation coefficient/ Spearman rank correlation coefficient ≥ 0.80
	-	ICC < 0.70 or Pearson correlation coefficient/Spearman rank correlation coefficient < 0.80
Interrater reliability	+	ICC ≥ 0.70 or Pearson correlation coefficient/ Spearman rank correlation coefficient ≥ 0.80
	-	ICC < 0.70 or Pearson correlation coefficient/Spearman rank correlation coefficient < 0.80
Validity		
Content validity	+	The content of the assessment instrument is adequate, comprehensive, questions and tasks chosen to adequately reflect the content to be evaluated
	-	Not all selected questions and tasks reflect the content, content is not relevant, comprehensive
Criterion validity	+	Significant and stable relation between measurement and another instrument ($r \geq 0.70$) or with start/end measurement
	-	Poor measurement correlation with another instrument ($r < 0.70$) or start / end measurement
Structural validity	+	Correlation with instruments measuring the same ≥ 0.50 or correlation higher for unrelated elements in the instrument than for unrelated ones
	-	Correlation with instruments measuring the same < 0.50 or correlation with related elements in the instrument is lower than unrelated ones
Responsiveness		
	+	Able to detect clinically significant changes over time
	-	Cannot detect clinically significant changes over time
Cronbach`s α - Chronbach's α coefficient, ICC - interclass correlation coefficient		

Results

Identification of assessment tools

The initial search strategy returned 9721 articles. The duplicates were removed, titles and abstracts were reviewed and after excluding articles which did not meet the selection criteria, and a pool of 56 articles was subject to further examination. To make the search as comprehensive as possible, references from the included articles were studied and an additional 32 articles were included after applying the selection criteria.

As a result, a total of 88 studies were included in the report; 31 were administered in the United States, 42 in Europe (8 in Italy, 8 in the Netherlands, 6 in Norway, 4 in France, Germany and England each 3, Austria, Turkey, Sweden 2 studies each, Poland, Switzerland, Denmark and Finland each 1), 2 in Australia, 7 in Canada, and 4 in Asian countries (Korea, Israel, Iran). The studies look at groups of patients with various brain tumor diagnosis. The 74 articles included patients with primary tumors, of which 26 were diagnosed with glioma, 3- oligodendroglioma, 1- oligoastrocytoma, 3- astrocytoma, 4- adenoma, 1- meningioma, 1 case study had a mixed group with patients suffering from meningioma and glioblastomas. 28 of the studies did not categorize patients by their histologic type; instead, patients with primary brain tumors were evaluated. 9 studies evaluated patients with secondary brain tumors or with brain metastases. In 4 of the included studies, the functional abilities of patients with brain tumors are compared to those of a stroke patient or a patient with a brain injury.

All instruments mentioned in the articles were identified, yielding 86 assessment tools. According to research methodology, 9 assessment tools that were used in more than 10% of the research articles included in the study were used for further analysis: A list of these instruments, their abbreviations and the number of articles that have used that instrument are summarized in Table 2. Out of nine instruments included in the study, three are specific for patients with brain tumors: EORTC Quality of Life Questionnaire-Core 30 (EORTC QLQ-C30); EORTC Quality of Life Questionnaire-Brain Neoplasm 20 (EORTC QLQ-BN20); Functional Assessment of Cancer Therapy-Brain (FACT-Br), one is specific for patients with oncological diseases - Karnofsky Performance Scale (KPS), the other five ((Mini-mental State Examination (MMSE), Functional Independence Measure (FIM), Trial Making Test (TMT), Barthel Index (BI) and 36-Item Short Form Health Survey(SF-36)) are used for patients with various diagnoses.

Table 2
The most frequently used assessment instruments.

Assessment instrument	Abbreviation	N of studies mentioned	Frequency (%)
Karnofsky Performance Scale	KPS	42	48
Mini-Mental State Examination	MMSE	20	23
EORTC Quality of Life Questionnaire-Core 30	EORTC QLQ-C30	18	20
EORTC Quality of Life Questionnaire-Brain Neoplasm 20	EORTC QLQ-BN20	15	17
Functional Independence Measure	FIM	13	15
Trail Making Test	TMT	13	15
Barthel Index	BI	9	10
Functional Assessment of Cancer Therapy-Brain	FACT-BR	8	9
36-Item Short Form Health Survey	SF-36	8	9

Linking to the ICF

In total, 283 meaningful concepts were identified within all nine assessment instruments and linked to 394 most precise categories of the ICF. The detailed description on the linking is shown in Table 3. In two cases, the meaningful concepts could be linked most precisely to the component of Activities and Participation. In 12 cases, it was the first-level or chapter under the component of Activities and Participation. The content of the assessment tools was linked to 102 most relevant second-level categories of the ICF in total. Thirty-four of these categories were under the component of Body Functions and Structures, 50 – under Activities and Participation and 18 – Environmental Factors. Detailed comparison of the content between assessment tools are shown in Tables 4, 5 and 6 for components of Body Functions and Structures, Activities and Participation and Environmental Factors, respectively. No appropriate ICF category was found for 54 items following the ICF linking guidelines.

Table 3
Summary of linking the nine most frequently used assessment tools to the ICF

	KPS	MMSE	C30	BN-20	FIM	TMT	BI	FACT-BR	SF-36
N of meaningful concepts	32	11	42	22	19	NA	32	63	62
N of categories identified	71	18	52	29	31	16	39	66	72
N of unique categories identified	22	15	39	19	29	16	22	52	27
Perspective	Desc	Desc	Appr	Appr	Dep	Desc	Dep	Appr	Appr
Categorization			Int	Int				Int	Int
Body Functions									
2nd level		4	9	7	3	6	2	16	4
3d and 4th level		10	6	6		1		5	
Body structures									
2nd level								2	
Activities and Participation	1								1
1st level	1		5					2	4
2nd level	4		15	5	20	9	8	17	6
3d level		1	4	1	3		5	1	12
Environmental factors									
2nd level	13	9			1		7		
3d level	3								
Not classified									
Nc-health condition	6			2				2	
Nc-Quality of life			1	2				13	5
Nd-general health			1					2	6
Nd-physical health			3					1	2
Nd-mental health									2
Nd-disability	2								
Personal factors	1							1	2
Desc-Descriptive, Dep-Dependency, Appr-Appraisal, Int- Intensity, NC-not covered, ND- not definable									

Table 4
Content comparison of assessment tools linked to the component of Body Functions and Structures of the ICF

		KPS	MMSE	C30	BN-20	FIM	TMT	BI	FACT-BR	SF-36	Total
Body functions											
b110	Consciousness functions				x						1
b114	Orientation functions		xxx								1
b117	Intellectual functions						x				1
b126	Temperament and personality functions			x					xxx		2
b130	Energy and drive functions			xxx					x	x	3
b134	Sleep functions			x					x		2
b140	Attention functions		x	x		x	x		x		5
b144	Memory functions		x	x		x			x		4
b152	Emotional functions			xxx						xxx	2
b156	Perceptual functions		x		x		x		x		4
b160	Thought functions		x				x		x		3
b164	High level cognitive functions						x				1
b167	Mental functions of language		xxx		x				x		3
b172	Calculation functions		x								1
b176	Mental functions of sequencing complex movements		x								1
b210	Seeing functions				xxx		x				2
b260	Proprioceptive function				x				x		2
b265	Touch function								xxx		1
b270	Sensory functions related to temperature and other stimuli								x		1
b280	Sensation of pain			x	x				x	x	4
b440	Respiration functions			x							1
b455	Exercise tolerance functions			xxx							1
b510	Ingestion functions			x							1
b525	Defecation functions			x		x		x			3
b535	Sensations associated with the digestive system			x					x		2
b620	Urination functions				x	x		x			3
b730	Muscle power functions			x	xxx				x	x	4
b740	Muscle endurance functions				x						1
b760	Control of voluntary movement functions				x				x		2
b780	Sensations related to muscles and movement functions								x		1
b840	Sensation related to the skin				x				x		2
b850	Functions of hair				x						1
Total		0	8	13	12	4	6	2	17	4	
Body structures											
s730	Structure of upper extremity								x		1

x: 1 or 2 items included, xxx: 3 or more items included

		KPS	MMSE	C30	BN-20	FIM	TMT	BI	FACT-BR	SF-36	Total
s750	Structure of lower extremity								x		1
Total		0	0	0	0	0	0	0	2	0	
x: 1 or 2 items included, xxx: 3 or more items included											

Table 5
Content comparison of assessment tools linked to the component of Activities and Participation of the ICF

		KPS	MMSE	C30	BN-20	FIM	TMT	BI	FACT-BR	SF-36	Total
d1	Learning and applying knowledge									xxx	1
d110	Watching			x			x				2
d115	Listening						x				1
d160	Focusing attention						x				1
d163	Thinking						x				1
d166	Reading			x	x		x		x		4
d175	Solving problems					x			x		2
d177	Making decisions								x		1
d220	Undertaking multiple tasks						x				1
d230	Carrying out daily routine			x						x	2
d240	Handling stress and other psychological demands								x		1
d3	Communication								x		1
d310	Communicating with receiving spoken messages					x					1
d315	Communicating with receiving nonverbal messages					x	x				2
d320	Communicating with - receiving - formal sign language messages					x					1
d325	Communicating with - receiving - written messages					x					1
d330	Speaking				x	x			x		3
d335	Producing nonverbal messages		x			x					2
d340	Lifting and carrying objects			x		x					2
d345	Writing messages					x			x		2
d350	Conversation				x						1
d4	Mobility			x							1
d410	Changing basic body position							x		x	2
d415	Maintaining a body position			x	x				x		3
d420	Transferring oneself					xxx		x			2
d430	Lifting and carrying objects									xxx	1
d440	Fine hand use						x				1
d455	Hand and arm use						x				1
d450	Walking			x	x	x		xxx		xxx	5
d455	Moving around					x		xxx		xxx	3
d460	Moving around in different locations			x							1
d465	Moving around using equipment					x		x			2
d475	Driving								x		1
d5	Self-care	xxx							x		2
d510	Washing oneself			x		x		x		x	4
d520	Caring for body parts					x		xxx	x		3
d530	Toileting			x		x		x			3

x: 1 or 2 items included, xxx: 3 or more items included

		KPS	MMSE	C30	BN-20	FIM	TMT	BI	FACT-BR	SF-36	Total
d540	Dressing			x		x		x	x	x	5
d550	Eating			x		x		x	x		4
d560	Drinking								x		1
d598	Self-care										0
d6	Domestic life			x						x	2
d620	Acquisition of goods and services					x					1
d7	Interpersonal interactions and relationships			x						x	2
d710	Basic interpersonal interactions					x					1
d720	Complex interpersonal interactions					x					1
d750	Informal social relationships									xxx	1
d760	Family relationships			x	x				x	x	4
d770	Intimate relationships								x		1
d8	Major life areas			x						x	2
d840	Apprenticeship (work preparation)	xxx		x							2
d845	Acquiring, keeping and terminating a job	xxx		x							2
d850	Remunerative employment	xxx		x					x	x	4
d855	Non-remunerative employment	xxx		x							2
d870	Economic self-sufficiency			x							1
d9	Community, social and civic life			x						x	2
d910	Community life								x		1
d920	Recreation and leisure			x					x	xxx	3
Total		6	1	23	6	21	9	10	19	16	
x: 1 or 2 items included, xxx: 3 or more items included											

Table 6
Content comparison of assessment tools linked to the component of Environmental Factors of the ICF

		KPS	MMSE	C30	BN-20	FIM	TMT	BI	FACT_BR	SF-36	Total
e110	Products or substances for personal consumption	x									1
e115	Products and technology for personal use in daily living	x				x		x			3
e120	Products and technology for personal indoor and outdoor mobility and transportation	xxx						x			2
e310	Immediate family	xxx						x	x		3
e315	Extended family	xxx						x	x		3
e320	Friends	xxx						x	x		3
e325	Acquaintances, peers, colleagues, neighbors and community members	x									1
e330	People in positions of authority	x									1
e335	People in subordinate positions	x									1
e340	Personal care providers and personal assistants	xxx						x	x		3
e345	Strangers	x									1
e350	Domesticated animals	x									1
e355	Health professionals	x						x	x		3
e410	Individual attitudes of immediate family members								x		1
e415	Individual attitudes of extended family members								x		1
e420	Individual attitude of friends								x		1
e575	General social support services, systems and policies	x									1
e580	Health services, systems and policies	xxx									1
Total		15	0	0	0	1	0	7	8	0	
x: 1 or 2 items included, xxx: 3 or more items included											

Evaluating all 9 assessment tools, the most related ICF categories in the body function domain were b140 attention functions (n = 5), b144 memory functions (n = 4), b156 perceptual functions (n = 4), b280 sensation of pain (n = 4) and b730 muscle power functions (n = 4). FACT-BR, BN-20 and MMSE contained most concepts related to the Body functions and Structures. Five out of nine analysed assessment tools included concepts on d450 walking and d540 dressing. The BN-20 questionnaire contained meaningful concepts that could be linked to 23 second level categories of the Activities and Participation, covering all domains of this component. FIM was linked to 21 categories that did not cover chapters of Major life areas and Community, social and civic life.

Psychometric properties

For psychometric properties that are specific for brain tumor diagnosis, search in PubMed yielded 578 results for KPS, 18 for MMSE, 55 for EORTC QLQ-C30, 6 for EORTC QLQ-BN20, 5 for FIM, 36 for TMT, 14 for BI, 21 for FACT-Br, and 4 for SF-36. Headline screening resulted in identifying 1 study for EORTC QLQ-C30, 4 studies for EORTC QLQ-BN20, 3 studies for FACT-Br, and 1 study for SF-36. A search strategy for various diagnoses was implemented for the remaining assessment instruments as well as SF-36 and EORTC QLQ-C30 due to previous search strategy yielding only 1 result. As a result, for further analysis, 4 articles for KPS, 5 for MMSE, 1 + 5 for EORTC QLQ-C30, 4 for EORTC QLQ-BN20, 10 for FIM, 2 for TMT, 7 for BI 3 for FACT-Br, and 8 for SF-36 were included in this review. The psychometric properties for assessment instruments EORTC QLQ-C30, EORTC QLQ-BN20, FACT-Br un SF-36, that are specific to brain tumor diagnosis are summarized in Table 7. The psychometric properties analyzed in mixed diagnosis studies for EORTC QLQ-C30, MMSE, SF-36, BI, FIM, KPS, TMT are summarized below, see Table 8.

Table 7
The psychometric properties of assessment tools, specific to the brain tumor diagnosis.

Assessment instrument	Reliability			Validity			Responsiveness	Time	Research group	Author, Year
	Test-retest	Inter-rater	Intra-rater	Content	Structural	Criterion				
EORTC QLQ-BN20			+		+		+		n = 891, brain tumor	Taphoorn, 2010 (28)
			++		+			< 10 min	n = 350, glioma, meningioma	Shin, 2013 (29)
			+		+		+		n = 194, brain tumor	Khoshnevisan, 2012 (30)
			+		+				n = 100, brain tumor	Bunevičius, 2012 (31)
EORTC QLQ-C30			++			-	+	13–14 (SD 12) min	n = 366, brain tumor	Cheng, 2011 (32)
FACT-Br	+		+		+				n = 500, brain tumor	Arli, 2017 (33)
	±§		± †‡		+			5 to 10 min	n = 101, brain tumor	Weitzner, 199 (34)
	±†				+		+		n = 62, metastases in the brain	Thavarajah, 2014 (35)
SF-36			+		+			10 (40–45) min	n = 277, brain tumor	Bunevičius, 2012 (31)
*except Cognitive scale, † -except Social, family wellbeing domains, ‡ except Interaction with a physician domain; § - Functional Assessment of Cancer Therapy – General questionnaire analyzed. SD – Standard deviation										

Table 8
The psychometric properties analyzed in mixed diagnosis studies.

Assessment instrument	Reliability		Validity			Responsiveness	Time	Research group	Author, Year
	Test-retest	Inter-rater	Intra-rater	Content	Structural	Criterion			
EORTC QLQ- C30			++		+			n = 89, myeloma	Kontodimopoulos, 2011 (36)
			+ *		+			n = 105, breast cancer	Kontodimopoulos, 2011 (36)
			+ *		+			n = 28, lung cancer	Ozturk, 2009 (37)
			++		+	+		n112, lung cancer	Nicklasson, 2007 (38)
			+		+		11 min	n = 305, lung cancer	Aaronson, 1993 (39)
FIM			+		=			n = 93829, rehabilitation patients	Stineman, 1996 (40)
		+	+		+			n = 62, SCI; n = 51, stroke	Küçükdeveci, 2001 (41)
	+				+			n = 49, age > 50	Pollak, 1996 (42)
		+						n = 50, SCI	Karamehmetoglu, 1997 (43)
		+						n = 11 studies	Ottenbacher, 1996 (44)
			+		+	+		n = 11 102, mixed diagnosis	Dodds, 1993 (45)
					+	+		n = 1502, neurologic deficit	Ng, 2007 (46)
					+			n = 102, acute stroke	Tur, 2003 (47)
					+			n = 48, brain trauma	Hall, 2001 (48)
						+	30–40 min	n = 516, mixed diagnosis	Coster, 2006 (49)
BI	+	+	+		+			n = 459, stroke	Oveisgharan, 2006 (50)
			+		+			n = 258, stroke	Shah, 1989 (51)
		+		+		+	10.1 min (+/- 1.56)	n = 50, neurologic deficit	Röden-Jüllig, 1994 (52)
			+		+			n = 90, multiple sclerosis	Nicholl, 2004 (53)
		+						n = 273, neurologic deficit	(Rollnik, 2011) (54)
						+		n = 75, brain trauma	Liu, 2004 (55)

*except Cognitive scale

				+		n = 259, vascular brain damage; n = 107 brain trauma	Houlden, 2006 (56)
SF-36	+	+	+			n = 1980, mixed	Brazier, 1992 (57)
			+	+		n = 124, stroke	Anderson, 1996 (58)
			+	+		n = 252, n-198, endometriosis	Stull, 2014 (59)
	+	+				n = 37, Parkinsons	Steffen, 2008 (60)
	+					n = 209, stroke	Dorman, 1998 (61)
			+			n = 514, brain trauma	Guilfoyle, 2010 (62)
				+		n = 120, brain trauma	Paniak, 1999 (63)
MMSE		+	+	+		n = 207, brain trauma	Elhan, 2005 (64)
	+		+		10 min	n = 63, no impairments; n = 206, cognitive impairments	Folstein, 1975 (65)
		+				n = 48, age > 50	Molloy, 1997 (66)
		+				n = 72, stroke	Toglia, 2011 (67)
				-		n = 112, stroke	Blake, 2002 (68)
KPS	+		+			n = 52, tumor	Yates, 1980 (69)
	+			+		n = 100, mixed diagnosis	Grieco, 1984 (70)
	+			+		n = 47, tumor	Mor, 1984 (71)
	+			+		n = 93, tumor	Schag, 1984 (72)
TMT	+		+		A part 180 seconds	n = 484, age > 50	Cangoz B, 2009 (72)
		+	+		B part 300 seconds	n = 117, neurologic deficit	O'Donnell, 1994 (73)
*except Cognitive scale							

Discussion

This study identified nine rehabilitation assessment instruments that have most commonly been referred to in the literature for adults with brain tumors, that covers all components of the ICF, and has good psychometric properties. As far as the authors are aware, this is the only systematic review of assessment instruments used for adults with brain tumors. However, this systematic review did not identify one unique assessment instrument for the target group. This patient group is specific in a way that there is no unifying patient-specific clinical set of symptoms and their symptoms depend on various other factors.(15)

Five of these tools are used for objective assessment: KPS, MMSE, FIM, TMT, BI, four are self-assessment tools: FACT-Br, SF-36, EORTC QLQ-C30, EORTC QLQ- BN20.

The most frequently used assessment instrument is the Karnofsky Performance Scale as it is used as a criterion for the selection of participants by measuring their level of physical activity.(16) This assessment tool is developed for general assessment of oncological patients(17) and reflects overall ability to perform usual daily activities (component of Activities and Participation of the ICF) in the context of help needed from other people (Environmental Factors).

Only three of these instruments are specifically intended for evaluation in patients with brain tumors: EORTC QLQ-C30; EORTC QLQ-BN20; FACT-Br; they are all linked to the quality of life. Moreover, the EORTC team recommends that QLQ-C30 and QLQ-BN20 tools be used together.(18) These two tools cover both functioning components of the ICF and from the perspective of content, complement each other. QLQ-C30 contains more specific questions on problems specific to patients with brain tumors.(19, 20) The QLQ-C30 and the QLQ-BN20 provide comprehensive information about the patient's quality of life, but this is often overlooked in studies identified in this systematic review. The FACT-Br questionnaire has been used less and it has as good properties in terms of intra-rater reliability and structural validity as other two specific quality of life measurements, contains problems that has not been included in any of previous tools, and can clearly be important for this population, such as handling stress or driving a car. It also considers important Environmental factors, such as help and attitudes of family members and friends, as well as health professionals. Some important concepts also overlap with the SF-36 that have developed as a multipurpose tool that is used for assessment of functional health and well-being(21) and has been widely used for patient-reported outcomes in populations with different diagnosis.(22) Therefore, this could be good choice to use the SF-36, if the comparison between populations is needed.

Between the most used assessment tools, the FIM and BI has been listed. As SF-36, these instruments are non-specific to diagnosis, and both have been widely used in different rehabilitation populations.(23–25) Both scales, the FIM and the BI, are performance based assessment tools and both analyze the level of independence in most important activities of daily living, psychometric properties have been profoundly analyzed, and the ceiling effect for the BI can be observed when compared to the FIM.(26) However, the psychometric properties of the objective assessment instruments specific for the patient group have not been proven; therefore, their psychometric properties were demonstrated in patients suffering from stroke, traumatic brain injury (TBI) or similar neurological condition. Interestingly, two neuropsychological assessment tools (the MMSE and the TMT) are mentioned between the most frequently for persons with brain tumors. It can be explained with the fact that cognitive impairments are a common symptom in patients with brain tumors.(4) Both instruments focus mostly on the cognitive functions of the component of the Body Functions and Structures of the ICF and both are performance based. However, the psychometric properties of the MMSE have been better documented.

Using the ICF framework, it was possible to link the majority of elements identified in the assessment instruments to certain categories. Some elements could not be linked since they covered topics such as quality of life, personal factors, or certain elements not defined in the ICF. Body Function categories were dominated by MMSE, TMT, EORTC QLQ-BN20, EORTC QLQ-C30, activity and participation categories – FIM, BI, KPS, but FACT-Br viewed these two domains equally. Environmental factors were assessed by EORTC QLQ-30, FACT-Br, FIM, BI and KPS. Given that the clinical picture of brain tumor patients is similar to that of other neurological conditions, such as stroke(6) or TBI(7), the ICF Core Sets were reviewed for stroke and TBI(27) and their categories were compared to categories identified in this systematic review. Comprehensive core sets for stroke listed 13 categories in body functions and structures, 14 in activities and participation, and 23 categories in environmental factors that were not identified in assessment instruments analyzed in this study. Comprehensive core sets for TBI listed 10 categories in body functions domain, 22 in activities and participation, and 28 categories in environmental factor domain that were not identified in any of 9 assessment instruments analyzed within this study. This can be explained by the fact that the most frequently used assessment instruments do not cover all the possible impairments for people with brain tumors.

Given that the ICF Core Sets for stroke and TBI were compared to categories identified in this review and they proved to be overall covering similar areas it can be concluded that all 9 assessment tools identified in this study can be appropriate and specific assessment instruments for patients with brain tumors, as they have been proven valid, reliable and responsive to a variety of neurological conditions. Further research is recommended to assess reliability, validity, and responsiveness of assessment instruments specifically for brain tumor patient groups.

Conclusions

Between the nine most frequently used assessment instruments in clinical studies one was a generic tool for overall description of activity level for patients with diagnosis of cancer, three were diagnosis specific self-assessment tools, one was multipurpose tool for assessment of functionality and health status, two were widely used tools in rehabilitation for assessment of activities of daily living, and two were neurocognitive tests. These tools cover all components of the International Classification of Functioning, Disability and Health and have proven to have good psychometric properties; however, the assessment tools that are not diagnosis specific, still have to be validated for the brain tumor population.

Since the content and administration varies, the choice of the tool used for assessment of patients with brain tumor depends on the clinical question posed, as well as the aim of the use of this tool.

Declarations

Ethics approval and consent to participate

Not applicable

Consent for publication

Not applicable

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Not applicable

Authors' contributions

LG developed the design and study protocol, were involved in data analysis and interpretation, AP were involved in the data analysis, interpretation of results and preparing the manuscript, SC were involved in the data analysis, GB were involved in the development of study protocol, data interpretation and preparing the manuscript. All authors read and approved the final manuscript.

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Figures

Figure 1

Flow diagram of the systematic literature search