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CoCo - participation: The development and clinical use of a novel inventory measuring cognitive complaints in daily life

Lauriane A. Spreij [a], David Sluiter [a,b], Isabel K. Gosselt [a], Johanna M.A. Visser-Meily [a,b] and Tanja C.W. Nijboer [a,c]

[a]Center of Excellence for Rehabilitation Medicine, UMC Utrecht Brain Center, University Medical Center Utrecht, and De Hoogstraat Rehabilitation, Utrecht, Netherlands; [b]Department of Rehabilitation, Physical Therapy Science & Sports, UMC Utrecht Brain Center, University Medical Center Utrecht, Netherlands; [c]Department of Experimental Psychology, Helmholtz Institute, Utrecht University, Utrecht, Netherlands

ABSTRACT

Cognitive difficulties can be subtle and only come to light when patients return home from inpatient care and start to participate in society. Subjective cognitive complaints often interfere with participation, hence capturing cognitive complaints systematically is important. We developed a patient- and relative-reported measure to assess cognitive complaints during daily life activities across the memory, attention and executive domain for patients with acquired brain injury (ABI). The inventory *Cognitive Complaints - Participation* (CoCo-P) was created based on a literature review, consultations with experts, semi-structured interviews with patients, and a quantitative study. The inventory was administered to patients with ABI ($n = 46$), their relatives ($n = 33$) and healthy controls ($n = 102$) to finalize the inventory. We examined the reported complaints per daily life activity and cognitive domain of patients and healthy controls, and we compared the patients' and relatives' reports. The majority of patients (87–96%) experienced cognitive complaints, mostly related to attention, at work/education, during leisure activities, and in contact with family/friends and community. Patients reported more cognitive complaints than relatives. The CoCo-P seems appropriate to capture cognitive complaints in daily life in patients with mild ABI. Additional research is needed in terms of reliability and validity.

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CONTACT Lauriane A. Spreij l.a.spreij@umcutrecht.nl Department of Rehabilitation, Physical Therapy Science & Sports, UMC Utrecht Brain Center, University Medical Center Utrecht, Heidelberglaan 100, Utrecht 3584 CX, Netherlands

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Introduction

Acquired brain injury (ABI), mostly caused by stroke or traumatic brain injury (TBI) (Cicerone et al., 2000), frequently results in impairments in memory (Das Nair & Lincoln, 2007; Spreij, Visser-Meily, Van Heugten, & Nijboer, 2014), attention (Virk, Williams, Brunsdon, Suh, & Morrow, 2015), and executive function (Chung, Pollock, Campbell, Durward, & Hagen, 2013; Cicerone, Levin, Malec, Stuss, & Whyte, 2006). Cognitive impairments can be subtle and often only come to light when patients return home from the hospital or rehabilitation centre and start to participate in society (e.g., work, travel). *Participation* refers to the engagement of a person in daily life activities in a social context (Viscogliosi, Desrosiers, Belleville, Caron, & Ska, 2011). The presence of cognitive impairment is strongly associated with restrictions in participation (Ezekiel et al., 2018; Jette, Keysor, Coster, Ni, & Haley, 2005; Mole & Demeyere, 2018; Viscogliosi et al., 2011) and is the greatest burden to patients and their families (Ponsford, Olver, Ponsford, & Nelms, 2003).

Assessment of cognitive impairments is mostly done with neuropsychological tests. These tests, however, often fail to objectify subtle disorders and to determine which daily life difficulties the patient is likely to encounter (Bielak, Hatt, & Diehl, 2017; Chaytor & Schmitter-Edgecombe, 2003). In addition, cognitive impairments are not necessarily an indication of cognitive complaints, and vice versa (Clarke, Genat, & Anderson, 2012; Duits, Munnecom, Van Heugten, & Van Oostenbrugge, 2008; Landre, Poppe, Davis, Schmaus, & Hobbs, 2006; Rijsbergen, Van Mark, De Kort, & Sitskoorn, 2014). Cognitive complaints may also interfere with participation (Benedictus, Spikman, & Van Der Naalt, 2010; Robison et al., 2009; van der Naalt, van Zomeren, Sluiter, & Minderhoud, 1999); hence systematically capturing cognitive complaints is important (Rijsbergen et al., 2014).

However, suitable inventories that measure cognitive complaints during daily life activities are not available. Several instruments, like the Stroke Impact Scale (scale – memory and thinking) (Duncan, Wallace, Studenski, Lai, & Johnson, 2001), Cognitive Failure Questionnaire (Broadbent, Cooper, FitzGerald, & Parkes, 1982), Brain Injury Complaint Questionnaire (Vallat-Azouvi et al., 2018), and the Checklist for Emotional and Cognitive Consequences (CLCE-24) (van Heugten, Rasquin, Winkens, Beusmans, & Verhey, 2007) are available to identify cognitive complaints, yet the items are not directly related to daily life activities. On the contrary, several instruments particularly focus on daily life activities in a social context (i.e., participation), such as the Frenchay Activities Index (Holbrook & Skilbeck, 1983), Instrumental Activities of Daily Living (Lawton & Brody, 1969), Assessment of Life Habits (Fougeyrollas & Noreau, 2002), and the Utrecht Scale for Evaluation of Rehabilitation – Participation (USER-P) (Post et al., 2012), yet the focus is not on cognition as the reported restrictions may also be caused by motor, emotional and/or behavioural problems.

The primary aim of this study was to develop an inventory for patients with ABI to measure cognitive complaints across several cognitive domains as well as across several daily life activities. In a sequence of steps (Wiklund et al., 2016), an inventory suitable for patients with ABI was developed: (1) a literature search explored the availability of inventories measuring cognitive complaints on level of participation; (2) modifications were made to suit our target population after consulting an expert panel; (3) semi-structured interviews were held with patients ($n = 7$) to evaluate face validity (i.e., subjective evaluation whether the test seems to measure what it reports to measure); and (4) a quantitative study was conducted to finalize the inventory by administering the inventory in patients with ABI, their relatives and healthy controls. A secondary aim was to develop a version for relatives as impairment in self-awareness and the overestimation of cognitive abilities are common issues in ABI patients (Fischer, Trexler, & Gauggel, 2004; Kelley et al., 2014; Prigatano, Altman, & O'Brien, 1990; Sbordone, Seyranian, & Ruff, 1998). Based on the finalized inventory, we compared the reported complaints across daily life activities (e.g., work, travel), cognitive domains (i.e., memory, attention, executive function) and the level of fatigue between patients and healthy controls. Finally, we compared the patients' and relatives' reports regarding the cognitive complaints and the perceived level of fatigue.

Methods

Development of the cognitive complaints - participation (CoCo-P)

Literature search and gap analysis

A literature search was conducted and identified multiple inventories measuring cognitive complaints and/or participation (See Appendix A1 for an overview). Only the Cognitive Impairment in Daily Life (CID) (Johansson, Marcusson, & Wressle, 2016) was considered to meet the criteria to measure cognitive complaints, across cognitive domains, directly related to several daily life activities. This inventory was, however, developed for patients with a neurodegenerative disorder, such as mild cognitive impairment and dementia. As ABI and neurodegenerative disorders significantly differ in pathology, demographics (e.g., age) and cognitive sequelae, we set out to develop a new inventory based on the structure of the CID.

Expert panel and revision

We arranged two meetings with an expert panel that consisted of healthcare professionals (rehabilitation physicians and occupational therapists). Based on their expertise, we aimed to select daily life activities (e.g., work, finances, driving) in which our target population (i.e., outpatients with ABI, living at home) frequently reports complaints. Also, the response options were adjusted and based on the USER-P (Post et al., 2012) and reflected different grades of independence and effort (0 [independent without effort], 1 [independent with effort],

2 [with help], 3 [not possible]). It included a fourth response option (4 [not applicable]), as some activities (e.g., driving a car, cooking) are not applicable for some patients. Emoticons were used in the response options, in addition of the written words, to denote the different points on the scales.

Next, we arranged two meetings with cognitive neuroscientists. Attention, memory and reasoning abilities (i.e., problem solving ability that requires both memory and executive functioning; Spielberger, 2004) are the basic functions required to complete tasks and solve everyday problems (Bielak et al., 2017). We established on three cognitive models presenting memory (Squire, 1992, 2004), attention (Petersen & Posner, 1990, 2012; Posner & Rothbart, 2007) and executive function (Ylvisaker, Szekeres, & Feeney, 1998) to use as theoretical framework for the selection of the items. We selected items focusing on memory (i.e., retrospective memory, prospective memory), attention (i.e., arousal, orienting, monitoring, sustained) or executive function (i.e., planning, self-evaluating, initiative, flexibility) across each daily life activity. Language and visual-perceptual functions were not included in the inventory. Language disorders (e.g., aphasia) and lower-level visual disorders (e.g., scotoma, diplopia) are often prominent in daily life and relatively more easily recognized by clinicians and patients. Lower-level visual disorders are also frequently regarded as *pre*-cognition. In contrast, higher-order perceptual disorders (e.g., prosopagnosia, simultanagnosia) are more challenging to capture. Luckily, suitable inventories for both lower- and higher-level visual-perceptual disorders as well as language disorders are already available, such as the Cerebral Visual Disorders (CVD) (Kerkhoff, Schaub, & Zihl, 1990), the Screening Test for Cognitive Communication (STCC) (Paemeleire, 2014), and the Communicative Participation Item Bank (CPIB) (Baylor, Burns, Eadie, Britton, & Yorkston, 2011). Based on the expert meeting, a first draft was conducted.

Patient panel and revision

The draft version was administered in seven patients, and semi-structured interviews were conducted to evaluate face validity. See Table 1 for the

Table 1. Demographical and clinical characteristics of the patients that were interviewed.

	Patients $n = 7$
Male (*n*)	3
Age in years (median, range)	47.5 (28–55)
Level of Education (*n*)	
Low	1
Moderate	0
High	6
Type of ABI (*n*)	
Stroke	3
TBI	2
Brain tumour resection	2
Time ABI onset (median, range)	33 months (21–54)

Abbreviations: Acquired Brain Injury (ABI); Traumatic Brain Injury (TBI).

demographical and clinical characteristics of these patients. Five patients were visited at home and two patients performed the evaluation by e-mail. We asked patients whether any important daily life activities were missing. We included five questions that could be answered on a Visual Analogue Scale (VAS) ranging from 0–10: (1) How clear was the instruction?; (2) How clear were the items?; (3) How clear were the response options?; (4) How familiar were the daily life activities?; and (5) How do you evaluate the length of the inventory? Additional remarks were administered.

For each question, the mean VAS score was above 9, for the exception of one question (How clear were the items?) that had a mean score of 7.1. Based on their suggestions, we adjusted the formulation of several items. Also, the time frame was not clear, so we clarified that the items reflected the patients' *current* state (i.e., post ABI onset). The response options were appropriate and well understood by the patients.

Face validity was considered adequate as all patients considered the daily life activities relevant and the items representative for their difficulties. Three patients did feel emotional and behavioural changes were missing in the inventory. We considered their suggestion, however, we felt that including those topics was not in line with our main scope of the inventory (i.e., cognitive complaints post-ABI). Fatigue was also reported as a common complaint especially after consecutive activities, which is in line with previous research (Visser-Keizer, Hogenkamp, Westerhof-Evers, Egberink, & Spikman, 2015). Therefore, we included an item measuring fatigue after each daily life activity by using a VAS (range 0–10 cm). Patients are asked to indicate in what extend a daily life activity is tiring along a visual analogue line that extends between two extremes (i.e., "not tiring at all" to "extremely tiring").

Preliminary inventory used in quantitative study

A preliminary version of the inventory was developed based on the expert meetings and semi-structured interviews with patients. The patient-reported and relative-reported measures contained 42 items focusing on memory, attention or executive function over 11 daily life activities (i.e., work/education, leisure activities, travel, driving, finances, use of medication, family life, contact with family/friends, contact with community, cooking, grocery shopping). After each activity the level of fatigue was measured using a VAS. See Table 2 for an overview of the preliminary version that was used in the quantitative study.

Quantitative study

Participants

Patients with ABI, their relatives and healthy controls were asked to participate. We recruited patients with ABI who received outpatient rehabilitation in either the *University Medical Centre Utrecht* or *De Hoogstraat Rehabiliation Centre*, the

Table 2. Preliminary version used in the quantitative study: overview of the items for each daily life activity across the cognitive (sub)domains.

Daily life activity	Items	Cognitive domain
Work/education	(1) Planning activities for the day/week	EF Planning
	(2) Paying attention to my work	A Sustained
	(3) Performing my activities in busy surroundings	A Monitoring
	(4) Tolerating bright displays	A Monitoring
	(5) Performing activities without extra breaks	A Sustained
	(6) Remembering information	M Retrospective
	(7) Checking my work	EF Self-evaluating
	Fatigue	
Leisure activities	(8) Staying awake during activities	A Arousal
	(9) Doing several activities consecutively	A Sustained
	(10) Performing leisure activities	EF Initiative
	(11) Remembering related people	M Retrospective
	Fatigue	
Travel	(12) Planning a journey	EF Planning
	(13) Adjusting the plan	EF Flexibility
	(14) Remembering the arrival/departure time*	M Prospective
	Fatigue	
Driving	(15) Paying attention to other road users	A Orienting
	(16) Staying awake while driving	A Arousal
	(17) Remembering unfamiliar routes*	M Retrospective
	(18) Maintaining the appropriate speed	EF Self-evaluating
	Fatigue	
Finances	(19) Planning my budget and spending	EF Planning
	(20) Paying the bills on time	EF Initiative
	Fatigue	
Use of medication	(21) Planning new prescription	EF Planning
	(22) Remembering taking my medication	M Prospective
	(23) Taking my medication*	EF Initiative
	(24) Intake of medication at fixed times	EF Planning
	Fatigue	
Family life	(25) Organizing activities for my family	EF Initiative
	(26) Remembering events or conversations	M Retrospective
	(27) Participating in family life	EF Initiative
	Fatigue	
Contact with family/friends	(28) Conversing in busy surroundings	A Orienting
	(29) Maintaining social events without extra breaks	A Sustained
	(30) Remembering names of family members/friends	M Retrospective
	(31) Maintaining contact with family/friends	EF Initiative
	Fatigue	
Contact with community	(32) Remembering names of people I just met*	M Retrospective
	(33) Making appointments	EF Initiative
	Fatigue	
Cooking	(34) Checking ingredients before cooking	EF Planning
	(35) Paying attention to cooking	A Sustained
	(36) Remembering the order	M Retrospective
	(37) Maintaining the right temperature	EF Self-evaluating
	(38) Accurately estimating the time	EF Planning
	(39) Multitasking while cooking	EF Flexibility
	Fatigue	
Grocery shopping	(40) Planning the needed products	EF Planning
	(41) Remembering the products	M Prospective
	(42) Finding the products	EF Planning
	Fatigue	

Abbreviations: memory (M); attention (A); executive function (EF).
*These items were excluded from the final inventory (See "2.2.3. Finalizing the inventory based on data of the quantitative study").

Netherlands. Patients had to meet the following inclusion criteria: (1) aged between 18–80 years old; and (2) fluent in Dutch. Patients were asked if a close relative was willing to participate. Furthermore, the healthy controls had to meet the following inclusion criteria: (1) aged between 18–80 years old; (2) fluent in Dutch, and (3) no history of neurological and/or psychiatric disorders. Healthy controls were recruited among acquaintances of the researchers and by using advertisements in online newsletters and websites. All participants gave written informed consent. The experiment was performed in accordance with the Declaration of Helsinki. The research protocol was approved by the Medical Ethics Committee of the University Medical Centre (METC protocol number 17-407/C).

Procedure

Patients (and relatives) were invited by a rehabilitation physician or a neuropsychologist to participate. After confirmation, the CoCo-P along with the informed consent form was sent by post. Patients were instructed to bring the completed forms to a scheduled appointment or return them by post. Healthy controls returned the completed forms by post.

Finalizing the inventory based on the data of the quantitative study

To finalize the inventory, we revised the response distributions of each item within healthy controls and patients (See Appendices A2 and A3). The response options (four-point scale) were dichotomized into "no complaints" (i.e., [0] independent, without effort) and "complaints" (i.e., [1] independent, with effort, [2] with help or [3] not possible). The presence of floor or ceiling effects were important determinants. Items were deleted from the final version and further analyses when: (1) >20% of healthy controls reported "complaints" on the item in question (which means the item can be considered "quite challenging," even for healthy controls); and (2) <10% patients reported "complaints" on the item in question (which means the item can be considered "not challenging enough"). More than 20% of the healthy controls reported complaints on item 14 (i.e., remembering the time of arrival and departure), 17 (i.e., remembering unfamiliar routes), and 32 (i.e., remembering names of people I just met). These items were excluded as they were not suitable in differentiating between patients with ABI and healthy controls. Regarding item 14 and 17, this finding might be explained by the fact that nowadays technology (e.g., application on phone, navigational system) is used during these activities. So performing these activities on its own merits might be considered challenging. The exclusion of item 32 caused the daily life activity "contact with community" to contain only one item (i.e., item 33). For this reason, item 33 was added to "contact with family/friends," and the daily life activity was renamed into "contact with family/friends and community." Only two patients (<10%) reported complaints on item 23 (i.e., taking

my medication). Due to the lack of variance, this item was excluded from the final inventory and further analyses.

The daily life activity "use of medication" (i.e., items 21 [planning prescription refill]; item 22 [remembering taking my medications]; item 24 [intake of medication at fixed times]) seemed not applicable in our patient population. However, we did not exclude this activity from our inventory because 20–33% of the patient that used medication did report complaints on these items.

As a result of a review of available literature, expert meetings with health professionals and cognitive neuroscientists, semi-structured interviews with patients, and a quantitative study, the final version of the inventory was developed. The *Cognitive Complaints - Participation* (CoCo-P) is a patient-reported and/or relative-reported measure that contains 38 items focusing on memory, attention or executive function over 10 daily life activities (i.e., work/education, leisure activities, travel, driving, finances, use of medication, family life, contact with family/friends and community, cooking, grocery shopping). An English translation of the inventory is presented in Appendix A4 (see supplementary material). Note that the results in this study are obtained with the original Dutch version.

Statistical analyses on data of the quantitative study with the final inventory

Demographic and clinical characteristics. We collected data on sex, age and level of education. Level of education was assessed using a Dutch classification system (Verhage, 1965), that consists of 7 levels, with 1 being the lowest (less than primary school) and 7 being the highest (academic degree). These levels were converted into three categories for analysis: low (Verhage 1–4), average (Verhage 5), and high (Verhage 6–7). Non-parametric tests (Kruskal–Wallis non-parametric ANOVA and Chi-square test for categorical variables) were used to compare demographic characteristics between the patients and healthy controls. Additionally, we extracted the following characteristics from the medical files: ABI type (i.e., stroke, TBI, brain tumour resection), time since ABI onset, lesion side, and the current state regarding work employment. If a neuropsychological assessment was scheduled within three months around the administration of the inventory, we collected the patient's neuropsychological performance on four tests (i.e., Mini-Mental State Examination – 2nd Version [MMSE-2], Rey Auditory Verbal Learning Test [RAVLT], Digit Span, Trail Making Test B [TMT]) to give an indication of the cognitive sequelae on group level.

Reported complaints per daily life activity. We presented the results in percentages of patients or healthy controls reporting complaints per daily life activity (10 activities). The four-point scale was dichotomized into "no complaints" and "complaints." If any complaints were reported ([1] independent with effort, [2] with help, [3] not possible) on at least one of the items within the activity, the

participant was classified into the "complaints" category. The percentages of patients and healthy controls who reported that the activity was "not applicable" were reported. In addition, we created a hierarchy among the complaints and differentiated between the level of *restrictions, dependence,* and *incapability*. Patients were considered *restricted,* when any restrictions were reported ([1] independent with effort) on at least one item within the activity. Patients were considered *dependent*, when help was needed ([2] with help) on at least one item within the activity. Patients were considered *uncapable*, when they reported to be uncapable to perform the task ([3] not possible) on at least one of the items within the activity.

Furthermore, the level of fatigue (VAS score) was compared between the patients and the healthy controls per daily life activity using a Mann–Whitney *U* tests (adjusted *p* for 10 tests = .005).

Reported complaints per cognitive domain. We presented the results in percentages of patients or healthy controls reporting complaints per cognitive domain (3 domains). Similar to the procedure mentioned above, we created a hierarchy among the complaints and differentiated between the level of *restrictions, dependence,* and *incapability*.

Furthermore, we computed a *total complaint score* (sum score) based on all items as global indication of cognitive complaints. In addition, complaints scores per cognitive domain were computed (i.e., *memory complaint score*, *attention complaint score*, *executive complaint score*). Only items that were applicable for the individual were included (i.e., items rated [0] independent without effort, [1] independent with effort, [2] with help, [3] not possible). To obtain the same range between the scores, the complaints scores were converted to a 0–100 scale with the formula:

$$\text{Complaints Score} = \frac{\text{Mean score}}{3\ (\text{maximum score per item})} \times 100.$$

Higher scores indicated a higher degree of reported complaints. The median and the interquartile range were computed for patients and healthy controls. A Wilcoxon signed-rank test (two related samples) was used to compare the *complaint scores* within the patient group (adjusted *p* for 3 tests = .017).

Comparison between patients' and relatives' reports. A Wilcoxon signed-rank test (two related samples) was used to compare the *complaints scores* (3 domains) between patients and their relatives (adjusted *p* for 3 tests = .017). In addition, a Wilcoxon signed-rank test was used to compare the level of fatigue (mean VAS) per daily life activity (10 activities) as reported by patients and their relatives (adjusted *p* for 10 tests = .005).

Results

Demographic and clinical characteristics

We invited 76 ABI patients to participate and 28 patients declined for several different reasons (e.g., no time, personal reasons). In total, we recruited 48 ABI patients and 107 healthy controls. We had to exclude 2 patients and 4 healthy controls from the current study as no written informed consent was obtained (only verbal consent was given). One healthy control was excluded because she had a neurological disorder (i.e., mild Transient Ischemic Attack [TIA]) in the past. Finally, we included 46 patients and 102 healthy controls for the analyses. From the 46 patients, 33 relatives were included. See Table 3 for demographic and clinical characteristics. Brain lesion was mostly due to a TBI (57%). All patients were in the chronic phase of rehabilitation (>3 months post ABI onset), and 52% of the patients was either back to work or in process of reintegration. Between the patients and healthy controls, there was no significant difference regarding sex ($\chi^2(1) = .48$, $p = .488$), nor age ($U = 2161.00$, $z = -.77$, $p = .443$), nor education ($\chi^2(2) = 4.81$, $p = .090$). Patients reported a higher level of cognitive complaints (as measured with the *total complaints score*) compared to healthy controls ($U = 216.00$, $z = -8.95$, $p < .001$).

Reported complaints per daily life activity

The highest percentage of patients reported complaints during "contact with friend/family and community" (96%), "leisure activities" (89%), and "work/education" (87%) (see Table 4). The highest percentage of healthy controls reported complaints during "work/education" (32%), "contact with family/friends and community" (32%), and "cooking" (24%). The percentage of patients reporting *restrictions* (22–46%), *dependence* (0–24%), and *incapability* (2–50%) varied greatly between daily activities (see Table 4 and Figure 1). The percentage of healthy controls reporting *restrictions* (8–31%), *dependence* (0–6%), and *incapability* (0–3%) varied less. Regarding fatigue, patients reported more fatigue during each daily life activity compared to healthy controls (see Table 5).

Reported complaints per cognitive domain

A high percentage of patients reported complaints regarding memory (94%), attention (98%) and executive function (96%), when compared to reported complaints regarding memory (38%), attention (47%), executive function (36%) of healthy controls (see Table 6). The highest percentage of patient reported *incapability* (37–65%), when compared to *restrictions* (24–37%) and *dependence* (9–20%). The highest percentage of healthy controls reported *restrictions* (36–44%), when compared to *dependence* (2–6%) and *incapability* (0–3%).

Table 3. Demographic and clinical characteristics of the participants in the quantitative study.

	Patients $n = 46$		Relatives $n = 33$	Healthy controls $n = 102$
Male (%)	52.2		42.4	46.0
Age in years (mean, SD)	46.93 (12.86)		47.84 (11.48)	48.37 (15.09)
Level of Education (%)				
Low	4.3		9.1	0
Moderate	28.3		24.2	23.7
High	67.4		66.7	76.3
Type of ABI (%)				
Stroke	32.6			
TBI	56.5			
Brain tumour resection	10.9			
Time ABI onset (median, range)	15 months (3–177)			
Lesion side (%)				
Left	23.9			
Right	30.4			
Bilateral	26.1			
Not visible on scan	17.4			
Unknown	2.2			
Return to work/study (%)				
Completely	8.7			
Yes, but fewer hours	21.7			
In process of reintegration	21.7			
No	34.8			
Unknown	13.1			
MMSE-2 0–30 (mean, SD)	28.9 (1.45)	$n = 25$		
RAVLT percentile				
Immediate (median, <10th percentile)	18.5 (34.8%)	$n = 42$		
Recall (median, <10th percentile)	32.5 (23.9%)	$n = 42$		
Recognition 0–30 (median, <27)	29 (10.9%)	$n = 42$		
Digit Span Scale 0–20				
Total (median, <7th scale)	10 (21.7%)	$n = 43$		
TMT percentile				
A-B (median, <10th percentile)	58 (10.8%)	$n = 43$		
Total Complaint Score 0–100 (median, IQR)	30.19 (31.20)		22.81(31.21)	.95 (3.84)

Abbreviations: Acquired Brain Injury (ABI); Traumatic Brain Injury (TBI); Mini-Mental State Examination – 2nd version (MMSE-2); Rey Auditory Verbal Learning Test (RAVLT); Trail Making Test – version B (TMT-B).

Regarding the *complaints score* of the patients, the median was 26 for *memory*, 42 for *attention*, and 23 for *executive function*. The median for the healthy controls was 0 for each cognitive domain. See Figure 2 for the distribution of the *complaints score* per cognitive domain for both groups. The *complaints score* was higher for attention compared to memory ($z = -3.96$, $p < .001$) and executive functions ($z = -5.82$, $p < .001$) within patients. Demographical characteristics (i.e., sex, age and level of education) did not influence the *complaints scores* (memory, attention, executive function) within the current sample of patient with ABI (see Appendix A5 in supplementary material).

Comparison between patients' and relatives' reports

The *complaints scores* of patients were significantly higher for memory and attention, compared to the complaints scores of relatives (see Table 7). Patients and relatives had a similar *complaints score* for executive functions. Patients and relatives did not differ on the perceived level of fatigue during the 10 daily life activities (see Table 8).

Table 4. Percentage of patients and healthy controls reporting complaints per daily life activity.

Patients ($n = 46$)	N/A (%)	No complaints (%)	Complaints (%)	Restricted (%)	Dependent (%)	Incapable (%)
Work/education	8.7	4.3	87	21.8	15.2	50
Leisure activities	0	10.9	89.1	45.6	6.5	37
Travel	6.5	28.3	65.2	36.9	19.6	8.7
Driving	13	32.7	54.3	43.4	0	10.9
Finances	4.3	54.4	41.3	28.3	2.1	10.9
Use of medication	28.3	32.6	39.1	21.7	15.2	2.2
Family life	13	8.7	78.3	28.3	23.9	26.1
Contact family/friends and community	0	4.3	95.7	34.8	10.9	50
Cooking	6.5	8.7	84.8	43.5	8.7	32.6
Grocery shopping	6.7*	22.2	71.1	42.8	17.4	10.9
Healthy controls ($n = 102$)	**N/A (%)**	**No complaints (%)**	**Complaints (%)**	**Restricted (%)**	**Dependent (%)**	**Incapable (%)**
Work/education	2	65.6	32.4	31.4	1	0
Leisure activities	0	85.3	14.7	14.7	0	0
Travel	0	91.2	8.8	7.8	1	0
Driving	7.8	79.5	12.7	12.7	0	0
Finances	0	90.2	9.8	9.8	0	0
Use of medication	50	39.2	10.8	9.8	1	0
Family life	6.9	75.5	17.6	11.7	5.9	0
Contact family/friends and community	0*	68.3	31.7	29.7	0	2
Cooking	4.9	71.6	23.5	18.6	2	2.9
Grocery shopping	1	79.4	19.6	18.6	1	0

Note: We created a hierarchy among the complaints and differentiated between the level of *restrictions, dependence,* and *incapability*.
Abbreviations: Not applicable (N/A).
*missing values on all items within the activity for one participant.

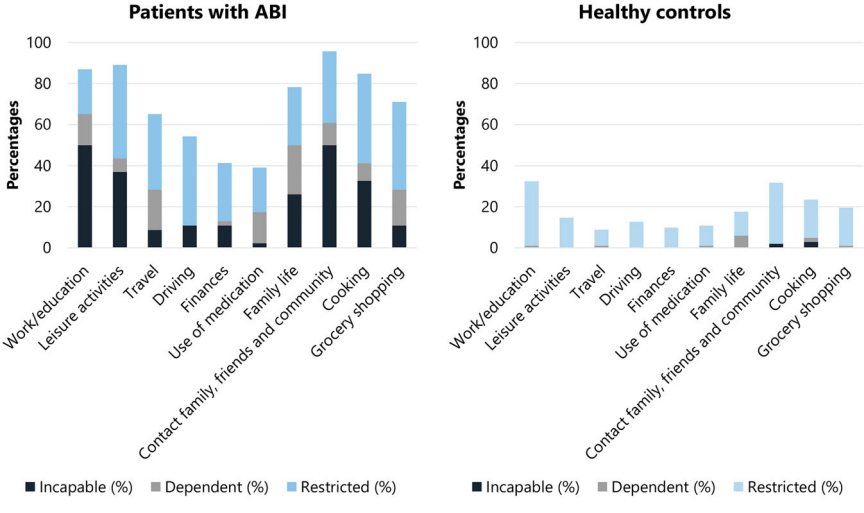

Figure 1. Percentage of patients reporting complaints per daily life activity. A hierarchy was created among the complaints and differentiated between the level of *restrictions, dependence,* and *incapability*.

Table 5. Comparison of the level of fatigue (mean VAS scores) per daily life activity between patients and healthy controls.

	VAS score (mean [SD])		Statistics
	Patients ($n = 46$)	Healthy controls ($n = 102$)	Mann–Whitney U tests
Work/education	7.45 (1.75)	3.16 (2.31)	$U = 282.50$, $z = -7.64$, $p < .001$*
Leisure activities	6.11 (2.47)	1.67 (1.70)	$U = 386.00$, $z = -7.94$, $p < .001$*
Travel	6.08 (2.32)	2.10 (1.95)	$U = 474.50$, $z = -7.35$, $p < .001$*
Driving	5.47 (2.92)	1.90 (1.94)	$U = 500.50$, $z = -5.95$, $p < .001$*
Finances	4.01 (3.19)	1.48 (1.93)	$U = 1012.00$, $z = -4.97$, $p < .001$*
Use of medication	2.03 (2.25)	0.75 (1.19)	$U = 532.50$, $z = -3.34$, $p = .001$*
Family life	6.02 (2.49)	1.34 (1.55)	$U = 301.50$, $z = -7.95$, $p < .001$*
Contact family/friends and community	5.52 (2.59)	1.49 (1.64)	$U = 520.50$, $z = -7.47$, $p < .001$*
Cooking	4.45 (2.92)	1.37 (1.76)	$U = 743.00$, $z = -5.85$, $p < .001$*
Grocery shopping	5.27 (3.17)	1.45 (1.79)	$U = 728.50$, $z = -6.30$, $p < .001$*

*Adjusted $p < .005$.
Note: The number of patients varies as only valid answers (without missing and non-applicable items) are included.

Discussion

Based on available literature, expert meetings with health professionals and cognitive neuroscientists, semi-structured interviews with patients, and a quantitative study, the inventory *Cognitive Complaints - Participation* (CoCo-P) was developed as a patient- and relative-reported measure to assess cognitive complaints during daily life activities. The majority of patients (87–96%) who participated in the quantitative study experienced cognitive complaints at work/education, during leisure activities, and/or in contact with family/friends and community. This is probably due to the dynamic and demanding nature of such daily life activities, where one is required to perform multiple operations simultaneously while dealing with environmental distractions (e.g., background noise) and time pressure. Performing adequately in those demanding situations requires more from attentional processes (McCulloch, 2007). Previous literature also reports that the presence of cognitive complaints negatively affects the possibility to return to work (Benedictus et al., 2010; van der Naalt et al., 1999) and the possibility to resume leisure and social activities post ABI (Robison et al., 2009). We found much lower percentages of healthy controls reporting cognitive complaints. However, we found a similar pattern regarding the most affected daily life activities. The highest percentages of heathy controls (31–32%) reported complaints during work/education and in contact with family/friends and community. It is therefore likely that those daily life activities do require more from cognitive processes, compared to other daily life activities. Also, patients reported more fatigue during all daily life activities compared to healthy controls. The fatigue VAS score was considered as an independent measure to give insight in the level of fatigue during daily life activities regardless of the presence or absence of cognitive complaints. Furthermore, we found that complaints related to attention were more frequently reported compared to complaints related to memory or executive functions by patients with ABI. These

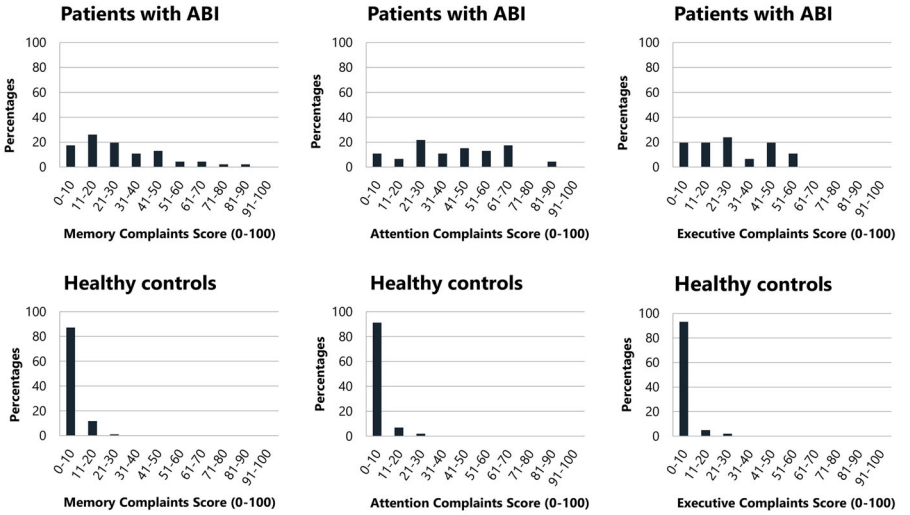

Figure 2. The distribution of *complaints scores* for patients with ABI and healthy controls. The converted *complaints scores* to a 0–100 scale are presented on the x-axis. Higher scores indicated a higher degree of reported complaints. The percentages of patients are presented on the y-axis.

Table 6. Percentage of patients and healthy controls reporting complaints per cognitive domain.

Patients ($n = 46$)	N/A (%)	No complaints (%)	Complaints (%)	Restricted (%)	Dependent (%)	Incapable (%)	Range	Q1	Median	Q3	IQR
Memory	0	6.5	93.5	37	19.5	37	0–83	18	26	43	25
Attention	0	2.2	97.8	23.9	8.7	65.2	0–85	26	42	58	32
Executive Function	0	4.3	95.7	24	19.5	52.2	0–57	11	23	43	32
Healthy controls ($n = 102$)	N/A (%)	No complaints (%)	Complaints (%)	Restricted (%)	Dependent (%)	Incapable (%)	Range	Q1	Median	Q3	IQR
Memory	0	61.8	38.2	36.2	2	0	0–29	0	0	5	5
Attention	0	52.9	47.1	44.2	0	2.9	0–30	0	0	4	4
Executive Function	0	63.7	36.3	28.5	5.8	2	0–27	0	0	3	3

Note: We created a hierarchy among the complaints and differentiated between the level of *restrictions, dependence,* and *incapability*. In addition, the median and interquartile range of the *complaints score* are presented.
Abbreviations: Not applicable (N/A).

Table 7. Comparison of the *complaints scores* (higher scores indicate a higher level of complaints) between patients' and relatives' reports.

	Complaints score (median [IQR])		Statistics
	Patients ($n = 33$)	Relatives ($n = 33$)	Wilcoxon signed-rank test
Memory complaints score (0–100)	27.78 (25)	19.05 (28)	$z = -2.42$, $p = .015$*
Attention complaints score (0–100)	40.00 (34)	26.67 (40)	$z = -2.64$, $p = .008$*
Executive complaints score (0–100)	23.33 (33)	19.30 (33)	$z = -1.83$, $p = .067$

*Adjusted $p < .017$.

findings are consistent with a previous review that found a percentage of 29–92% of stroke patients reporting complaints (measured by questionnaires or interviews) about concentration, mental speed and memory (Rijsbergen et al., 2014).

Patients reported more cognitive complaints regarding memory and attention (as measured with the *complaints scores*) than their relatives. This might reflect too little knowledge about the possible consequences of ABI among relatives (Hochstenbach, Prigatano, & Mulder, 2005). Subtle problems and the impact on daily life may not be recognized or understood by relatives, leading to an overestimation of patients' ability (Fordyce & Roueche, 1986; Hochstenbach et al., 2005). For instance, relatives have overestimated patients with ABI in their communication abilities (McClenahan, Johnston, & Densham, 1990, 1992; Seel et al., 1997), or overall functioning (Cavallo, Kay, & Ezrachi, 1992; Cusick, Gerhart, & Mellick, 2000). Previous research shows that agreement tends to be lower for invisible symptoms (e.g., memory problems), but higher for observable symptoms (e.g., writing) (Hochstenbach et al., 2005; Vallat-Azouvi et al., 2018). Fatigue was probably more observable for relatives, hence patients and relatives reported a comparable level of fatigue. A note of caution is due here since we cannot state which underlying process causes the discrepancy between the patients' and relatives' reports. Future research could shed light on this matter.

Table 8. Comparison of the level of fatigue (mean VAS score) as reported by patients and their relatives, split per daily life activity.

	VAS score (mean [SD])		Statistics
Daily life activity	Patients ($n = 33$)	Relatives ($n = 33$)	Wilcoxon signed-rank test
Work/education	7.71 (1.58)	7.35 (2.21)	$z = -1.06$, $p = .291$
Leisure activities	6.31 (2.24)	5.97 (2.53)	$z = -.78$, $p = .437$
Travel	6.22 (1.98)	6.50 (2.32)	$z = -.76$, $p = .446$
Driving	5.63 (2.83)	6.22 (3.07)	$z = -1.87$, $p = .062$
Finances	4.14 (3.02)	4.01 (2.97)	$z = -.86$, $p = .388$
Use of medication	1.88 (2.20)	1.90 (1.94)	$z = -.28$, $p = .778$
Family role	5.92 (2.26)	5.87 (2.57)	$z = -.34$, $p = .732$
Contact family/friends and community	5.59 (2.33)	5.45 (2.30)	$z = -.29$, $p = .775$
Cooking	4.61 (3.02)	4.67 (2.89)	$z = -.63$, $p = .530$
Grocery shopping	5.33 (3.04)	5.83 (2.89)	$z = -1.50$, $p = .134$

*Adjusted $p < .005$.
Note: The number of patients varies as only valid answers (without missing and non-applicable items) are included.

Strengths and limitations

Involvement of experts, patients and relatives

The strength of this study is the process of development, where we followed a sequence of steps including the consultation of experts and patients. The inventory is based on well-known cognitive models (theory-based) (Petersen & Posner, 1990, 2012; Posner & Rothbart, 2007; Squire, 1992, 2004; Ylvisaker et al., 1998), but also based on the clinical input of healthcare professional and patients (experienced-based). Especially, the patients' engagement in research can potentially lead to an improved development of patient-reported outcomes (Domecq et al., 2014; Wiklund et al., 2016). However, we did not involve the relatives in the development of the relative-reported inventory. Relatives were not interviewed regarding missing daily life activities and specific items. This could be considered as a limitation. However, we do not expect that the involvement of relatives would have resulted in great modifications, because the activities of the CoCo-P can be considered the most characteristic for participation. For instance, previous research suggest that homemaking for others (e.g., cooking), interpersonal relations (e.g., contact with friends and family), major life areas (e.g., work) and community-based roles outside of home or work (e.g., leisure) represent participation (Post et al., 2012; Whiteneck & Dijkers, 2009). These activities are included in the CoCo-P. In addition, the involved patients with mild impairments were considered capable to evaluate the completeness of the daily life activities.

Patient sample

The sample size of the patient group was relatively small. In addition, the group was relatively high-educated and mildly cognitively impaired. Even though the CoCo-P appears to be suitable for all patients with ABI, it remains to be seen how feasible it is for low-educated patients or for patients with moderate to severe cognitive impairments. One might argue that a subjective evaluation of daily life difficulties might be more challenging for patients with a lower education (Boynton, Wood, & Greenhalgh, 2004) or for patients with severe injury-related cognitive impairments (Barrett, 2009; Reeves et al., 2018). Items such as "Do you have attentional problems?" are often considered abstract and challenging by patients. In the CoCo-P, however, the items describe specific cognitive tasks during daily life activities, which is expected to be less challenging. In addition, the frequencies of the cognitive complaints (as measured with the CoCo-P) remain unknown in an ABI population with more severe impairments. Future research should include a larger, more heterogenous sample of patients with respect to type of ABI and severity. This will especially allow the exploration of possible differences in frequencies of complaints between diagnosis-related groups (e.g., stroke, TBI) varying in ABI severity (i.e., mild, moderate, severe).

Given the aim of the current study (developing an inventory to capture cognitive complaints during daily life activities for patient with ABI) the inclusion of patients

with mild cognitive impairment could be considered as a strength, as the discrepancy between relatively good test results (on neuropsychological tests) and reported complaints is strikingly common within this group. A novel inventory for systematically assessing cognitive complaints in this group is crucial. This group is also a growing population in rehabilitation medicine, because of the improved neurological treatment (e.g., mechanical thrombectomy, intravenous thrombolytic treatment) and the increased use of early multidisciplinary rehabilitation interventions (Barreto, 2011; Campbell, Donnan, Mitchell, & Davis, 2016; Cifu & Stewart, 1999; Maulden, Gassaway, Horn, Smout, & DeJong, 2005).

Another limitation is the fact that we did not exclude patients with comorbid disorders (e.g., psychiatric or neurological), which might have influenced the frequencies of cognitive complaints. For example, affective disturbances (e.g., depression, irritability, anxiety) can influence subjective reports (Clarke et al., 2012). However, comorbidity is common after ABI (Garrelfs, Donker-Cools, Wind, & Frings-Dresen, 2015), so inviting all patients in the outpatient rehabilitation programme probably increased the representativeness of our sample.

Cognitive domains and subdomains

We selected items focusing on memory (i.e., retrospective memory, prospective memory), attention (i.e., arousal, orienting, monitoring, sustained) or executive function (i.e., planning, self-evaluating, initiative, flexibility) based on well-known cognitive models (Petersen & Posner, 1990, 2012; Posner & Rothbart, 2007; Squire, 1992, 2004; Ylvisaker et al., 1998). The cognitive domains, however, might lack relevant subdomains. For instance, items are missing related to processing speed (as part of attention) and inhibition (as part of executive function), which are commonly impaired in ABI patients (Chung et al., 2013; Cicerone et al., 2000; Veltman, Brouwer, van Zomeren, & van Wolffelaar, 1996). Furthermore, one could argue that the items belong to more than one cognitive (sub)domain, because the cognitive tasks described in the items involve multiple cognitive processes.

Future research

Future research will address the reliability and the validity of the CoCo-P. The reliability could be evaluated in terms of the internal consistency by using the McDonald's omega (McDonald's ω), which is considered the best estimate when the scale in question is multidimensional (Dunn, Baguley, & Brunsden, 2014; Watkins, 2017; Zinbarg, Revelle, Yovel, & Li, 2005). The calculation of the McDonald's ω requires the application of a factor analytic model, which requires a large sample size (Watkins, 2017; Zinbarg, Yovel, Revelle, & McDonald, 2006). A factor analytic model will identify the structure of the inventory by revealing whether the items reflect the three underlying and independent cognitive domains (i.e., memory, attention, executive function). Next, the validity should be addressed in terms of construct validity (i.e., examination whether the inventory measures the theoretical

constructs of interest) by estimating its association with other patient-reported measures (e.g., USER-P, CLCE-24). Furthermore, the *complaints scores* per cognitive domain could be compared with the scores on a neuropsychological assessment, which would reveal the relation between the reported complaints and underlying cognitive impairments. Finally, we found that healthy controls are unlikely to show a *complaint score* higher than 5 per cognitive domain (highest Q3 = 5 for the *memory complaint score*). The *complaints scores* are easy to use clinically and seems appropriate in differentiating between cognitively healthy controls and patients reporting cognitive complaints. However, more established analyses are needed to determine a valid cut-off score. Future research should focus on investigating the sensitivity and specificity (positive and negative predicted value) in relation to an external instrument measuring cognitive complaints (e.g., CLCE-24).

Clinical implications

Especially during outpatients rehabilitation, the primary goals are to maximize functional independence and participation (Post et al., 2012; Wade & de Jong, 2000). Neuropsychological assessment examines the cognitive impairments that could hamper participation. Cognitive complaints may also negatively affect participation. For this reason, previous research emphasized the need for patient-reported measures to capture and quantify the difficulties patients encounter in daily life (Carrigan & Barkus, 2016; Meadows, 2011; Wiklund et al., 2016). The CoCo-P can complement a neuropsychological assessment by capturing the subjective cognitive complaints in a standardized manner, and, just as important, by assessing the impact of cognitive complaints on participation. The CoCo-P can be used in a multidisciplinary team (e.g., neuropsychologists, occupational therapists) to determine the focus of the intervention (activity-focused/domain-focused). Finally, the CoCo-P can be used as a metric to assess cognitive complaints longitudinally and to evaluate the effect of the intervention.

Conclusion

In conclusion, the CoCo-P is a patient- and relative-reported measure to assess cognitive complaints during daily life activities in patients with ABI. The majority of patients (87–96%) experienced cognitive complaints at work/education, during leisure activities, and in contact with family/friends and community. The CoCo-P can be used to capture the subjective cognitive complaints in a standardized manner, and, just as important, to assess the impact of cognitive complaints on participation. The *complaints scores* per cognitive domain are easy to use clinically and seems appropriate to differentiate between cognitively healthy controls and patients reporting cognitive complaints in daily life. Future research will address the reliability and validity of the CoCo-P.

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ORCID

Lauriane A. Spreij http://orcid.org/0000-0001-5558-9746
David Sluiter http://orcid.org/0000-0001-8834-848X
Isabel K. Gosselt http://orcid.org/0000-0001-8086-8843
Johanna M.A. Visser-Meily http://orcid.org/0000-0002-5955-8012
Tanja C.W. Nijboer http://orcid.org/0000-0001-6683-0267

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