

RESEARCH REPORT

Comprehensive Assessment of Reading in Aphasia (CARA) reading questionnaire—German version

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Abstract

Background: Reading comprehension is frequently impaired in persons with aphasia (PWA). For goal-setting and outcome measurement, speech and language therapists (SLTs) need to determine an individual's perspective of their reading difficulties and everyday reading activities. The Comprehensive Assessment of Reading in Aphasia (CARA) reading questionnaire provides a person-centred tool to find out the individual perception of reading functions, reading-related emotions and reading activities in PWA. It was developed and evaluated in English. So far, there is no equivalent instrument in German.

Aims: To translate and adapt the CARA reading questionnaire into German language and culture, to evaluate its practicability and acceptance, and to provide the first psychometric properties of the German version.

Methods & Procedures: Based on translation and adaptation guidelines, we conducted two forward translations that were merged and then adapted. A back translation was prepared and compared with the original version. It was found to be semantically equivalent by one of the authors of the original version. We performed pilot testing with 12 PWA, and the pilot version was adapted according to the comments of these participants. We then collected data on self-reported perception of reading and on psychometric properties of the translated and adapted German version. A total of 22 German-speaking PWA completed the questionnaire at least five times during an intervention study. We analysed retest reliability with Spearman correlation, internal consistency with Cronbach's alpha, internal responsiveness with the standardized response mean, as well as the relationship between outcomes of the questionnaire and text comprehension measures using repeated measures correlations.

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Outcomes & Results: Our data suggest good practicability and acceptance of the German version of the CARA reading questionnaire as well as appropriate validity, reliability and sensitivity to measure therapy-induced change. We found moderate correlations between outcomes of the questionnaire and text-level reading speed.

Conclusions & Implications: The German version of the CARA reading questionnaire could be helpful in intervention planning and goal-setting with German-speaking PWA. By using the questionnaire, SLTs can find out about a person's individual perception of reading difficulties as well as individually relevant reading activities. The questionnaire provides a tool to measure change and is therefore valuable to demonstrate self-reported individual progress. As reading speed seems to be an indicator of personal perception of reading difficulty, it is important to consider reading speed in reading interventions and in reading comprehension assessments.

KEYWORDS

alexia, aphasia, comprehension, personal perception, reading, translation

WHAT THIS PAPER ADDS

What is already known on the subject

- Reading comprehension is frequently impaired in PWA. Reading preferences, the perception of difficulties and the impact on everyday life reading activities are specific to the individual and thus need to be known for goal-setting, intervention planning and monitoring of change. As part of a comprehensive assessment of reading, Morris et al. developed a person-centred English language questionnaire for this purpose. So far, there is no equivalent tool in German.

What this paper adds to the existing knowledge

- In this study, we translated and adapted the questionnaire to German language and culture, and analysed its validity and reliability with German-speaking PWA. We demonstrated that the German version is accessible for German-speaking PWA, and that it has appropriate validity, reliability and sensitivity to measure self-reported change. Outcomes of the questionnaire correlate with text level reading speed.

What are the potential or actual clinical implications of this work?

- The German version of the questionnaire could be a valuable self-reported outcome measure to assess individual perceptions of reading and to measure progress (as perceived by an individual) as a consequence of recovery or intervention in either clinical or research settings. As reading speed might be an indicator of everyday life reading as perceived by an individual, it should be considered in reading assessments and interventions.



INTRODUCTION

For many people, reading is an essential element in everyday life. It is a prerequisite for participation in society, for developing knowledge and potential, and for achieving individual goals (Organisation for Economic Cooperation and Development (OECD), 2006). Constructing a coherent representation of read information in memory involves a complex interaction of linguistic and cognitive resources (Kendeou et al., 2014). Reading comprehension has been described in many cognitive models. Following the Construction-Integration Model by Kintsch (2018), readers transform the superficial exact wording of a text (i.e., *surface structure*) into its semantic content (i.e., the *textbase*). The textbase consists of the *microstructure* and the *macrostructure*. While the microstructure represents all detailed information of a text, macrostructure refers to the more global information inferred by selecting relevant information, deleting irrelevant information and forming more general or superordinate propositions. The actual outcome of reading, that is, individual *situational models*, is constructed by continuously integrating the information from the textbase and prior background knowledge (Kintsch, 2018).

After acquired brain injuries such as stroke or traumatic brain injury, reading comprehension can be impaired. This may affect various processes involved in reading comprehension such as recognizing letters, identifying words, retrieving lexical-semantic knowledge or constructing micro- and macrostructure as well as situational models (Chesneau & Ska, 2015; Perfetti, 1999). It may then be difficult to understand linguistic entities of different complexity including words, sentences, paragraphs and longer texts. As a result of these functional impairments, patients may not be able to read and understand medication schedules, recipes, timetables for public transport, job requirements, e-mails or books. This constrains participation in everyday life and affects communication, self-care, family roles, employment as well as domestic and social life (Simmons-Mackie & Kagan, 2007; Webster et al., 2018; World Health Organisation (WHO), 2005).

Problems in reading comprehension affect a considerable proportion of persons with aphasia (PWA). In a sample of 81 PWA of varied aphasia type, severity and time post-onset, 70% experienced difficulties in reading and understanding longer units such as paragraphs (Webster et al., 2021). These problems may persist after basic-level linguistic recovery; they may be experienced in everyday life reading even when general aphasia assessments are not able to capture them any more (Chesneau & Ska, 2015). Despite these difficulties, reading remains important for the majority of PWA (Webster et al., 2021).

According to the International Classification of Functioning, Disability and Health (ICF; WHO, 2005), interventions should improve a patient's ability to participate in everyday life (Bühler et al., 2005). Outcomes have traditionally focused on isolated linguistic abilities related to the ICF level of body functions (e.g., naming objects or syntax production) (Kagan et al., 2008). According to the Living with Aphasia: Framework for Outcome Measurement (A-FROM; Kagan et al., 2008), an individual's life and quality of life with aphasia is at the intersection of four interacting life domains: (1) participation; (2) personal factors such as personal identity, attitudes and feelings; (3) severity of aphasia; and (4) communication and language environment. Outcomes and treatments may thus focus on any of these domains or domain intersections. The A-FROM highlights that individual PWA should be involved in determining relevant and important outcomes and that outcomes should 'capture client perspectives, particularly as they relate to participation, personal factors, and quality of life' (Kagan et al., 2008, p. 270).

For goal-setting and outcome measurement, speech and language therapists (SLTs) need to know which everyday life reading abilities and activities are important to a particular person and which specific difficulties this person experiences. Reading activities as well as the impact of impairments on everyday life are individual and the personal perception of reading does not necessarily correlate with performance-based reading comprehension scores (Webster et al., 2021, 2022). Thus, in goal-setting, it is very important to consider both self-reported and performance-based assessments (Webster et al., 2022). In preparation for an intervention study on text-level reading comprehension in PWA (Thumbeck et al., 2021), we searched for self-reported outcome measurement instruments for reading in aphasia. Individual perceptions of reading in aphasia can be collected with different methods such as interviews (e.g., Kjellén et al., 2017; Webster et al., 2018), questionnaires (e.g., Knollman-Porter et al., 2015) or participant observations (e.g., Lynch et al., 2013). Alternative communication options such as rating scales and pictures facilitate the use with people with communication impairments (Carlsson et al., 2007). The choice of the method depends on the purpose: Interviews and participant observations create valuable in-depth information, but they are more time-consuming and less standardized compared with questionnaires (Döring & Bortz, 2016). In clinical contexts, time and resources are often limited. Thus, in clinical goal-setting, in monitoring self-reported change following intervention or recovery, and particularly in intervention studies with multiple participants and repeated assessments, questionnaires are more efficient,

replicable and feasible than interviews and participant observations (Webster et al., 2021).

So far, there is no questionnaire in German to collect comprehensive, self-reported information on reading in aphasia. In English, there are three questionnaires about reading after acquired brain injury. (1) The Reading Confidence and Emotions Questionnaire (RCEQ) was developed primarily in a context of patients with traumatic brain injury (Cocks et al., 2010). It includes items on confidence and on emotions when reading silently and aloud both before and after the brain injury. Many items focus on reading aloud. Even though the questionnaire considers reading in different contexts (e.g., alone or in front of other people), it does not include different reading materials. (2) Knollman-Porter et al. (2015) designed a questionnaire to investigate pre- and post-aphasia reading experiences, feelings and preferences. It considers a range of reading materials, settings, frequency of reading activities and use of support for reading comprehension. (3) The Comprehensive Assessment of Reading in Aphasia (CARA; Morris et al., 2023) provides several performance-based subtests on reading comprehension as well as a self-reported questionnaire (as described by Webster et al., 2021) which assesses the individual perception of reading ability, reading-related emotions and reading activities in PWA. It was designed in collaboration with PWA. Based on their preferences, the questionnaire concentrates on current reading (rather than comparing pre- and post-stroke reading). It is an aphasia-friendly, more accessible questionnaire which aims to reduce the demands placed on reading comprehension during administration. Facilitated by pictures, visual scales, and pointing and sorting procedures, PWA rate their perception in three sections (current reading abilities, thoughts and feelings about reading, reading activities). The CARA questionnaire is the only one of these three questionnaires on which information on psychometric properties is available.

To summarize, each of these three questionnaires has its advantages. For our purpose (using the questionnaire as a self-reported outcome in a repeated measures intervention study with PWA), the CARA questionnaire (as described by Webster et al., 2021) was most suitable: Its comprehension demands are reduced to a minimum due to its aphasia-friendly design, it is quick and easy to administer, and its psychometric properties are appropriate. Its focus on current reading without items on pre-stroke reading is not only in line with the preferences of PWA (Webster et al., 2021) but also with our objective to monitor change in post-stroke reading. Furthermore, it includes items on different reading materials, which is important because the perception of difficulties differs subject to the material (Webster et al., 2021). As opposed to Knollman-Porter et al. (2015),

the CARA questionnaire does not include questions on settings and frequency of specific reading activities. However, the frequency of reading experiences seems to be less important to PWA than their meaningfulness (Knollman-Porter et al., 2015). The CARA questionnaire captures a broad range of individually meaningful reading activities regardless of their frequency, while the rating option 'not applicable' still allows identification of irrelevant activities.

Thus, the objective of this study was to translate and adapt the CARA reading questionnaire (as described in Webster et al., 2021) to German, to evaluate its practicability and acceptance, and to provide first psychometric properties from German-speaking PWA. Furthermore, Webster et al. (2022) conducted correlational analyses between self-reported scores on the questionnaire and performance-based assessments of single-word, sentence and paragraph reading comprehension. Despite some trends, the relationship between those reading measures and the personal perception of reading was not significant (Webster et al., 2022). Some PWA present with outcomes within the normal range in basic linguistic abilities, but still report difficulties in text level reading comprehension (Chesneau & Ska, 2015). So far, the relationship between outcomes of the CARA questionnaire and text level reading comprehension with regard to texts exceeding the paragraph level has not been investigated. Chesneau (2012) states that in reading assessments, reading speed sometimes remains the only indicator of text comprehension impairments. Reading speed in text level silent reading in PWA is often slower (but may sometimes also be faster) compared with healthy controls (Meteyard et al., 2015). Problems in reading speed and efficiency were also reported by five out of six participants in Knollman-Porter et al. (2015). In fact, more than 70% of PWA are not or not completely satisfied with their reading speed (Webster et al., 2021). Qualitative studies suggest a connection between reading speed and reading activities: Effortful and slow reading as well as the necessity to re-read information hinders some PWA from accessing materials they enjoyed before aphasia (Webster et al., 2018). Given this potential impact of reading speed on reading activities, on personal perception of reading abilities and on reading-related emotions, we investigated the relationship between the questionnaire's outcomes and text level reading comprehension (accuracy and reading speed).

In the following sections, we present translation and adaptation procedures based on Wild et al. (2005). Furthermore, we report on first psychometric properties, the relationship between the personal perception of reading and performance-based outcomes in text-level reading comprehension, as well as the potential use of the German version.

MATERIALS AND METHODS

CARA questionnaire

The original English version of the CARA questionnaire (as described by Webster et al., 2021) is a part of the CARA (Morris et al., 2023) which also provides performance-based subtests on single word, sentence and paragraph-level reading comprehension. The questionnaire was developed based on a literature review, an interview study with 10 participants, consultation with PWA, pilot testing, data acquisition with 81 participants and a review. It was designed to be evidence-based, informed by a holistic perspective on reading as suggested by the ICF (WHO, 2005) and accessible for PWA (minimal need for reading, picture support, simple instructions, applicable with non-verbal responses). The final version consists of three sections:

- Section A (current reading) focuses on current reading ability and difficulties. The items are introduced by the phrase ‘At the moment, how difficult do you find reading and understanding’, followed by ‘single words/short sentences/paragraphs/a book/reading aloud/concentrating on reading/remembering what you have read’. PWA indicate their perception on a five-point rating scale ranging from ‘impossible’ to ‘no problem’ with smileys as visual support at both endpoints.
- Section B is entitled ‘thoughts and feelings about reading’. The seven items take into account thoughts and feelings such as finding reading enjoyable, easy or important, feeling confident, satisfied with reading speed, motivated or happy to try to read. Responses are indicated on a five-point rating scale ranging from ‘no’ to ‘yes’ with the same visual support as in section A (current reading) at both endpoints.
- In section C (reading activities), PWA sort picture cards representing 15 different reading materials such as labels, signs, letters or newspaper articles on four descriptors depending on their level of difficulty (impossible/avoid, trying to read but difficult, trying to read but ok, no problem). The option ‘not applicable’ allows people to indicate if an activity is not relevant, for example, they never read timetables.

For each section, the points add up to a section score. PWA indicate their answers non-verbally but can provide verbal comments alongside the ratings. SLTs mark the responses on a scoring sheet and note additional comments. Analyses of the psychometric properties of the

CARA questionnaire demonstrated appropriate validity and reliability (Webster et al., 2021) (Table 1).

Translation and adaptation procedures

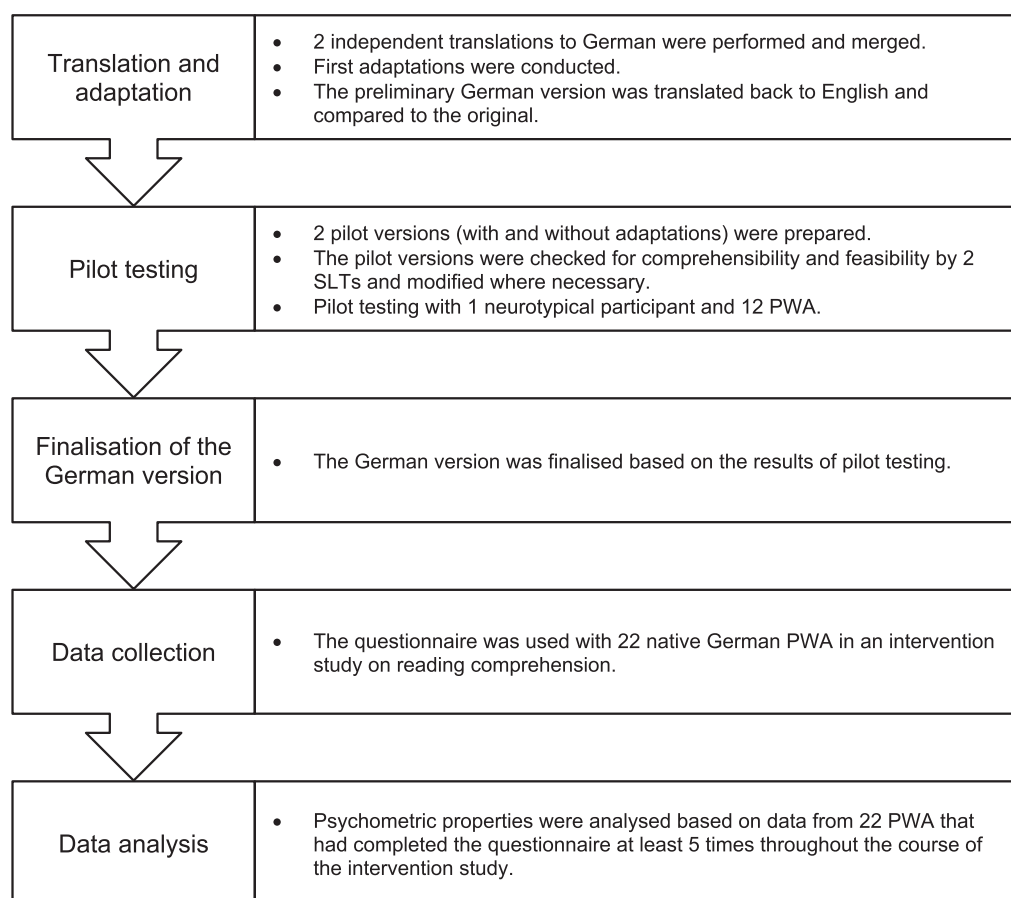
The quality of translated and adapted diagnostic instruments is influenced by translation and adaptation methods. Procedures may include only a forward translation (translation of the original language version into the target language). However, Maneesriwongul and Dixon (2004) suggest the inclusion of a back translation (translation of the new target language version back into its original language) and testing in the target language including measures of internal consistency to enhance quality. Therefore, we based our translation and adaptation procedures on the steps outlined in Principles of Good Practice for the Translation and Cultural Adaptation Process for Patient-Reported Outcomes Measures (Wild et al., 2005) which include two independent forward translations, a back translation and pilot testing. In addition to these principles, we analysed first psychometric properties based on data from an intervention study described in Thumbek et al. (2021). Figure 1 presents an overview of the realized workflow for translation and adaptation as well as the subsequent analysis of psychometric properties.

Table 2 presents the steps and critical components that were conducted based on Wild et al. (2005). In addition to the authors of the present study, three further SLTs and two translators were involved in these procedures. They were recruited by contacting translators and SLTs in Munich and Erfurt. We completed all 10 steps apart from step 6, harmonization, which was not applicable as it requires harmonization with other translated versions that do not exist (Table 2). Furthermore, we modified the following steps: (1) We added steps 3a (proofreading) and 3b (adaptation) to reach semantic, idiomatic, experiential and conceptual equivalence (Beaton et al., 2000); (2) as Wild et al. (2005) present flexible procedures for step 7 (cognitive debriefing), we defined steps 7a–c to clarify our procedures. As required in step 10, we will describe each step in more detail in this section. Further testing of psychometric properties of the adapted version was informed by Beaton et al. (2000) and by the International Test Commission’s Guidelines for Translating and Adapting Tests (2018).

In step 1 (preparation), the lead author of the CARA questionnaire paper (Webster et al., 2021), JW, gave permission and agreed to be involved in the instrument translation process. Explanations of concepts were provided in Webster et al. (2021). ST was determined as key in-country person.

TABLE 1 Psychometric properties of the original CARA reading questionnaire as described in Webster et al. (2021)

Construct validity	Based on a literature search, an interview study, discussions with PWA, a pilot study and a review
Face validity	PWA considered the items of the questionnaire as relevant for reading
Construct validity and reliability	Substantial loading (> 0.40) of all responses in exploratory factor analysis, good internal consistency (Cronbach's alpha = 0.932)
Test-retest reliability	28 participants, significant strong positive correlation ($r_s(26) = 0.927, p \leq 0.001$)

**FIGURE 1** Workflow in constructing and evaluating the German version of the CARA reading questionnaire

In step 2 (forward translation), two independent forward translations (F1 and F2) of the items, the instructions and the scoring sheet were created, the first forward translation (F1) by ST and the second forward translation (F2) by a professional translator with a master's degree in translation studies. Both translators are native German speakers, reside in Germany and are certified in English proficiency on C1-level according to the Common European Framework of Reference for Languages. ST is an

SLT and has clinical experience with the target group of German-speaking PWA. Both forward translators were provided with the explanations of concepts available in Webster et al. (2021). To preserve the accessibility for PWA, the translators were instructed to consider psycholinguistic parameters such as word frequency, typicality, familiarity and age of acquisition, to keep sentences short, and to avoid subordinate clauses as well as object topicalization.

TABLE 2 Steps and critical components in the translation and cultural adaptation of the CARA reading questionnaire into German based on Wild et al. (2005)

Steps	Critical components	Involved persons
1. Preparation	<ol style="list-style-type: none"> 1. Obtain permission to use the instrument 2. Invite the instrument developer to be involved 3. Develop an explanation of the concepts in the instrument 4. Recruit key in-country person(s) to the project 	JW ^a ST ^b determined as key in-country person
2. Forward translation	<ol style="list-style-type: none"> 1. Development of at least two independent forward translations (into German) 2. Provision of an explanation of the concepts in the instrument to the key in-country person(s) and forward translators 	Two forward translators: ST ^b Professional translator ^c
3. Reconciliation 3a. Proofreading ^e 3b. Adaptation ^e	Reconciliation of the forward translations into a single forward translation To preserve content validity and reach a maximum amount of semantic, idiomatic, experiential and conceptual equivalence, the merged forward translation was proofread, and possible adaptations with regard to the target population were discussed	Both forward translators including ST ^b , JW ^a , FD ^d
4. Back translation	Back translation of the reconciled translation into the source language (English)	Professional translator ^f
5. Back translation review	Review of the back translation against the source language	JW ^a , ST ^b
6. Harmonization	Harmonization of all new translations with each other and the source version	Not conducted
7. Cognitive debriefing	Cognitive debriefing of the new translation with at least five patients drawn from the target population to explore alternative wording, comprehensibility, interpretation and cultural relevance	
7a. Preparation of two pilot versions	One pilot version without adaptations and one pilot version with adaptations were prepared to discuss alternatives with PWA	JW ^a , ST ^b
7b. Check for comprehensibility and feasibility	Pilot versions were checked by SLTs with clinical experience	Two German native SLTs including FD ^c
7c. Pilot testing	One neurotypical participant and 12 PWA completed the pilot versions and answered a questionnaire on alternative wording and procedure options	Three German native SLTs including ST ^b
8. Review of cognitive debriefing results and finalization	Cognitive debriefing results were reviewed and the translation finalized	JW ^a , ST ^b , FD ^c
9. Proofreading	Finalized translation was proofread	FD ^c
10. Final report	Report on the development of the translation	JW ^a , ST ^b , FD ^c

Notes:

^aJW: an SLT with clinical experience, native English, first author of the article on the original CARA reading questionnaire.

^bST: an SLT with clinical experience, native German, C1-level proficiency in English.

^cProfessional English—German translator: a native German, C1-level proficiency in English.

^dFD: an SLT with clinical experience, German native.

^eAdditional steps based on Beaton et al. (2000).

^fProfessional German—English translator: a native English, C1-level proficiency in German.

In step 3 (reconciliation), ST and the second forward translator discussed the two forward translations F1 and F2. ST merged them into one forward translation (F1/F2) and consulted JW in case of alternative wording options that resulted in different meaning. This merged forward translation (F1/F2) was then proofread by FD. We conducted first adaptations leading to version F1/F2A: Inspired by the Reading Confidence and Emotions Questionnaire (Cocks et al., 2013), we added the items ‘A.8 How

difficult do you find talking about what you read?’ and ‘B.8 Do you get angry if there is something you cannot read?’ Based on clinical experience with German-speaking PWA, we included the option to talk about negative emotions even though the English speaking PWA preferred to focus on positive emotions. We added instructions for assessors to enhance standardized procedures. In the original five-point scales in section A (current reading) and B (thoughts and feelings about reading), PWA may chose midpoints

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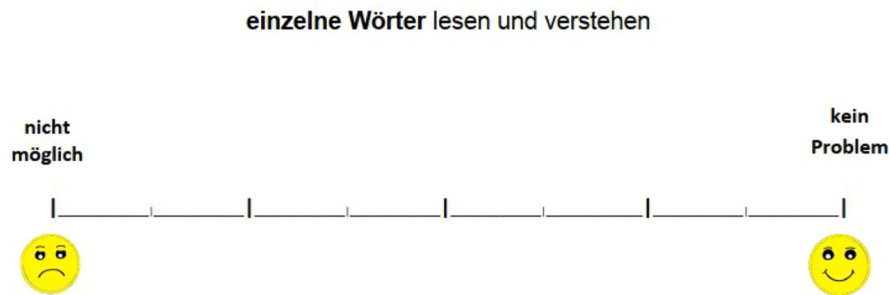


FIGURE 2 Exemplary item that demonstrates the nine-point scale and allows PWA to indicate their answer in a non-verbal way between 'nicht möglich' (impossible) and 'kein problem' (no problem) [Colour figure can be viewed at wileyonlinelibrary.com]

in between two points. To enhance accessibility as well as sensitivity, we visualized these midpoints resulting in nine-point scales (Figure 2).

In step 4 (back translation), a professional native English translator translated the merged and adapted forward translation (F1/F2A) back to English (version B). The translator has a master's degree in applied languages and translation studies and is certified on a C1-level in German. She was provided neither with the original CARA questionnaire nor with its description in Webster et al. (2021). She was instructed to aim for semantic and conceptual equivalence and to use easy wording. The target group of the questionnaire was described as adults with language difficulties due to stroke.

In step 5 (back translation review), JW and ST independently reviewed the back translation (B) and compared it to the original version. Despite differences in wording, no semantic or conceptual differences were revealed. In section C (reading activities), the category of 'not applicable' had been translated to 'unimportant'. To ensure that it was 'unimportant' due to interest/need rather than ability, we added instructions to ask the PWA why this answer was selected. This ensured the rating should not have been 'impossible/avoid'. As the original CARA questionnaire is part of a bigger reading assessment and has no introduction specifically for the questionnaire, we added an introduction to explain the objectives of the questionnaire. In accordance with the original, we added a simplified written version of the verbal instructions to the patient version. English language black and white drawings of reading materials in section C (reading activities) were substituted by German language versions.

Step 6 (harmonization of new translations) was not applicable as no translations into other languages than German were available.

Rationales of step 7 (cognitive debriefing) were to assess the level of comprehensibility, to test translation alternatives and to identify issues that cause confusion. In accordance with JW, in step 7a, we developed two pilot versions (P1 without adaptations, P2 with adaptations) including exemplary items to demonstrate possible adaptations as well as wording and procedure alternatives. We prepared a questionnaire to ask PWA for their preferences. In step 7b, two experienced German SLTs commented on the comprehensibility and feasibility of the two pilot versions. Table A1 in Appendix A shows the adaptation options explored in the final pilot version P2 and in the exemplary items. In step 7c, we performed pilot testing with one neurotypical participant and 12 PWA. Inclusion criteria for participation in pilot testing were aphasia regardless of severity and time post-onset, German as a native language, and age of at least 18 years. We did not include persons with uncorrected impairment in vision or hearing, additional neurological or psychiatric diseases (e.g., schizophrenia, Parkinson's disease, dementia), or pre-morbid dyslexia. Participants were recruited by contacting SLTs in Munich, Germany. Three SLTs participated in data collection in their regular practice rooms. All PWA were able to complete one of the pilot versions and the questionnaire on alternative wording and procedure options including the opportunity to suggest further modifications.

In step 8 (review of cognitive debriefing results and finalization), we then finalized the German version according to the results of pilot testing and in collaboration with JW. Final adaptations along with rationales and decisions in wording and procedures are presented in Table A1 in Appendix A. The final version contains eight items in section A (current reading), eight items in section B (thoughts and feelings about reading) and 16 items in section C (reading activities). Participants rate all items by pointing on a

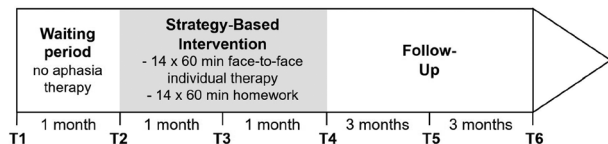


FIGURE 3 Study design; T1–T6 represent assessments

scale with visual support at the extremes. Main changes compared with the original version are: (1) visualization of mid-points resulting in a nine-point scale (as opposed to a five-point scale; see Figure 2 for an example); (2) two additional items (A.8 At the moment, how difficult do you find talking about what you read?; B.8 Do you get angry if there is something you cannot read?); (3) sorting procedures in section C (reading activities) were changed to rating procedures congruent with the procedures and the visualized rating scales in section A (current reading) and section B (thoughts and feelings about reading)—the option ‘not applicable’ is presented in a box below the rating scale; and (4) in section C (reading activities), the item ‘computer’ was split into two items (i.e., e-mail and websites).

As required in step 9 (proofreading), the final version was proofread by FD.

The final report, step 10 (report on the development of the translation), is presented in this article.

DATA COLLECTION

In the previous section, we outlined the translation and adaptation procedures. Despite high-quality procedures, cross-cultural adaptation may affect psychometric properties. For the retention of psychometric properties, it is therefore recommended to conduct further testing of the adapted version (Beaton et al., 2000). We analysed data collected during a repeated measures intervention study targeting text level reading comprehension (Thumbeck et al., 2021). In addition to the analyses of psychometric properties, we investigated the relationship between the self-reported outcome of the questionnaire and performance-based outcomes on text level reading comprehension (accuracy and reading time).

Study design

The study was approved by the ethics committee of *Deutscher Bundesverband für akademische Sprachtherapie und Logopädie* (reference number 20-10074-KA-Munm Erw+Ko). Data acquisition during the intervention was preregistered on *Deutsches Register Klinischer Studien* (DRKS; DRKS00021411). Figure 3 shows a simplified version of the trial design (for details, see Thumbeck et al., 2021).

The finalized version of the questionnaire was used at six assessments (T1: before a 4-week waiting period, T2: after the waiting period/before the intervention period, T3: in the middle of the intervention period, T4: after the intervention period, T5 and T6: follow-up assessments). At T2 and T4 (i.e., before and after the intervention), reading comprehension was measured with additional tools such as the subtest Text Reception of the MAKRO Screening (Büttner, 2018). The intervention consisted of teaching reading strategies that focused on the situational model, macrostructure, microstructure and surface structure. The strategies (use of advance organizers, summarization and re-reading, asking questions and providing answers, using referential links and elaboration) were applied in 14 face-to-face sessions, of 60 min each, plus homework, according to a treatment protocol provided in Thumbeck et al. (2021).

Participants

We analysed data of 22 persons with post-stroke chronic aphasia or residual aphasia across different syndromes and of varied severity (excluding global aphasia and severe problems in written language; $n = 22$ up to T5, $n = 19$ at T6 as three participants dropped out before the second follow-up). Inclusion and exclusion criteria for participating PWA are listed in Table 3. Participants had to provide written informed consent prior to inclusion. Table 4 summarizes information on the participants.

Setting

Participants were recruited between December 2020 and July 2021 all over Germany with a regional focus on rural and urban Munich by contacting rehabilitation centres, support groups and newsletters of professional SLT associations. Intervention and assessment sessions were conducted until June 2022 in settings licenced by the German public health insurance system by 12 qualified SLTs including ST and by four supervised SLT students. COVID measures (e.g., face masks) were implemented according to state regulations.

Outcome measures

Outcomes extracted from the larger dataset were the German version of the CARA questionnaire, the subtest Text Reception of the MAKRO Screening (Büttner, 2018) and participant descriptors (i.e., age, gender, education, history of aphasia).

TABLE 3 Inclusion and exclusion criteria

Inclusion criteria	<ul style="list-style-type: none"> • Age: at least 18 years • Aphasia according to the <i>Aachener Aphasia Test</i> (AAT) (Huber et al., 1983) OR no current symptoms/only residual aphasia according to the latest AAT assessment but previously diagnosed aphasia and current language difficulties (subjective or perceived by an SLT) • Scores outside the normal range in the German version of the <i>Test de Compréhension de Textes</i> (TCT-D; Chesneau, 2012) • Native language: German • At least 3 months post-onset
Exclusion criteria	<ul style="list-style-type: none"> • Global aphasia AND/OR severe problems in word-level reading (score < 12 in the AAT subtest 'single word reading comprehension') AND/OR severe problems in written language more generally (score < 22 in the category 'written language' in the AAT) • Neurological, psychiatric or any other disease that impedes a (repeated) assessment and valid interpretation with the AAT or TCT-D (particularly if the disease can result in decreasing or strongly fluctuating linguistic or cognitive performance) • Pre-morbid dyslexia

TABLE 4 Details of participants included in the analyses

Age	Mean = 58.6 yearsSD = 10.6Range = 28.5–76.3 years
Gender	13 male, 9 female
Formal education	Eight less than 12 yearsFourteen 12 years or more
Age at onset of aphasia	Mean = 52.4 yearsSD = 13.2Range = 13.3–74.5 years
Time post-onset	Mean = 6.2 yearsSD = 6.3Range = .5–25.7 years
Aphasia syndrome according to AAT (Huber et al., 1983)	2 Wernicke5 Broca5 Amnesic2 Not classifiable5 No or residual aphasia3 Unknown

At all assessments T1–T6, participants completed the German version of the CARA reading questionnaire. In accordance with the original total score summation procedures, we calculated individual section scores and total scores by adding up the points indicated by the participants on the visual scales in each section or across all items, respectively. In the adaptation procedures, two items that do not exist in the original version were added to section A (current reading; item A8) and section B (thoughts and feelings about reading; item B8). To allow a direct comparison of psychometric properties of the English and the German version, we also calculated section scores excluding these additional items. In section C (reading activities) we calculated the total score as presented in the original version. However due to the 'not applicable' option, each participant selected and rated a different number of reading activities. To account for this, we additionally calculated a proportion measure $C_{\text{individual}}$ (C_{ind}) by dividing the total score of section C (reading activities) by the number of selected activities.

At assessments T2 and T4, the participants completed the subtest Text Reception of the MAKRO Screening (Büttner, 2018). This subtest provides two parallel versions in which the participants read a narrative text and answered 10 written single-choice questions (five each on implicit

and explicit information). Participants were instructed to read the text silently at their own pace and to answer follow-up questions without looking back into the text. For analyses, we used the outcomes (1) total score (representing reading comprehension accuracy; each correct answer was rated with 3 points, adding up to a total possible score of 30 points); and (2) reading time (the time taken by a participant to read the text, measured in seconds) (Büttner, 2018).

Data analysis

Test–retest reliability was analysed with Spearman's correlation coefficient between assessments T1 and T2 (i.e., before and after the waiting period), internal consistency with Cronbach's alpha coefficient for data from assessment T1. Within section C (reading activities), across all participants, 38 items (out of 352) were rated as 'not applicable'. For internal consistency analysis, rather than code as 0 which may result in unwarrantedly reduced internal consistency, items were coded as the individual mean rating of this section (C_{ind}). Internal responsiveness—the ability to detect change—was analysed using the standardized response mean (SRM) effect size which is defined as

the ratio of observed change and the standard deviation in the change score. High SRM values therefore indicate high mean change in relation to a low level of variability (Husted et al., 2000). We used mean change between T1 (before the waiting and the intervention periods) and T4 (after the waiting period and 14 sessions of strategy-based intervention). SRMs should be interpreted with regard to the correlation coefficient between respective repeated measurements (Middel & Van Sonderen, 2002). Furthermore, we addressed internal responsiveness by comparing measures from T1 and T4 with the Wilcoxon test for paired samples. Analyses were conducted with IBM SPSS Statistics for Windows, version 28.0 (IBM Corp., Armonk, NY, USA). Furthermore, we conducted repeated measures correlations using *R* (R Core Team, 2022) with the package *rmcorr*, *R* package version 0.4.6 (Bakdash & Marusich, 2017, 2022). The repeated measures correlation coefficient r_{rm} can be used for non-independent observations (e.g., in repeated measures designs) and ranges between -1 and 1 . It increases statistical power compared with using data from only one assessment and is more appropriate than averaging individual outcomes across more than one assessment (Bakdash & Marusich, 2017). We used repeated measures correlations to analyse correlations between the three different CARA sections and to explore relationships between the questionnaire and MAKRO Text Reception outcomes (i.e., MAKRO Text Reception total score, reading time; Büttner, 2018). Additional comments or explanations made by participants while rating items in the German version of the CARA questionnaire were not analysed but are used for illustrative purposes in the Discussion.

RESULTS

In this section, we first present descriptive results of the German version of the CARA questionnaire about the perception of reading in the German sample. Then, we describe the results of data analyses with regard to (1) psychometric properties and (2) the relationship between personal perception of reading (i.e., results in the German version of the CARA questionnaire) and performance-based text comprehension measures (i.e., results in the MAKRO Screening, subtest Text Reception; Büttner, 2018).

Perception of reading

Participants' ratings at the first assessment (T1) are depicted in Figure 4 (section A, current reading), Figure 5 (section B, thoughts and feelings about reading) and Figure 6 (section C, reading activities).

The perception of difficulties in reading was related to the length and complexity of reading material. In section A (current reading), reading abilities rated as easiest to perform were reading and understanding single words, short sentences and reading aloud whereas reading and understanding paragraphs and books as well as remembering, concentrating and talking about what was read were perceived most difficult by PWA.

As the results of section B (thoughts and feelings about reading) show, PWA may not always feel confident in reading or satisfied with their reading speed. Reading is not perceived as an easy task and PWA may experience anger when not being able to read something. Nevertheless, reading is considered very important and PWA may find reading enjoyable and be motivated and happy to try reading.

As shown by the results of section C (reading activities), individual participants in this study perform a range of reading activities. Reading activities related to technologies such as computers or cell phones were not relevant for everyone in this sample. Activities perceived as most difficult were reading and understanding books, instructions, newspaper articles, formal letters and websites.

Psychometric properties

Table 5 summarizes the results of our analyses on the questionnaire's psychometric properties. For sections A (current reading) and B (thoughts and feelings about reading), we present results for two analyses each, one including and one excluding items A8 and B8 which are not part of the original English version.

We found significant positive correlations between initial assessment and retest after 4 weeks without therapy (total score sections A–C, $r_s(21) = 0.746$, $p < 0.001$) indicating acceptable retest reliability. Retest reliability was high for sections A (current reading) and B (thoughts and feelings about reading). Although significant, retest reliability was lower for section C (reading activities) suggesting that selected reading activities may fluctuate over time (e.g., adverts and leaflets might be thrown out at the time of one assessment but read at the time of another assessment, or text messages might not be read initially but participants may have read a family member's text message before retest). To take this into account, we calculated C_{ind} (total score section C divided by the number of actually selected activities, excluding 'not applicable'). C_{ind} should represent a participant's overall ability to perform the individually relevant reading activities and has higher retest reliability ($r_s(21) = 0.725$, $p < 0.001$) than the total score of section C (reading activities) which does not take into

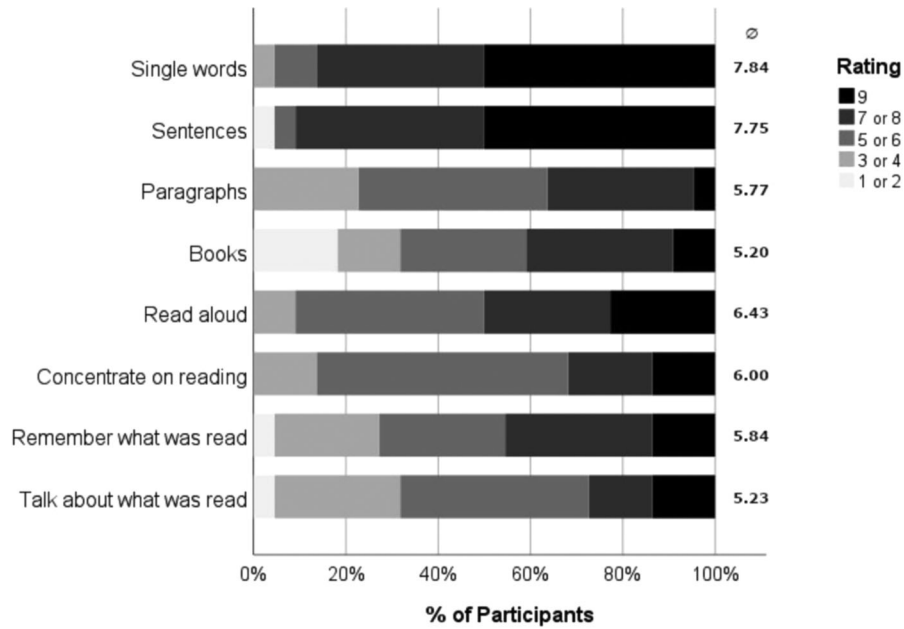


FIGURE 4 Section A (current reading): Distribution of ratings across participants; 1 = impossible, 9 = no problem; Ø = mean rating of the group for each item; *n* = 22

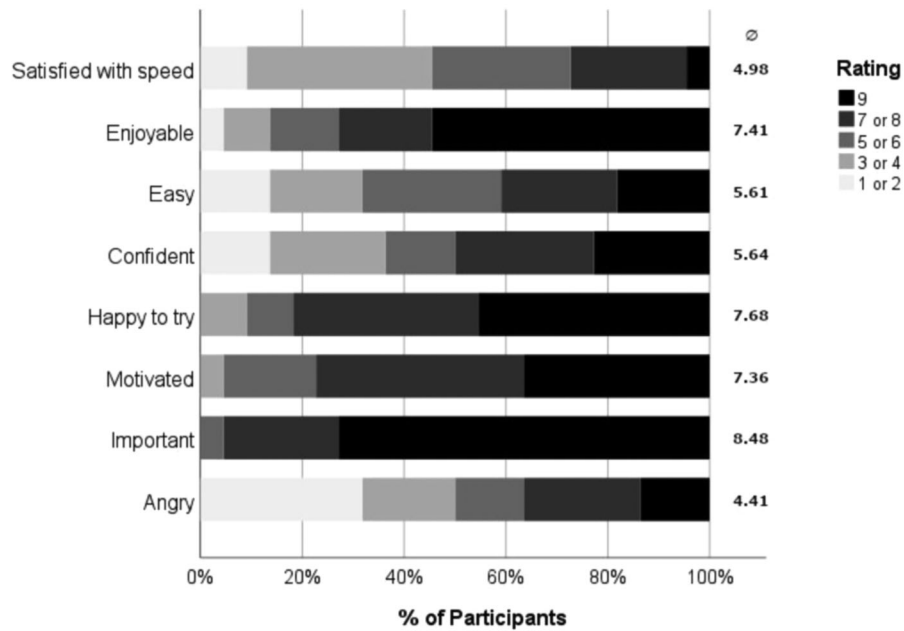


FIGURE 5 Section B (thoughts and feelings about reading): Distribution of ratings across participants; 1 = no, 9 = yes; Ø = mean rating of the group for each item; *n* = 22

account the number of activities selected ($r_s(21) = 0.595, p = 0.004$).

Overall, our results suggest the questionnaire is responsive and can detect change: Between T1 and T2 after four weeks without therapy, SRM values were trivial to small, and no significant differences were detected in the Wilcoxon signed-ranks test. However, analyses with pre- and post-intervention scores from assessments T1 and T4 demonstrate a large SRM of 1.467 in the total score and

significant increases in post-intervention median scores in the Wilcoxon signed-ranks test, which supports the assumption that therapy-induced change in the individual perception of reading abilities, emotions and activities can be measured with the German version of the CARA questionnaire.

Internal consistency was analysed with Cronbach's alpha (Table 5) as well as with correlations between the sections (Table 6). The total score (sections A–C) showed

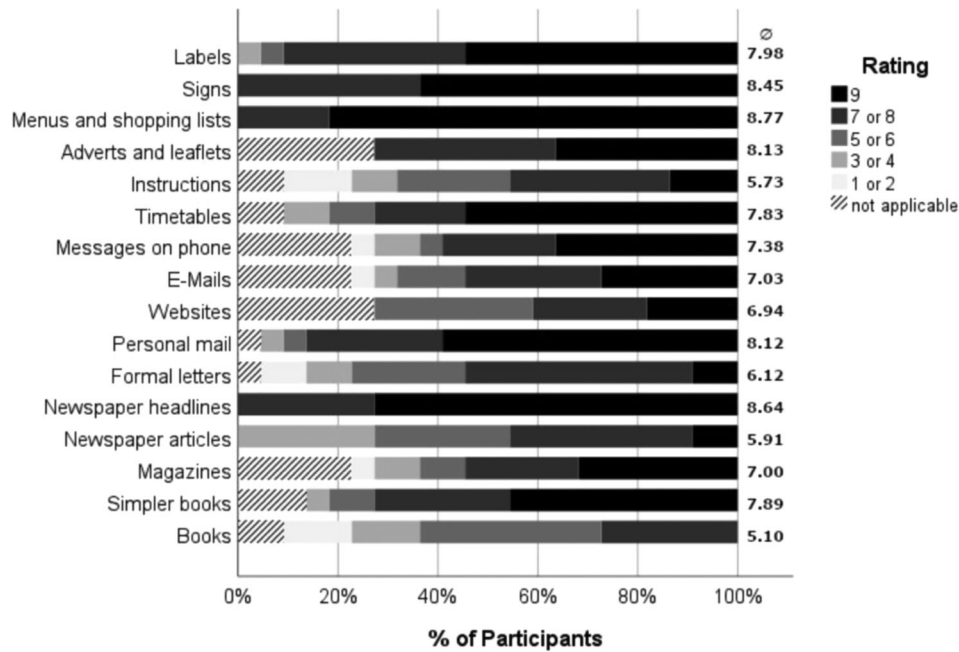


FIGURE 6 Section C (reading activities): Distribution of ratings across participants; 1 = impossible, 9 = no problem; Ø = mean rating of the group for each item; $n = 22$

good internal consistency (Cronbach's $\alpha = 0.888$). Repeated measures correlations between the adapted sections A–C based on data from six assessments (22 participants up to T5, 19 participants at T6) revealed moderate to strong significant positive correlations between the sections.

Relationship between personal perception and text comprehension

Results in the MAKRO subtest Text Reception (total score, reading time; Büttner, 2018) are presented in Table A2 in Appendix A. Repeated measures correlations between the outcomes in the German questionnaire and the outcomes in MAKRO Screening revealed significant negative correlations with reading time, but not with MAKRO Text Reception total score. Results are presented in Table 7.

DISCUSSION

Perception of reading

The German version of the CARA questionnaire is the first German language tool to assess individual perceptions of reading and to investigate change in reading in aphasia in a person-centred way. It measures self-reported perceptions and—if used repeatedly—change in reading performance, in thoughts and feelings about reading, and in everyday life reading activities. With a mean rating of 8.5 out of 9

in importance of reading, the data of our participants confirm the importance of reading in everyday life for PWA despite difficulties and reduced confidence in their own reading abilities. For our German-speaking participants, as for the English speaking PWA in Webster et al. (2021), reported problems in reading and understanding increased with increasing length and complexity of content. Understanding paragraphs or books as well as concentrating, remembering and talking about what was read was perceived more difficult than understanding single words or short sentences. The self-reported individual difficulties in concentrating and remembering what was read corroborate findings on complex interactions between linguistic and cognitive functions outlined in previous work on reading in aphasia (e.g., Meteyard et al., 2015). When rating items with regard to cognitive functions, some participants explained that they could read, for example, one page in a newspaper but would not be able to concentrate on a second page, they would get distracted by surrounding noise, or they would understand content while reading but would have trouble remembering it.

Psychometric properties

The realized translation and adaptation procedures included back translation as well as testing in the target language with analysis of internal consistency and thus fulfil recommendations by Maneesriwongul and Dixon (2004). First psychometric properties analysed with data from 22 German-speaking PWA suggest appropriate

TABLE 5 Psychometric properties of the adapted German version of the CARA reading questionnaire

Score	Retest reliability	Internal consistency	Internal responsiveness		
Analysis	Spearman correlation	Cronbach's alpha	SRM ^a	SRM ^a	Wilcoxon test for paired samples
Data based on assessments	T1 ^b , T2 ^c	T1 ^b	T1 ^b , T2 ^c	T1 ^b , T4 ^d	T1 ^b , T4 ^d
Total score (sections A–C)	$r_s(21) = 0.746$ $p < 0.001$	0.888	0.238	1.443	T1 median = 206.50 T4 median = 235.75 $Z = -3.880$ $p < 0.001$
Section A: Current reading					
Adapted German version (A1–A8)	$r_s(22) = 0.718$ $p < 0.001$	0.746	0.097	1.030	T1 median = 48.00 T4 median = 57.00 $Z = -3.529$ $p < 0.001$
German version, CARA items only (A1–A7)	$r_s(22) = 0.760$ $p < 0.001$	0.687	0.059	0.990	T1 median = 43.50 T4 median = 50.25 $Z = 3.495$ $p < 0.001$
Section B: Thoughts and feelings about reading					
Adapted German version (B1–B8)	$r_s(22) = 0.748$ $p < 0.001$	0.783	0.184	0.776	T1 median = 52.00 T4 median = 56.00 $Z = -3.070$ $p = 0.001$
German version, CARA items only (B1–B7)	$r_s(22) = 0.781$ $p < 0.001$	0.802	0.197	0.701	T1 median = 47.25 T4 median = 54.50 $Z = -2.835$ $p = 0.003$
Section C: Reading activities					
Adapted German version (C1–C16)	$r_s(21) = 0.595$ $p = 0.004$	0.866	0.232	0.921	T1 median = 103.50 T4 median = 118.00 $Z = -3.117$ $p < 0.001$
C_{ind}^e	$r_s(21) = 0.725$ $p < 0.001$	n.a.	n.a.	n.a.	T1 median = 7.34 T4 median = 7.98 $Z = -2.971$ $p = 0.002$

Notes:

^aSRM, standardized response mean.^bPre-therapy.^cPre-therapy reassessment, $n = 21$ in section C and in total score due to missing data in section C for one participant.^dPost-therapy.^eC_{ind} = total score section C divided by the number of selected activities.

quality of the German version: All participants who were included in this study were able to complete the German version of the questionnaire. This suggests that the German version remains accessible across different severity degrees of aphasia. Apart from data analyses, construct and face validity of the original version were based on literature search, an interview study, discussions

with PWA, a pilot study and review, and items and design were constructed in collaboration with PWA. In addition to the items considered relevant by PWA in the original version, the German-speaking PWA involved in pilot testing felt a need to include an item taking into account the communicative dimension of reading (additional item A8) as well as an item regarding negative feelings (additional



TABLE 6 Internal consistency: Correlations between the sections of the adapted questionnaire

Section	A: Current reading	B: Thoughts and feelings
B: Thoughts and feelings	0.707*	
C: Reading activities	0.561*	0.505*
C_{ind}^a	0.684*	0.566*

Notes: Repeated measures correlation matrix; r_{rm} coefficient (Bakdash & Marusich, 2017, 2022).

^a C_{ind} = total score section C divided by the number of selected activities.

* $p < 0.01$ (two-tailed).

item B8). Besides, the answers to the questionnaire in pilot testing of the German version provide no reason to assume cultural differences in reading concepts and in the perception of reading abilities between English and German PWA, which suggests a similar face validity of the German version compared with the original version. In fact, no conceptual differences were revealed in the back translated German version compared with the original. We suggest conducting factor analysis in studies with larger sample sizes. With regard to objectivity and in line with the original version, the German version contains instructions and suggested wording for administration. Nevertheless, we point out that all efforts should be made to support understanding in the context of aphasia. As recommended in literature on test quality (e.g., Moosbrugger & Kelava, 2007), all reliability analyses with our first data from 22 PWA resulted in values larger than 0.7. The original version has somewhat better retest reliability ($r_s(26) = 0.927$, $p < 0.001$) and internal consistency (Cronbach's alpha = 0.932) than the adapted German version ($r_s(21) = 0.746$, $p < 0.001$; Cronbach's alpha = 0.888). This might be attributed to the change in scale (nine-point instead of five-point), the modified procedures in section C (reading activities) or the additional items A8 and B8 in the German version. At the same time, these adaptations might improve the questionnaire's capacity to detect smaller scale changes in individual perceptions in retest: In fact, including the adapted items A8 and B8 reduced retest reliability but increased SRM values, which indicates that—in the context of strategy-based reading interventions—these items are particularly sensitive to change. Due to their effect on responsiveness and the patients' comments in pilot testing, we recommend keeping items A8 and B8 in the German version. In section C (reading activities), the individual relevance of specific reading activities may change over time. Therefore, we recommend taking into account the individually selected range of reading activities by calculating C_{ind} (total score section C divided by the number of selected activities).

C_{ind} has better retest reliability than the regular score of section C (reading activities). Correlations between the sections are overall similar to the ones found for the original English questionnaire.

Relationship between text comprehension and personal perception of reading

Though expecting that reading comprehension accuracy could have some degree of influence on an individual's perception of reading, we found no significant correlation between the MAKRO Text Reception total score (as a measure of text comprehension accuracy; Büttner, 2018) and the personal perception of reading as captured in the questionnaire. There are several possible explanations: First, in line with our results, Webster et al. (2022) found no significant correlations (though tendencies) with performance-based measures of single-word, sentence and paragraph comprehension accuracy. Their case studies illustrate that persons with severe impairments in performance-based reading comprehension measures may nevertheless have high questionnaire scores, and vice versa (Webster et al., 2022). Personal perception may be influenced by the priority an individual attributes to reading, by a lack of awareness or by compensatory strategies: One of our participants who selected 'no problem' in reading newspaper articles or formal letters commented that whenever he experiences difficulties, he asks his wife for help. For some individuals, objective reading comprehension impairments may therefore not be perceived as a limiting factor in reading abilities, reading-related emotions and everyday reading activities, whereas for others, subtle objective reading comprehension impairments that may not even be detected in regular screenings may substantially impact the individual perception of reading. Second, MAKRO Text Reception requires the understanding of a narrative text. Many skills and activities in sections A and C are not at text level, for example, single words, sentences, signs, shopping lists or timetables. This may also partly account for the lack of a correlation between the two measures. A third possible explanation is that our sample consisted mostly of persons with moderate to residual aphasia. MAKRO was initially designed to measure moderate to severe macrostructural impairments in persons with dysexecutive symptoms (Büttner, 2018). The MAKRO Text Reception total score may not be sufficiently sensitive to differentiate across subtle or residual impairments. The lack of variation across participants in our sample, with performance at ceiling in the MAKRO Text Reception total score, may contribute to our findings. Finally, despite a generally high statistical power of repeated measures correlations, we should keep in mind that our sample was limited in size.

TABLE 7 Correlations between the German version of CARA questionnaire outcomes and MAKRO text reception outcomes (Büttner, 2018)

Outcome	MAKRO text reception total score	MAKRO text reception reading time
Total score: (sections A–C)	0.234	–0.527*
Section A: Current reading	0.118	–0.359
Section B: Thoughts and feelings	0.236	–0.475*
Section C: Reading activities	0.346	–0.521*
C_{ind}^a	0.358	–0.482*

Notes: Repeated measures correlation matrix; r_{tm} coefficient (Bakdash & Marusich, 2017, 2022).

C_{ind} = total score section C divided by the number of selected activities.

* $p < 0.05$ (two-tailed).

However, we found significant moderate negative correlations between the questionnaire (i.e., total score, section B, section C) and reading time in MAKRO Text Reception (Büttner, 2018). In line with qualitative studies (e.g., Webster et al., 2018), the results support the assumption that reading speed impacts an individual's perceived ability to read and to engage in specific reading activities. As described in the introduction, reduced reading speed is a common problem in aphasia. Interindividual differences in reading speed exist also in neurotypical readers, and reading speed measures have been shown to correlate with reading comprehension measures and with the amount of propositions recalled after reading (Kintsch & Keenan, 1973; Landerl & Reiter, 2002; Zimmermann et al., 2014). Reading speed captures mainly basic reading processes such as the automaticity of decoding (Kuhn et al., 2010; Zimmermann et al., 2014). A lower degree of automaticity requires the reader to shift attention and cognitive resources to decoding processes. In turn, less cognitive resources are available for higher level comprehension processes (Kuhn et al., 2010). The relevance of reading speed in the perception of how well a reading activity could be performed was illustrated by one of our participants: He commented that he was able to read and understand certain materials very well, but it would take him longer to do these activities and he would get tired after a certain length of material. Therefore, he did not want to select 'no problem' when rating certain—particularly longer—items. Despite perceiving himself as capable of reading and understanding accurately (as represented in the MAKRO Text reception total score), his reduced reading speed affected the perception of his reading. Taking more time to read written material in aphasia may on the one hand be a direct consequence of underlying impairments in linguistic and cognitive functions. On the other hand, reduced reading speed could also be interpreted in terms of speed–accuracy trade-offs and adaptation mechanisms in aphasia (Evans et al., 2019): Taking more time could contribute to better reading comprehension accuracy, but in case of an adaptation deficit, it is possible that taking more time does

not translate into meaningful improvements in accuracy. Evans et al. (2019) suggest that adaptation deficits may contribute to slowed performance in various language-related tasks in aphasia. In case of adaptation deficits in reading in aphasia, and in light of the correlation between reading speed and the self-rated perception of reading, it could be an interesting approach to train PWA to find appropriate reading time thresholds for specific reading activities (Evans et al., 2019). Overall, reading time may not only be a more sensitive measure than reading comprehension accuracy (i.e., MAKRO Text Reception total score) for mild and residual impairments as suggested by Büttner (2018), but it may also be an indicator for real-life difficulties in reading as perceived by an individual.

As described in the introduction, the A-FROM (Kagan et al., 2008) outlines the outcome domains participation, personal factors, cognitive and linguistic performance as well as environment. Each of these domains should be considered in outcome measurement. The results of the correlational analysis show that personal perception is not closely aligned to performance-based outcomes. The questionnaire captures (1) the personal perspective of cognitive and linguistic performance (section A, current reading), (2) personal factors such as attitudes and feelings (section B, thoughts and feelings about reading), and (3) the personal perception of participation (section C, reading activities). Thus, it essentially complements outcomes within other domains (e.g., performance-based subtests). Reading speed seems to be an interesting link between the domains cognitive and linguistic performance on the one hand and personal perceptions on the other hand. Furthermore, the A-FROM domain participation requires consideration of activities in relation to roles, responsibilities and relationships (Kagan et al., 2008). When using the German version of the questionnaire for goal-setting, it seems thus important to relate the activities presented in section C (reading activities) to these aspects of a person's life.

It is also important to keep in mind that finding significant change in a performance-based assessment does

not necessarily indicate a clinically significant change (i.e., change that is experienced as meaningful by an individual). The German version of the questionnaire (or specific items of it) could serve as a self-reported outcome measure and as an independent external anchor to which the results of performance-based outcome measures could be related to when defining their minimal important change value. This development of ‘Minimal Important Change benchmarks [...] should be a key research endeavour’ (Breitenstein et al., 2022, p. 25).

Clinical implications

The results of this study suggest three major clinical implications:

First, despite experienced difficulties in reading, reading remains important for the majority of PWA. As reading is relevant to participate in many different life domains, this study highlights the importance to include reading comprehension in aphasia assessment and therapy. The descriptive results suggest focussing not only on small linguistic units such as letters, words and sentences, but to consider longer and more complex material relevant for everyday life reading activities as well as cognitive functions relevant for reading.

Second, the results confirm that constructs measured by performance-based reading assessments (e.g., MAKRO Text Reception total score) are not the same as constructs measured by self-reported reading outcomes (e.g., CARA reading questionnaire). Whereas performance-based reading assessments evaluate specific isolated reading processes which are often located at the ICF level of body functions, self-reported reading outcomes reflect the application of these processes in everyday life reading. Personal perceptions might mirror not only objective difficulties, but also coping strategies when reading in individual settings with unique reading objectives and motivations. The importance to consider personal factors such as attitudes and feelings in outcome measurement has been clearly highlighted by PWA and their families (Kagan et al., 2008). Until now, no tool was available in German language to determine an individual’s perception of their reading. For intervention planning, goal-setting and success monitoring in aphasia therapy, the German version of the CARA questionnaire is thus an important complement to performance-based outcomes.

Third, correlations between text level reading speed and outcomes in the questionnaire highlight the importance of text level reading speed for a positive perception of reading experiences. Interventions could aim to speed up reading while keeping trade-offs in reading comprehension accuracy to a level that allows a satisfactory completion of a given reading activity. In favour of an increased reading

speed and a potentially more positive reading experience, it might be beneficial for certain reading activities to train PWA not to waste too much time with decoding elements irrelevant to the given activity and thus losing track of the bigger picture due to limited cognitive resources (Evans et al., 2019).

Limitations

It is important to acknowledge several general limitations of self-reported questionnaires: Despite their uncomplicated, efficient administration procedures and their value to assess an individual’s experience, self-reported outcomes may be influenced by wider feelings such as mood or other circumstances such as the mere presence of a researcher. They bear a risk of bias (i.e., social desirability bias, response bias), and inherent to rating scales, participants have limited flexibility to express themselves (Cohen et al., 1988; Demetriou et al., 2015). The authors of the original version addressed this problem as well as potential difficulties in understanding the questions of the questionnaire by including PWA during the construction of the questionnaire, by selecting relevant items together with the target group, and by using an aphasia-friendly format. Crucially, the use of a questionnaire and rating scales allowed people with limited verbal ability to express their views about reading. Combining the German version of the CARA questionnaire—as in the original CARA—with more objective performance-based subtests may be a way to balance out social desirability bias and response bias.

Another limitation of this study relates to the translation and adaptation procedures. Although the procedures fulfil requirements presented in corresponding guidelines, a pilot test with bilingual subjects who complete both language versions could have improved the quality even more (Maneesriwongul & Dixon, 2004). As this technique requires a substantial number of bilingual subjects (in this case German–English bilingual subjects with aphasia), it is used less frequently and would not have been feasible in this project.

Finally, the data used for the analyses of the psychometric properties of the German version is limited in sample size and was collected during an intervention study. Data collected during an intervention study may be subject to a response–shift bias as the intervention may have affected participants’ understanding and awareness of their reading abilities and difficulties (Rosenman et al., 2011).

SUMMARY AND CONCLUSIONS

In this study, we translated and adapted the CARA questionnaire (as described in Webster et al., 2021), a

person-centred English language reading questionnaire for PWA, into German. The translation and adaptation process included forward and back translation and involved persons of the target group. We analysed data of 22 PWA who completed the questionnaire multiple times throughout an intervention study. Our data suggest that the German version is practicable with PWA across broad aphasia severity ranges. The adapted German questionnaire demonstrates appropriate psychometric properties in validity and reliability analyses. While outcomes of the questionnaire did not correlate with performance-based measures of text level reading comprehension accuracy, we found moderate correlations with text level reading speed. This suggests that in interventions and assessments, reading speed should be considered as a potential factor contributing to everyday life reading experiences. As a self-reported tool, the questionnaire allows collection of information on personal perceptions which cannot be captured with other existing German instruments. The importance to include the outcome domain of personal identity, attitudes, feelings and individual perceptions has been stressed by PWA and their family members (Kagan et al., 2008). The German version of the CARA questionnaire is thus an important complement to tools which prioritize other outcome domains of the ICF (WHO, 2005) and the A-FROM (Kagan et al., 2008). In clinical therapy settings with PWA, the German version can be useful for person-centred goal-setting, intervention planning and measurement of self-reported change. In research, the questionnaire may also be used in combination with performance-based reading assessments to evaluate the efficacy of specific intervention methods.

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CONFLICT OF INTEREST STATEMENT

The authors declared no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

PATIENT CONSENT STATEMENT

The Participants Section also includes the information that participants had to provide written informed consent before inclusion. The information that "Patient consent for publication is not applicable as no details relating to individual persons have been included" is in no other section than section Patient Consent Statement.

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APPENDIX

TABLE A1 Adaptation options, rationales and decisions after pilot testing

Topic	Adaptation options	Rationale	Decision
Additional items	<ul style="list-style-type: none"> A.8 At the moment, how difficult do you find talking about what you read? B.8 Do you get angry if there is something you cannot read? 	Both items are inspired by Cocks et al. (2013). A.8 assumes a social dimension of reading and that reading inspires social interactions (Rosebrock & Nix, 2011)	Both items were included
Scale	Visualization of midpoints resulting in a nine-point scale instead of a five-point scale	To enhance accessibility as well as sensitivity to therapy-induced change	Nine-point scale
Procedure in section C	<ul style="list-style-type: none"> Pointing on a nine-point scale instead of a four-point sorting procedure Instructions: We suggest noting patients' comments on the scoring sheet and explaining that there could be answers such as 'trying to read but difficult' between the end points of the scale 	To have coherent procedures in all sections and to allow for a higher degree of differentiation when analysing change in repeated measurements	Nine-point scale
Additional examples	<ul style="list-style-type: none"> B.0 At the moment, do you find making a cup of tea or coffee easy? C.0 weather forecast 	Suggested by one of the reviewing clinical linguists, the original version provides an example for section A only	Examples were included
Alternative wording: scale descriptors	<ul style="list-style-type: none"> 'Ich versuche es, ist aber schwierig'/'schwierig' 'Ich versuche es und es geht mittelmäßig'/'mittelmäßig' 	Alternative wordings yielded in the discussion about the two independent forward translations	Longer version
Alternative wording: 'not applicable'	'trifft nicht zu'/'unwichtig'/'lese ich nie'/'brauche ich nie'	One of the reviewing clinical linguists suggested alternative and more common wording options	<i>Trifft nicht zu</i>
Alternative wording: Item C.7.	'Nachrichten auf dem Handy'/'SMS'/'Nachrichten'/'Textnachrichten'	Alternative wordings yielded in the discussion about the two independent forward translations	SMS
Alternative items	One item: computer versus two items: websites and e-mail	To differentiate reading activities on a computer	Two items: websites and e-mail

TABLE A 2 Results in MAKRO subtest text reception (Büttner, 2018); $n = 22$

	Assessment T2	Assessment T4
score (out of 30)	Total Mean = 25.5	Mean = 26.0
	Median = 27.0	Median = 27.0
	SD = 3.8	SD = 4.0
	Range = 18.0–30.0	Range = 18.0–0.0
	Below cut-off: $n = 9$	Below cut-off: $n = 9$
	Above cut-off: $n = 13$	Above cut-off: $n = 13$
Re tin	Mean = 217.4 s	Mean = 204.7 s
	Median = 142.5	Median = 146.0
	SD = 154.1	SD = 189.5
	Range = 65.0–599.0	Range = 61.0–928.0
	Longer than cut-off: $n = 10$	Longer than cut-off: $n = 10$
	Faster than cut-off: $n = 12$	Faster than cut-off: $n = 12$