Aphasiology

Establishing Consensus on a Definition of Aphasia: An e-Delphi Study of International Aphasia Researchers

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Abstract

Background: Definitions reflect the current state of knowledge about a health condition. An agreed definition of aphasia is central to the progression of the science and clinical practice relevant to aphasia.

Aim: To establish consensus on a definition of aphasia.

Methods & Procedures: A three-round modified e-Delphi study was conducted with aphasia researchers who were members of the Collaboration of Aphasia Trialists (CATs). In round one, participants were provided with a draft definition developed by the Societal Impact and Reintegration Working Group of CATs. Participants were asked whether they agreed with the definition and were asked to comment on any aspects that they perceived to require amendment. Comments were collated and analysed using inductive content analysis. In round two, participants were presented with the collated and de-identified results of the first round and the participants were asked to vote 'yes/no' on two contentious aspects of the definition. In round three, agreement on the revised definition was again sought using closed 'yes/no' voting. Consensus was defined *a priori* as at least 70% agreement by 80% of all CATs members. CATs membership fluctuated across the study period and ranged between 131 and 141 members.

Outcomes & Results: The proposed definition was *Aphasia is a communication disability due to an acquired impairment of language modalities caused by focal brain damage. Aphasia may affect participation and quality of life of the person with aphasia as well as their family and friends. Aphasia masks competence and affects functioning across relationships, life roles and activities, thereby influencing social inclusion, social connectedness, access to information and services, equal rights, and wellbeing in family, community and culture.*

Two main categories of proposed amendments to the definition were identified: (1) definition of aphasia as a communication disability versus a language impairment; and (2) definition of aphasia as being the result of a focal or diffuse lesion. After three rounds of surveys, consensus was unable to be achieved with an almost even split across participants on both amendment issues.

Conclusion: Further debate about the use of the term communication disability to describe aphasia and whether aphasia is a result of focal or diffuse lesions is required before consensus is again attempted.

Background

There is no universal agreement upon a definition of aphasia in research or clinical practice. Hence, the research literature uses the term “aphasia” to describe the language impairment of any acquired brain injury including dementia, stroke, traumatic brain injury and brain tumour. In practice, the term aphasia has been used to describe only the language impairment. The consequences of aphasia are not encompassed with the term and therefore it can restrict funding of services to people with aphasia.

A consistent definition allows for comparison of studies, enables better identification and treatment of aphasia in clinical practice, and would also make it easier to raise awareness if the definition used has the same meaning (Simmons-Mackie et al., 2020; Worrall et al., 2016). A consistent and coherent use of one definition is believed to support those familiar with aphasia, e.g. people with aphasia, clinicians, researchers, in explaining the relevance of providing accessibility and therapy as well as funding services, care and research (Elman et al., 2000). A definition that is compatible with well-known terms from the International Classification of Functioning, Disability and Health (ICF), a universal classification system to be used in health and health-related settings across disciplines and languages (World Health Organization, 2001) will also contribute to cross-cultural and cross-disciplinary understanding. The standardization of terminology within the ICF and within a definition of aphasia also allows for greater consistency in database records that affect funding for services including insurance eligibility. Consistency with ICF terminology also highlights the consequences of living with aphasia.

Definitions of health terms have to be periodically reviewed and updated based on advances in science and technology. For example, the definition of a stroke was updated in 2013 to include criteria that can be seen in advanced neuroimaging techniques (Sacco et al., 2013). An update of the definition of aphasia is proposed due to the widely accepted universal

framework of health, the ICF, as well as a better understanding of the effect of a language impairment in all aspects of life.

Aphasia Definitions through History

New knowledge and changing interprofessional interests in aphasia have influenced the definition of aphasia over the years. Numerous definitions of aphasia mirror specific historical landmarks in research, while others can be viewed as expressions of specific linguistic or neurological epistemologies.

Looking back at what is considered to be the new era in this field, the mid nineteenth century, aphasiology was established as a science and early theories of localisation became prominent including Paul Broca's theory of language lateralisation. Not until 1864 was the word aphasia used by Armand Trousseau replacing aphemia and other words describing parts of the symptom complex that characterises aphasia today (Tesak & Code, 2008). In the late nineteenth century the localisation theories were refined as more research about language centers in the brain took place together with emerging theories and models from psycholinguistics and neuropsychology (Tesak & Code, 2008).

Through the twentieth century, aphasia intervention became more established and new research techniques like neuroimaging and more robust research designs with control groups influenced how aphasia was defined. The complexity of aphasia revealed in the clinic has contributed to a multidisciplinary approach combining medical explanation models with psychological and linguistic models. In many of the different definitions, there are common characteristics in how aphasia is described. For example, aphasia is 1) a language impairment; 2) an acquired condition occurring after normal language acquisition; 3) of neurological origin and related to the central nervous system; 4) occurs after damage to the language

dominant hemisphere; and 5) affecting all language modalities, perhaps mentioning production and comprehension of oral and written language. A few examples of definitions reflecting this are:

> "*A general language deficit that crosses all modalities and is often characterized by other sequelae of brain damage. (Reduced available vocabulary, Impaired verbal retention span, Impaired perception and production of messages)*." (Schuell et al., 1964, p. 131).

> "*Aphasia refers to the disturbance of any or all of the skill, associations and habits of spoken or written language, produced by injury to certain brain areas that are specialized for these functions*." (Goodglass & Kaplan, 1983, p. 5).

However, many definitions also state that aphasia is caused by focal damage and is not due to general cognitive damage or decline. For example, Rosenbek et al. (1989) state that:

> "*Aphasia is an impairment, due to acquired and recent damage of the central nervous system, of the ability to comprehend and formulate language. It is a variety of impairments in auditory comprehension, reading, oral expressive language, and writing. The disrupted language may be influenced by physiological inefficiency or impaired cognition, but it cannot be explained by dementia, sensory loss or motor dysfunction*." (Rosenbek et al., 1989, p. 53).

McNeil and Pratt (2001) summarise how definitions of aphasia have changed from 1877 to 1989 and argue that a more explicit definition will benefit the progress of aphasia. They advanced the definition:

> *Aphasia is a multimodality physiological inefficiency with verbal symbolic manipulations (e.g. association, storage, retrieval, and rule implementation). In isolated form it is caused by focal damage to cortical and/or subcortical structures of the hemisphere(s) dominant for such symbolic manipulations. It is affected by and affects other physiological information processes to the degree that they support, interact with, or are supported by the symbolic deficits.* (McNeil & Pratt, 2001, p. 907).

A common feature of definitions of aphasia has been focused on the linguistic deficit. These definitions do not reflect the globally accepted biopsychosocial framework used by the World Health Organization in ICF (World Health Organization, 2001) or the LPAA framework used in North America (Chapey et al., 2000). Definitions emphasize only the "impairment" domain of the ICF. The consequences of how aphasia affects the functioning of the person in everyday life are not included (Isaksen, 2014; Papathanasiou & Coppens, 2013; Papathanasiou et al., 2017). Hence the primary aim of this study was to update the definition of aphasia to include its consequences.

This study has been overseen by the Collaboration of Aphasia Trialists (CATs) (https://www.aphasiatrials.org), an organisation developed to enhance aphasia research, knowledge, skills, methodologies and infrastructure. CATs is an international multidisciplinary network consisting of aphasia investigators in rehabilitation, social science, psychology, linguistics and language research. One of the objectives for CATs is to facilitate members' access to data, resources, consensus statements and expertise, and to promote knowledge transfer between researchers in different settings. One of the aims of The CATs Working Group on Societal Impact and Reintegration is to co-ordinate a consensus activity to establish the optimum approach to capturing functional communication and societal

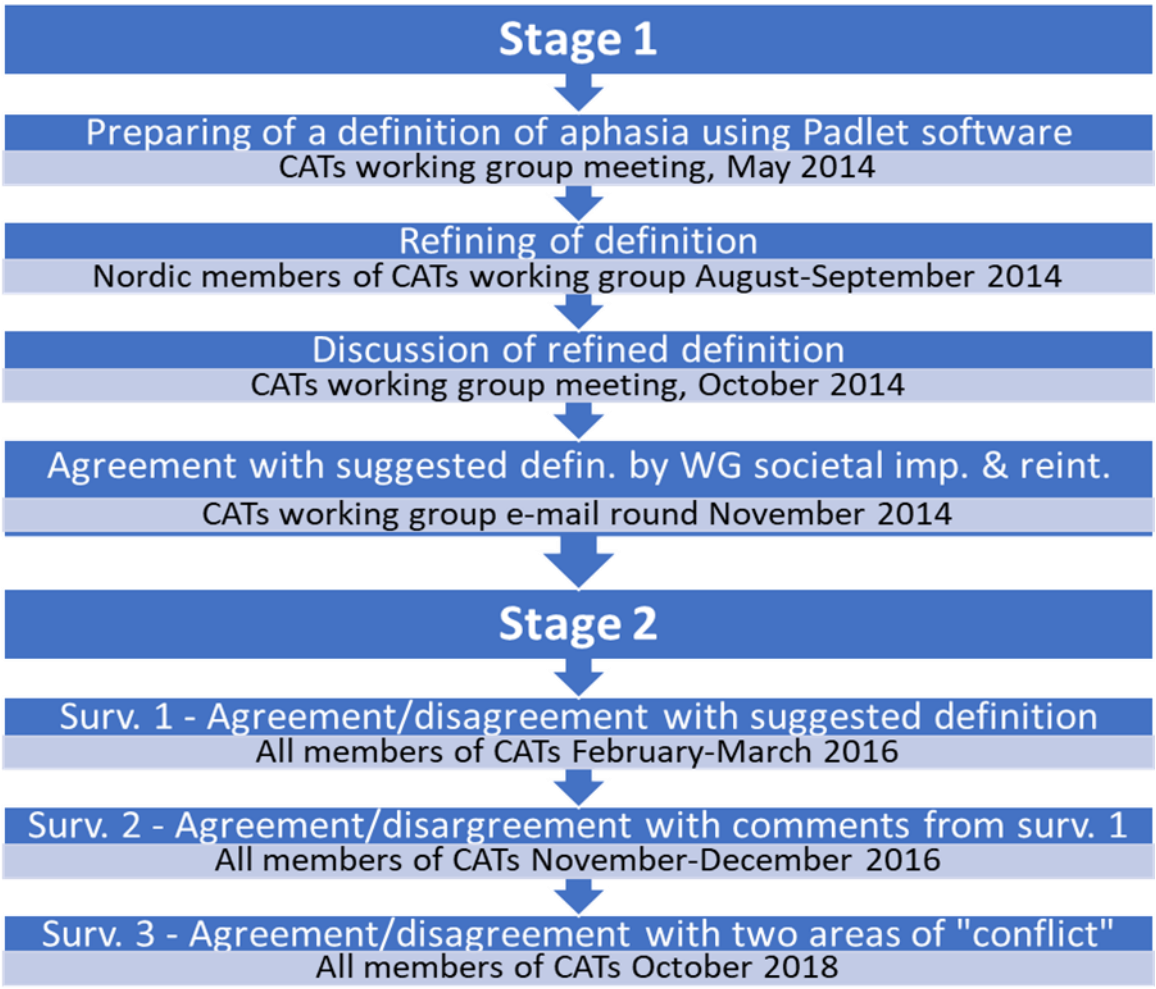
reintergration outcomes of aphasia rehabilitation. This working group initiated an update of the definition of aphasia to include the consequences of aphasia. This process began with establishing a set of common terminology within the group. The impetus for gaining a consensus on the definition of aphasia within CATs was to facilitate more effective communication between the working groups of CATs using a modified e-Delphi method contrasting ealier and current definitions propounded by individual researchers as seen above. The overall aim of the study was to establish consensus (70% agreement by 80% of all the multi-disciplinary CAT members; over the years of the study) on a new definition of aphasia that included its consequences.

Methods & Procedures

Design

The current study was conducted in two stages. In stage 1, a draft definition of aphasia was developed through expert opinion and a non-systematic review of literature. In stage 2, a three-round modified e-Delphi exercise was used to refine and establish consensus on the definition of aphasia (see figure 1 for an overview of this process).

Figure 1 Flow chart of the modified e-Delphi process and timeline



Stage 1. Drafting a Definition of Aphasia

A draft definition of aphasia was developed during a meeting of the CATs Working Group on Societal Impact and Reintegration in May 2014. Using Padlet-software, all participating members of the working group contributed ideas towards the content of a definition. Based on all the contributions during the meeting, the Nordic members of the working group refined a preliminary definition of aphasia. This definition was first discussed in a new meeting within the working group in October 2014 and then circulated by email to all members of the working group in November 2014. Feedback was given and adjustments were made until an agreement was reached within the working group on a suggested definition of aphasia that

could be presented to all the members of CATs. The suggested definition was inspired by previous definitions that included the consequences of aphasia, especially Papathanasiou and Coppens (2013) and Kagan (1995).

Stage 2. Modified e-Delphi Technique

A three-round modified e-Delphi exercise was used to try to establish consensus on a definition of aphasia. The e-Delphi technique has been widely used in consensus processes within healthcare research (Keeney et al., 2006) and is a preferred method because of its convenience and low costs (Wilkes, 2015). Definitions related to a disorder have earlier been sought through Delphi methods, e.g., the definition of fetal growth restriction and fetal growth restrictions in twin pregnancies both made by international panels of experts (Gordijn et al., 2016; Khalil et al., 2019).

The Delphi technique uses structured rounds of questionnaires, which may contain quantitative (closed) and qualitative (open) questions, to collect opinions and feedback on the area of consensus from the selected participants (Falzarano & Zipp, 2013). A Delphi study begins with a questionnaire being sent to knowledgeable people on the topic in which consensus is sought. The second round shows the summarized data from the first round as well as the participants' own response. Repeated rounds are conducted until a consensus is reached (Falzarano & Zipp, 2013; Keeney et al., 2006). E-Delphi has previously been successfully used to gain consensus amongst aphasia researchers (Wallace et al., 2016). The Delphi technique was modified for this study to become more iterative. In round 3, we sought to explore the reasons for non-consensus; new items were presented to address disagreements. The participants were not asked to consider their new responses in each round in light of their previous responses.

Participants

Convenience sampling was used to recruit aphasia researchers. Participants were members of CATs, at the time of this study, an EU funded network of mostly European aphasia researchers across more than 31 countries. The total number of CATs members ranged between 131 and 141 during the study period, due to growing membership between rounds. All CATs members were invited to participate in each round of the Delphi exercise via email. Each email contained a link to a survey using SurveyMonkey (www.surveymonkey.com). For all three rounds, emails were sent to all members of CATs excluding the two members creating the surveys (KB and LW). Demographic information was collected only in round 3, showing that CATs members come from a range of disciplines; speech and language therapy, medicine, public health, social science, linguistics/clinical linguistics/psycholinguistics/neurolinguistics, neuropsychology, psychology, statistics, and nursing.

Data Collection and Analysis

Round 1: In round 1, participants were presented with the draft definition and asked to indicate whether they agreed with it or not, using closed "yes" and "no" options. A second, optional open-ended question was presented and asked participants to comment on the content and wording of the definition. This round was open for a period of approximately one month during February 2016. Reminder emails were sent out twice during this period.

Round 1 analysis: Participant responses to the agreement question were analysed using frequencies. Participant responses to the optional open ended question (n=13) were exported to Microsoft Word and analysed thematically, searching for recurring themes in the responses (see table 1 for themes).

Table 1 Themes from analysis of open ended questions n=13

Suggested changes	Number of respondents suggesting this change
Damage may not only be focal	4
Language impairment not communication disability	4
Add sign language	2
Exclude reading and writing	1
Change QoL of friends with social environment	1
Change may affect to mostly affects	1

Round 2: The results from the Round 1 of the survey were presented as a short summary in the introduction to Round 2 of the survey. The second round sought to establish agreement on two key issues identified in round 1. Participants were asked: (1) Should aphasia be defined as a result of a focal or a diffuse lesion; and (2) Should aphasia be defined as a communication disability or a language impairment. Responses to each question were closed "yes" or "no" choices. Round 2 was open for a period of approximately one month during November 2016. Reminder emails were sent out twice during this period.

Round 2 analysis: Participant responses to the two questions were analysed using frequencies.

Results from the two first rounds of the survey were presented to the members of CATs at the CATs conference in Rotterdam in February 2017 for a member check. The results of the survey and the feedback after the presentation showed that the two questions raised in the second survey were letigimate.

Round 3: Based on the results of the second round, in round 3 the participants where presented with arguments on the same two issues raised in Round 2 of the survey to determine if further information would provide greater clarity and hence achieve consensus. In this round we also asked the participants whether they where speech and language therapists

(SLTs) or belonged to other professions to see if possibly profession influence their point of view on the two areas of conflict.We considered SLTs to be the only profession where the number of members was large enough to constitute a separate group. Round 3 was open for a period of approximately one month (October 2018). Reminder emails were sent out twice during this period.

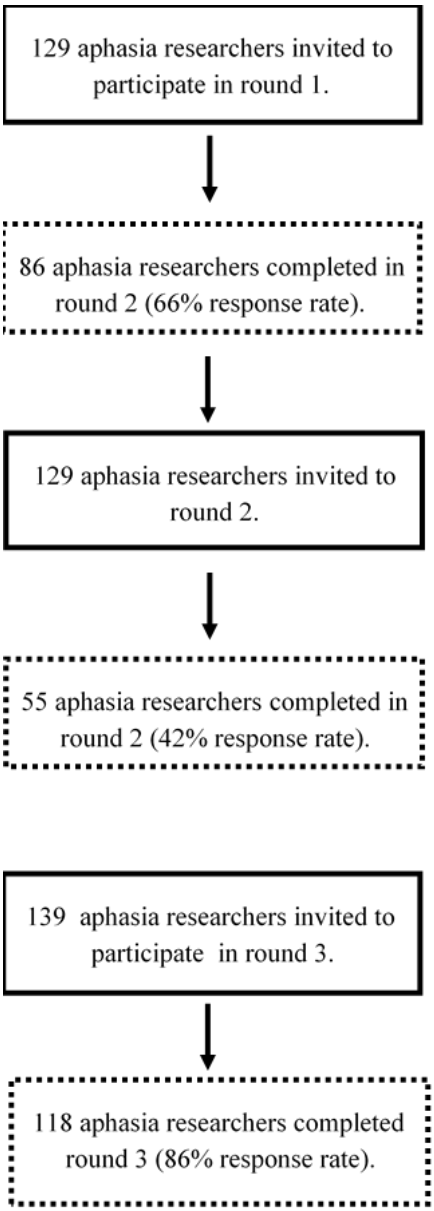
Definition of Consensus

Hasson et al. (2000, p. 1010) propose that the agreement level required for consensus depends on the importance of the question and the impact of a high or low level of agreement and response rate will have on the implementation team. In some cases a 51% agreement/response rate is sufficient while in others a 100% agreement/response rate is needed. We judged that some members would not respond due to language differences and relevancy of the project to their current research, but also thought that the majority would respond because of their membership in CATs. We therefore required a response rate of 80% of the membership. The consensus level of 70% agreement was chosen because there was considerable literature that reflected a difference of opinion. At the same time, the implementation of a consensus definition would require a majority groundswell of opinion that would likely influence others. Prior to the study, we chose to set the margins for consensus at 70% agreement from 80% of the members.

Results

Participant response rates and attrition varied across the three e-Delphi rounds (see figure 2 for an overview).

Figure 2 Flow chart of participant response rates and attrition across three e-Delphi rounds



Stage 1:

The agreed definition by the CATs Working Group Societal Impact and Reintegration was as follows:

> *Aphasia is a communication disability due to an acquired impairment of language modalities caused by focal brain damage. Aphasia may affect participation and quality of life of the person with aphasia as well as their family and friends. Aphasia masks competence and affects functioning across relationships, life roles and activities, thereby influencing social inclusion, social connectedness, access to information and services, equal rights, and wellbeing in family, community and culture.*

The members were also presented with the following rationale for using these terms in the definition:

Communication Disability is a broad umbrella term that includes all communication-related impairments, activity limitations, and participation restrictions.

Focal lesion – the term aphasia is most often applied when the health condition causing it is a result of a focal lesion (for example,a stroke or tumour). Aphasia has also been used for health conditions resulting from diffuse lesions, often involving additional cognitive impairments (for example dementia, traumatic brain injury). Speech and language therapists frequently use the term cognitive communication disorders instead of aphasia for these health conditions.

Language modalities – comprehension and production of both spoken, written and signed language (i.e. talking, understanding, reading, writing and sign language).

Participation – active involvement in a life situation.

Quality of life – individuals' perceptions of their position in life in the context of the culture and value system in which they live and in relation to their goals, standards, and concerns[1].

Aphasia masks competence – the ability to reveal competence successfully or efficiently, normally shown through conversation is disabled.

Wellbeing in family, community and culture – Optimal wellbeing comes from a state of fulfilment in which a person realises their own potential within family and / or community. Working towards optimal wellbeing might require 'inner work', but also interventions to address cultural values and promote cohesion and social integration within a family or community.

Stage 2:

Round 1. An email with a link to the online survey was sent out to 129 members of CATs; 86 researchers completed the survey equating to a 66% response rate (not meeting the 80% criterion for completion). Participants were asked whether they agreed with the suggested definition as stated above. A total of 68 respondents (79%) agreed with the presented definition. Participants were also invited to comment on this suggested definition in a free text space provided. Despite the high rate of agreement for the definition, analyses of the open ended question revealed two recurring themes mentioned by several of the participants : 1) Aphasia should not be limited to focal lesions and 2) Aphasia is a language impairment and not a communication disability.

Round 2. Since the response rate in the first round was below the 80% participation threshold, consensus was not reached. As the two themes from the thematic analysis of the first round of the survey showed that several participants wanted to change the wording of the definition regarding two themes, a second survey was distributed to see if these two themes were seen as important to more participants than the first round had shown. The second round of the survey was sent to 129 members of CATs, with the following two questions:

1. *Should aphasia be defined as a result of a focal or both focal and diffuse lesions?*
2. *Should aphasia be defined as a communication disability or a language impairment?*

The response rate for the second survey was again below the threshold for acceptance (42%) and there was no agreement for either of the two questions with 55% voting for focal lesion and 55% voting for aphasia being a language impairment not a communication disability. Therefor, consensus was not reached.

Round 3. Due to the very low response rate and the low rate for agreement in the second survey, we chose to send out a third survey, expanding on the two discussed items of disagreement to 139 members of CATs. In this third round, information on whether the respondents were SLTs or belonged to other professions was collected in order to explore if there was a relationship between this factor and key sources of disagreement amongst the group.

The following texts were provided to further explain the issues of 1) location of lesion, and 2) communication disability vs. language impairment:

1. *Should aphasia be defined as a result of a focal or a diffuse lesion?*

   The term aphasia is most often applied when the health condition causing it is a result of a focal lesion (for example stroke and tumour). Aphasia has also been used for health conditions resulting from diffuse lesions often involving additional cognitive impairments (for example dementia, traumatic brain injury). Speech and language therapists frequently use the term cognitive communication disorders instead of aphasia for these health conditions.
2. *Should aphasia be defined as a communication disability or a language impairment?*

   The original definition that we sent out stated that aphasia is a communication

disability due to an acquired impairment of language. The intent was to describe aphasia under the broad umbrella term of communication disability which incorporates the impairment, activity limitation and participation restriction and is consistent with the terms used in the ICF. It emphasizes that aphasia is more than a language impairment and has consequences beyond language. The more traditional definition is that aphasia is a language impairment only, causing a communication disability. This restricts the use of the term aphasia to the language impairment only.

A total of 117 members participated in round three. Of this group, 68% (n=80) identified their disciplinary background as "Speech and Language Therapy". The remaining 32% (n=37) described their disciplinary background using an open text field. This group represented a wide range of disciplines and fields including: linguistics/ clinical linguistics/ psycholinguistics/ neurolinguistics (n=13), medicine (n=7), neuropsychology/ psychology (n=6), neuroscience (n=3), social science (n=2), public health (n=1), technology (n=1), statistics (n=1), health services research (n=1), and nursing (n=1). The results from the third survey reached the required response rate (84%), but the consensus rate for both questions were only 50%. This indicated that there was still a considerable disagreement on the two issues, and the study was stopped. Comparing the answers from speech and language therapists/pathologists with answers from other professions, there was a tendency for SLTs to vote in favour of focal lesion (53%) and communication disability (58%), with responses from other professions not accepting focal lesion (42%) and communication disability (46%). The results showed no concensus in either groups.

Discussion

After three rounds of surveys sent to the members of CATs, we were not able to establish a consensus on a new definition of aphasia. The reason for the lack of concensus for the first

two rounds were lower than required response rates (69%, 42% respectively). The third round achieved a response rate of 84% and therefore achieved the required 80% response rate. With a mean response rate of 34.6% for completed electronic surveys (Cook et al., 2000, p. 829), our response rates of 69% and 43% should be considered reasonable. The apriori determined response rate of 80% may have been unneccessarily ambitious. While reducing the required response rate may be considered in future research, the capacity to achieve a representative sample may be compromised. Future studies may need to consider optimising the factors that produce higher response rates such as pre-contacting potential participants, personalised transmission emails and considered timelines and number of follow up requests (Cook et al., 2000).

When an adequate response rate was achieved in Round 3, there was a near 50% agreement for both the issues tested in the previous round so that the pre-set agreement rate of 70% for consensus was not achieved. The almost equal distribution of agreement versus disagreement on these two issues is a clear sign that there is further work to be done conceptualising the issues and explicating the advantages and disadvantages of both arguments.

The two issues that continue to prevent a consensus were the type of lesions (focal or diffuse) that cause aphasia and whether the term aphasia should be defined as a communication disability or a language impairment. This shows that the main impetus for changing the definition (*Aphasia is a communication disability due to an acquired impairment of language modalities caused by focal brain damage)* is in dispute. We recommend that further in-depth discussions must be facilitated before attempting to gain consensus.

The concept that aphasia is a communication disability stems from the terminology of the ICF (World Health Organization, 2001). The term “functioning” is the neutral term for all body functions, activities and participation. The term “disability” is the negative equivalent and

overarching term for impairments, activity limitations and participation restrictions. Using this taxonomy, impairments of language, speech, voice, and hearing are all communication disabilities because they also have accompanying communication activity limitations and participation restrictions. The ICF would describe the language impairment, communication activity limitation and participation restriction associated with aphasia as a communication disability. The advantage of the broader communication disability term is that other speech, language, voice and hearing impairments are encompassed so that awareness of communication disability overall is raised, regardless of the cause of the impairment. The communication disability term is also analogous to terms such as physical disability or learning disability. Aphasia has traditionally been considered an impairment therefore a transition to the broader ICF term of disability has not yet been made by the CATs network.

The finding of a lack of consensus around the focal or diffuse nature of the lesion in aphasia was unexpected. While the literature is replete with examples of language disorders associated with dementia or head injury being labeled as aphasia, previous definitions of aphasia have stated that aphasia is a result of a focal lesion. We expected that the majority of aphasia researchers would follow that part of the definition. It appears that this is not the case, at least within the CATs membership. Two possible reasons may explain this finding: Firstly, it is possible that members favoured *diffuse* lesion given the increasing interest in primary progressive aphasia caused by neurodegenerative diseases in speech and language therapy (e.g.Volkmer et al., 2019). Secondly, it is possible that members were constrained by the survey wording (i.e. forced to choose) and hold views that align with there being several sets of association pathways (fronto-temporal, parieto-temporal, occipito-temporal, and fronto-frontal connections) in language connectivity (Tremblay & Dick, 2016) and therefore did *not* choose *focal*. The distribution of responses is also of interest, with only slightly more SLTs favoring defining aphasia as a result of a focal lesion, while other professionals were less in

favor of this. These findings suggest that there is a shift in how aphasia researchers define aphasia and therefore, future work still needs to be aimed at inter-disciplinary discussion to understand the root of differing perspectives and arrive at a shared description.

Of interest, the part of the definition using terminology to describe the consequences of aphasia, was not challenged by members of the CATs network. We refer to the second and third sentences of the definition, repeated here for ease:

> *Aphasia may affect participation and quality of life of the person with aphasia as well as their family and friends. Aphasia masks competence and affects functioning across relationships, life roles and activities, thereby influencing social inclusion, social connectedness, access to information and services, equal rights, and wellbeing in family, community and culture.*

We offer two likely explanations for this finding: Firstly, there has been a significant body of qualitative (and quantitative) research literature published in the last two decades that highlights the far-reaching life impact and consequences of aphasia on people and their families (Hilari et al., 2012; Manning et al., 2019). Secondly, we propose that the increased acceptance of the WHO ICF in aphasia rehabilitation research and practice is likely to have promoted acceptance of a broader definition. Specifically, in research, the WHO ICF has been increasingly used to frame clients' goals (e.g.Worrall et al., 2011) and prioritized treatment outcomes (e.g.Wallace et al., 2017), as well as evaluate content of assessments/ outcome measures (Brandenburg et al., 2015). In clinical practice, there have been calls to adopt a broader scope of practice (Simmons-Mackie & Kagan, 2007) and the development of new comprehensive assessments (e.g.Simmons-Mackie et al., 2014).

There are immediate and broader implications of these findings. More immediately, it suggests that CATs members have a range of views on cause and impairment/ disability interpretation of aphasia. This is likely to lead to differing priorities in research being undertaken by members, and a missed opportunity to raise awareness of aphasia as a communication disability by an international organisation. More broadly, it suggests that researchers and clinicians are likely to favour interpretations that align with their own perspective which will subsequently manifest in different approaches to diagnosis, assessment and treatment. Continued fragmentation of the field of aphasiology seems counterproductive in a world of increasingly constrained resources, and there is a clear need for researchers of all disciplinary orientations to work together to achieve clarity for the community they serve – people with aphasia and their family members.

Limitations and further Research

A potential limitation to this research was the distribution of the survey to CATs members only. The sample was participants in the 31 countries of CATs members. High aphasia publication rate countries such as the United States, Canada, Australia, Japan and China are not proportionally represented in the CATs membership which predominantly has members from the European continent. It is therefore recommended that future consensus efforts represent all regions of the international community of aphasia researchers. Furthermore, consensus research should endeavour to include the views of all stakeholders; in this survey, the views of people with aphasia and immediate family members. Those who experience and live with aphasia were not considered. Indeed, consensus definition research in health conditions has demonstrated the positive impact of patient involvement as Delphi participants, for example making a novel distinction between *symptoms and consequences* in the resulting

definition (Keane et al., 2020). In addition, the members of CATs are primarly researchers and not clinicians, indicating that clinicians could be included as well.

As noted previously, evidence would suggest that pre-contact, personalised contact, and more follow up would improve the response rate. In addition, generation of more debate around the two issues may increase the interest level of respondents and importantly help clarify the issues. Eletronic online methods and international perspectives are crucial in this field, so continued use of eDelphi consensus methodologies here is advocated. However, more consideration of constituent parts of the definition is needed i.e. voting on each element within the definition, with open-text boxes for respondents to indicate reasons for their choices. Moreover, generation of the definition elements themselves through comprehensive stakeholder engagement using a more traditional Delphi process may result in a more representative definition of aphasia. As Delphi methods are challenging for people with aphasia, a comparable consensus technique (i.e. nominal group method) would be advocated to ensure that their perspectives are included. Additionally, further clarification of the purpose of the definition at the outset of the consensus exercise is advised, as the intent of it´s use will influence respondents' decision-making.

Conclusion

There was a lack of consensus of whether the definition of aphasia should describe aphasia as a communication disability or a language impairment and whether focal lesions and/or diffuse lesions should be included in the definition. Expanding the definition of aphasia to include reference to participation, quality of life and the impact of consequences on a range of life areas for people and their families was unchallenged in this consensus process. More international and multidisciplinary discussion of these issues is needed.

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Text for footnotes:

[1] Definition adopted verbatim from https://www.who.int/healthinfo/survey/whoqol-qualityoflife/en/