

Social participation in working-age adults with aphasia: An updated systematic review

Caitlin Pike, Alta Kritzinger, Bhavani Pillay

Department of Speech-Language Pathology and Audiology, University of Pretoria, Pretoria, South Africa

Corresponding author: Caitlin Pike; University of Pretoria, Private Bag X20, Pretoria, Hatfield, 0028; 072 326 1192; caitpike@gmail.com

Co-author: Professor Alta Kritzinger; University of Pretoria, Private Bag X20, Pretoria, Hatfield, 0028; 012 420 2949; alta.kritzinger@up.ac.za

Co-author: Bhavani Pillay; University of Pretoria, Private Bag X20, Pretoria, Hatfield, 0028; 012 420 4919; bhavani.pillay@up.ac.za

The research was planned by all three authors, conducted by Caitlin Pike and the article written up by Caitlin Pike, Alta Kritzinger and Bhavani Pillay.

Abstract

Background: A previous systematic review found limited data regarding social participation in working-age people with aphasia (PWA). This population has many roles to fulfill, that are negatively affected by aphasia. A review of recent studies may reveal more information on challenges in re-establishing social roles and thus may inform treatment thereof.

Method: The aim was to provide an updated systematic review on social participation in PWA under 65 years of age. Studies from 2005-2017 were searched from Scopus, Pubmed and Psychinfo. Search terms were derived from the International Classification of Functioning, Disability and Health (ICF) and the Aphasia- Framework for Outcomes Measures (A-FROM). Aspects of

domestic life, interpersonal relations and interactions, education and employment and community, civic and social life were investigated.

Results: From 2,864 initial hits, 11 studies were identified, all of which were on the American Speech-Language-Hearing Association (ASHA) Level III of evidence. The studies indicated that participation in domestic life is reduced and PWA showed reduced social networks, loss of friendships and changes in the quality of marital relations. Few PWA returned to work or spent time on education. Limitations in community, civic and social life were noted and there were contradictory findings on the impact of contextual factors on social participation. There was an increase in research into contextual factors impacting on social participation in PWA and in the use of conceptual frameworks in the last decade.

Conclusions:. Social participation in working-age adults is limited across the social domains. While the ICF conceptual framework is increasingly used, no studies used the A-FROM. There is greater use of standardised assessments and larger sample sizes.

Keywords: stroke, aphasia; social participation, working-age, young, middle-age, ICF

Introduction

There is an increase in stroke incidence between the ages of 20 and 54¹. This is of concern as individuals with stroke in young and middle adulthood face particular challenges in regaining meaningful involvement in their roles as providers, partners and parents, which may no longer be required in later years^{2,3}. Aphasia is one of the strongest predictors of poor functional recovery following a stroke⁴ and impacts on many facets of daily life.

A number of participation intervention approaches have been developed, the goal of which are to maximize re-engagement in daily life^{5,6}. One approach, the Life Participation Approach to Aphasia [LPPA], emphasizes the concerns of the PWA within the treatment process⁷. Another, the World Health Organization International Classification of Functioning, Disability and Health [WHO- ICF]⁷, helps to re-direct the focus to health, well-being and quality of life (QOL)⁷. An ICF compatible conceptual guide has been developed for aphasia: Living with Aphasia- Framework for Outcome Measurements [A-FROM]⁸. This framework was developed to guide outcome measurements, with emphasis on real-life outcomes⁸.

These approaches are reflective of goals identified by PWA and their families. A key area in which PWA would like to improve is life participation^{9,10} and this aspect is highlighted as fundamental to living successfully with aphasia¹¹. Of concern is the finding that SLTs continue to be anchored in traditional medical models of treatment¹².

Consistent with the development of and subsequent drive towards the use of these approaches, there appears to be increasing research into social participation or QOL of PWA^{2,13,14}, however there appears to be limitations in the literature. In their systematic review (1960-2005) on social participation of PWA under 65 years, Dalemans et al. (2008) found that restrictions are evident across the social participation domains. The authors identified the need for increased use of a clear conceptual framework and well-defined concepts². They found that many studies had small sample sizes and used few standardized assessments. The researchers were unable to identify studies describing community, civic and social life, one of the domains in “Activity and Participation” of the ICF, and they note a lack of research into the impact of the environment on social participation and return to work. It is evident that much is still unknown about the participation of working-age PWA.

When considering the dearth in literature, the increasing incidence in as well as the significant impact of aphasia on working-age adults, an expanded understanding of the social participation of these individuals is needed^{1-3,9,11}. With this knowledge, assessment and treatment procedures can be adjusted to the unique needs of this population for improved functional outcomes. This leads to the research question: What is known about the impact of aphasia on social participation in working-age adults with stroke-related aphasia and what is the level of evidence of these studies from the last decade?

Method

Study design

A systematic review was completed according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Protocols [PRISMA-P]¹⁵ checklist.

Study inclusion criteria

Three electronic databases were searched, based on relevance to the subject field: Scopus, PsychINFO and PubMed. The main search terms were: “aphasia”, and/or “stroke”, together with terms related to social participation according to the ICF and A-FROM frameworks: domestic life, relationships, education, employment, leisure, community life, social life and civic life. Additional terms included “quality of life”, “long-term outcomes”, “well-being” and “self-esteem”.

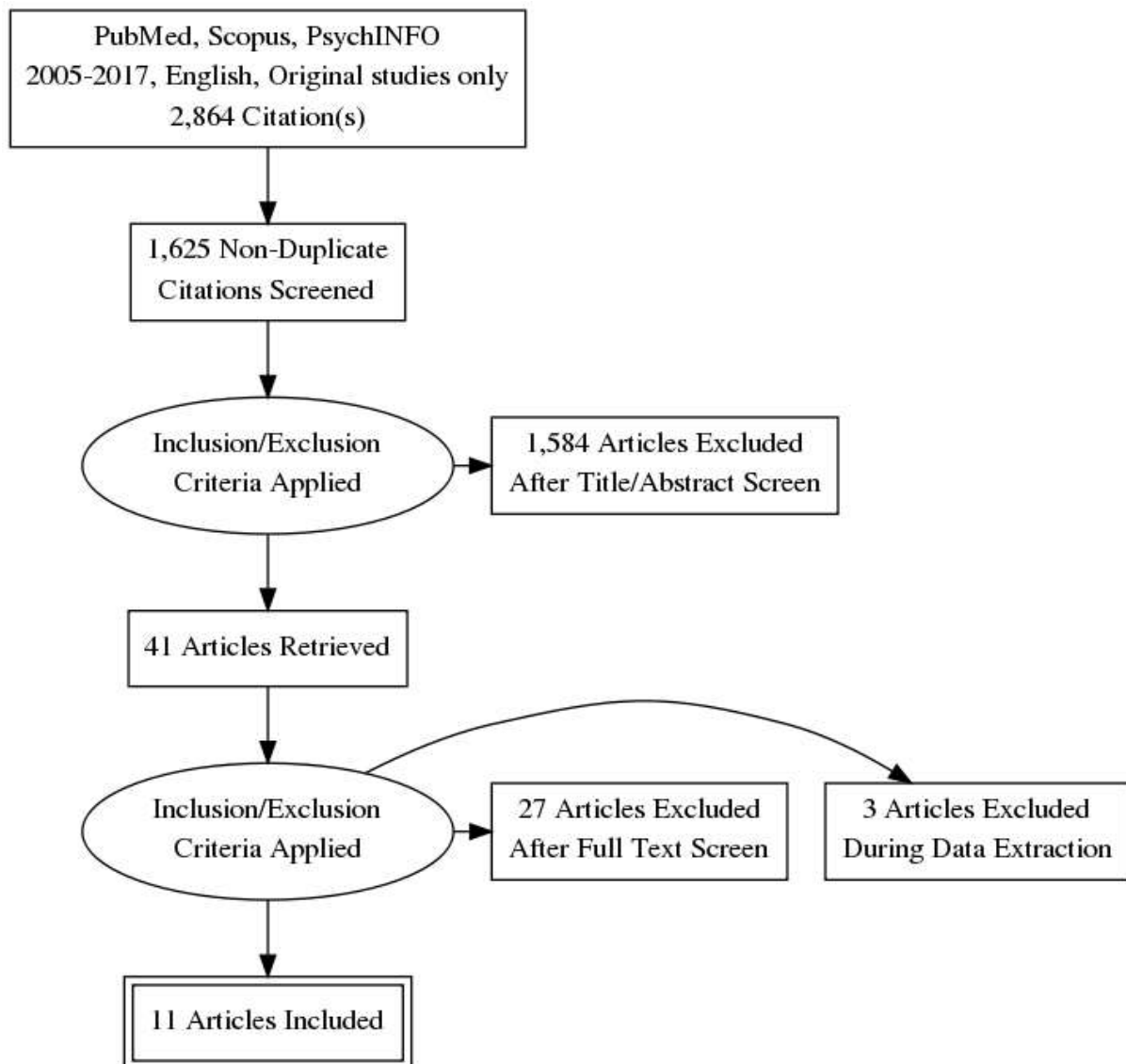


Figure 1. PRISMA flow chart of selection process

Study selection

Three searches were conducted with the last search being run on 24/01/2017. Using this electronic search strategy (limits: 2005-2017, English, original articles), the initial search yielded 2,864 articles. This time limit was set as the review completed by Dalemans et al. (2008) included studies until 2005. A software program, Covidence, was used to synthesize searches, identify duplicates and review articles. Following removal of duplicates, 1,625 articles remained. The articles' titles and abstracts were reviewed and articles that discussed aphasia in conjunction with an identified social

participation aspect were included for full-text review. Forty-one articles met the criteria (Figure 1).

The following exclusion criteria were identified for the final review phase:

- Fewer than six PWA of 18 and 65 years, to eliminate single case studies which represent the lowest level of evidence on the American Speech-Language Hearing Association (ASHA) evidence rating scale ¹⁶, and may not significantly contribute to a systematic review
- Percentage of PWA was less than 10% in quantitative studies
- Mean age of the PWA was more than 65
- PWA were not separately outlined in the population characteristics
- PWA were not stroke-related
- Participants presenting with aphasia after more than one stroke
- Only the acute phase (0-3 months) was reported on
- The measurement instrument, methodology and/or statistical/qualitative analysis were not described
- Spouses or carers described their own needs in relation to the PWA
- QOL was measured, but findings were not described in terms of social participation
- Social participation aspects were not separately described in the study outcomes
- Social participation was discussed according to changes following a treatment program

Data collection process and data items

Data was extracted from the 11 selected articles and compiled into pre-developed tables. These tables were structured according to the ICF social participation domains, as initial

Table 1. Characteristics of included studies (n=11)

Author and year of publication	Social participation aspect/domain(s) studied	Q/QL	Country	Sampling method	Mean age in months (R/SD)	Sample size
Dalemans, De Witte, Wade, & Van den Heuvel (2010)	Contextual factors impacting on social participation	QL	Netherlands	Purposive sampling, with criteria to include different aphasia severities, genders, levels of mobility and time post-onset	57,4 (R 45-71)	13 PWA 12 Caregivers
Dalemans, De Witte, Beurskens, Van den Heuvel, & Wade (2010)	Domestic life, Education and employment, Factors impacting on social participation	Q	Netherlands	Purposive sampling	64,2 (R 35-87)	150 PWA
Darrigrand et al. (2011)	Domestic life, Factors impacting on social participation	Q	France	Convenience sampling, part of a larger study of stroke patients with aphasia	Severe aphasia: 63.7 (SD 15.1) Moderate aphasia: 64.1 (SD 10.4)	27 PWA (severe) 9 PWA (moderate)
Fotiadou, Northcott, Chatzidaki, & Hilari (2014)	Interpersonal relations and interactions, Education and employment, Community, civic and social life, Factors impacting on social participation	QL	Greece	Purposive sampling of blogs sustained by a sole author who had aphasia following a stroke, and which reflected on their social network	48.8 (R 26-69)	10 PWA
Hilari & Northcott (2006)	Interpersonal relations and interactions, Education and employment	Q	United Kingdom	Cluster sampling framework	61.6 (R 21-92)	83 PWA
Łapkiewicz & Grochmal-bach (2008)	Interpersonal relations and interactions	QL	Poland	Purposive sampling of married couples, with one partner with severe aphasia	58.7	22 PWA (and partner) 21 Stroke, no aphasia (and partner)
Lee, Lee, Choi, & Pyun, (2015)	Domestic activities, Education and employment, Community,	Q	South Korea	Convenience sampling of patients with post-stroke aphasia (≥ 6 months)	59.2 (SD 7.2)	32 PWA 42 Control, no,

	civic and social life					stroke, no aphasia
Matos, Jesus, & Cruice (2014)	Domestic life, Interpersonal relations and interactions, Education and employment, Community, civic and social life	QL	Portugal	Unclear	65 (R 41-80)	14 PWA 14 Family members 10 SLT
Mazaux, Lagadec, De Sèze, Zongo, Asselineau, Douce, Trias, Delair, Darrigrand (2013)	Domestic life	Q	France	Convenience sampling, part of a larger study of stroke patients with aphasia	65.1 (R 13.5)	100 PWA
Naess, Hammersvik, & Skeie (2009)	Interpersonal relations and interactions, Education and employment	Q	Norway	Purposive sampling from computer-based hospital registries	42 (R 24-49)	20 PWA 175 Control with stroke, no aphasia
Pommerehn, Delboni, & Fedosse (2016)	Domestic activities, Interpersonal relations and interactions, Community, civic and social life	QL	Brazil	Convenience sampling from members of a group	48.25 (R 25-67)	12 PWA

Abbreviations: CVA: Cerebral Vascular Accident, NPO: Non-Profit Organisation, OT: Occupational Therapist, PWA: Person with Aphasia, Q: Quantitative, QL; Qualitative, R; Range, SD: Standard deviation, SLT: Speech-language therapist

article review indicated that this continues to be the predominant framework used, as opposed to the A-FROM. The data items investigated are as follows:

1. Characteristics of the study, including title, author(s), year of publication, country, type of study, sampling method, mean age, sample size, social participation domain investigated, measurements used and the assessment period post-stroke (Table 1)
2. The impact of aphasia on social participation domains: domestic life, interpersonal life, education and employment, community, civic and social life.

Risk of bias in selected studies

An adapted version of the Newcastle-Ottawa Quality Assessment Scale [NOS]¹⁷ was used (Appendix B). This tool was developed to assess the quality of non-randomised studies¹⁷. Each study was judged on three broad categories: study group selection, group comparability and outcomes with a greater number of stars indicating a higher level of evidence¹⁷. The content validity and inter-rater reliability of this rating scale have been established¹⁷.

The widely accepted American Speech-Language-Hearing Association [ASHA] level of evidence rating scale were also used to categorise the selected studies (ASHA, 2004). This scale rates studies on four levels based on the research design used, with the lowest rating being IV and the highest being I (see Table 2). The ratings were independently completed by two of the researchers, and differences noted were resolved after discussion.

As evident in Table 2, all the studies were rated as Level III according to the ASHA rating scale, which is classified as ‘well-designed, non-experimental studies’. On the NOS rating scale a wide range of levels of evidence were obtained, with the studies displayed from highest to lowest levels of evidence, and alphabetically, where

Table 2. Quality assessment and level of evidence of selected studies

Source	ASHA level of evidence	Selection (Maximum 5 stars)				Comparability (Maximum 2 stars)	Outcome (Maximum 3 stars)		Total stars
		Representativeness of the sample	Sample size	1. Non-respondents 2. Controls	Ascertainment of aphasia	Comparability of subjects in different outcome groups on the basis of design or analysis. Confounding factors controlled	1. Assessment of social participation 2. Same method for case and control	Statistical test	
Mazaux et al. (2013)	III	(b) somewhat representative of the average in the target population*	(a) justified and appropriate*	1. (a) comparability between respondents' and non-respondents' characteristics is established and satisfactory* 2. no control	(a) validated measurement tool on follow up**	(a) controlled for aphasia* (b) controlled for age, language*	1. (c) self-report 2. N/A	(a) clearly described and appropriate*	8/10
Dalemans, de Witte, Beurskens et al. (2010)	III	(b) somewhat representative of the average in the target population*	(a) justified and appropriate*	1. (a) comparability between respondents' and non-respondents' characteristics is established and satisfactory* 2. (b) hospital controls	(a) screening tool with moderate validity*	(a) controlled for aphasia* (b) controlled for age, time post stroke and premorbid conditions*	1. (c) self-report 2. Yes	(a) clearly described and appropriate*	7/10
Darrigrand et al. (2011)	III	(c) selected group of participants	(b) not justified	1. (a) comparability between respondents' and	(a) validated measurement tool on follow up**	(a) controlled for aphasia* (b) controlled for age, language*	1. (c) self-report 2. Yes	(a) clearly described and appropriate*	6/10

				non-respondents' characteristics is established and satisfactory* 2. (b) hospital control					
Hilari & Northcott (2006)	III	(b) somewhat representative of the average in the target population*	(a) justified and appropriate*	1. (b) comparability between respondents and non-respondents is not satisfactory 2. no control	(a) screening tool with moderate validity*	(a) controlled for aphasia* (b) controlled for post-stroke time period and pre-morbid conditions*	1. (c) self-report 2. N/A	(a) clearly described and appropriate*	6/10
Matos et al. (2014)	III	(c) selected group of participants	(b) not justified	1. (a) comparability between respondents' and non-respondents' characteristics is established and satisfactory* 2. (c) No description	(a) validated measurement tool**	(a) controlled for aphasia* (b) controlled for age, language, living place, cognitive and hearing functioning*	1. (b) self-report 2. N/A	N/A No statistical test conducted. Qualitative analysis (Thematic analysis based on ICF)	5/10
Naess et al. (2009)	III	(c) selected group of participants	(b) not justified	1. (a) comparability between respondents' and non-respondents' characteristics is established and satisfactory* 2. (b) hospital control	(b) non-validated assessment tool for aphasia, but the tool is available*	(a) controlled for aphasia* (b) controlled for age*	1. (c) self-report 2. Yes	(a) clearly described and appropriate*	5/10
Łapkiewicz & Grochmal-bach (2008)	III	(c) selected group of participants	(b) not justified	1. (c) no description of the response rate or	(a) validated measurement tool**	(a) controlled for aphasia*	1. (b) self-report 2. Yes	(a) clearly described and appropriate*	4/10

				the characteristics of the responders and non-responders 2. (b) hospital control					
Lee et al. (2015)	III	(c) selected group of participants	(b) not justified	1. (c) no description of the response rate or the characteristics of the responders and non-responders 2. (b) hospital control	(a) screening tool with moderate validity*	(a) controlled for aphasia* (b) controlled for language, time post-stroke, pre-morbid conditions, functioning at assessment*	1. (c) self-report 2. Yes	(a) clearly described and appropriate*	4/10
Dalemans, de Witte, Wade et al. (2010)	III	(c) selected group of participants	(b) not justified	1. (b) comparability between respondents and non-respondents not satisfactory 2. (c) no control	(a) screening tool with moderate validity*	(a) controlled for aphasia* (b) controlled for time post-stroke, age, living place, caregiver*	1. (c) self-report 2. N/A	N/A No statistical analysis. Qualitative analysis with use of an online software program. Description fair.	3/10
Fotiadou et al. (2014)	III	(c) selected group of participants	(b) not justified	1. (a) comparability between respondents' and non-respondents' characteristics is established and satisfactory* 2. (c) no control	(c) no description of a measurement tool	(a) controlled for aphasia* (b) controlled for language, age, content*	1. (c) self-report 2. N/A	N/A No statistical analysis. Framework analysis completed. Method of analysis qualitative and well described	3/10

Pommerehn et al. (2016)	III	(c) selected group of participants	(b) not justified	1. (c) no description of the response rate or the characteristics of the responders and non-responders 2. (c) no control	(c) no description of the measurement tool	(a) controlled for aphasia* (b) controlled for age, participation in therapy*	1. (c) self-report 2. N/A	N/A No statistical analysis. Thematic analysis based on ICF.	2/10
-------------------------	-----	------------------------------------	-------------------	---	--	--	------------------------------	--	------

appropriate. For the purpose of interpretation, a score of 0-3/10 stars was classified as a low level of evidence, a score of 4-6/10 stars as a moderate level of evidence and 7-10/10 stars as a high level of evidence. Two studies obtained a high level of evidence, six a moderate level of evidence and three a low level of evidence.

Data analysis

Thematic analysis was used to organize the data. This was done according to the social participation domains identified in the ICF. In addition, the contextual factors impacting on social participation were investigated.

Results

Domestic life

Domestic activities include social activities (e.g. shopping, home-making) and other secondary activities of daily living². Studies that met the criteria were published from 2010 to 2016 (Table 3). The Echelle de Communication Verbale de Bordeaux (ECVB) was used in two studies that were part of a single cohort study and that were on moderate and high levels of evidence^{18,19}. This questionnaire investigates communication activity in daily living. The factors identified as being the most challenging for working-age PWA in both studies were: using the phone, using checks and credit cards and communicating in social activities. Activity limitations in communication were more severe for individuals with severe aphasia than those with moderate aphasia¹⁹. Two studies^{20,21} used the Community Integration Questionnaire (CIQ)^{22,23}, a tool divided into three subscales: Home Integration, Productivity and Social Integration. The Home Integration subscale indicates the frequency of participating in activities such as shopping and housekeeping. Both studies, one on a

Table 3. Domestic life

Author	Measurements instruments	Mean months post onset (R/SD)	Concepts	Results
Mazaux et al. (2013)	Orgogozo's score, Barthel Index, ASRS, BDAE (French version), TLC, ECVB	(R 12-18)	domestic activities	Most impaired activities: conversation on complex themes, using the phone for a meeting, using checks and credit cards, communicating during social activities. Least impaired: asking for daily living needs, talking about one's wishes and purposes, expressing feelings, conversation with relatives, answering on a phone, reading time and reading family post/mail. ECVB scores associated with work status and type of job at inclusion, stroke severity at inclusion and follow-up, aphasia severity at inclusion and follow-up, auditory comprehension impairment on inclusion, BDAE items of auditory comprehension, fluency, naming, reading and writing at follow-up, mean number of SLT sessions, depression at follow-up.
Dalemans, De Witte, Beurskens et al. (2010)	Structured interview, FAST, Barthel Index, COOP-WONCA, Personal Factors Questionnaire, Environmental Factors Questionnaire, CIQ	90.6 (R 6-372)	home integration	Home integration score of 4.8 (max score: 12) on CIQ subscale (SD: 3.6 Range: 0-12).
Darrigrand et al. (2011)	Orgogozo's score, Barthel Index, ASRS, BDAE (French version), TLC, ECVB	(R 12-18)	communication activities of daily life	Persons with severe aphasia present with severe activity limitations in communication, with performance three times lower than individuals with moderate aphasia and four times lower than individuals without aphasia. Aphasia severity and communication disability, but not non-verbal communication, at follow-up, are related to the initial severity of aphasia. Most impaired factors: using a phone, credit card, chequebook, reading and filling in administrative documents, communication behaviours in social life. Non-verbal communication performance was not associated with aphasia severity.
Matos et al. (2014)	In-depth semi-structured interview	29 (R 3-89)	domestic activities	PWA reported difficulties participating in household tasks, but this was not identified as the domain most impacted by the aphasia.
Lee et al. (2015)	Modified Barthel Index; FAST;	29.1	home integration	Home integration scores: PWA- Mean: 2.6, SD: 3.0, Control- Mean: 5.6,

	GDS; CIQ; SAQOL-39	(SD 20.6)		SD: 3.0. PWA spent less time on activities of market, finance, shopping. No significant difference observed in meal preparation and household activities. Factors impacting on home integration: activities of daily living and mobility.
Pommerehn et al. (2016)	ICF checklist	52 (R 26.4-136.8)	household chores, acquisition of goods and services, meal preparation, helping others	Predominant difficulties with meal preparation, household chores, goods and services acquisition and helping others.

Abbreviations: ASRS: Goodglass and Kaplan Aphasia Severity Rating Scale, Barthel Index: Barthel Activities of Daily Living Index, BDAE: Boston Diagnostic Aphasia Examination, CIQ: Community Integration Questionnaire, COOP-WONCA: Dartmouth Coop Functional Health Assessment Charts/Wonca, ECVB: Echelle de Communication Verbale de Bordeaux, GDS: Geriatric Depression Scale, FAST: Frenchay Aphasia Screening Test, R: Range, SAQOL-39: Stroke and Aphasia Quality of Life Scale-39, SD: Standard deviation, TLC: Test Lillois de Communication

moderate level and the other on a low level of evidence, found low scores in home integration. The final studies with low and moderate levels of evidence used a semi-structured interview²⁴, and the ICF checklist²⁵. These studies found limitations in domestic tasks, with Pommerehn et al. (2016) identifying predominant difficulties in meal preparation, household chores, goods and services acquisition and helping others.

Interpersonal relations and interactions

This domain includes all formal and informal relationships². This was investigated in six studies from 2006 to 2016 (Table 4). Two studies conducted analyses according to the ICF^{24,25}. One used a social network questionnaire and the Medical Outcome Study Social Support Survey (MOS-SSS)²⁶. The Dyadic Adjustment Scale (DAS) and Marital Communication Questionnaire (MCQ) were used in one study²⁷ and another used the Communication Effectiveness Index (CETI)²⁸. The final study used a framework analysis of blog content²⁹.

On a moderate level of evidence, significant differences between PWA and people with stroke, and no aphasia were found with regard to social isolation ($p=0.054$; Fisher exact)²⁸. Aphasia impacts on numerous relationships. In marriage, PWA identify a loss of harmony, satisfaction, cohesion, emotional expression and a loss in faith in the value of marriage²⁷. The marital changes appear to be more extensive for PWA than for individuals with stroke, but no aphasia²⁷. Interestingly, 86.3% of PWA found their relationships with their children were maintained or improved following the stroke, and 75.4% of PWA reported this to be true for relations with other relatives²⁶. A number of the identified studies, on a moderate to low level of evidence, indicated a reduction in social networks of PWA, particularly friendships^{24-26,29}. Studies with a low level of evidence note limitations in all relations²⁵ and found particular challenges with in-depth

Table 4. Interpersonal relations and interactions

Author	Measurements instruments	Mean months post onset (R/SD)	Concepts	Results
Hilari & Northcott (2006)	SAQOL-39, MOS-SSS, a social network questionnaire	42 (R 13-250)	social networks, perceived social support, HRQL	86.3% of PWA reported maintained or increased contact with their children, and 75.4% with their relatives, while 63.9% reported less contact with friends, with 30% being unable to name a single close friend. Decreased social network size (Mean: 10; Mode 4), with the general population having between 8-15 members in their social network. Size of social network in women, social companionship and informational support associated with HRQL. Overall PWA felt well supported, particularly in tangible support.
Matos et al. (2014)	In-depth semi-structured interview Analyses according to ICF framework	29 (R 3-89)	interpersonal relationships	PWA reported significant changes in their relationships, and noted changes or loss of friendships.
Naess et al. (2009)	MASRS, Nottingham Health Profile questionnaire part I, SSS, NGA, CETI	≥ 60	social isolation	Aphasia is associated with social isolation (p= 0.054; Fisher exact).
Łapkiewicz & Grochmal-bach (2008)	MMSE, GDS, CNBA, BNT (Polish version), TT, DAS, MCQ	6	marital coherence, perceived support, QOL	PWA found a loss of harmony, satisfaction, cohesion, emotional expression, faith in the value of marriage. PWA showed more extensive changes in the marriage as well as in more significant areas of marriage as compared to individuals with stroke and no aphasia.
Fotiadou et al. (2014)	Thematic analysis of blog content using Framework Analysis	≥ 12	social networks, social support, family dynamics; factors impacting on social relationships	In-depth conversations more challenging, reduced participation in family activities, higher degrees of dependence and changed family dynamics and roles. Contact with friends was reduced (communication and physical difficulties impacting). Wider social networks mostly reduced (related to reduced work and community activities as well as environmental barriers and fatigue). Other people's reactions as well as support towards the PWA had a big impact on the individual.
Pommerehn et al.	ICF checklist	52	relationships	Predominant difficulties with informal and formal relations with family

(2016)		(R 26.4-136.8)	and strangers.
--------	--	----------------	----------------

Abbreviations: Barthel Index: Barthel Activities of Daily Living Index, BNT: Boston Naming Test, CETI: Communication Effectiveness Index, CIQ: Community Integration Questionnaire, CNBA: Cracow Neuropsychological Battery for Aphasia Examinations, COOP-WONCA: Dartmouth Coop Functional Health Assessment Charts/Wonca, DAS: Dyadic Adjustment Scale, FAST: Frenchay Aphasia Screening Test, GDS: Geriatric Depression Scale, HRQL: Health Related Quality of Life, MASRS; Montgomery-Asberg Depression Rating Scale, MCQ: Marital Communication Questionnaire, MMSE: Mini-Mental-State Examination, MOS-SSS: Medical Outcome Study Social Support Survey, NGA: Norsk Grunntest for Afasi, QOL: Quality of Life, R: Range, SAQOL-39: Stroke and Aphasia Quality of Life Scale-39, SD: Standard deviation, SSS: Scandinavian Stroke Scale, TT: Token Test

conversations and participation in family activities²⁹. PWA experienced a higher degree of dependence and changes in the roles they played²⁹.

Education and employment

Education includes informal, vocational training and higher education, while employment consists of informal, remunerative and non-remunerative employment, excluding domestic work². These seven studies (2006-2016) are reflected in Table 5. Two studies on a moderate to high level of evidence used the Productivity subscale of the CIQ, with both finding limitations in productivity^{20,21}. Attention was given to return to work^{13,24,28,29} and the ability to participate in work activities^{24,25}. Overall, the studies indicated a greatly reduced productivity level, with few working-age participants returning to paid employment. In a study on a moderate level of evidence, it was found that PWA spent less time on education than individuals without aphasia²⁰. The data from an additional study with a low level of evidence indicated that five out of twelve PWA noted moderate or severe limitations in informal education²⁵.

Community, civic and social life

This includes leisure and recreational activities². The four studies (2010-2016) are shown in Table 6. In two studies with moderate and high levels of evidence respectively, the Social Integration subscale of the CIQ was used^{20,21}, which indicated reduced social integration in working-age PWA, with a decrease in time spent on leisure activities²⁰. The remaining two studies on moderate and low levels of evidence respectively, used the ICF to report on their findings^{24,29}. Of the aspects investigated, restrictions in recreation and leisure activities were noted. Restrictions in community life, political life and citizenship were also found²⁵.

Table 5. Education and employment

Author	Measurements instruments	Mean months post onset (R/SD)	Concepts	Results
Dalemans, de Witte, Beurskens et al. (2010)	Structured interview, FAST, Barthel Index, COOP-WONCA, Personal Factors Questionnaire, Environmental Factors Questionnaire, CIQ	90.6 (R 6-372)	productivity	Mean productivity score on subscale of CIQ (SD: 1.6, Range: 0-5) (max score=5).
Hilari & Northcott (2006)	SAQOL-39, MOS-SSS, a social network questionnaire	42 (R 13-250)	return to work	No PWA returned to full-time employment. Only 6% of PWA were involved in part-time or voluntary work/students, and 56% were of working age.
Matos et al. (2014)	Semi-structured interview	29 (R 3-89)	employment	PWA reported loss of employment and changes in their ability to participate at work.
Naess et al. (2009)	MASRS, Nottingham Health Profile questionnaire part I, SSS, NGA, CETI	≥ 60	return to work	Of ischemic stroke patients employed before the incident, 33% of PWA and 69% of those without aphasia were employed on follow-up.
Lee et al. (2015)	Modified Barthel Index; FAST; GDS; CIQ; SAQOL-39	29.1 (SD 20.6)	productivity	Productivity scores: PWA (Mean: 0.3; SD: 0.8), Control (Mean: 2.8, SD: 1.8). PWA spent less time on education than the control group.
Fotiadou et al. (2014)	Thematic analysis of blog content using Framework Analysis	≥ 12	return to work, factors impacting return to work	2/10 individuals were employed post-stroke. Factors impacting return to work: aphasia, fatigue, older age, epilepsy, short attention span and difficulty multitasking.
Pommerehn et al. (2016)	ICF checklist	52 (R 26.4-136.8)	employment	Predominant difficulties with basic economic transactions and performing paid work.

Abbreviations: Barthel Index: Barthel Activities of Daily Living Index, CETI: Communication Effectiveness Index, CIQ: Community Integration Questionnaire, COOP-WONCA: Dartmouth Coop Functional Health Assessment Charts/Wonca, FAST: Frenchay Aphasia Screening Test, GDS: Geriatric Depression Scale, MASRS; Montgomery-Asberg Depression Rating Scale, MOS-SSS: Medical Outcome Study Social Support Survey, NGA: Norsk Grunntest for Afasi, R: Range, SAQOL-39: Stroke and Aphasia Quality of Life Scale-39, SD: Standard deviation, SSS: Scandinavian Stroke Scale

Table 6. Community, civic and social life

Author	Measurements instruments	Mean months post onset (R/SD)	Concepts	Results
Dalemans, de Witte, Beurskens, et al. (2010)	Structured interview, FAST, Barthel Index, COOP-WONCA, Personal Factors Questionnaire, Environmental Factors Questionnaire, CIQ	90.6 (R 6-372)	social integration	Mean social integration score of 8.4 (SD= 2.2, range: 2-12) (max score: 20).
Matos et al. (2014)	Semi-structured interview	29 (R 3-89)	recreation and leisure	PWA reported particular restrictions in participating in recreation and leisure activities.
Lee et al. (2015)	Modified Barthel Index; FAST; GDS; CIQ; SAQOL-39	29.1 (SD 20.6)	leisure activities, socialising	PWA spent less time on leisure activities than the control group. Social integration score: PWA (Mean 5.7, SD: 3.0), Control (Mean: 9.9, SD: 2.2). Social integration associated with QOL. Frequency of social contact with friends, number of places visited and attendance of meetings was decreased in PWA. Less going out than the control group.
Pommerehn et al. (2016)	ICF checklist	52 (R 26.4-136.8)	community life, recreation and leisure, religion and spirituality, political life and citizenship	Participants noted the greatest disability in community life, followed by recreation and leisure and political life and citizenship.

Abbreviations: Barthel Index: Barthel Activities of Daily Living Index, CIQ: Community Integration Questionnaire, FAST: Frenchay Aphasia Screening Test, GDS: Geriatric Depression Scale, R: Range, SAQOL-39: Stroke and Aphasia Quality of Life Scale-39, SD: Standard deviation

Table 7. Contextual factors impacting on social participation

Author	Measurements instruments	Mean months post onset (R/SD)	Concepts	Results
Dalemans, Witte, Beurskens, et al. (2010)	Structured interview, FAST, Barthel Index, COOP-WONCA, Personal Factors Questionnaire, Environmental Factors Questionnaire, CIQ	90.6 (R 6-372)	personal factors, environmental factors	Factors impacting social participation: age, gender, performance on fADLs and aphasia severity ($\beta= 0.205$). Environmental and personal factors do not independently impact on social participation.
Dalemans, de Witte, Wade, et al. (2010)	FAST Pre-structured diary Semi-structured interview Focus group interview	61.5 (R 16- 132)	engagement, personal factors, social factors, environmental factors,	The level of engagement in social activities is more important than the number of activities. Personal factors: motivation, physical and psychological condition, communication skills; Social factors: the role of the central caregiver, characteristics of the communication partners (willingness, skills and knowledge); Environmental factors: quietness and familiarity of living place.
Pommerehn et al. (2016)	ICF checklist	52 (R 26.4-136.8)	contextual factors	Most reported the following factors as facilitators of social participation: attitude, physical, practical or emotional support from people PWA lives with, however certain individuals noted these same factors as barriers to participation. Additional barriers identified: services, training policies, work and employment.

Abbreviations: Barthel Index: Barthel Activities of Daily Living Index, CIQ: Community Integration Questionnaire, COOP-WONCA: Dartmouth Coop Functional Health Assessment Charts/Wonca, FAST: Frenchay Aphasia Screening Test R: Range, SD: Standard deviation

Contextual factors

Three studies (2010-2016) investigated contextual factors impacting on social participation of PWA^{21,25,30} (Table 7).

A number of personal factors were identified to impact on participation in young PWA: motivation, physical and psychological condition and communication skills³⁰. Environmental factors found to impact the PWA were the role of the central caregiver, characteristics of the communication partners (willingness, skills, knowledge) and quietness and familiarity of the living place³⁰. The support of individuals with whom the PWA lives had a positive impact on social participation³⁰. Furthermore, PWA found additional barriers to social participation to be services, systems and re-integration policies in employment²⁵. These personal and environmental factors were identified in two low level of evidence studies. Contrastingly, in a study with a high evidence rating, contextual factors were not significantly associated with social participation in aphasia²¹.

Discussion

Main findings

A systematic review was completed to investigate social participation in four life domains (domestic activities, interpersonal relations and interactions, education and employment and community, civic and social life) in working-age adults (18-65 years) with aphasia. Eleven articles were identified to be pertinent to the topic.

There appears to be limitations in the knowledge regarding the social participation of this population. Overall, it is evident that social participation across the four domains is greatly reduced for young PWA.

Domestic life has been relatively well researched, with varied concepts investigated. Three assessment tools/frameworks were used, namely the ICF, CIQ and the ECVB. Of those studies using the ICF, one mapped the participants' responses onto the framework, with findings focused largely on household tasks, while the other study included a checklist that investigated a number of concepts (e.g. acquisition of goods and services, preparing meals). The CIQ investigates concepts such as preparing meals, housework and caring for children and the ECVB investigates concepts such as conversing with family members, making phone calls and using a credit card, from a more communicative perspective. While certain items overlap, the concepts assessed are varied and are reflective of the ICF. It is evident that domestic life for young individuals is negatively impacted by aphasia. This finding is in agreement with those found by Dalemans et al. (2008) in their systematic review. Dalemans et al. (2008) found nine studies in this domain and the current study identified six, however a greater percentage of the studies in the current review made use of standardized assessments.

Interpersonal relations and interactions in PWA are affected, with PWA reporting a reduction in the number of people within their social network, with particular loss of friendships, and negative changes in the quality of their marital relationships. Two of the six studies were analyzed according to the ICF, with consensus across the studies regarding the negative impact of aphasia on this life domain. Although a wide variety of concepts were investigated, the findings are reflective of those found by Dalemans et al. (2008).

A number of studies investigated education and employment, with two studies using the ICF. Two studies used the Productivity subscale of the CIQ, which investigated work, training and volunteer programs and is well-reflective of the ICF. The remaining studies used interview formats or patient history reviews. Few PWA

returned to work and many reported changes in their ability to participate in work tasks/productive activity. Two studies made mention of education, reporting that PWA spent less time on education than individuals without stroke and that some PWA felt moderate to severe limitations in their ability to participate in educational-type activities. The attention to education appears to be a new avenue of research in PWA, as Dalemans et al. (2008) did not identify findings on this topic in their review.

The domain with the most limited research was that of community, civic and social life. Two studies reported on the Social Integration domain of the CIQ, which investigates items such as going out and leisure activities. Both studies found limitations in social integration, which was also noted by a study analyzing interview findings of participants according to the ICF. Dalemans et al. (2008) found similar results in leisure activities, but were unable to identify research on the remaining aspects of this domain. In the current review, only one study commented on all aspects of this domain (community life, recreation and leisure, religion and spirituality, political life and citizenship). It appears that PWA found greatest limitations in community life, followed by recreation and leisure and political life and citizenship. Few individuals found limitations in religion and spirituality.

An area of more recent research is the impact of contextual factors on social participation in PWA. While one study did not find that contextual factors impact on social participation, the remaining two studies did, with a key environmental factor in both studies being the support of the central caregiver of the PWA.

The current review is in agreement with many of the findings reported in Dalemans et al. (2008). Of interest is the attention given to items identified as limitations or areas for further research. The researchers of the previous review indicated the need for increased use of a conceptual framework. It is evident that the

ICF is becoming more widely used, which may enable more comparable results, however, the use is still fairly limited. It was noted that the A-FROM is not being used in research in this population. As this framework was developed in 2008, it would be expected that it would be more frequently used in recent years. Dalemans et al. (2008) also identified the need for research into the environmental factors impacting on social participation, and although limited, there is increasing research into this aspect. Two studies included comparison of social participation in stroke PWA, to stroke participants without aphasia, which was identified as a component for further research². While a number of self-developed questionnaires were used in the studies included in this review, there appears to be an increased trend towards using more standardized assessment measures. An encouraging factor is the apparent larger sample sizes in the included studies, which contributes to the reliability and generalizability of the findings. It appears that this rising population of young PWA is receiving increasing attention.

Study limitations

While the use of a conceptual framework is more evident than in the Dalemans et al. (2008) review, there were a number of studies in which the concept of participation was not well defined, which limited data synthesis. There still appears to be limited research focusing exclusively on working-age PWA. While a mean age limit of 65 was set, and the younger population is highlighted with this criterion, it is not possible to set a clear distinction between the young and old population of PWA as yet. While every effort has been made to identify all studies related to social participation, limitations in search terms and the databases selected may have resulted in pertinent studies not being included.

Future research

While there is increased use of the ICF in studies, additional research is warranted to allow a more in-depth understanding of social participation, with a clear conceptual framework (ICF or A-FROM). The research on the impact of contextual factors on social participation appears limited and contradictory. All the studies included in the review were conducted in high-income countries, with the exception of one conducted in Brazil, which is an upper-middle income country³¹. Social participation is likely to be influenced by contextual factors, such as a county's per capita income. It is clear that studies from low to middle income countries is largely missing from existing data. While a few studies compare the social participation of young PWA to young adults with stroke, and no aphasia, this requires additional investigation.

Conclusion

Working-age PWA experience limitations across social participation domains. There is contradictory information regarding the impact of contextual on social participation in PWA, although a number of factors have been identified. The ICF is being used more frequently to guide research studies in social participation, but there is still a lack of consistency in the use of concepts, and to a certain extent, standardized assessment tools. These factors lead one to interpret the findings with caution.

Geolocation information

This systematic review was conducted in Pretoria, South Africa.

Acknowledgements

Competing interests

The authors declare that they have no financial or personal relationships that may have

inappropriately influenced them in the writing of the article.

Authors' contributions

C.P. (University of Pretoria) main researcher. C.P. (University of Pretoria), A.K. (University of Pretoria) and B.P. (University of Pretoria) planned the research and wrote the article.

References

1. Kissela BM, Khoury JC, Alwell K, et al. Age at stroke: temporal trends in stroke incidence in a large, biracial population. *Neurology*. 2012;79(17):1781-1787. doi:10.1212/WNL.0b013e318270401d.
2. Dalemans RJP, De Witte LP, Wade DT, Van den Heuvel WJA. A description of social participation in working-age persons with aphasia: a review of the literature. *Aphasiology*. 2008;22(10):1071-1091. doi:10.1080/02687030701632179.
3. Putaala J, Metso AJ, Metso TM, et al. Analysis of 1008 consecutive patients aged 15 to 49 with first-ever ischemic stroke: the Helsinki young stroke registry. *Stroke*. 2009;40(4):1195-1203. doi:10.1161/STROKEAHA.108.529883.
4. Fang Y, Chen X, Li H, Lin J, Huang R, Zeng J. A study on additional early physiotherapy after stroke and factors affecting functional recovery. *Clin Rehabil*. 2003;17:608-617. doi:10.1191/0269215503cr655oa.
5. Kagan A, Simmons-Mackie N. Beginning with the end: outcome-driven assessment and intervention with life participation in mind. *Top Lang Disord*. 2007;27(4):309-317.

6. Roth FP, Worthington CK. *Treatment Resource Manual for Speech-Language Pathology*. 3rd ed. Clifton Park: Thomson Delmar Learning; 2005.
7. Hallowell B. *Aphasia and Other Acquired Neurogenic Language Disorders*. San Diego: Plural Publishing. Pre-publication release; 2017.
8. Kagan A, Simmons-Mackie N, Rowland A, et al. Counting what counts: a framework for capturing real-life outcomes of aphasia intervention. *Aphasiology*. 2008;22(3):258-280. doi:10.1080/02687030701282595.
9. Worrall L, Sherratt S, Rogers P, et al. What people with aphasia want: their goals according to the ICF. *Aphasiology*. 2011;25(3):309-322. doi:10.1080/02687038.2010.508530.
10. Isaksen JK. It really makes good sense: the role of outcome evaluation in aphasia therapy in Denmark. *Int J Lang Commun Disord*. 2014;49(1):90-99. doi:10.1111/1460-6984.12049.
11. Brown K, Worrall LE, Davidson B, Howe T. Living successfully with aphasia: a qualitative meta-analysis of the perspectives of individuals with aphasia, family members, and speech-language pathologists. *Int J Speech Lang Pathol*. 2012;14(2):141-155. doi:10.3109/17549507.2011.632026.
12. Gauvreau CA, Le Dorze G, Laliberté M-P, Alary Gauvreau C. A pilot study on how speech-language pathologists include social participation in aphasia rehabilitation. *Aphasiology*. 2016;30(10):1117-1133. doi:10.1080/02687038.2015.1100708.
13. Hilari K, Needle JJ, Harrison KL. What are the important factors in health-related

- quality of life for people with aphasia? A systematic review. *Arch Phys Med Rehabil.* 2012;93(1 SUPPL.):S86-S95.e4. doi:10.1016/j.apmr.2011.05.028.
14. Graham JR, Pereira S, Teasell R. Aphasia and return to work in younger stroke survivors. *Aphasiology.* 2011;25(8):952-960.
doi:10.1080/02687038.2011.563861.
 15. Shamseer L, Moher D, Clarke M, et al. Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015: elaboration and explanation. *BMJ.* 2015;349(3):g7647. doi:10.1136/bmj.g7647.
 16. American Speech-Language-Hearing Association [ASHA]. *Evidence-Based Practice in Communication Disorders: An Introduction.* Rockville; 2004.
 17. Wells GA, Shea B, O'Connell D, et al. The Newcastle-Ottawa Scale (NOS) for assessing the quality of nonrandomised studies in meta-analyses.
http://www.ohri.ca/programs/clinical_epidemiology/oxford.asp. Published 2014.
Accessed March 30, 2017.
 18. Mazaux JM, Lagadec T, De Sèze MP, et al. Communication activity in stroke patients with aphasia. *J Rehabil Med.* 2013;45(4):341-346.
doi:10.2340/16501977-1122.
 19. Darrigrand B, Dutheil S, Michelet V, Rereau S, Rousseaux M, Mazaux J-M. Communication impairment and activity limitation in stroke patients with severe aphasia. *Disabil Rehabil.* 2011;33(13-14):1169-1178.
doi:10.3109/09638288.2010.524271.
 20. Lee H, Lee Y, Choi H, Pyun SB. Community integration and quality of life in

- aphasia after stroke. *Yonsei Med J.* 2015;56(6):1694-1702.
doi:10.3349/ymj.2015.56.6.1694.
21. Dalemans RJP, De Witte LP, Beurskens AJHM, Van den Heuvel WJA, Wade DT. An investigation into the social participation of stroke survivors with aphasia. *Disabil Rehabil.* 2010;32(20):1678-1685.
doi:10.3109/09638281003649938.
 22. Willer B, Ottenbacher KJ, Coad ML. The Community Integration Questionnaire: a comparative examination. *Am J Phys Med Rehabil.* 1994;73:103-111.
 23. Dalemans RJ, De Witte LP, Beurskens AJ, Van den Heuvel WJ, Wade DT. Psychometric Properties of the Community Integration Questionnaire Adjusted for People With Aphasia. *Arch Phys Med Rehabil.* 2010;91(3):395-399.
doi:10.1016/j.apmr.2009.10.021.
 24. Matos MA, Jesus LMT, Cruice M. Consequences of stroke and aphasia according to the ICF domains: views of Portuguese people with aphasia, family members and professionals. *Aphasiology.* 2014;28(7):771-796.
 25. Pommerehn J, Delboni MCC, Fedosse E. International Classification of Functioning, Disability and Health, and aphasia: a study of social participation. *CoDAS.* 2016;28(2):132-140. doi:10.1590/2317-1782/201620150102.
 26. Hilari K, Northcott S. Social support in people with chronic aphasia. *Aphasiology.* 2006;20(1):17-36. doi:10.1080/02687030500279982.
 27. Łapkiewicz E, Grochmal-Bach B. Aphasia and changes in the quality of marital relations. *Neuropsychologica.* 2008;6(3):237-246.

28. Naess H, Hammersvik L, Skeie GO. Aphasia among young patients with ischemic stroke on long-term follow-up. *J Stroke Cerebrovasc Dis.* 2009;18(4):247-250. doi:10.1016/j.jstrokecerebrovasdis.2008.10.005.
29. Fotiadou D, Northcott S, Chatzidaki A, Hilari K. Aphasia blog talk: how does stroke and aphasia affect the carer and their relationship with the person with aphasia? *Aphasiology.* 2014;28(11):1301-1319. doi:10.1080/02687038.2014.928665.
30. Dalemans RJP, De Witte LP, Wade DT, Van den Heuvel WJA. Social participation through the eyes of people with aphasia. *Int J Lang Commun Disord.* 2010;45(5):537-550. doi:10.3109/13682820903223633.
31. World Bank Group. World Bank country and lending groups- country classification. <https://datahelpdesk.worldbank.org/knowledgebase/articles/906519-world-bank-country-and-lending-groups>. Published 2017. Accessed May 11, 2017.