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Abstract

Purpose: To identify important treatment outcomes from the perspective of people with aphasia and their families using the ICF as a frame of reference.

Methods: The nominal group technique was used with people with aphasia and their family members in seven countries to identify and rank important treatment outcomes from aphasia rehabilitation. People with aphasia identified outcomes for themselves; and family members identified outcomes for themselves and for the person with aphasia. Outcomes were analysed using qualitative content analysis and ICF linking.

Results: A total of 39 people with aphasia and 29 family members participated in one of 16 nominal groups. Inductive qualitative content analysis revealed the following six themes: (1) Improved communication; (2) Increased life participation; (3) Changed attitudes through increased awareness and education about aphasia; (4) Recovered normality; (5) Improved physical and emotional well-being; and (6) Improved health (and support) services. Prioritised outcomes for both participant groups linked to all ICF components; primarily Activity/Participation (39%) and Body Functions (36%) for people with aphasia, and Activity/Participation (49%) and Environmental Factors (28%) for family members. Outcomes prioritised by family members relating to the person with aphasia, primarily linked to Body Functions (60%).

Conclusions: People with aphasia and their families identified treatment outcomes which span all components of the ICF. This has implications for research outcome measurement and clinical service provision which currently focuses on the measurement of Body Function outcomes. The wide range of desired outcomes generated by both people with aphasia and their family members, highlights the importance of collaborative goal setting within a family-centred approach to rehabilitation. These results will be combined with other stakeholder perspectives to establish a core outcome set for aphasia treatment research.

MeSH Keywords: Aphasia, Patient-Relevant Outcome, Treatment Outcome, ICF, Patient Involvement, Family Caregivers.

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Which outcomes are most important to people with aphasia and their families? An international nominal group technique study framed within the ICF.

Wallace, S. J., Worrall, L., Rose, T., Le Dorze, G., Cruice, M., Isaksen, J., Pak Hin Kong, A., Simmons-Mackie, N., Scarinci, N., & Alary Gauvreau, C.

Achieving outcomes that are important to consumers is a key factor in maximising the value of healthcare (Porter & Lee, 2013). This conceptualisation of value reflects a broader shift in health care towards person-centred services which seek to meet individual needs in holistic ways (World Health Organization., 2007). In aphasia rehabilitation, the value of measuring consumer-important outcomes has steadily gained momentum in the realm of clinical outcome measurement, evident in the development of the person-centred, aphasia-specific framework Living with Aphasia: Framework for Outcome Measurement (A-FROM) (Kagan et al., 2008). Underpinning A-FROM are values which affirm the integral role of consumers in both determining the relevancy of outcomes and in judging when meaningful life change has occurred. In research, the outcomes selected to demonstrate the effects of an intervention must reflect the research question; they must also be able to capture the effects of a treatment in a manner which is meaningful to end-users. If research is to translate to practice — informing individual, clinical, and policy decision making; outcomes must communicate treatment effectiveness in terms which are meaningful to consumers, clinicians, and policy makers. Currently, there is a lack of evidence to inform the selection of stakeholder-important aphasia treatment outcomes and a lack of consensus amongst aphasia researchers about what constitutes a meaningful treatment outcome.

The Cochrane Collaboration have conducted systematic reviews of studies assessing the effectiveness of speech and language therapy (Brady, Kelly, Godwin, & Enderby, 2012) and transcranial direct current stimulation (tDCS) (Elsner, Kugler, Pohl, & Mehrholz, 2015) for the improvement of aphasia following stroke. While both reviews designated functional communication (i.e., communication in real-life situations) as the primary review outcome, none of the studies included in the review of tDCS (n=12), and less than half (n=23 of 51, 45%) of the studies included in the review of speech and language therapy measured this construct. Further, in randomised control trials of aphasia treatments, impairment or Body Function outcomes have been more often measured, with less emphasis on broader constructs such as quality of life, functional communication, or psychosocial outcomes (Brady et al., 2012; Elsner et al., 2015; Xiong, Bunning, Horton, & Hartley, 2011). The incongruence between the primary outcomes selected in systematic reviews and those measured in individual studies highlights a lack of consensus within the research community regarding important treatment outcomes in aphasia rehabilitation. Core outcome set (COS) development is one approach being used across a variety of health fields to gain consensus on research outcomes.

A COS is an agreed standardised set of outcomes and outcome measures which should be measured in all research trials of a given health condition (Williamson & Clarke, 2012). COS development seeks the perspectives of multiple stakeholder groups and uses consensus processes to reach agreement on a minimum set of outcomes (Clarke, 2007; Williamson et al., 2012) (see Core Outcome Measures in Effectiveness Trials Initiative (http://www.comet-initiative.org/). Core outcomes do not restrict the measurement of study specific outcomes, but rather enable efficient use of research findings beyond the individual study, in for example systematic reviews (Brady et al., 2014). A key benefit of COSs is increased compatibility of data across studies, enabling data pooling and data comparisons; standard elements in outcome measurement may also deter the selective reporting of outcomes in research. Furthermore, the use of COSs is increasingly encouraged by funding bodies (European Commission; 2016). In COS development, inclusion of the consumer perspective is deemed particularly important to ensure that relevant and meaningful outcomes are represented (Williamson et al., 2012).

Seeking the perspectives of consumers regarding important research outcomes is both ethical and effective (Boote, Telford, & Cooper, 2002). Foremost, it is right to include consumers in research which concerns them. This moral imperative is reflected in The United Nations' Convention on the Rights of Persons with Disabilities (UN General Assembly, 2006) and the World Health Organization World Report on Disability (World Health Organization., 2011). People who live with disability have a right to full participation and inclusion in society, including the right to contribute to services, policy, and research. Furthermore, consumer participation in health care and research is no longer merely an ideal; it is increasingly policy (Department of Health., 2010; National Health and Medical Research Council and The Consumers Health Forum of Australia Inc., 2002, 2005), as well as a recommendation of funding bodies (National Institute for Health Research., 2015; O'Donnell & Entwistle, 2004) and reporting standards (Chan et al., 2013; Higgins & Green, 2011). Consumer involvement in the selection of research outcomes is also effective. The involvement of patients and their family members in COS development has been found to have a significant impact on research (de Wit, Abma, Koelewijn-van Loon, Collins, & Kirwan, 2013). Patients have contributed to research agendas by identifying novel outcomes of importance (Arnold et al., 2008; Carr et al., 2003; Kirwan et al., 2003; Mease et al., 2008; Sanderson et al., 2012; Sanderson, Morris, Calnan, Richards, & Hewlett, 2010; Serrano-Aguilar et al., 2009), have provided a unique perspective in the prioritisation of outcomes (Bartlett et al., 2012; Morris et al., 2014; Sinha, Gallagher, Williamson, & Smyth, 2012), and have contributed to the development of patient-reported outcome measures (Kirwan et al., 2011; Morris et al., 2014). Additional reported benefits of consumer involvement include improved communication between researchers and patients, mutual empowerment, and improvements in research culture and stakeholder attitudes (de Wit, Abma, Koelewijn-van Loon, Collins, & Kirwan, 2014).

There has been a lack of research investigating the outcomes which are most important to people with aphasia and their families. Existing research examining goal setting and living successfully with aphasia has demonstrated that people living with aphasia (people with aphasia and their families) frame their goals, perspectives, and experiences within the broader context of their lives. Worrall and colleagues (Worrall et al., 2011) examined the goals of people with aphasia in Australia against the framework of the ICF. Participant goals spanned all components of the ICF; however the majority of goals linked to the Activity/Participation component, highlighting the importance of communication in real-life situations for people with aphasia. Brown and colleagues (Brown, Worrall, Davidson, & Howe, 2011) investigated the meaning of living successfully with aphasia from the perspectives of people with aphasia, their family members, and treating speech pathologists. The authors’ synthesis of qualitative data from three separate studies found that living successfully with aphasia requires communication to be considered from a holistic point of view. Participation in meaningful activities and relationships, support from family and friends, and communication across these contexts, were all identified as important factors in living successfully with aphasia. Research has also explored the effects of third-party disability (disability experienced by significant others, as a result of a family members’ health condition) on family members of people with aphasia, as well as their own goals for rehabilitation. Grawburg and associates (Grawburg, Howe, Worrall, & Scarinci, 2013b) examined third-party disability in aphasia, finding that family members experience widespread negative outcomes which linked to the Body Functions and Activity/Participation components of the ICF. Third-party disability relating to Body Functions linked exclusively to the ICF mental functions chapter, relating predominantly to emotional functions such as anxiety, frustration, stress, guilt, sadness, and loneliness. Negative outcomes relating to Activity/Participation covered a broader range of ICF chapters including general tasks and demands, communication, self-care, domestic life, interpersonal interactions and domestic relationships, major life areas, and community, social and civic life. Family members of people with aphasia have also identified a broad range of goals for themselves relating to participation in rehabilitation, communication, relationships, information and support, well-being, and coping; again demonstrating the broad impacts of aphasia (Howe et al., 2012b). Hence, both people with aphasia and their family members frame their goals, experiences, and perspectives about living with aphasia holistically, within the broader context of their lives. Therefore, there is a need to determine whether people living with aphasia frame desired treatment outcomes with similar scope.

Studies investigating outcomes that are important to consumers are increasingly including an international perspective (Bartlett et al., 2012; Heiligenhaus et al., 2012; Schmitt, Langan, Stamm, Williams, & Harmonizing Outcome Measurements in Eczema Delphi, 2011). Around the world, the lived experience of disability differs under the influence of unique social, economic, and cultural factors (Ginsburg & Rapp, 2013). The need to consider the global validity of outcomes has been highlighted by COS developers (Sanderson et al., 2012) who found different outcomes of importance across cultural groups. The experience of aphasia and resulting communication disability can be expected to vary around the world, being influenced by the conceptualisation of disability, availability, and access to health services and socio-cultural factors. The global validity of research findings may therefore be maximised by sampling international perspectives.

The international applicability of research findings can also be improved through the use of a common metric. In stroke and aphasia research the International Classification of Functioning, Disability and Health (ICF) (World Health Organization., 2001) is widely used as a: framework for describing functioning and disability (including third-party disability) (Cruice, 2008; Grawburg, Howe, Worrall, & Scarinci, 2013a; Howe, Worrall, & Hickson, 2008); means for classifying categories of outcome measures (Salter, Jutai, Teasell, Foley, & Bitensky, 2005; K Salter, JW Jutai, R Teasell, NC Foley, J BItensky, et al., 2005; K. Salter et al., 2005); classification tool for analysing the content of outcome measures (Brandenburg, Worrall, Rodriguez, & Bagraith, 2015; Xiong et al., 2011); and data linking tool (Grawburg, Howe, Worrall, & Scarinci, 2014; Worrall et al., 2011). Recent research examining the goals of people with aphasia (Worrall et al., 2011) and the outcomes experienced by family members of people with aphasia (Grawburg et al., 2014) have used ICF data linking. Using this method of data analysis, concepts can be coded to the ICF using standard rules (Cieza et al., 2002; Cieza et al., 2005), allowing a systematic and standardised exploration of concepts which uses a universal language and can be compared across studies.

The current study is part of a program of research known as ROMA (Improving Research Outcome Measurement in Aphasia; (see Wallace, Worrall, Rose, & Le Dorze, 2014)) which aims to develop a COS for aphasia treatment research. Development of a COS is sought through an international consensus conference informed by two phases of research: 1) consensus on stakeholder-important outcomes; and 2) a systematic review of the measurement properties of aphasia outcomes measures. The present study is one of three studies in phase 1. Consensus processes with aphasia researchers (Wallace, Worrall, Rose, & Le Dorze, submitted) and aphasia clinicians and managers (Wallace, Worrall, Rose, & Le Dorze, In press) have been conducted and are reported elsewhere. The current study aimed to identify important outcome domains for people with aphasia and their family members using consensus processes, qualitative analysis, and ICF linking.

Methods

Study Design

This international study used a multiple methods research design, comprising nominal group ranking, qualitative content analysis, and ICF linking. To maximise the diversity of participants sampled, sites were established in seven countries: Australia, Canada, Hong Kong (China), Denmark, South Africa, the United Kingdom (UK), and the United States of America (USA); representing four of the six world regions as defined by the World Health Organization (World Health Organization., 2014). Overarching ethical approval for this project was obtained from the Behavioural and Social Sciences Ethical Review Committee at The University of Queensland in accordance with the National Health and Medical Research Council's guidelines. Ethical approval was obtained at international sites in accordance with local requirements. Additional approvals were granted by The University of West England, United Kingdom, and the Centre for Interdisciplinary Research in Rehabilitation of Greater Montreal (CRIR), Canada.

Participants

Participants were recruited at each site by a local speech pathologist. A total of 39 people with aphasia and 29 family members of people with aphasia participated in the current study. Method of recruitment varied across sites; people with aphasia were recruited through: research registries, aphasia research centres, rehabilitation centres, and community aphasia groups. Family members were recruited using convenience sampling, with each participant with aphasia invited to nominate a family member to participate in a separate group discussion.

Inclusion criteria for people with aphasia were: (a) aged 18 years or over; (b) diagnosis of aphasia as a result of stroke (presence and severity of aphasia confirmed by a speech pathologist or by diagnostic assessment results); (c) able to participate in the nominal group technique process (as judged by the local speech pathologist); and (d) living in the community. Exclusion criteria were comorbid cognitive, sensory, neurological, and/or mental health impairments (e.g., dementia, severe depression, Parkinson's disease). People with aphasia of any severity level were eligible for inclusion in this study. Classification of severity was based on the local speech pathologists own assessment records and/or clinical judgement. Severity was broadly categorised as either mild-moderate or severe and was recorded for the purposes of ensuring that people with more severe aphasia were represented in the sample. No inclusion or exclusion criteria were applied to the family member nominated by the person with aphasia. Participant characteristics for both groups are detailed in tables 1 and 2. In total, nine nominal groups were held with people with aphasia and seven groups with family members. Each group contained between three and six participants.

Table 1. Participant Characteristics – People with Aphasia (n= 39)

Participant Characteristics	Number of Participants (%)
Age	
Range, 42-86 years; mean ± SD = 64 ± 10.6	
< 70 years	26 (66.7)
≥ 70 years	13 (33.3)
Gender	
Male	27 (69.2)
Female	12 (30.8)
Aphasia severity	
Mild - Moderate	31 (79.5)
Severe	8 (20.5)
Months since onset of aphasia	
Range, 4 - 204 months; mean ± SD = 57.4 ± 47.3	
< 18 months	10 (25.6)
≥ 18 months to < 36 months	5 (12.8)
≥ 36 months	24 (61.5)
Country	
United Kingdom	10 (25.6)
Australia	8 (20.5)
Hong Kong, China	6 (15.4)
United States of America	5 (12.8)
Denmark	4 (10.3)
Canada	3 (7.7)
South Africa	3 (7.7)
Main language spoken	
English	24 (61.5)
Cantonese	6 (15.4)
Danish	4 (10.3)
French	3 (7.7)
Spanish	1 (2.6)
Zulu	1 (2.6)
Highest level of education completed	

Tertiary	20 (51.3)
Secondary	13 (33.3)
Primary	5 (12.8)
Not reported	1 (2.6)
Employment status	
Not engaged in paid employment	37 (94.9)
Engaged in paid employment	2 (5.1)
Currently receiving speech therapy	
No	23 (59)
Yes	16 (41)

Table 2. Participant Characteristics – Family Members (n=29)

Participant Characteristics	Number of Participants (%)
Age	
Range, 17-85 years; mean ± SD = 63.3 ± 14.5	
< 70 years	20 (69)
≥ 70 years	8 (27.6)
Not reported	1 (3.4)
Gender	
Female	23 (79.3)
Male	6 (20.7)
Country	
Australia	7 (24.1)
Hong Kong, China	6 (20.7)
Denmark	5 (17.2)
United States of America	5 (17.2)
Canada	3 (10.3)
South Africa	3 (10.3)
Main language spoken	
English	14 (48.3)
Cantonese	6 (20.7)
Danish	5 (17.2)
French	3 (10.3)
Zulu	1 (3.4)
Highest level of education completed	
Tertiary	13 (44.8)
Secondary	13 (44.8)
Primary	3 (10.3)
Employment status	
Not engaged in paid employment	22 (75.9)
Engaged in paid employment	7 (24.1)

Informed Consent

In accordance with recommendations for obtaining informed consent from research participants with aphasia (Kagan & Kimelman, 1995), information about the study was provided both verbally and in writing. Information sheets and consent forms were designed using “aphasia friendly” principles to maximise comprehension (Rose, Worrall, Hickson, & Hoffmann, 2010). Translations of written materials were prepared for non-English speaking participants.

Procedure

The nominal group technique. This study used the structured group decision-making process known as the nominal group technique (NGT) (Delbecq, Van de Ven, & Gustafson, 1975a). In this technique a group of participants are asked to respond to a question posed by a group facilitator, taking turns to give responses until saturation occurs. Participants then rank or prioritise their responses, and individual votes are tallied to identify the ideas rated highest by the group as a whole. The NGT was selected for this study as it has previously been used as a means of achieving consensus on outcomes, outcome domains, and outcome instruments for inclusion in COSs (Douglas et al., 2009; Heiligenhaus et al., 2012; Khanna et al., 2008; Lamb et al., 2005). Importantly, the NGT is an appropriate and effective technique for use with people with aphasia. The structured, round-robin process of idea presentation inherently supports communication by allowing equal participation across group members, a particularly important consideration when a group is comprised of participants with varying levels of aphasia severity. The turn-taking approach used in the NGT also provides time for communication to be facilitated using supported conversation techniques (Kagan, Black, Duchan, Simmons-Mackie, & Square, 2001), again enabling the participation of individuals with diverse communication abilities. A further advantage of this technique is that it encourages ‘hitchhiking’, the stimulation of ideas in response to other group member responses (Delbecq, Van de Ven, & Gustafson, 1975b). Hitchhiking further increases opportunities for participation and allows people with aphasia to easily express congruence with a comment and/or to build on the ideas of other group members. The NGT has been previously used successfully with groups of two to nine people with aphasia (Garcia, Laroche, & Barrette, 2002; Lomas, Pickard, & Mohide, 1987). Studies using the NGT have reported increased difficulty in prioritisation as group numbers increase (Aspinal, Hughes, Dunckley, & Addington-Hall, 2006; Vella, Goldfrad, Rowan, Bion, & Black, 2000), accordingly group size was capped at a maximum of six people.

The nominal question. The nominal question was piloted in two stages, with multiple iterations of the question resulting from pilot feedback. The first iteration of the nominal question was developed through: (1) examination of existing research in a range of health areas which have used the NGT with consumers to identify important outcomes; and (2) discussion amongst the authors of the current study. The resulting question was then piloted with a group of aphasia clinicians and researchers. The pilot group identified that the nominal question should be: (1) broad enough to not be leading; (2) able to capture a range of outcomes without restricting discussion to specific aspects of language or communication; (3) relevant and meaningful to both the person with aphasia and their family members; and (4) specific enough to stimulate discussion regarding outcomes relevant to aphasia treatment. The revised question (which differed slightly between participant groups) was then piloted with people with aphasia and their family members in Australia: (1) People with aphasia: What would you most like to change about your communication and the way aphasia affects your life? (2) Family members of people with aphasia: What would you most like to change about your family member's communication and the way aphasia affects your life? All participants received the nominal question in writing prior to attending their face-to-face nominal group meeting to allow additional time for reflection and understanding of the question. The nominal question was presented to people with aphasia in multiple modalities and using supported conversation techniques (Kagan, 1998). No further changes were made to the nominal questions following the pilot groups in Australia, hence the data from these groups are included in the current study.

Methodological consistency. To ensure methodological consistency across sites, a detailed manual outlining procedures for organising and running the nominal groups was developed. Site co-ordinators were also given access to a video recording of the pilot group held in Australia. A member of the primary investigation team was present to co-facilitate data collection at four of the seven international sites. Each nominal group was video and/or audio recorded to enable data checking.

Nominal group procedures. Nominal groups were conducted in the primary language of group participants. Groups in Australia, South Africa, the USA, and the UK were conducted in English; groups in Hong Kong were conducted in Cantonese; groups in Quebec, Canada were conducted in a combination of English and French; and groups in Denmark were conducted in Danish. Each group was facilitated by speech pathologist experienced in aphasia research. Facilitators who conducted the group in a language other than English translated the results to English. Two hours was allocated for the running of each nominal group. The following process was used in the group sessions:

1. The nominal question was presented in multiple modalities and in an "aphasia friendly" format to optimise the participants' comprehension of the question. Supported conversation techniques for adults with aphasia (Kagan, 1998) were used throughout the groups. Specifically: (1) multi-modal communication including the use of gesture, written key words, and drawing, were used to facilitate comprehension and to clarify the ideas communicated by participants; (2) techniques such as the provision yes/no or fixed-choice questions, provision of appropriate avenues for response, and adequate time to respond, were used to ensure that participants with aphasia could express themselves and respond to questions; and (3) participant responses were verified, e.g. using writing to reflect, expand or summarise what has been communicated (Kagan, 1998).

2. Following a period of quiet reflection and individual response generation, each participant was invited to share one response with the group. This continued in rounds until saturation of ideas was reached (i.e., no new ideas were able to be generated by the group).

3. If necessary, responses were clarified and consolidated by the group facilitator, with similar responses grouped together and duplicates combined or deleted.

4. Participants selected and ranked the three outcomes they considered most important, in order of importance (see figure 1).

Analysis

Nominal group rankings. To present results quantitatively, participants' rankings were scored and summed. The outcome that was ranked as the most important was given a score of 3, the second most important was scored as 2, and the third most important was scored as 1. These scores reflected the relative importance of the outcomes to the participants. Scores were then summed to provide a prioritised list of the most important outcomes for each group.

Content analysis. The list of prioritised outcomes generated by each nominal group was analysed using inductive content analysis procedures (Graneheim & Lundman, 2004). Content analysis was used to gain an in-depth understanding of the desired outcomes of participants. Meaning units within outcomes were identified and organised into content codes, sub-categories, categories, and themes.

Rigour. A process of peer debriefing was used to enhance the rigour and trustworthiness of the content analysis. A full content analysis was completed by one author using the procedures of Granheim and Lundman (Graneheim & Lundman, 2004). At the completion of this analysis, 100% of participant responses were examined and discussed with a co-author to ensure that reasonable interpretations had been made and to check the accuracy and appropriateness of coding, categorization, and higher order themes. As the interpretation of some prioritised outcomes was highly contextually dependent, the analysis of the outcomes from each data collection site was further checked by the co-author who collected that data. This additional process ensured that the interpretation and classification of participant responses were culturally and linguistically appropriate and reflected the context of the preceding discussion within the nominal groups. An ‘audit trail’ (see Koch, 2006) was maintained to provide a full record of the analysis process from raw data (i.e., list of outcomes generated by participants), to data reduction and interpretation (i.e., identification and interpretation of meaning units), to analysis products (i.e., codes, sub-categories, categories and themes).

ICF coding. ICF coding was used to systematically classify outcomes using an internationally comparable framework. Each code generated in the content analysis was linked to the ICF (World Health Organization., 2001) using the linking process outlined by Cieza and associates (Cieza et al., 2002; Cieza et al., 2005) and additional rules devised by Worrall and associates (Worrall et al., 2011). Content codes were linked to the most precise ICF code possible, where necessary more than one code was used. Coding was performed by one author, with peer checking by all co-authors. The resulting ICF codes were analysed in terms of their representation across ICF components and between stakeholder groups.

Inter-rater reliability. In order to assess the reliability of coding, a 30% sample of content codes was independently linked to the ICF by another researcher experienced in use of the ICF. Level of agreement was assessed using the kappa statistic (Cohen, 1960). Kappa statistic provides a measure of agreement beyond that which would be expected by chance alone (Cohen, 1960). Using this statistic, a value of 1 indicates perfect agreement and 0 indicates chance agreement. Bootstrapping (using Stata® statistics/data analysis) was used to generate 95% confidence intervals for the kappa statistic.

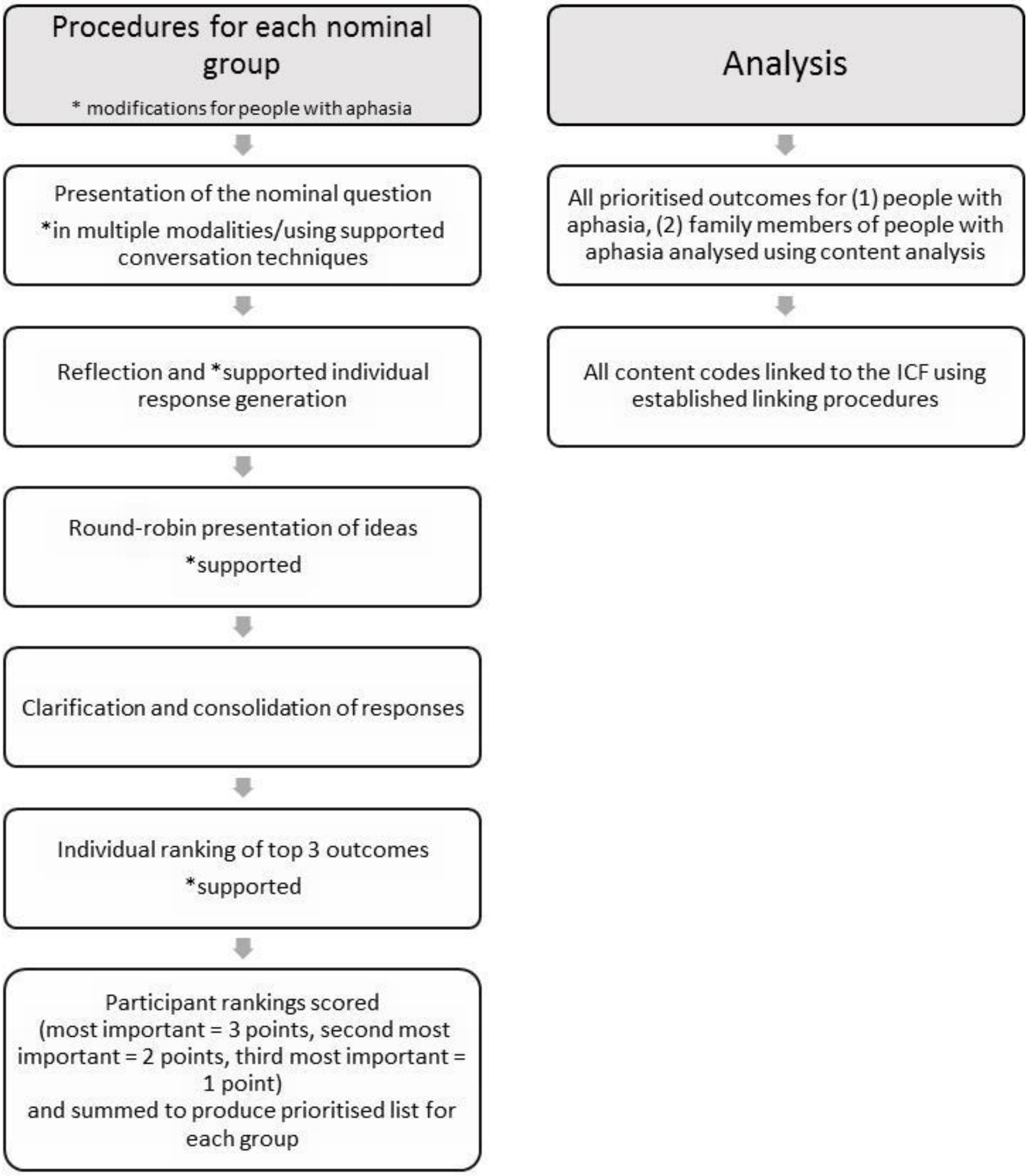

Figure 1. Procedures and Analysis for Nominal Groups

Results

Thirty-nine people with aphasia and 29 of their family members participated in one of 16 nominal groups. The participants with aphasia generated a total of 172 outcomes. During the ranking procedure, 83 of these outcomes were prioritised by participants (i.e., ranked 1, 2, or 3). Family members generated a total of 167 outcomes; prioritising 63 of these outcomes in the ranking procedure. The outcomes identified by family members related to both themselves, i.e., in relation to the impact of aphasia on their own lives and to their family member with aphasia. The outcomes identified by people with aphasia related only to themselves. The outcomes prioritised by participants using the NGT were analysed using both qualitative content analysis and ICF linking and are reported below.

Qualitative Content Analysis

Desired outcomes for people with aphasia. Outcomes for people with aphasia were generated by both the participants with aphasia and their family members, in their separate groups. Inductive content analysis of the 83 outcomes prioritised by the participants with aphasia resulted in 120 content codes. These codes were categorised into six themes, 20 categories and 42 sub-categories (refer to tables 3a and 5). Inductive content analysis of the 63 outcomes generated by family members resulted in 43 content codes which related to outcomes for the person with aphasia and 60 content codes relating to the family member themselves. Codes relating to the person with aphasia were categorised into four themes, 12 categories and 22 sub-categories (refer to tables 3b and 5). The results from both participant groups that related to the person with aphasia are integrated and discussed below.

Improved communication. Responses most frequently related to the theme of improved communication for the person with aphasia. People with aphasia prioritised outcomes which related to improved language function e.g., “To speak in longer words and sentences” (participant with aphasia, Denmark). These outcomes related to a wide range of language modalities encompassing verbal and written expression, auditory and reading comprehension, discourse, word finding, and numeracy. Also frequently prioritised, were outcomes relating to participation in conversation e.g., “Understand or improve phone conversations” (participant with aphasia, USA) and effective communication e.g., “To be able to express myself loud and clear” (participant with aphasia, Denmark). People with aphasia expressed a desire to communicate their emotions, reduce communication breakdown and stress, to communicate independently, and to ‘keep up’ in conversation. Participants with aphasia also expressed a desire to participate in ‘normal’ and more complex conversations, including discussions, conversation in groups, and conversations via the telephone. Other important outcomes for participants with aphasia related to a desire to use technology to support communication e.g., “Use technology (e.g. Facebook and Skype) to stay in touch” (participant with aphasia, Australia).

Family members generated outcomes relating to the person with aphasia that also related to both language function and communication more broadly. The vast majority of outcomes reflected a desire for their family member with aphasia to have improved language function e.g., “Learning key words – speaking and/or writing” (family member participant, Australia). Family members also wanted the person with aphasia to be able to communicate effectively. Reflective of the desired outcomes of the participants with aphasia, family members wanted the person with aphasia to be able to communicate beyond the level of basic needs to be able to express their thoughts, wishes, and emotions e.g., “That she verbally or non-verbally could communicate the thoughts and wishes she is stuck with inside” (family member participant, Denmark). Family members also wanted the person with aphasia to be able to use multi-modal communication and to improve other communicative functions including speech and hearing.

Increased life participation. Outcomes relating to the person with aphasia’s participation in life and life roles were important to both participant groups. People with aphasia prioritised outcomes relating to maintaining and increasing social networks and friendships, participating in their own interests, and having the ability to work and complete education e.g., “I would like to have a social life/friends” (participant with aphasia, USA), “To return to the ‘Welcome Choir’” (participant with aphasia, UK), and “Get to work; including evaluation of being able to work” (participant with aphasia, UK). Family members generated outcomes relating to life participation for the person with aphasia which related primarily to participation in relationships e.g., “Expand communication for a better social life” (family member participant, South Africa).

Both participant groups prioritised outcomes relating to a desire for the person with aphasia to have increased independence in various life roles e.g., “To be able to take medication on time without others’ help” (participant with aphasia, Hong Kong) and “More independence in communication and activities” (family member participant, USA).

Changed attitudes through increased awareness and education about aphasia. People with aphasia identified outcomes which related to a desire for increased awareness and education about aphasia and associated impacts e.g., “People don’t know what aphasia is. Awareness about aphasia” (participant with aphasia, Australia) and “To educate family, and carers, doctors and nurses about effect of aphasia…” (participant with aphasia, UK). Participants also wanted changed attitudes towards people with aphasia through increased awareness, e.g., “Attitude and awareness of aphasia” (participant with aphasia, Australia).

Recovered normality. Outcomes relating to the person with aphasia’s recovery or return to ‘normal’ were prioritised by both the people with aphasia and their family members. These outcomes related to acceptance of changed circumstances; and recovery of communication skills, pre-morbid identity, personality, and life roles e.g., “To be seen as the same person I was before” (participant with aphasia, UK) and “Communicate things he did before – car servicing” (family member participant, South Africa).

Improved physical and emotional well-being. People with aphasia and their family members prioritised outcomes which related to the physical and emotional well-being of the people with aphasia. This included desired improvements in confidence, physical and cognitive functions, and feelings about self, e.g., “More dignity and respect” (participant with aphasia, Australia) and “…not the end of the world/not be so hard on self” (family member participant, USA).

Improved health services. Outcomes relating to improving health services were important to people with aphasia. This included a desire for greater access to both health services and health-related equipment e.g., “For software and aids to be freely available and used in the NHS so everyone gets it” (participant with aphasia, UK). Family members also prioritised outcomes relating to health services, however these were in reference to themselves and not the person with aphasia.

Table 3a. Content Analysis of Outcomes Prioritised by Participants with Aphasia – "What would you most like to change about your communication and the way aphasia affects your life?"

Themes	Categories	Sub-categories
Improved communication (person with aphasia)	To have improved language function	▪ To have improved verbal expression ▪ To have improved comprehension and auditory comprehension ▪ To have improved word finding ▪ To have improved reading and reading comprehension ▪ To have improved written expression ▪ To have improved discourse at sentence level ▪ To have improved use of numbers
	To communicate effectively	▪ To express myself clearly, ask questions and write lists ▪ To help my communication partners communicate, including tools to support communication ▪ To communicate my emotions ▪ To reduce communication breakdown and stress ▪ To be able to communicate independently and be understood by others ▪ To use/understand money when shopping
	To be able to participate in conversation	▪ To keep up with conversation and change in topic ▪ To have complex conversations, including giving explanations and conversation via the telephone ▪ To be included in conversations and group conversations ▪ To have normal and meaningful conversations
	To use technology to support communication	▪ To use Facebook and Skype to communicate ▪ To use the telephone and answering machine to communicate
	To have improved speech function	▪ To have improved articulation and speech volume
	To have improved hearing	

Increased life participation (person with aphasia)	To participate in relationships	▪ To have increased social life/friendships and less isolation ▪ To maintain existing relationships
	To be able to work and complete my education	▪ To return to work/complete my schooling ▪ To have greater workplace flexibility and tolerance
	To participate in my own interests	▪ To participate in specific activities e.g. sport, singing ▪ To participate in my own interests and hobbies
	To have increased independence with activities including medication management	
Changed attitudes through increased awareness and education about aphasia	To have increased education about aphasia and stroke	▪ To have increased aphasia education for the general public and the workplace ▪ To have increased aphasia education for families, children and carers ▪ To have increased aphasia education for health professionals ▪ To have increased stroke education for families and children
	To change attitudes about aphasia	▪ To have improved public attitudes towards aphasia ▪ To receive more respect from others
	To increase public awareness of aphasia	
Recovered normality (person with aphasia)	To recover communication	▪ To regain, maintain and improve communication ▪ To use my own dialect again ▪ To recover more easily and quickly
	To return to ‘normal’	▪ To regain my pre-morbid identity and not be defined by aphasia ▪ To regain and feel my pre-morbid confidence
	To be able to accept my changed circumstances	

Improved physical and emotional well-being (person with aphasia)	To have improved physical function	▪ To have improved mobility and energy ▪ To have improved physical function including hand function
	To have improved cognitive function	▪ To have improved thinking and concentration ▪ To have improved memory
	To have more self-confidence, dignity and determination	
Improved health services	To have greater access to health services and equipment	▪ To have access to and funding for services, software and aides

Table 3b. Content Analysis of Outcomes Prioritised by Family Members (Relating to the Person with Aphasia) – "What would you most like to change about your family member's communication…"

Themes	Categories	Sub-categories
Improved communication (for the person with aphasia)	For the person with aphasia to have improved language function For the person with aphasia to be able to communicate effectively For the person with aphasia to use multi-modal communication For the person with aphasia to have improved speech function	▪ For the person with aphasia to have improved verbal expression ▪ For the person with aphasia to have improved written expression ▪ For the person with aphasia to have improved discourse – sentence level ▪ For the person with aphasia to communicate thoughts and wishes and understanding ▪ For the person with aphasia to communicate effectively with family ▪ For the person with aphasia to express emotions
Recovered normality (for the person with aphasia)	For the person with aphasia to be able to accept their changed circumstances For the person with aphasia to return to 'normal' For the person with aphasia to recover their communication	▪ For the person with aphasia to adjust to and accept new circumstances ▪ For the person with aphasia to be open to assistance and the opinions of others ▪ For the person with aphasia to rest when needed ▪ For the person with aphasia to regain their pre-morbid identity and personality ▪ For the person with aphasia to fulfil their pre-morbid communication roles
	For the person with aphasia to have more positive feelings	▪ For the person with aphasia to reduce their frustration ▪ For the person with aphasia to maintain a good mood

Improved physical and emotional wellbeing (for the person with aphasia)		▪ For the person with aphasia to have increased optimism and appreciation of others
	For the person with aphasia to have improved cognitive function	▪ For the person with aphasia to have improved memory ▪ For the person with aphasia to have improved concentration
	For the person with aphasia to have improve physical function	▪ For the person with aphasia to have improved mobility
Increased life participation (for the person with aphasia)	For the person with aphasia to participate in activities and relationships	▪ For the person with aphasia to have improved social life ▪ For the person with aphasia to maintain routines ▪ For the person with aphasia to have safe participation in activities
	For the person with aphasia to have increased independence	▪ For the person with aphasia to be more independent in activities and communication ▪ For the person with aphasia to take personal responsibility for their learning

Family members – desired outcomes for themselves. Family members identified desired outcomes for themselves, relating to the impact of aphasia on their own lives. Inductive content analysis of 63 outcomes resulted in 60 content codes relating to outcomes for the family member themselves. These outcomes were organised into six themes, 13 categories and 33 sub-categories (refer to tables 4 and 5). These results are presented below in order of frequency:

Improved communication. Family members generated outcomes for themselves which related to their role as a communication partner. They expressed a desire to communicate effectively with the person with aphasia, to engage in conversation with the person with aphasia, and to use technology to support communication with the person with aphasia. Family member participants also expressed a desire for a better understanding of how to facilitate and support communication, and reduce communication breakdown e.g., "Family understand more about how to communicate (give more time etc)" (family member participant, USA). Family members also wanted to be able to effectively express more abstract concepts such as emotions and feelings in a way that could be understood by their family members with aphasia e.g., "To express our feelings" (family member participant, Canada).

Family members prioritised outcomes relating to participation in conversation focusing on a desire for meaningful conversation between spouses. This included a desire for conversation and discussion with their loved one with aphasia which surpassed the exchange of basic needs e.g., "Deeper conversation/more in-depth discussion" (family member participant, USA).

Increased life participation. Family members identified outcomes which related to life participation, specifically being able to participate in activities of interest and to be able to participate in activities as a couple e.g., "To be able to enjoy outings to different places of interest" (family member participant, Australia). Family member participants also emphasised outcomes relating to their own participation in family relationships and friendships, expressing a desire to socialise more, feel less isolated, have more support, and to have greater balance and independence in spousal relationships e.g., "More balance between partners" (family member participant, Denmark) and "To take time for ourselves" (family member participant, Canada).

Improved health and support services. Family members prioritised outcomes which related to improving health and social support services. These outcomes focused on the delivery of services like, holistic rehabilitation and case management as well as access to therapies, counselling, and respite, e.g., “Routine respite/counselling for family” (family member participant, Australia).

Changed attitudes through increased awareness and education about aphasia. Outcomes relating to increased aphasia awareness and education and changed family attitudes about aphasia were important to family members. This included a desire to feel better understood in family relationships and to have increased education for the general public and family members, e.g., “To enhance public awareness of aphasia, so that the general public will understand the communication needs of PWA (person with aphasia) as well as the pressure of PWA's family members” (family member participant, Hong Kong).

Improved emotional well-being. For family members, outcomes relating to their emotional well-being were important. Family members expressed a desire to have more enjoyment, optimism, and positivity in life; as well as fewer feelings of anxiety and frustration, e.g., “Less frustration/ more patience” (family member participant, Australia) and “Constantly worried – is he comfortable, is he in pain? All the responsibility on your shoulders” (family member participant, South Africa).

Recovered normality. Family members prioritised outcomes relating to their own desire to return to ‘normal’ and to recover communication with their family member living with aphasia. This included returning to previous activities, having hope for the future, enjoying life, and regaining a sense of individuality, e.g., “To have individuality back” (family member participant, Australia) and “To know that things will improve” (family member participant, Canada).

Table 4. Content Analysis of Outcomes Prioritised by Family Members (for Themselves) – "What would you most like to change about … the way aphasia affects your life?"

Themes	Categories	Sub-categories
Improved communication (family members)	To be able to communicate effectively with the person with aphasia	▪ To have communication and mutual understanding ▪ For family to understand how to facilitate and support communication ▪ To have tools to support communication, comprehension and cognition ▪ To reduce communication breakdown ▪ To understand the person with aphasia's emotions and to express my emotions in a way that can be understood
	To be able to participate in conversation with the person with aphasia	▪ To have spousal conversation ▪ To have deeper conversation and in-depth discussion ▪ To participate in meaningful conversation
	To use technology to support communication with the person with aphasia	
Increased life participation (family members)	To participate in family relationships and friendships	▪ To have independence, balance, and less responsibility in spousal relationships ▪ To socialise with family and friends and feel less isolated ▪ To have family support ▪ Family adjustment to living with a person with aphasia
	To participate in activities	▪ To participate in activities as a couple ▪ To participate in outings to places of own interest ▪ To have financial support for activities
Improved health and support services	To have access to health and support services	▪ To have access to family respite and counselling ▪ To have access to physical and psychological therapy
	To have appropriate delivery of services	▪ To have holistic rehabilitation which includes family ▪ To have case management

Changed attitudes through increased awareness and education about aphasia	Increased education about aphasia	▪ To have increased aphasia education for the general public ▪ To have increased aphasia education for families
	Changed family attitudes about aphasia	▪ To have understanding and improved attitudes in spousal relationships ▪ To feel understood by family
	Increased public awareness of aphasia	
Improved emotional well-being (family members)	To have positive feelings	▪ To have more enjoyment and positivity ▪ To have increased optimism and determination ▪ To reduce frustration and increase patience
	To have less anxiety	
Recovered normality (family members)	To return to ‘normal’	▪ To return to pre-morbid activities ▪ To enjoy life again ▪ To have my individuality back
	To recover communication	▪ To know communication will improve and have hope for the future ▪ To improve communication

Table 5. Desired Outcomes: Themes by Participant Group

People with aphasia	Family members	
	For the person with aphasia	For themselves
1. Improved communication	1. Improved communication	1. Improved communication
2. Increased life participation	2. Recovered normality	2. Increased life participation
3. Changed attitudes through increased awareness and education about aphasia	3. Improved physical and emotional well-being	3. Improved health and support services
4. Recovered normality	4. Increased life participation	4. Changed attitudes through increased awareness and education about aphasia
5. Improved physical and emotional well-being		5. Improved emotional well-being
6. Improved health services		6. Recovered normality

ICF Linking

People with aphasia. The outcomes prioritised by participants with aphasia were linked to the most specific level of the ICF possible; resulting in a total of 121 linkages (refer to table 6). Important outcomes for people with aphasia spanned all ICF components. The majority of codes linked to the Activity/Participation (39%) and Body Functions (36%) components. Codes also linked to the contextual factor components of the ICF, with 22% linking to Environmental Factors and 3% relating to Personal Factors.

Family member outcomes relating to the person with aphasia were linked to the ICF, resulting in 40 linkages in total (refer to table 6). The majority of codes linked to the Body Functions (60%) and Activity/Participation (33%) components. A small number of codes linked to Environmental (2%) and Personal Factors (5%). ICF linkages for people with aphasia are presented in tables 7a and 7b.

Table 6. Distribution of Linkages to ICF Components

ICF component	People with aphasia n (%)	Family members Relating to the person with aphasia n (%)	Relating to themselves n (%)
Body Functions	44 (36.4)	**24 (60)**	11 (18)
Activity/Participation	**47 (38.8)**	13 (32.5)	**30 (49.2)**
Environmental Factors	26 (21.5)	1 (2.5)	17 (27.9)
Personal Factors	4 (3.3)	2 (5)	3 (4.9)
Total linkages	121	40	61

Table 7a. ICF Linkages: Important Outcomes to Participants with Aphasia

ICF component (number of codes linked to component)	ICF chapter (number of codes linked to chapter)	ICF code	ICF category description (number of codes linked to category)
Body Functions (44)	b1 Mental functions (37)	b1266	Confidence (2)
		b1300	Energy level (1)
		b1301	Motivation (1)
		b1400	Sustaining attention (1)
		b144	Memory functions (1)
		b1442	Retrieval of memory (1)
		b152	Emotional functions (3)
		b160	Thought functions (1)
		b1670	Reception of language (3)
		b16700	Reception of spoken language (3)
		b16701	Reception of written language (3)
		b16710	**Expression of spoken language (8)**
		b16711	Expression of written language(1)
		b1672	**Integrative language functions (8)**
	b2 Sensory functions and pain (1)	b230	Hearing functions (1)
	b3 Voice functions (4)	b3100	Production of voice (1)
		b320	Articulation functions (2)
		b340	Alternative vocalization functions (1)
	b7 Neuromusculoskeletal and movement-related functions (2)	b7	Neuromusculoskeletal and movement-related functions (2)
Activities/Participation (47)	d1 Learning and applying knowledge (4)	d1551	Acquiring complex skills (1)
		d166	Reading (1)
		d170	Writing (2)

	d2 General tasks and demands (4)	d2102	Undertaking a single task independently (1)
		d2202	Undertaking multiple tasks independently (2)
		d240	Handling stress and other psychological demands (1)
	d3 Communication (24)	**d3**	**Communication (8)**
		d310	Communicating with – receiving – spoken messages (1)
		d330	Speaking (1)
		d350	**Conversation (7)**
		d355	Discussion (1)
		d3504	Conversing with many people (1)
		d360	**Using communication devices and techniques (4)**
		d3602	Using communication techniques (1)
	d4 Mobility (1)	d4	Mobility (1)
	d5 Self-care (1)	d5702	Maintaining one's health (1)
	d7 Interpersonal interactions and relationships (2)	d720	Complex interpersonal interactions (1)
		d7500	Informal relationships with friends (1)
	d8 Major life areas (4)	d810-839	Education (1)
		d845	Acquiring, keeping and terminating a job (1)
		d8450	Seeking employment (1)
		d860	Basic economic transactions (1)
	d9 Community, social and civic life (7)	d9	Community, Social and Civic life (1)
		d920	Recreation and leisure (1)
		d9204	Hobbies (2)
		d9205	Socializing (3)
Environmental Factors (26)	e1 Products and technology (3)	e1250	General products and technology for communication (1)
		e1251	Assistive products and technology for communication (2)
	e3 Support and relationships (6)	e310	Support and relationships: Immediate family (3)
		e330	Support and relationships: People in positions of authority (1)
		e340	Support and relationships: Personal care providers and personal assistants (1)

		e355	Support and relationships: Health professionals (1)
	e4 Attitudes (5)	e4	Attitudes (1)
		e430	Individual attitudes of people in positions of authority (1)
		e460	Societal attitudes (3)
	e5 Services, systems and policies (12)	e565	Economic services, systems and policies (1)
		e5800	Health services (1)
		e5801	Health systems (1)
		e585	**Education and training services, systems and policies (7)**
		e5900	Labour and employment policies (1)
		e5902	Labour and employment services (1)
Personal Factors (4)	Personal factors (4)	pf	Dialect (1)
		pf	Coping skills (1)
		pf	Identity (2)

Table 7b. ICF Linkages: Important Outcomes to Family Members (Relating to the Person with Aphasia)

ICF component (number of codes linked to component)	ICF chapter (number of codes linked to chapter)	ICF code	ICF category description (number of codes linked to category)
Body Functions (24)	b1 Mental functions (23)	b1	Mental functions (1)
		b1301	Motivation (1)
		b1400	Sustaining attention (1)
		b144	Memory functions (1)
		b152	**Emotional functions (5)**
		b1521	Regulation of emotion (1)
		b1670	Reception of language (1)
		b16710	**Expression of spoken language (7)**
		b16711	Expression of written language (3)
		b1672	Integrative language functions (2)
	b3 Voice functions (1)	b320	Articulation functions (1)
Activity/Participation (13)	d2 General tasks and demands (2)	d2202	Undertaking multiple tasks independently (1)
		d230	Carrying out daily routine (1)
	d3 Communication (7)	**d3**	**Communication (6)**
		d360	Using communication devices and techniques (1)
	d4 Mobility (1)	d4	Mobility (1)
	d5 Self-care (1)	d570	Looking after one's health (1)
	d7 Interpersonal interactions and relationships (2)	d7	Interpersonal interactions and relationships (1)
		d7101	Appreciation in relationships (1)

Environmental Factors (1)	e3 Support and relationships	e340	Personal care providers and personal assistants (1)
Personal Factors (2)	Personal factors (2)	Pf	Pre-morbid roles
		Pf	Pre-morbid personality

Family members. The desired outcomes of family members for themselves were linked to the ICF, resulting in 61 linkages (refer to table 6). The majority of codes linked to the Activity/Participation component (49%) and Environmental Factors (28%). The remaining codes linked to the Body Functions component (18%) and 5% of linkages were classified as Personal Factors. ICF linkages for family members are presented in table 8.

Table 8. ICF Linkages: Important Outcomes to Family Members (Relating to Themselves)

ICF component (number of codes linked to component)	ICF chapter (number of codes linked to chapter)	ICF code	ICF category description (number of codes linked to category)
Body Functions (11)	b1 Mental functions (11)	**b1265**	**Optimism (4)**
		b130	Energy and drive functions (1)
		b152	**Emotional functions (5)**
		b1521	Regulation of emotion (1)
Activity/Participation (30)	d1 Learning and applying knowledge (1)	d1	Learning and applying knowledge (1)
	d2 General tasks and demands (2)	d240	Handling Stress and other psychological demands (2)
	d3 Communication (13)	**d3**	**Communication (6)**
		d350	Conversation (2)
		d3503	Conversing with one person (1)
		d355	Discussion (1)
		d360	Using communication devices and techniques (3)
	d5 Self-care (1)	d570	Looking after one's health (1)
	d6 Domestic life (2)	d6602	Assisting others in communication (2)
	d7 Interpersonal interactions and relationships (9)	d7102	Tolerance in relationships (1)
		d7500	Informal relationships with friends (2)
		d760	Family relationships (2)
		d7701	**Spousal relationships (4)**
	d9 Community, social and civic life (2)	d9202	Arts and culture (1)
		d9205	Socializing (1)

Environmental Factors (17)	e1 Products and technology (2)	e1	Products and technology (1)
		e1650	Financial assets (1)
	e3 Support and relationships (4)	**e310**	**Support and relationships – immediate family (4)**
	e4 Attitudes (3)	e410	Individual attitudes of immediate family members (1)
		e415	Individual attitudes of extended family members (1)
		e460	Societal attitudes (1)
	e5 Services, systems and policies (8)	e5750	General social support services (3)
		e5800	**Health services (5)**
Personal Factors (3)	Personal factors (3)	Pf	Individuality
		Pf	Pre-morbid activities
		pf	Independence

Inter-Rater Reliability

Inter-rater reliability ranged from 0.73 (ICF component-level) to 0.52 (ICF chapter and 2nd level) (see table 9). Considered in reference to criteria for interpreting kappa values (Landis & Koch, 1977) this indicates substantial agreement (0.61-0.80) at a component-level and moderate agreement (0.41-0.60) at a the chapter and second level of the ICF.

Table 9. ICF Coding: Inter-Rater Reliability

*Bias corrected bootstrapped confidence intervals (1000 replications)

ICF level	Percentage agreement	Kappa (95%CI)*
Component (e.g. Body functions)	81.08	0.73 (0.55-0.91)
Chapter (e.g. b1 Mental functions)	59.46	0.52 (0.35-0.69)
Second level (e.g. b160 Thought functions)	54.05	0.52 (0.38-0.70)

Discussion

This study aimed to identify important treatment outcomes from the perspectives of people with aphasia and their family members in order to contribute to a COS for aphasia treatment research. At an overarching level, the results show that the desired treatment outcomes of people with aphasia and their family members span all components of the ICF framework. This finding provides confirmation and validation that whilst aphasia is, at the most fundamental level, a disorder of language function, its consequences are far-reaching. Both participant groups identified outcomes for themselves, which most frequently linked to the Activity/Participation component of the ICF, and within this component, to the Communication chapter. This suggests that people with aphasia and their family members consider participation in communication activities to be a key desired outcome of treatment. These results are consistent with research from Worrall and associates (Worrall et al., 2011) who found that the goals of people with aphasia span the full spectrum of the ICF, primarily linking to the Activity/Participation component. Furthermore, this finding is in step with systematic reviews of aphasia treatments which have selected functional communication as the primary review outcome (Brady et al., 2012; Elsner et al., 2015).

Whilst the outcomes identified by both participant groups most frequently linked to the Activity/Participation level of the ICF, Body Function outcomes were also very highly represented. Furthermore, where family members identified communication outcomes for the person with aphasia, those outcomes most frequently linked to language functions. The complementary nature of the outcomes identified by participants with aphasia and their family members highlights the synergistic relationship between the remediation of language impairment and communication in activities and everyday life. The need to consider communication from a holistic point of view, with emphasis on language function as well as communication more broadly in everyday contexts, has previously been identified as a key aspect of living successfully with aphasia (Brown et al., 2011).

The results of this study have important implications for aphasia treatment research which currently focuses on the measurement of Body Function outcomes. If aphasia research is to maintain relevancy and translate to clinical practice, it is essential to measure constructs that matter to people living with aphasia. The results of this study indicate that important treatment outcomes for people with aphasia and their family members occur across all components of the ICF; most frequently at Activity/Participation and Body Function levels.

At a thematic level, there was broad consistency in the desired outcomes of people with aphasia and those of their family members. The desired outcomes of both stakeholder groups encompassed the same overarching themes relating to: (1) Improved communication; (2) Increased life participation; (3) Changed attitudes through increased education and awareness about aphasia; (4) Increased emotional (and physical) well-being; (5) Improved health (and support) services; and (6) Recovered normality. Consistent with other COS development studies reporting multiple stakeholder perspectives (Bartlett et al., 2012; Morris et al., 2014; Sinha et al., 2012), the stakeholder groups in the current study differed in their prioritisation of outcomes. Of fundamental importance to both stakeholder groups was having improved communication and life participation; however family members prioritised improved health and support services more highly, whilst people with aphasia placed greater emphasis on outcomes relating to attitudes, awareness and education about aphasia, and recovery.

Important Outcomes for People with Aphasia

Not surprisingly, the outcomes desired by and for people with aphasia primarily related to improved communication. Outcomes related to the full spectrum of communication encompassing receptive and expressive language functions, participation in conversation, strategies to promote effective communication, communication partner skills, and use of technology to support communication. Both participant groups also expressed a desire for the person with aphasia to be able to communicate at a level beyond the expression of basic needs. Participants with aphasia and their family members shared a desire for the person with aphasia to have communicative abilities which allowed the expression of deeper thoughts and emotions. The prioritisation of this outcome by both participant groups exemplifies the integral role of communication in relationships and mirrors the body of literature documenting the negative impacts of aphasia on marital satisfaction (Williams, 1993), social relationships (Parr, 2007), and overall quality of life (Cruice, Worrall, & Hickson, 2006). Also of great importance to people with aphasia was increased life participation. Participants with aphasia prioritised outcomes which related to returning to work and schooling, and participation in their own interests and hobbies. There was again overlap in the desired outcomes of the participants with aphasia and their family members, with both groups wanting increased independence and reduced social isolation for the person with aphasia. The impact of aphasia on friendships and relationships is well documented in the literature (Davidson, Howe, Worrall, Hickson, & Togher, 2008; Northcott & Hilari, 2011); these results again highlight the importance of active participation in social networks for people with aphasia.

Third-Party Disability

The results of this study confirm the widespread impact that aphasia may have on families. In the current study, family member participants identified a wide range of desired outcomes for themselves relating to the impact of their family member's aphasia. This finding adds weight to research from Grawburg and associates (Grawburg et al., 2013a) which shows that the third-party disability (changes to functioning and disability as a result of another person's health condition) experienced by family members of people with aphasia can be attributed to the health condition of the person with aphasia.

The most important outcomes for family members related to Activity/Participation and Environmental Factor domains. Spousal and family relationships were of high importance to family members, with outcomes relating to a desire for increased independence, and greater balance and appreciation in relationships. Previous research has detailed the impact of aphasia on relationships citing: role changes and increased dependence from the person with aphasia (Grawburg et al., 2013a); negative changes in marital satisfaction following the onset of aphasia (Williams, 1993); and spousal stress as a result of communication impairment (Michallet, Tétreault, & Le Dorze, 2003). Family members also wanted increased involvement in rehabilitation, expressing a desire to learn more ways to support communicative interactions; to have tools to support communication, comprehension and cognition; and to be able to reduce communication breakdown. Improved health and support services were key desired outcomes for family members, who articulated a need for holistic family-based aphasia services, family respite and counselling, access to physical and psychological therapy and co-ordinated case management. These findings add weight to existing research which has examined the impact of stroke on family members (Pellerin, Rochette, & Racine, 2011) and the goals that family members of people with aphasia have for themselves (Howe et al., 2012a), and has identified the need for family-centred approaches to rehabilitation, including access to support and respite (Le Dorze & Signori, 2010).

Clinical Implications

The results of this study indicate a broad role for clinicians in aphasia rehabilitation which primarily focuses on remediation of language impairment and communication disability but which also extends to aphasia education; supporting clients in accepting their changed circumstances; and facilitating and coordinating access to complementary health and support services. Importantly clinicians should have a role in facilitating the achievement of outcomes in these areas not only for the person with aphasia but also for their family members. The wide range of treatment outcomes identified by family members in this study suggests a need for family-centred aphasia services which not only seek to meet the needs of people with aphasia, but also to define and address the specific goals of family members and significant others in rehabilitation. There is a clear and necessary role for clinicians in the provision of communication partner training and in ensuring appropriate access to support and health services, particularly those directed at supporting emotional wellbeing and family relationships. The complementary nature of the outcomes generated by the participants with aphasia and their family members highlights the importance of collaborative goal setting which includes family members. The categories of outcomes identified in this study may be used clinically as a starting point for goal-setting discussions.

Limitations and Future Research

While it was not the intention of this research to examine differences in outcome prioritisation between countries, this may be an area for future research. Subsequent studies examining cultural/country specific variations in outcomes and outcome prioritisation would require larger sample sizes. Future international research may also contribute additional data from other countries and participants that could validate the findings of this study.

This study represents the first stage of a larger project to develop a COS for aphasia treatment research. Further stakeholder perspectives are needed to gain a comprehensive picture of important outcomes from aphasia treatments. Accordingly two further studies have been conducted examining clinician (Wallace, Worrall, Rose, and Le Dorze, 2016a).and reseracher perspectives on treatment outcomes (Wallace, Worrall, Rose, and Le Dorze, 2016b). This information will be paired with a systematic review and meta-analysis of outcome measures in a final consensus process to develop a COS for aphasia treatment research.

Conclusions

People with aphasia and their family members identified important treatment outcomes which linked to all components of the ICF. Participants with aphasia prioritised outcomes which primarily linked to the Activity/Participation and Body Function ICF components. Family members prioritised outcomes for themselves which predominantly linked to the Activity/Participation component, and outcomes for their family member with aphasia which primarily linked to the Body Function component of the ICF. These findings have implications both in terms of research outcome measurement and clinical service provision. In research, the relevancy and translation of findings may be increased by measuring and reporting research outcomes which are important to people living with aphasia. The breadth of outcomes identified by participants provides a mandate for holistic, family-centred aphasia services that address the needs of both people with aphasia and their significant others.

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