The Top Ten Research Priorities in Aphasia from the Perspective of Various Stakeholder Groups (People with Aphasia, Carers and Healthcare Professionals).

Author: Dearbhla Harhen (13012169)

Supervisor: Professor Sue Franklin

Module code: SL6036

Date: 11\textsuperscript{th} May 2015

Word count: 6975
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Abstract

Title: The Top Ten Research Priorities in Aphasia from the Perspective of Various Stakeholder Groups (People with Aphasia, Carers, and Healthcare professionals).

Author: Dearbhla Harhen

Supervisor: Sue Franklin

Background  Pollock et al (2012) conducted a study using the James Lind Alliance methodology to identify the top ten research priorities relating to life after stroke from the perspective of various stakeholders. Results identified the area of aphasia as one of the top 10 research priorities in stroke.

Purpose  In this study, the authors aimed to identify the top ten research priorities in aphasia from the perspective of people with aphasia (PWA), carers and health care professionals.

Method  Participants were PWA (n=21), carers (n=7) and health care professionals (n=18). Thirty four proposed research priorities were given to each participant for ranking. These 34 had been identified in the study by Pollock et al (2012). PWA completed the questionnaire with assistance from the student researchers, using aphasia friendly strategies where needed as suggested by the literature (Dalemans et al 2009). Health care professionals completed the questionnaire via an online survey.

Results  The results revealed many differences in the chosen research priorities of each of the stakeholder groups. Two research priorities converged across all groups. These research priorities related to the delivery of speech and language therapy:

- *When is the best time after a stroke to deliver speech and language therapy?*
- *Which speech and language therapy treatments work best for aphasia?*

Conclusions

- The top ten research priorities in aphasia have been identified (See table 1).
- PWA can successfully be included in research.
• PWA, carers and health care professionals have many different perspectives on what priorities are important in research.
• Limited research has been conducted in the top ten priority areas.
Introduction and Literature Review

Public involvement in research priority setting is important to ensure the most relevant research questions are being answered (Gooberman-Hill et al 2013). Public and patient involvement in research is recognised to improve the “design, conduct and dissemination of research studies” according to the British Paediatric Unit Surveillance (2013, p.1). Viergever et al (2010) reviewed the literature around best practice in research priority setting. Nine themes were suggested as part of a “checklist” for best practice. Stakeholder participation was included as one these themes. The literature found stakeholder involvement to be an integral part of the process of research prioritisation (Lomas et al 2003).

“Generalized exclusion of people with aphasia occurs at the expense of the clinical validity of research findings and has severe consequences for the accessibility of stroke treatment and care for this group of patients”

(Brady et al 2013, p.195)

There are many reasons why aphasia research priorities must be set from the person with aphasia’s perspective in conjunction with caregivers and healthcare professionals. Literature suggests that PWA have been excluded from stroke studies in the past. The WHO’s International Classification of Functioning Disability and Health emphasises the importance of “activity and participation”. Excluding a population from research because of a communication impairment, sends a message of inequality. It also inhibits the progression of knowledge and advancements in the area of aphasia.

Exclusion

“Systematic exclusion of a group of people because of age, race, gender, or disability is discriminatory” (Brady et al 2013, p.193). Townend et al (2007) reviewed 129 studies that diagnosed depression following stroke. Of the 129 studies reviewed, aphasia screening methods were only mentioned in 57. Aphasia was not mentioned in 13
studies. Brady et al (2013) highlighted that in a Cochrane review of information provision after stroke, only one out of fourteen randomised control trials included PWA. Similarly, Hackett et al (2005) conducted a systematic review of observational studies of the frequency of depression after stroke. Data from 51 studies was collected between 1977 and 2002. It was reported that “All studies excluded people with communication difficulties (e.g. aphasia, confusion, dementia)” (p.1333).

Some research has explored quality of life in people with mild to moderate aphasia, however little is known about the quality of life of people with severe aphasia (Hilari and Byng 2011). The results of a study by Garcia and Connor (2011) suggest that people with mild to moderate aphasia can successfully participate in research. Five participants participated in individual semi-structured interviews. The interviews were conducted using an aphasia friendly format. Interview questions were based on the components of the ICF. Despite the study aiming to include people with aphasia, the inclusion criteria only included people with mild to moderate aphasia, which further highlights the exclusion of people with severe aphasia. The exclusion criteria of these studies highlight the blatant exclusion of PWA from research.

As well as exclusion from research, much of the literature that has been researched on aphasia has not been chosen by PWA, but by academics and healthcare professionals. Some studies have used proxies or family members to speak for the person with aphasia, however evidence shows that stroke survivors, caregivers and healthcare professionals may each hold different perspectives on what the most important research issues are (Boote et al 2011).

**Stakeholder Perspective**

Hilari et al (2007) conducted a study which compared the results of the Stroke and Aphasia Quality of Life Scale in PWA with their proxies. Fifty participants with mild to moderate aphasia participated as well as an equivalent number of proxies. The results showed similar answers, however some differences were reported. The authors stated that “Self report is more valid than proxy report” (p.1075). This suggests that even the
people who know the person with aphasia best may not be able to fully express their opinions and perceptions.

In a study by Lomas et al (1987), a nominal group process was used to create a quality of life measure. PWA and healthcare professionals were asked to create a list of important functional communication situations (Lomas et al 1987). Results revealed that PWA focused on the most social aspects of communication, as opposed to healthcare professionals who chose more daily functional communication activities. This identifies a difference of opinion in what aspect of communication is most important. A difference of perspective was also observed in a study by Zemva et al (1999). Twenty PWA and an equivalent number of family members were interviewed to find out the most commonly occurring limitations for PWA. PWA expressed that their biggest difficulty was related to communication, while family members rated behavioural and emotional changes as the most significant difficulty.

Brown et al (2012) conducted a qualitative meta-analysis of three studies to explore perspectives of PWA, family members and speech and language therapists. Data from the three original studies were reanalysed to identify common themes and differences among participants. The results showed common themes across the three groups which included

1. Participation
2. Meaningful relationships
3. Support
4. Communication
5. Positivity
6. Independence
7. Living successfully with aphasia as a journey over time

Despite the common themes that emerged, differences of opinion were still observed, for example the SLT group placed a strong emphasis on the importance of decision making and family involvement while only one person with aphasia highlighted this as important.
In a qualitative study by Matos et al (2013), the views of various stakeholders were explored. The study viewed the perspectives of 38 individuals of three stakeholder groups (14 individuals with aphasia, 14 family members and 10 speech and language therapists). Half of the participants with aphasia had mild to moderate aphasia and the other half had severe aphasia. Those with mild to moderate aphasia were interviewed in a group and those with severe aphasia were interviewed individually and given conversational supports. They were asked to identify the most significant long term consequences of stroke and aphasia. PWA reported more language and communication difficulties as opposed to family members and healthcare professionals who reported more emotional consequences. A limitation of this study was that participants who were interviewed in a group may not have felt comfortable expressing their true opinions in front of other people. Despite this limitation, the study does suggest that stakeholders have differing perspectives on the consequences of stroke.

The results of a study by Cranfill and Wright (2010) further supports this argument. In a prospective, observational, non-randomised group design, a quality of life scale was administered to 27 PWA, 7 speech and language therapists and 24 significant others (SOs). A diagnosis of aphasia was made on the Western Aphasia Battery (WAB). The mean age of the PWA was 70. The participants included 10 males and 14 females. Severity was determined based on a taped transcript of a picture description task from the WAB. All participants were administered the Stroke and Aphasia Quality of Life Scale-39 and the Quality of Communication Life Scales. All participants were asked to rate each item from 1 to 5 (5 being the most important and 1 being very unimportant). Facilitative communication strategies such as rephrasing were used to enhance the accuracy of results. The PWA responded from their own perspective. The SLTs and SOs responded based on what they thought the person with aphasia would have answered. The results showed that the SLT’s and SO’s answers were closely correlated to each other’s, but not to the PWA’s results. Cranfill and Wright (2010) concluded that “for objective criteria, experiences of the PWA, must be in the end submitted to the judgement of the person with aphasia” (p.996). Cranfill and Wright’s study also
suggests that all severities of aphasia can participate in research when appropriate communication strategies are implemented.

*Successful Inclusion*

A growing body of research has identified that people with mild, moderate and severe aphasia can participate in research if appropriate facilitative communication strategies are implemented. Dalemans et al (2009) conducted a qualitative and quantitative study to explore the effectiveness of aphasia friendly communication strategies. They concluded that people with all severities of aphasia can participate in research. Some of the strategies used are as follows:

- “The use of pre-structured diaries
- The use of in-depth interviews with attention to non-verbal communication
- Allowing as much time as needed
- Using pictograms
- Placing one question per page
- Bolding the key concepts in the question
- Using large font, visualizing the answering possibilities in words and in pictures
- Reducing the question length
- Excluding negatives in the question”

Dalemans et al (2009, p.948)

Palmer and Patterson (2013) conducted qualitative research to explore communication strategies to aid communication in PWA. The most effective methods included having a consistent meeting structure, using pictures, avoiding over complicated medical language and emphasising non-verbal activities (Palmer and Patterson 2013).
Brennan et al (2005) also studied the comprehension and expression of PWA when using aphasia friendly strategies. Nine people with mild to moderately severe aphasia were asked to read a battery of 90 paragraphs. They were asked to choose a word or paragraph from a choice of four to complete the paragraph. Results showed that by using simplified vocabulary and syntax, large print and increased white space, the participants could comprehend significantly more paragraphs than control paragraphs (Brennan et al 2005). The results also showed that visuals did aid comprehension of paragraphs but not significantly. Worrall et al (2005) synthesised the results of three studies to analyse the results of aphasia friendly communication. Results of each study showed positive benefits of using aphasia friendly formatting for written material, but that not all PWA prefer these formats. It was also suggested that further research is needed to assess the benefits of visual aids (e.g. photos, clipart etc). In light of these successful facilitative communication strategies, there is no longer a reason why PWA should be excluded from research as they have been in the past.

The research literature highlights four main points that call for the inclusion of PWA within research priority setting. They are as follows:

1. Stakeholder involvement is important to ensure the most relevant research questions are being answered.
2. PWA have been systematically excluded from research in the past.
3. PWA may have differing opinions in research priority setting than family members or health care professionals.
4. PWA can successfully participate in research once appropriate facilitative communication strategies are implemented.
**Aims of current study**

The current study draws on a previous study by Pollock et al (2012) which identified the top ten research priorities relating to life after stroke. As aphasia was identified as a top research priority, the researchers aimed to gather the top ten research priorities specific to aphasia. The aims of the study are as follows:

1. Identify the top ten research priorities in aphasia from PWA, carers and healthcare professionals to inform those who conduct and fund research.
2. Compare similarities and differences of research priorities between the various stakeholders.
3. Gather data from people with even severe aphasia by using facilitative communication strategies.

**Methods**

**Participants**

A total of 46 participants were included in the study (21 PWA, 7 carers, and 18 SLTs).

**Inclusion criteria**

Participants who had aphasia as a result of a stroke were included. Other forms of aphasia were excluded (primary progressive aphasia, acquired brain injury). Speech and language therapists who did not work in the area of aphasia were excluded.

**Procedures**

Ethics was obtained from the local hospital ethics committee. The three research students were trained in the James Lind Alliance (JLA) methodology at Glasgow Caledonian University by Dr Alex Pollock.
The James Lind Alliance Methodology

The JLA methodology is a quantitative approach using priority setting partnerships (PSPs) which aims to identify a top ten list of priorities for research shared by patients, carers and healthcare professionals. Priority setting partnerships work together, to gather uncertainties about the effects of treatment (James Lind Alliance 2015). These uncertainties are checked to ensure they cannot be answered by existing research. The uncertainties then go through a process of prioritisation, which aims to reach a shared top ten priorities from stakeholders. This method involves establishing a priority setting partnership; ranking the most important treatment uncertainties from patients, carers, and healthcare professionals (using surveys administered by e-mail, post, and at face-to-face meetings); and a final consensus meeting (Pollock et al 2012).

Using this methodology, Pollock et al (2012) identified the top ten research priorities relating to life after stroke. Five hundred and forty eight research questions were initially gathered. These were refined into 226 unanswered treatment uncertainties. Respondents objectively identified 24 shared priority treatment uncertainties. A representative group of 28 stroke survivors, carers, and health professionals attended a final meeting, reaching consensus on the top 10 research priorities relating. As previously stated, the area of “aphasia” was identified as a top ten research priority.

Identifying relevant research uncertainties

The researchers individually analysed each of the 226 research uncertainties from the Pollock et al (2012) study. Many of these uncertainties related to aphasia. Questions directly relating to aphasia were identified individually by each researcher. The researchers compared results and identified 34 research questions that directly related to communication difficulties post stroke.

As part of this study, a representative group of PWA, carers, and health professionals were to attend a final meeting, reaching consensus on the top 10 research priorities relating to life with aphasia post stroke. Due to unforeseen circumstances, the consensus meeting was unable to take place. The top ten priorities were gathered from a ranked questionnaire completed by the relevant stakeholders.
Online questionnaire

A questionnaire was designed containing the 34 research questions. An online version of the questionnaire was created via survey monkey. The questionnaire was piloted on three speech and language therapists to ensure instructions were clear. The SLTs were instructed to rank the top ten research priorities most important to them. A score of “1” was ranked as the most important and “10” was ranked as the least important. After receiving ethical approval, the questionnaire was emailed to a data base of 103 speech and language therapists provided by the Department of Health Sciences at the University of Limerick. Twenty four respondents replied in total. All were speech and language therapists who worked in the area of aphasia. Six of these questionnaires were excluded as they were completed incorrectly i.e. they did not chose a complete top ten.

Aphasia Friendly Questionnaire

An aphasia friendly version of each question was also made to be used where needed by PWA. Questions were converted into simple English to ensure they were accessible. Each question was converted to a large font, put in bold and each printed on a separate white strip of paper as recommended by the literature (Dalemans et al 2009). Pictures that matched each question were printed and included where possible to aid comprehension. Pictures were not included in questions with abstract themes. The aphasia friendly questions were then piloted. The researchers contacted stroke clubs in Dublin, Cork, Wexford, Galway and Wicklow via email with an aphasia friendly information booklet attached to each email. Four stroke club organisers replied and permission was received for the researchers to attend each stroke club meeting. Dates and times were arranged. On arrival at each meeting, the researchers gave an introduction to each stroke club group about the research project using the aphasia friendly information booklet. Written consent was obtained from each participant using an aphasia friendly consent form. The questionnaire was completed by 15 PWA at Irish stroke clubs. Eight PWA opted to complete the questionnaire in their home with assistance from a researcher. Two people with severe aphasia began the questionnaire but chose not to complete it. Their results were not included.
**Carer Questionnaire**

The questionnaire was given to carers who were present at the stroke clubs. Instructions were attached to each questionnaire. Seven carers completed the questionnaire.

**Considerations when completing the questionnaire with PWA**

Many factors were considered before giving the questionnaire to the PWA. This was to ensure the questionnaire was as accessible as possible.

1. **Severity**
   
   As aphasia affects everyone differently, information was obtained from the stroke club organiser or carer where possible with regards to the client’s receptive and expressive language ability, reading ability, vision, hearing difficulties, cognition etc. Advice was obtained regarding appropriate strategies specific to each participant that would aid communication. The PWA was also asked which mode of communication they preferred. This was to ensure the client felt as comfortable as possible while completing the questionnaire in a mode most suitable to their ability e.g. reading the question aloud vs using pictures, speaking slowly or a combination of strategies. Included in the study were people with mild aphasia (n=4), moderate aphasia (n=11) and severe aphasia (n=6). As previously stated, 2 people with severe aphasia did not complete the full questionnaire. Their results were excluded. A total of 6 people with severe aphasia were included in the results.

2. **Carer assistance**
   
   Where possible, the PWA were asked to complete the questionnaire without the assistance of a carer. This was to ensure accuracy of the results and also because certain questions were quite personal, e.g. questions regarding depression. When the PWA opted to have their carer present, every attempt was made possible to ensure accuracy. For example if a carer intervened for other reasons that to assist in the translation a question, the PWA was
reminded by the researcher to answer based on their own opinion. Three PWA were assisted by carers.

3. **Understanding**

Some of the PWA who had severe receptive difficulties at times misunderstood the reason for the questionnaire. This may be due to receptive language difficulties, processing difficulties or memory difficulties that had occurred secondary to their stroke. At times PWA opted to answer the question as opposed to rank its research importance. For example, when asked "*What is more effective, individual therapy or group therapy?*", some answered "*Group*". When this occurred, the researcher referred back to the aphasia friendly information booklet and/or rephrased the question to more simplified language. Some of the questions included in the questionnaire were quite specific to treatment. Instead of asking, for example "*Is transcranial magnetic stimulation important for research*" the PWA was asked "*Have you heard of Transcranial Magnetic Stimulation?*" If the PWA had not heard of a specific treatment, it was considered not important by the researcher.

4. **Fatigue**

As it is established that PWA often fatigue later in the day, the researchers organised for the questionnaire to be completed earlier in the day where possible. The researchers frequently reminded the PWA that they were welcome to take a break at any time.

**Analysis of results**

Results were calculated using the James Lind Alliance scoring system and documented using an excel sheet. A question rank “1” was awarded 10 points, “2” was ranked 9 points, “3” was ranked 8 points and so forth. If two questions scored the same amount of points, the highest amount of times a question was chosen in the top ten was taken into consideration to decide the higher ranked question. The results were calculated separately for each group and then combined to obtain an overall top ten. Each researcher calculated the results independently to provide inter-rater reliability.
Results

The following tables display the ranked top ten research priorities of: PWA, carers and speech and language therapists (table 1), PWA (table 2), carers (table 3), and speech and language therapists (table 4). They display the rank, score and number of times each research question was selected.

<table>
<thead>
<tr>
<th>Rank</th>
<th>Research Priority</th>
<th>Score</th>
<th>No of times selected</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>When is the best time after stroke to deliver speech and language therapy?</td>
<td>176</td>
<td>27</td>
</tr>
<tr>
<td>2</td>
<td>Which speech and language therapy treatments work best for aphasia?</td>
<td>158</td>
<td>30</td>
</tr>
<tr>
<td>3</td>
<td>What is the best amount and intensity of speech and language therapy for aphasia?</td>
<td>120</td>
<td>23</td>
</tr>
<tr>
<td>4</td>
<td>Is speech and language therapy helpful more than 1 year after a stroke?</td>
<td>118</td>
<td>19</td>
</tr>
<tr>
<td>5</td>
<td>Do communication aids and software packages improve communication in patients with aphasia?</td>
<td>112</td>
<td>18</td>
</tr>
<tr>
<td>6</td>
<td>How can carers be helped to communicate with someone with aphasia?</td>
<td>108</td>
<td>20</td>
</tr>
<tr>
<td>7</td>
<td>Do slowing down, providing written material, allowing time for questions and using conversation partners help communication for someone with aphasia?</td>
<td>93</td>
<td>14</td>
</tr>
<tr>
<td>8</td>
<td>Do social communication groups improve confidence in people with communication problems?</td>
<td>92</td>
<td>18</td>
</tr>
<tr>
<td>9</td>
<td>What is the best way to improve understanding (cognition) after stroke?</td>
<td>88</td>
<td>21</td>
</tr>
<tr>
<td>10</td>
<td>What is the best way to improve the production of structured sentences in people with aphasia?</td>
<td>88</td>
<td>15</td>
</tr>
</tbody>
</table>
### Table 2

#### The Top research Priorities of PWA

<table>
<thead>
<tr>
<th>Rank</th>
<th>Research Priority</th>
<th>Score</th>
<th>No. of times selected</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Which speech and language therapy treatments work best for aphasia?</td>
<td>92</td>
<td>15</td>
</tr>
<tr>
<td>2</td>
<td>When is the best time after stroke to deliver speech and language therapy?</td>
<td>82</td>
<td>11</td>
</tr>
<tr>
<td>3</td>
<td>Is speech and language therapy helpful more than 1 year after a stroke?</td>
<td>74</td>
<td>12</td>
</tr>
<tr>
<td>4</td>
<td>How can carers be helped to communicate with someone with aphasia?</td>
<td>51</td>
<td>9</td>
</tr>
<tr>
<td>5</td>
<td>Do slowing down, providing written material, allowing time for questions and using</td>
<td>49</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>conversation partners help improve communication with people with aphasia?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>What is the best way to improve the production of structured sentences in people</td>
<td>46</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>with aphasia?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Can trained volunteers and carers help improve communication after stroke?</td>
<td>45</td>
<td>10</td>
</tr>
<tr>
<td>8</td>
<td>What is the best way to manage feelings of panic due to aphasia?</td>
<td>43</td>
<td>9</td>
</tr>
<tr>
<td>9</td>
<td>What is the best way to help people with aphasia to return to driving after</td>
<td>43</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>stroke?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.1</td>
<td>What is the best way to improve understanding (cognition) after stroke?</td>
<td>42</td>
<td>8</td>
</tr>
<tr>
<td>10.2</td>
<td>What is the best way to treat depression in people with aphasia following stroke?</td>
<td>42</td>
<td>8</td>
</tr>
</tbody>
</table>
### Table 3

The Top research Priorities of Carers

<table>
<thead>
<tr>
<th>Rank</th>
<th>Research Priority</th>
<th>Score</th>
<th>No. of times selected</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Do slowing down, providing written material, allowing time for questions and using conversation partners help improve communication with people with aphasia?</td>
<td>37</td>
<td>4</td>
</tr>
<tr>
<td>2</td>
<td>How can carers be helped to communicate with someone with aphasia?</td>
<td>29</td>
<td>4</td>
</tr>
<tr>
<td>3</td>
<td>When is the best time after stroke to deliver speech and language therapy?</td>
<td>27</td>
<td>5</td>
</tr>
<tr>
<td>4</td>
<td>What is the best way to help people recover from aphasia?</td>
<td>24</td>
<td>4</td>
</tr>
<tr>
<td>5</td>
<td>Do social communication groups improve confidence in people with communication problems after stroke?</td>
<td>18</td>
<td>3</td>
</tr>
<tr>
<td>6</td>
<td>Which speech and language therapy treatments work best for aphasia?</td>
<td>16</td>
<td>3</td>
</tr>
<tr>
<td>7</td>
<td>What stimulation techniques are useful for enhancing the engagement of stroke patients with severe cognition and communication impairment?</td>
<td>16</td>
<td>2</td>
</tr>
<tr>
<td>8</td>
<td>Can trained volunteers and carers help improve communication after stroke?</td>
<td>15</td>
<td>4</td>
</tr>
<tr>
<td>9.1</td>
<td>What is the best amount and intensity of speech and language therapy for aphasia?</td>
<td>15</td>
<td>2</td>
</tr>
<tr>
<td>9.2</td>
<td>Is speech and language therapy helpful for patients more than 1 year after stroke?</td>
<td>15</td>
<td>2</td>
</tr>
<tr>
<td>9.3</td>
<td>Can transcranial magnetic stimulation help people with aphasia?</td>
<td>15</td>
<td>2</td>
</tr>
<tr>
<td>Rank</td>
<td>Research Priority</td>
<td>Score</td>
<td>No. of times selected</td>
</tr>
<tr>
<td>------</td>
<td>-----------------------------------------------------------------------------------</td>
<td>-------</td>
<td>-----------------------</td>
</tr>
<tr>
<td>1</td>
<td>What is the best amount and intensity of speech and language therapy for aphasia?</td>
<td>81</td>
<td>16</td>
</tr>
<tr>
<td>2</td>
<td>Do communication aids and software packages improve communication in patients with aphasia?</td>
<td>76</td>
<td>11</td>
</tr>
<tr>
<td>3</td>
<td>When is the best time after stroke to deliver speech and language therapy?</td>
<td>67</td>
<td>11</td>
</tr>
<tr>
<td>4</td>
<td>Has the National Stroke Strategy impacted on the provision of services for patients with long term communication problems following stroke?</td>
<td>57</td>
<td>8</td>
</tr>
<tr>
<td>5</td>
<td>Which speech and language therapy treatments work best for aphasia?</td>
<td>50</td>
<td>11</td>
</tr>
<tr>
<td>6</td>
<td>What is the best way to help people with aphasia return to work?</td>
<td>48</td>
<td>7</td>
</tr>
<tr>
<td>7</td>
<td>Do social communication groups improve confidence in people with communication problems after stroke?</td>
<td>47</td>
<td>8</td>
</tr>
<tr>
<td>8</td>
<td>Can cognitive behavioural therapy (CBT) help recovery of speech?</td>
<td>37</td>
<td>6</td>
</tr>
<tr>
<td>9</td>
<td>Can Adult Education improve stroke acquired literacy/numeracy problems?</td>
<td>36</td>
<td>5</td>
</tr>
<tr>
<td>10</td>
<td>What is the best way to diagnose and assess depression in people with aphasia following stroke?</td>
<td>35</td>
<td>6</td>
</tr>
</tbody>
</table>
Discussion

Convergence and Divergence between groups

The top ten research priorities in aphasia have been identified from the stakeholders that are affected most by aphasia post stroke. A client centred approach that catered for specific communication needs was implemented to ensure people with even severe aphasia were included. Five of the top ten priorities directly related to the delivery and effectiveness of speech and language therapy. The remaining research priorities related to communication aids and software packages, carers communication, general communication strategies, communication groups, and cognition. Similarities and differences of results were observed across groups.

Only two questions converged from the PWA, carers, and the speech and language therapist’s top ten. These questions were ranked 1\textsuperscript{st} and 2\textsuperscript{nd} in the combined top ten. They included: “When is the best time after stroke to deliver speech and language therapy?” and “Which speech and language therapy treatments work best for aphasia?” These were the only two research priorities that converged between the SLTs and PWA. When comparing the PWA to the carers, six priorities converged in their top ten. These six questions involved communication strategies for carers and PWA. Four questions converged between the carers and the SLTs. Three of these related to the delivery of speech and language therapy and one related to the effects of social communication groups.

Psychosocial aspects of aphasia and social communication groups

Aspects of depression were included in the top ten of both the PWA and the SLTs. The SLTs ranked “What is the best way to diagnose and assess depression in people with aphasia following stroke?” as their 10\textsuperscript{th} most important research priority. The PWA ranked “What is the best way to treat depression in people with aphasia following stroke?” as their 10\textsuperscript{th} most important priority.

Although these questions did not make the combined top ten, they are of interest as the literature suggests that many people with aphasia have depression due to the isolating nature of the impairment (Parr et al 1997). Herrmann and Wallesch (1993)
suggest that a person’s motivation, language processing, and cognitive performance are directly affected by an individual’s emotional state. A PubMed database search revealed that some research has been done in this area, with 369 articles present when the terms “aphasia AND depression” were searched. Two hundred and twenty three articles were present when the terms “aphasia AND depression AND diagnosis” were searched. One hundred and seventy six articles were present when the terms “aphasia AND depression AND treatment” were searched.

Davidson and Worrall (2013) suggest group therapy as an effective and underutilised approach to address such psychosocial factors in PWA. Interestingly, the carers and SLTs both included “Do social communication groups improve confidence in people with communication problems?” in their top 10. However, the PWA did not. The search terms “Aphasia AND Social AND Groups” were typed into the PubMed database to reveal 80 articles. Results from articles about group therapy have so far yielded positive results. Elman (2007) reviewed the evidence for aphasia groups. She found that taken together, the quantitative and qualitative data regarding aphasia group treatment provide support for both psychosocial and speech–language benefits of aphasia group participation. She states that research has highlighted the psychosocial benefits of group therapy. It is unsurprising that aspects of depression, and communication groups were included in combined the top ten research priorities as PWA have been found to have restricted social activities (Cruice et al 2006), and fewer friendships (Parr et al 1997) compared to before the stroke. There are currently only 23 stroke support groups held throughout Ireland according to the Irish Heart Foundation (2014). The positive outcomes of these studies should not be ignored, as benefits of group therapy are vast according to Byng and Duchan (2005). They include “creating authentic involvement, creating engaging experiences, establishing user control and equalising social relations” (Byng and Duchan 2005, p.906). Further study is warranted in the area of depression in aphasia and the benefits of communication groups.

The PWA ranked “What is the best way to manage feelings of panic due to aphasia?” as their 8th most important research priority. Neither the carers nor the SLTs included this in their top ten. This is of interest as much of the literature relating to psychosocial
aspects of aphasia focuses on depression. Little research has been done in the area of anxiety or panic. Only 4 articles were present when “aphasia AND panic” were searched on the PubMed database. One hundred and five articles were present when “aphasia AND anxiety” were searched. Unfortunately this a gross overestimate, as many of the articles did not directly relate to the search terms used.

Speech and language therapy and treatments for aphasia

The carers and PWA included the question “What is the best way to improve the production of structured sentences in people with aphasia?” in their top ten. The SLTs did not include this in their top 10. This is surprising as this question is specific to speech and language therapy. Perhaps this is because SLTs were familiar with effective treatments of improving structured sentences. Aphasia can impair many aspects of sentence processing including structure, verb processing and grammatical morphology (Marshall 2013). Therapy treatments with a considerable evidence base have been developed. It has been demonstrated that therapy for word-retrieval and production disorders can be effective (Wiseburn & Mahoney, 2009). Treatment of Underlying Forms (TUF) has been reported to result in improved production and comprehension of complex “wh” questions (Thompson et al 2003). Positive outcomes were reported on measures of word retrieval across all studies in a review by Boyle (2011). A single case study by Webster et al (2005) resulted in positive widespread changes in sentence production, when therapy targeted predicate argument structure and word retrieval. Despite these positive outcomes, more research is warranted in this area because of the complex nature and variability of aphasia. There are different opinions of the underlying causes of sentence productions deficits. Marshall (2013) states that selecting a treatment approach to improve sentences production is difficult due to “contradictions in the literature” (p.212).

The SLTs selected “cognitive behavioural therapy” as a specific treatment they would like researched. The PWA and carers did not include this in their top ten. Perhaps this is because they were unfamiliar with this treatment. The carer group included the question “Can transcranial magnetic stimulation help people with aphasia?” as their 8th most important research priority. This is surprising as this treatment is generally
used for the treatment of depression as opposed to aphasia. A PubMed search identified 1563 when the terms “Transcranial magnetic stimulation AND depression” were searched. The terms “transcranial magnetic stimulation AND aphasia” revealed only 147 articles. As only seven participants were included in the carer group, this question may have only been important to a small number of people.

Unlike the PWA and carers, the SLTs chose the question “Do communication aids and software packages improve communication in patients with aphasia?” Perhaps this was because the majority of PWA and carers included in the study were over the age of 70. Research suggests that many older adults have negative attitudes towards technology, particularly feelings of inadequacy and anxiety (Laguna and Babock 1997). Furthermore there is considerable evidence suggesting that older adults find learning about computers more difficult than younger people do (Dickinson et al 2007).

**Returning to work and returning to driving**

The SLTs included “What is the best way to help people with aphasia return to work?” as their 6th priority, unlike the PWA and carers who did not include this priority in their top ten. Perhaps this is because the majority of participants in the study were retired and did not feel this was important. A younger cohort of participants may have ranked this priority as important. Graham et al (2011) state that “traditional rehabilitation often does not account for language impairments that impact vocational status” (p.952). A single case study by Morris et al (2011) highlights the complex nature of returning to work with aphasia and the challenges faced by health care professionals to facilitate success. Wozniak and Kittner (2002) state that there is conflicting evidence as to the predictive nature of communication impairments on returning to work. A review by Daniel et al (2009) reported that between 0% and 100% of working-age stroke survivors return to work. This demonstrates the need for further research in this area.

The PWA included the question “What is the best way to help people with aphasia to return to driving after stroke” as 9th in their top ten research priorities. Neither the SLTs nor the carers ranked this priority in their top ten. A database search revealed
limited research in this area with only 13 articles present when the search term “aphasia AND driving” were typed into the PubMed database. One study by Mackenzie and Paton (2003) found that PWA who could not return to driving post stroke felt social activity and wellbeing had been affected. They also found that despite various difficulties including road sign recognition and related reading and auditory comprehension, people with even severe aphasia can drive post stroke (Mackenzie and Paton 2003). Further research is warranted in this area.

**Carer Communication**

Both the carers and the PWA ranked the following question in their top ten: “*How can carers be helped to communicate with someone with aphasia?*” PWA ranked this question as 4th in their top ten. Carers ranked this as the 2nd highest priority in aphasia research. The SLT group did not include this in their top ten. Furthermore the question “*Can trained volunteers and carers help improve communication after stroke?*” was also included as a research priority for PWA and carers but not included as important by SLTs.

A database search using the search terms “Carers AND Aphasia AND Communicate” revealed that approximately 18 studies had been completed on this topic in the past ten years. Research has identified the difficulties carers face when conversing with a family member with aphasia. A literature review by McGurk and Kneebone (2013) found evidence to suggest that carers of PWA commonly experience problems in the following areas: “role changes/new responsibilities, difficulties with social and leisure activities, communication difficulties with the stroke survivor, employment and financial problems, problems in dealing with health professionals, relationship difficulties, difficulties in family relationships, lack of support or respite, managing difficult behaviours in the stroke survivor, physical health problems/fatigue, and emotional health problems” (p.765). People with aphasia and carers have clearly identified “carer communication strategies” as a priority for future aphasia research.

Although little research has been conducted to help carers specifically, a vast amount of study had been conducted on conversation partner training. The 7th highest ranked
research priority across groups was “Do slowing down, providing written material, allowing time for questions and using conversation partners help communication for someone with aphasia?” The results of a systematic review by Simmons-Mackie et al (2010) suggest that using conversation partners is an effective way to improve communication activities for individuals with chronic aphasia. A study by Teasel et al (2009) suggest that supported conversation can enhance conversational skills for individual with aphasia and their conversation partner. However, Teasel et al (2009) also found limited evidence that training conversation partners improves social participation and well-being and recommended that further research be conducted on the benefits of conversation partner training.

Aphasia research conducted in the past 10 years

According to the PubMed database, 4661 research papers have been published on aphasia from 2005-2015 (See table 4). A data base search was conducted to determine approximately what percentage of the top ten research priorities have been researched in the past ten years. The search revealed that limited research has been conducted on the top ten priorities. Just 1.8 % of studies conducted from 2005 to 2015 focused on the highest ranking research priority “When is the best time after stroke to deliver speech and language therapy?” A higher percentage of research has been conducted on the 2nd highest ranking research priority, “Which speech and language therapy treatments work best for aphasia?” at 7.3%. The 9th highest ranking research question; “What is the best way to improve understanding (cognition) after stroke?” was researched 5.6%. Surprisingly, the remaining 7 research priorities have been involved, on average, in less than of 1% each of the total research conducted on aphasia in the past ten years. The lowest research question was the 4th highest ranking question; “Is speech and language therapy helpful more than 1 year after a stroke?” with zero research papers on the PubMed database. Less than 21 % of aphasia research conducted in the past ten years has focused on the top ten priorities most important to stakeholders.
<table>
<thead>
<tr>
<th>Rank</th>
<th>Research Question</th>
<th>Percentage of Aphasia Research Conducted from 2005-2015</th>
<th>No. of studies</th>
<th>Percentage of all studies from 2005-2015</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>When is the best time after stroke to deliver speech and language therapy?</td>
<td>Early rehabilitation AND Aphasia</td>
<td>88</td>
<td>1.8%</td>
</tr>
<tr>
<td>2</td>
<td>Which speech and language therapy treatments work best for aphasia?</td>
<td>Treatments AND Aphasia AND Speech and language therapy</td>
<td>341</td>
<td>7.3%</td>
</tr>
<tr>
<td>3</td>
<td>What is the best amount and intensity of speech and language therapy for aphasia?</td>
<td>Amount and Intensity AND Speech and language therapy AND Aphasia</td>
<td>2</td>
<td>.04%</td>
</tr>
<tr>
<td>4</td>
<td>Is speech and language therapy helpful more than 1 year after a stroke?</td>
<td>Speech and language therapy AND Aphasia AND 1 year.</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>5</td>
<td>Do communication aids and software packages improve communication in patients with aphasia?</td>
<td>Aphasia AND Communication Aids AND Software Packages</td>
<td>36</td>
<td>0.8%</td>
</tr>
<tr>
<td>6</td>
<td>How can carers be helped to</td>
<td>Carers</td>
<td>18</td>
<td>0.4%</td>
</tr>
<tr>
<td></td>
<td>Question</td>
<td>Strategy</td>
<td>Count</td>
<td>Percentage</td>
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<td>---</td>
<td>---------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------</td>
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<td>------------</td>
</tr>
<tr>
<td>7</td>
<td>Do slowing down, providing written material, allowing time for questions and using conversation partners help communication for someone with aphasia?</td>
<td>Aphasia AND Strategies AND Communication</td>
<td>39</td>
<td>0.8%</td>
</tr>
<tr>
<td>8</td>
<td>Do social communication groups improve confidence in people with communication problems?</td>
<td>Aphasia AND Social Groups</td>
<td>80</td>
<td>1.7%</td>
</tr>
<tr>
<td>9</td>
<td>What is the best way to improve understanding (cognition) after stroke?</td>
<td>Cognition AND Aphasia AND Stroke</td>
<td>260</td>
<td>5.6%</td>
</tr>
<tr>
<td>10</td>
<td>What is the best way to improve the production of structured sentences in people with aphasia?</td>
<td>Aphasia AND Sentences AND Treatment</td>
<td>111</td>
<td>2.4%</td>
</tr>
</tbody>
</table>

**Limitations**

Several evidence based communication strategies were implemented when completing the aphasia friendly questionnaire, however there is no way to ensure absolute accuracy of the results. This is particularly true for the people with severe receptive difficulties. Despite this limitation, the researchers believe that it is more
important to include the PWA and receive their views despite some inaccuracies. Perhaps in future studies including PWA, a practice questionnaire could be initially completed. The researchers found that the PWA had a better understanding of how to complete the questionnaire, as well as the purpose of the questionnaire, after a few questions had been completed. A practice questionnaire may increase accuracy.

Several of the people with severe aphasia took a longer than expected time to complete the questionnaire with the longest taking two hours. As a future recommendation it also would be beneficial to give the option of completing the questionnaire over a 1, 2 or 3 day period, depending on how tired the particular participant gets. This will increase accuracy and reduce pressure on the participant.

Due to paucity of numbers, only seven carers were included in the carer group. A larger sample of carers would provide a better representation of this group and allow for a more accurate comparison of results.

Conclusions

PWA, carers and healthcare professionals have many different perspectives on what are the top research priorities in aphasia. This study has identified the top ten research priorities in aphasia using a rigorous and person centred approach. Limited research has been done on these top priority areas. A database search revealed that less than 21% of aphasia research conducted in the past ten years has focused on these priorities. The results of the study present clear directions for future aphasia research. The study also indicates that people with even severe aphasia can successfully participate in research when appropriate communication strategies are implemented.
Acknowledgements

A sincere thank you to Professor Sue Franklin for her support, guidance and patience throughout this project.

Thank you to all the people who gave up their time to participate in the study. We could not have done it without you.

Thank you Sasha and Michelle for all your hard work on this project.

Last but certainly not least, a massive thank you to my parents for their unwavering love and support throughout this project.
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