The top 10 research priorities relating to long-term aphasia, following stroke

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by

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Abstract

Background: Studies with people with aphasia are warranted as this group is often excluded from research. Stakeholder derived research priorities are seen as an opportunity to identify what matters most to people with aphasia, their families and health professionals, and are desirable in order to inform research funding bodies.

Objectives: The purpose of this study is to report on the top 10 research priorities related to long term aphasia from the perspective of people with aphasia (PWA), their carers and speech and language therapists (SLT).

Methods: In this study we adopted the James Lind Alliance methodology, established to bring patients, carers and clinicians together in a ‘priority setting partnerships (PSP)’ to identify and prioritize unanswered research questions.

Results: 46 participants (21 PWA, 18 SLTs and 7 carers) were included in the study. A top 10 research priority list was derived for each. Research priorities were grouped into themes (‘General management strategies’, ‘Aphasia & Cognition’, ‘Aphasia, carers & family’, ‘Specific treatments’, ‘Aphasia & depression’ and ‘Communicating with PWA’) to facilitate identification of similarities and differences between groups. An overall top 10 was also established. The overall top 4 research priorities related to ‘General management strategies’ theme. The next 6 included 3 relating to ‘Communication with PWA’, 1 pertained to ‘Aphasia & Cognition’, 1 to ‘Aphasia & Carers’ and 1 to ‘Specific treatments’ theme.

Conclusions: The top 10 research priorities related to aphasia have been identified using a rigorous and person centered method. The top 10 should be used to provide guidance for researchers and funding bodies.

Keywords: Aphasia, James Lind Alliance, prioritization, life after stroke, research priority.
1. INTRODUCTION

Including a variety of stakeholder perspectives has been increasingly advocated as ethically desirable and operationally beneficial in influencing the setting of research priorities (Pollock et al. 2014). Particularly in the area of aphasia, this is warranted, as people with aphasia are often excluded from research (Dalemans et al. 2009). People with aphasia (PWA) rarely partake in setting research priorities and are often omitted from research due to their lack of language competencies. Recently, a growing number of research bodies have advocated the importance of including a variety of stakeholders, and particularly patients, as it has been shown that researchers’ and patients’ priorities differ. The James Lind Alliance (JLA) was set up to bring patients, carers and clinicians together to identify and address their most important uncertainties about the effects of care and treatment (Partridge & Scadding 2004). This methodology therefore focuses on deriving what is most important in research for all stakeholders involved. Through a consensus meeting, patients, clinicians and carers are brought together in partnership to identify the top 10 research priorities for a particular health care area. This rigorous and patient-centered approach will therefore offer an opportunity to PWA to be involved in research priority setting relating to aphasia.
1.1. Including people with aphasia in research

Aphasia is a term used to describe an individual who will have difficulties with any or all areas of language (expressive, comprehension, written and reading), as a result from brain injury. About 20-38% of people suffering from a stroke will have aphasia (Townend et al. 2007). However, the inclusion of PWA is not well documented in research (Dalemans et al. 2009; Brady et al. 2012; Matos et al. 2014). Brady et al. (2012) reported that of 14 randomized controlled trials included in a Cochrane review, only one included PWA. PWA are systematically excluded from research and this incorrectly represents the stroke population and, consequently, their overall needs. This is frequently seen in research, as people with the highest needs often have the poorest evidence base (Brady et al. 2012).

Pollock et al. (2012) conducted a study using the JLA methodology. The researchers gathered 226 unanswered research questions from carers, stroke patients and health care professionals, relating to life after stroke. Among the 226 unanswered questions, were 34 relating to aphasia, meaning that language difficulties alone constituted 7% of all possible issues relating to stroke. Additionally, an unanswered research question relating to aphasia figured in their top 3, indicating that a general stroke population and parties involved have prioritized a research question relating to aphasia. Yet, this population does not seem to be well represented in research. This is seen to be particularly true for people with severe aphasia and is highlighted to be due to their difficulties in understanding verbal instructions (Dalemans et al. 2009). PWA will also have difficulties producing language. Consequently, only people who have a competence in language are recruited for stroke research (Dalemans et al. 2009).

Language is crucial to expressing ourselves and understanding others. In research, expressing a perspective clearly and with a reflective style is seen to be part of the requirements of recruitment (Dalemans et al. 2008). However, communication isn’t necessarily only words. Other means and strategies can be used with PWA. Luck and Rose (2007) conducted a pilot study and interviewed 5 PWA and realized that a method adjustment was warranted when conducting research with PWA. They suggested stepping out of the conventional role of the interviewer by changing questioning style,
offering ideas to participants, and using supportive conversation techniques. Although a small number of participants were recruited and limited to having mild aphasia, the study was a start to offering valuable knowledge in changing communicative ways with PWA. In an in-depth interview study, Howe et al. (2008) identified a wide range of communication barriers and facilitators when communicating with a PWA. Among the communication facilitators, audio tape recordings, encouraging drawing, writing or gesturing for PWA were suggested to facilitate communication between researchers and participants during their study. Additionally, they found that the use of pictures to communicate a written summary of the study to PWA was helpful. This study has strength as it had a bigger number of participants (25) and PWA ranged from mild to severe aphasia.

Other ways identified to facilitate and include PWA in research is by using aphasia friendly formats. Beukelman (2007) identified that PWA prefer personally relevant photographs rather than non-personal photographs (Dalemans et al. 2009). Brennan et al. (2005)’s study indicated that simplified vocabulary and syntax, bigger print and white spaces with pictures contributed to increasing reading comprehension for PWA. These findings are important as this indicates that it is possible to include PWA in research and that it is not so much their inability to communicate that is the problem, but rather our inability to adapt to their communication modes. Furthermore, Dalemans et al. (2009) conducted both a qualitative and quantitative study, investigating social participation of people with aphasia. The study included PWA with mild, moderate and severe aphasia. The goal of their study was to suggest strategies and techniques for research in PWA. Having both a qualitative and quantitative methodology helped with both capturing PWA’s perspectives on strategies implemented in the study and also measuring these with tools. Strength was also gained in their study, as these tools were piloted with PWA and in speech therapy clinics. Results from their study inform us that (1) including PWA in research is possible with the use of communication strategies, (2) measurements can be adjusted by reducing the cognitive load and simplifying language, and (3) the challenge to include PWA in research should be taken up in order to promote accessibility (Dalemans et al. 2009).
1.2. Involving patients in research

Goodhare (1995) stated that patients should be part of setting the research agenda. This shows that a shift from a medical model perspective to a patient-centered focus was already encouraged. Goodhare (1995) argued that research couldn’t be done without patients, as the purpose of conducting research is usually for patients. Gooberman-Hill (2013) indicated that there are multiple reasons for involving patients in a study. Among the top three are: (1) moral and ethical arguments about citizens, (2) increasing relevance to research and (3) improving research quality. Additionally, striving to achieve good practice, means involving patients in research (Gooberman-Hill 2013). This reflects a well-known framework used today in intervention and which could also be applied to research. The International Classification of Disability and Functioning and Health (ICF) is a framework, which describes health, and health related states from a biopsychosocial model (WHO, 2001). As speech and language therapists, we are encouraged to have a holistic view when approaching intervention and assessment of a patient (Matos et al. 2014). The ICF gives a holistic approach and looks broadly at two main categories: Functioning and disability (body structures/ body functions and activities/participation) and contextual factors (environmental and personal factors). As well as defining therapy goals, the ICF has also been used to structure research findings (Matos et al. 2014). Indeed the ICF can be used as a guide to ensure that research is covering and addressing every need of a patient with aphasia by acknowledging the patient’s and clinician’s perspectives.

1.3. Influencing the research agenda.

Involving people with aphasia, their care givers and speech and language therapists will help set research priorities in the area of aphasia. This is because different parties involved think differently. Indeed, Lomas et al.’s (1987) work found that different stakeholders who partook in their research (PWA and clinicians) focused on different aspects. For example, they found that PWA emphasized social needs situations. On the other hand, clinicians tended to underestimate PWA’s focus on social needs and more readily prioritized social skills activities (Lomas et al. 1987). Their study highlighted a wide range of concerns relating to aphasia and although the study included a small
number of participants, it has successfully informed the need for change in professional practices in Portugal. This means that by involving a wider set of stakeholders, previously unrecognized topics and issues have been identified that require the attention of researchers (Elwynn et al. 2010).

Elwynn et al. (2010) used the JLA methodology for Asthma UK and reported that the results of their study will certainly influence the way in which research will be funded. For example, the top 3 priorities for Asthma related to management of the disease indicating that uncertainties still exist for all parties involved. Eleftheriadou et al. (2011) researched treatment uncertainties for vitiligo and reached a consensus of the top 10 research priorities, which they believed will also guide research and research funding (Eleftheriadou et al. 2011). This informs us that an agreed collaboration among participants is the key to generating a prioritized list for aphasia, to inform funding bodies of new research.

1.4. Aim of the study

We established a JLA Priority Setting Partnership (PSP) which aimed to explore and understand the perspectives of various stakeholders in the area of aphasia, by answering the questions: ‘what are the top 10 research priorities relating to long term aphasia, following stroke’. It is intentional that a number of stakeholders will be involved, as this is seen to help achieve meaningful outcomes in research priority setting and improve the quality, relevance and implementation of research (Pollock et al., 2014). This study specifically aims at:

- Identifying the top 10 research priorities relating to long term aphasia following stroke with equitable participation from patients with aphasia, their carers and health professionals working in aphasia care.
- Inform research funding bodies of the gaps in knowledge that these stakeholders face relating to aphasia.
2. METHOD

2.1. Study Design

This study explored the perspectives of 46 individuals who live with aphasia or work or care for people with aphasia, incorporating the views of 3 stakeholder groups: PWA, carers and speech and language therapists (SLTs). This study was established through the JLA which works by establishing ‘priority setting partnerships (PSP)’, which brings patients and clinicians together in order to identify research priorities to inform future research. The JLA believes that addressing uncertainties about the effects of treatments should become accepted as a much more routine part of clinical practice (James Lind Alliance 2015). The JLA definition of a treatment uncertainty is as follows: (1) no up-to-date, reliable systematic reviews of research evidence addressing the uncertainty about the effects of treatment exists (2) up-to-date systematic reviews of research evidence show that uncertainty exists (James Lind Alliance 2015).

A JLA methodology is therefore congruent with studies aiming to seek a variety of stakeholder perspectives to inform research priorities. We chose this approach in the current study, as we were concerned with exploring all areas related to aphasia. We felt it important to include a variety of stakeholder views, as these will emphasize the areas of need for more research pertaining to aphasia. This will be done by narrowing the 34 treatment uncertainties relating to aphasia, by asking participants to rate their top 10 in a questionnaire. (See appendix no.1, pp. 30)

These treatment uncertainties were gathered from a previous study conducted by Pollock, St George, Fenton and Firkins (International Journal of stroke: 2012), carried out to explore research priorities relating to life after stroke. Their study was also established through the JLA with participants comprising of stroke survivors, carers and health professionals. The treatment uncertainties, which are in the form of questions, were gathered from stroke clubs/groups, individual stroke survivors, carers, health professional groups/meetings and individual health carers. 548 treatment uncertainties were identified by stakeholders. These treatment uncertainties were checked to examine whether they pertained to the effects of treatment in stroke and whether these were unanswered by research. 226 unique answered treatment uncertainties
were then compiled and used for their study. Results from the study are available and have importance in influencing future research in life after stroke. Although the research wasn’t directly aimed at aphasia, 34 research priorities relating to communication figured in the 226 treatment uncertainties. The current study will use Pollock et al.’s (2012) 34 treatment uncertainties relating to aphasia, ensuring these are expressed in accessible language.

2.2. Participants

A total of 46 participants were included in this study. These included 18 SLTs (settings included: 3 community, 10 acute, 4 rehabilitation, 1 other), 21 PWA (severity range: 4 mild, 11 moderate, 6 severe), and 7 carers. PWA were recruited by contacting stroke clubs across Dublin via email or by phone to arrange a date to deliver the questionnaire. PWA and carers, different from those in the stroke clubs, were also personally contacted by mail across Dublin, Cork, Wexford, Wicklow and Galway. The letter informed them of the research and gave them the option to participate in our study. To facilitate them, we visited them in their homes to deliver the questionnaire. SLTs were contacted by email and sent a survey monkey version of the questionnaire to fill out.

SLTs were sourced from Clinical Therapies databases of speech and language therapists. PWA and their carers were sourced through Dublin, Wexford, Galway, Cork and Wicklow stroke clubs, using Dr. Caroline Jagoe from Trinity College Department of Clinical Speech and Language studies as a gatekeeper.

2.3. Criteria of inclusion

All participants:

(1) All participants needed to be over 18 years of age

(2) Can be of either gender and ethnicity

(3) Participants should speak English or Irish as their first language

PWA:

(4) Mild, moderate or severe aphasia
(5) That a person’s aphasia resulted from a stroke.

**Carers:**

(6) Had to be carers of people with aphasia

**SLTs:**

(7) SLTs worked in either acute/ rehabilitation or community with PWAs

Two PWA were excluded from the total of participants due to not meeting the criteria as having aphasia resulting from a stroke. One participant had aphasia as a result of an acquired brain injury and the other had primary progressive aphasia.

### 2.4. Materials

#### 2.4.1. People with Aphasia

The 34 treatment uncertainties (TU) relating to aphasia, compiled from Pollock et al.’s study (2012), were altered into aphasia friendly text by using large font and converted into 34 individual strips to facilitate a PWA. Additionally, ‘ramps’ were created using ‘buzz words’ and real life pictures in order to help a PWA with moderate to severe aphasia to understand the question. This also assisted the researchers to explain the TUs. An information sheet was then compiled using an aphasia friendly format. The purpose was to inform a PWA of the research and more importantly that all information would be kept private and confidential and that they were free to stop at any time. A consent form was also developed and ensured participants had an understanding of the project. The information sheet and questionnaire were subsequently assembled into a pack. Each pack was sent to stroke clubs and families in order to familiarize themselves with it and agree to participate in the project.

#### 2.4.2. Carers

The same TUs were used however, these were kept in a questionnaire format. The researchers added a tick box next to each question in order to facilitate the selection of the TUs for carers. An additional sheet was compiled with 2 columns to facilitate the ranking of their top 10 RP (*See appendix no. 2, pp. 31*).
2.4.3. Speech and Language Therapists

The 34 TUs were formatted into Survey Monkey and sent to SLTs via email. Each question had a drop box option and participants were asked to choose 10 TUs out of the 34 and then rate them from 10 = most important to 1= least important. All others could be either skipped or rated “0”.

2.5. Procedures

The research was conducted in 3 phases. Due to unforeseen circumstances, phase 4 has been delayed until August 2015.

2.5.1 Phase 1

2.5.1.1. Methodology training

Two postgraduate researchers (PGR) were trained in the JLA methodology at Glasgow Caledonian University by Dr. Alex Pollock and Brigit St Georges. The aim of the training was (1) to familiarize ourselves with the goal of the methodology (2) discuss how to collect and analyze data for phase 3 and (3) how to run and analyze data from the consensus meeting (phase 4).

2.5.2. Phase 2

2.5.2.1. Gathering Information and materials

The aphasia friendly materials were created by the 3 PGRs. The set up and materials were subsequently piloted on an experienced SLT. Outcomes included ensuring constant reminders of the goal of the study: i.e. asking the question: ‘which question would you find most important in research?’ Additionally, the 3 PGRs modified the ramps to include more ‘real’ pictures. Survey Monkey was also created by 1 PGR and piloted on 2 speech and language therapists to ensure the practicality of the survey and that instructions were coherent. Outcomes included modifying instructions in the emails, which were reported ambiguous at times. These were subsequently emailed to 103 SLTs in Ireland.
2.5.2.2. Contacted stroke clubs in Ireland

We were given 6 stroke association contact numbers and contacted each of them to arrange a date to meet in the stroke clubs. We were facilitated by our supervisor in providing us with details of stroke groups restricted to aphasia. 3 stroke clubs from Dublin respondent favorably and information packs were sent for all participants to familiarize themselves with the questionnaire. For some of the participants, the 3 PGRs travelled to their homes in Cork, Wicklow, Wexford, Galway and Dublin to administer the questionnaire with PWA and their carers.

2.5.3. Phase 3

2.5.3.1. Major Ethical considerations

Before starting the questionnaire, each PGR read through the aphasia friendly information booklet with all participants. Each participant was also shown the questionnaire and explained the delivery method to ensure all participants understood their level of involvement in the study. A consent form was then presented to them before taking part in the study. This was an opportunity for each participant to ensure they understood the research and for the PGR to answer any questions. The consent form was aphasia friendly so PWA could point to areas they did not understand. More importantly, this informed any participant that all information was kept private and that they could stop the research at any time without providing a reason. Consent was gained from SLTs when taking the survey online.

2.5.3.2. Delivery of the questionnaire

The delivery of the questionnaire was different for each group. However, the overall goal for all groups was to obtain a top 10 from each person. This involved reading through each 34 TUs and choosing their top 10 TUs which they would like to see prioritized in research, referred to as research priorities (RP). Emphasis was placed on what was personally the most important RPs for them. Once 10 RPs were chosen, each participant was asked to rank their 10 RPs from 1= most important to 10=least important.
Delivery of the questionnaire for PWA

It was essential that in each case the 3 PGRs facilitated the questionnaire on a one to one basis with each PWA. The single strips were used for each question, which facilitated a PWA’s understanding. If the TU was not understood ramps were provided with a picture and key words. This facilitated their understanding and helped reduce the language load. Three coloured laminated sheets were also created (red = important, green= somewhat important, blue =not important). PWA were instructed to first sort each 34 strips into the different piles. For example, if they found a TU ‘important’, this was placed on the red laminated sheet. The goal of this process was for PWA to have a smaller pile of TUs to rank their top 10 from. Once an important pile was created, the PGR counted the important ones. If the number was above 13 strips, the sorting procedures needed to be repeated. If the total was below 10 strips, then the ‘quite important’ pile needed to be sorted into ‘important’ and ‘quite important’. It was observed that obtaining at least 10 strips and a maximum of 13 strips in the important pile facilitated the ranking process for a PWA. Once there were 10-13 strips, PWA were asked to rank them from 1= most important to 10 =least important. Ten cards were created with numbers 1-10 to help PWA rank their top 10 RPs. These were lined in front of PWA, which facilitated easy viewing of their top 10 and enabled them to move the cards and strips around. The PGR read through each important strips and the PWA placed the strip were they felt was personally most important to them.

It was important to give time to PWA. Using simple language and repeating the questions were found to be useful strategies. Usually most participants preferred that the PGR read the question with them to reduce the language load. Additionally, supporting them throughout the process and listening to their own experiences was very much an important part of the project. Participants usually answered the question in order to show their experience with aphasia, which was valuable insight. However this resulted in a longer process as some of the participants needed continual reminders that there wasn’t a need to answer those questions; instead would they like research to answer the question. It was imperative with more severe cases to listen to their reactions to each question and use gesture in order to make sure that both the PGR and PWA understood one another correctly.
Delivery of questionnaire for carers

Carers were given the questionnaire separately. The 3 PGR encouraged these participants to fill it in their own time while a PGR administered the questionnaire with a PWA. The PGR provided information about the research and ensured that the carers understood the project. The consent form enabled carers to ask any questions before signing and completing the questionnaire.

Delivery of questionnaire for SLTs

Questionnaires were formatted into survey monkey and emailed to 103 SLTs. Twenty respondents replied. However, 2 were excluded as the questionnaire was completed incorrectly.

2.5.4. Phase 4

Due to unforeseen circumstances, phase 4 was not possible. As part of the key phases of the JLA, the last phase (4) involves a consensus meeting to agree the top 10 research priorities (RPs). The procedure involves a representative group of stakeholders including health professionals, PWA and carers, different from those who participated in phase 3, to attend the final consensus meeting. These stakeholders were to work in small groups, facilitated by the PGR, to identify the top 10 RPs. These are to be discussed in a plenary session and the final top 10 RPs are subsequently agreed and confirmed.

2.6. Data Analyses

Results were gathered and analyzed using Excel sheets to establish a ranking for each stakeholder group, as well as establishing an overall top 10. Each PGR analyzed data separately and then compared the results to ensure inter-rater reliability.
3. RESULTS

The tables below illustrate the top 10 RPs established for 21 PWA, 7 carers and 18 SLTs. An overall top 10 was also derived for all stakeholders involved. Scores were calculated as follows: 10 points = rank 1 all the way down to 1 point= rank 10. Ranking is as follows: 1= most important RP, 10= least important RP. Results were analyzed by grouping each RP into themes to facilitate analysis of similarities and differences between each group. The themes are as follows: ‘General management strategies’, ‘Aphasia & cognition’, ‘Aphasia, carers & family’, ‘Specific treatments’, ‘Aphasia & depression’ and ‘Communicating with PWA’.

<table>
<thead>
<tr>
<th>Questions</th>
<th>Score</th>
<th>Rank</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is the best amount and intensity of SLT for aphasia?</td>
<td>81</td>
<td>1</td>
<td>General management strategies</td>
</tr>
<tr>
<td>Do communication aids and software packages improve communication in PWA?</td>
<td>76</td>
<td>2</td>
<td>Communicating with PWA</td>
</tr>
<tr>
<td>When is the best time after stroke to deliver speech and language therapy?</td>
<td>67</td>
<td>3</td>
<td>General management strategies</td>
</tr>
<tr>
<td>Has the HSE National Clinical Programme helped PWA after stroke?</td>
<td>57</td>
<td>4</td>
<td>General management strategies</td>
</tr>
<tr>
<td>Which speech and language therapy treatments work best for aphasia?</td>
<td>50</td>
<td>5</td>
<td>General management strategies</td>
</tr>
<tr>
<td>What is the best way to help PWA return to work?</td>
<td>48</td>
<td>6</td>
<td>General management strategies</td>
</tr>
<tr>
<td>Do social communication groups improve confidence in PWA after stroke?</td>
<td>47</td>
<td>7</td>
<td>Communicating with PWA</td>
</tr>
<tr>
<td>Can Cognitive Behavioural Therapy help the recovery of speech?</td>
<td>37</td>
<td>8</td>
<td>Specific treatments</td>
</tr>
<tr>
<td>Can Adult Education Improve stroke acquired literacy/numeracy problems?</td>
<td>36</td>
<td>9</td>
<td>Specific treatments</td>
</tr>
<tr>
<td>What is the best way to diagnose and assess depression in PWA after stroke?</td>
<td>35</td>
<td>10</td>
<td>Aphasia &amp; depression</td>
</tr>
</tbody>
</table>
### Table 2 Top 10 carers

<table>
<thead>
<tr>
<th>Questions</th>
<th>Score</th>
<th>Rank</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do slowing down, providing written material, allowing time for questions and using conversation partners help improve communication with PWA?</td>
<td>37</td>
<td>1</td>
<td>Communicating with PWA</td>
</tr>
<tr>
<td>How can carers be helped to communicate with someone with aphasia?</td>
<td>29</td>
<td>2</td>
<td>Aphasia, carers &amp; family</td>
</tr>
<tr>
<td>When is the best time after stroke to deliver speech and language therapy?</td>
<td>27</td>
<td>3</td>
<td>General management strategies</td>
</tr>
<tr>
<td>What is the best way to help people recover from aphasia?</td>
<td>24</td>
<td>4</td>
<td>General management strategies</td>
</tr>
<tr>
<td>Do social communication groups improve confidence in people with communication problems after stroke?</td>
<td>18</td>
<td>5</td>
<td>Communicating with PWA</td>
</tr>
<tr>
<td>Which speech and language therapy treatments work best for aphasia?</td>
<td>16</td>
<td>6</td>
<td>General management strategies</td>
</tr>
<tr>
<td>What stimulation techniques are useful for enhancing the engagement of stroke patients with severe cognition and communication impairments?</td>
<td>16</td>
<td>7</td>
<td>Aphasia &amp; cognition</td>
</tr>
<tr>
<td>Can trained volunteers and carers help improve communication after stroke?</td>
<td>15</td>
<td>8</td>
<td>Aphasia, carers &amp; family</td>
</tr>
<tr>
<td>What is the best amount and intensity of speech and language therapy for aphasia?</td>
<td>15</td>
<td>9</td>
<td>General management strategies</td>
</tr>
<tr>
<td>Is speech and language therapy helpful for patients more than 1 year after stroke?</td>
<td>15</td>
<td>10</td>
<td>General management strategies</td>
</tr>
<tr>
<td>Can transcranial magnetic stimulation help people with aphasia?</td>
<td>15</td>
<td>10</td>
<td>Specific treatments</td>
</tr>
</tbody>
</table>
Table 3: Top 10 PWA

<table>
<thead>
<tr>
<th>Questions</th>
<th>Score</th>
<th>Rank</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Which speech and language therapy treatments work best for aphasia?</td>
<td>92</td>
<td>1</td>
<td>General management strategies</td>
</tr>
<tr>
<td>When is the best time after stroke to deliver speech and language therapy?</td>
<td>82</td>
<td>2</td>
<td>General management strategies</td>
</tr>
<tr>
<td>Is speech and language therapy helpful for patients more than 1 year after stroke?</td>
<td>74</td>
<td>3</td>
<td>General management strategies</td>
</tr>
<tr>
<td>How can carers be helped to communicate with someone with aphasia?</td>
<td>50</td>
<td>4</td>
<td>Aphasia, carers &amp; family</td>
</tr>
<tr>
<td>Do slowing down, providing written material, allowing time for questions and using conversation partners help improve communication with PWA?</td>
<td>49</td>
<td>5</td>
<td>Communicating with PWA</td>
</tr>
<tr>
<td>What is the best way to improve the production of structured sentences in people with aphasia?</td>
<td>46</td>
<td>6</td>
<td>Specific treatments</td>
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<tr>
<td>Can trained volunteers and carers help improve communication after stroke?</td>
<td>45</td>
<td>7</td>
<td>Aphasia, carers &amp; family</td>
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<tr>
<td>What is the best way to help people with aphasia return to driving after stroke?</td>
<td>43</td>
<td>8</td>
<td>General management strategies</td>
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<tr>
<td>What is the best way to manage feelings of panic due to aphasia?</td>
<td>43</td>
<td>9</td>
<td>General management strategies</td>
</tr>
<tr>
<td>What is the best way to treat depression in PWAs following stroke?</td>
<td>42</td>
<td>10</td>
<td>Aphasia &amp; depression</td>
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<tr>
<td>What is the best way to improve understanding (cognition) after stroke?</td>
<td>42</td>
<td>10</td>
<td>Aphasia &amp; cognition</td>
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<td>Questions</td>
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<td>When is the best time after stroke to deliver speech and language therapy?</td>
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<td>1</td>
<td>General management strategies</td>
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<tr>
<td>Which speech and language therapy treatments work best for aphasia?</td>
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<td>2</td>
<td>General management strategies</td>
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<tr>
<td>What is the best amount and intensity of speech and language therapy for aphasia?</td>
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<td>4</td>
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<tr>
<td>How can carers be helped to communicate with PWA?</td>
<td>108</td>
<td>6</td>
<td>Aphasia, carers &amp; family</td>
</tr>
<tr>
<td>Do slowing down, providing written material, allowing time for questions and using conversation partners help improve communication with PWA?</td>
<td>93</td>
<td>7</td>
<td>Communicating with PWA</td>
</tr>
<tr>
<td>Do social communication groups improve confidence in PWA after stroke?</td>
<td>92</td>
<td>8</td>
<td>Communicating with PWA</td>
</tr>
<tr>
<td>What is the best way to improve cognition (understanding) after stroke?</td>
<td>88</td>
<td>9</td>
<td>Aphasia &amp; cognition</td>
</tr>
<tr>
<td>What is the best way to improve the production of structured sentences in PWA?</td>
<td>88</td>
<td>10</td>
<td>Specific treatments</td>
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</table>

Results differed for each group. Two RPs were similar across the 3 group’s top 10: ‘Which speech and language therapy treatments work best for aphasia?’ and ‘When is the best time after stroke to deliver speech and language therapy?’. The PWA and carer group had the most RPs in common (6 RPs) while, the carers and SLT group had 4 shared RPs whereas the PWA and SLT group had 2. The PWA group included all 6 themes, while carers included 5 themes and SLTs 4. The majority of each group’s RPs related to ‘General management strategies’ theme. As a result, RPs relating to ‘General management strategies’ culminated as the top 4 in the overall top 10 research priorities.
4. DISCUSSION

In this study, a top 10 research priorities list was derived for each stakeholder group (PWA, Carers and SLTs) to determine each group’s RPs. The results were analyzed separately. Similarities and differences were then compared across groups and between groups (PWA and carers, carers and SLTs, PWA and SLTs). An overall top 10 was also established combining each stakeholder’s top 10.

Results differed across groups with some similarities, which were expected as PWA, carers and SLTs all have differing experiences and knowledge (Brown et al. 2011). The idea is that these differing perspectives would contribute towards developing research priorities in partnership. This is because current research in Aphasiology suggests that there are mismatches between the priorities of SLTs and PWA (Brown et al. 2011).

4.1. Similarities & Differences

4.1.1. Similarities & differences across groups

Similarities across each group included 2 questions that figured in each group’s top 10: ‘When is the best time after stroke to deliver SLT’ and ‘Which treatments work best for aphasia?’. Additionally, questions relating to ‘General management strategies’ figured as a majority in each group’s top 10. Each group also included at least 1 RP relating to ‘Specific treatments’ and at least 1 concerning ‘Communicating with PWA’. Further differences were noted comparing the carers and PWA group with the SLT group. For instance, carers and PWA included questions pertaining to ‘Aphasia, carers & family’ while the SLT group contained RPs relating to ‘Specific treatments’ and ‘Communication with PWA’. These differences aren’t’ surprising as carers and PWA will have personal and relational needs in rehabilitation whereas SLTs will be interested in efficacy and outcomes of treatments related to aphasia.

4.1.2. Similarities & differences between groups

Results were also analyzed between each group. The most similar groups were the PWA and carer group while the PWA and SLT group were largely different. PWA and carer groups had over half of the RPs in common (6RPs). In addition to the 2 communal RPs
across the groups, both groups included: ‘Do slowing down, providing written material, allowing time for questions and using conversation partners, help improve communication with PWA’, ‘How can carers be helped to communicate with someone with aphasia?’, ‘Can trained volunteers and carers help improve communication after stroke?’ and ‘Is speech and language therapy helpful for patients more than one year after stroke?’. Both group’s themes also covered a wide range of themes, which corresponded to domains of environmental factors and participation on the ICF, such as ‘What is the best way to help people with aphasia return to driving?’ and ‘Do slowing down, providing written material, allowing time for questions and using conversation partners, help improve communication with PWA’.

Differences between both groups included PWA’s top RPs pertaining to ‘General management strategies’ and carer’s top RPs pertaining to ‘Communicating with PWA’ and ‘Aphasia, carers & family’. Halle and Le Dorze (2014) found that carer needs centered around being trained on how to help the aphasic person with their language and communication needs. While PWA included RPs from all the themes, carers did not include one pertaining to ‘Aphasia & depression’. The SLT and carer groups had 4 RPs in common. In addition to the 2 communal RPs for all groups, both groups included: ‘What is the best amount and intensity of SLT for aphasia?’ and ‘Do social communication groups improve confidence in PWA after stroke?’ which means that both groups are concerned with priorities relating to ‘Communicating with PWA’ and ‘General management strategies’. Differences between the 2 consisted of carers including 2 RPs relating to the theme ‘Aphasia, carers & family’ and 1 pertaining to ‘Aphasia & cognition’ while the SLT group included more RPs pertaining to ‘Specific treatments’ and 1 concerning ‘Aphasia & depression.

The SLT and PWA group similarities included a majority of their RPs relating to ‘General management strategies’. Differences across both groups consisted of no other RPs in common apart from the overall shared 2 RPs. RPs for PWA covered all themes while SLTs covered specific themes such as: ‘General management strategies’, ‘Specific treatments’, ‘Communicating with PWA’ and ‘Aphasia & depression’.
4.1.3. The overall top 10

The top 4 RPs related to ‘General management strategies’. The next 6 consisted of 3 RPs relating to ‘Communication with PWA’, 1 RP related to ‘Aphasia, carers & family’, 2 to ‘Specific treatments’ and 1 to ‘Aphasia & cognition’.

4.2. Database search conducted for overall top 10 RPs

The overall top RPs were grouped into different themes below: (1) Speech and Language Therapy (SLT) treatments in aphasia, (2) Activity and participation: communicating with PWA, (3) Body structures and functions: aphasia and understanding, and (4) Specific treatments in SLT. A database search was subsequently conducted for each RP investigating whether these are unique answered research uncertainties. Below is an attempt to answer each question in relation to the evidence base.

4.2.1. SLT treatment in aphasia

Conventionally, speech and language therapy is an impairment-based approach that focuses on improving functional communication by targeting the underlining linguistic deficit (Zumbansen & Thiel 2014). Studies have yielded some evidence that SLT intervention in functional, receptive and expressive language in PWA is effective in comparison to no SLT intervention (Brady et al. 2012).

**Top 1: What is the best time after stroke to deliver SLT?**

Exactly when SLT should be delivered is still an open question. A Cochrane review has demonstrated that there is little evidence base to suggest optimal delivery time of SLT post stroke and that the effects of high-intensity SLT in the acute phase are still unknown (Brady et al. 2012).

**Top 2: Which SLT treatments work best for aphasia?**

There is a wide range of treatments for aphasia to target the vast amount of aphasic syndromes resulting from stroke (Dobkin & Dorsch 2013). And there is no “gold standard” for the treatment of aphasia (Crinion 2012). There have been holistic program therapies developed to improve functional communication (Zumbansen & Thiel...
2014). However, currently no conclusive evidence shows one SLT approach being better than another on functional communication outcomes (Brady et al. 2012; Zumbansen & Thiel 2014).

**Top 3: What is the best amount and intensity of SLT for aphasia?**

More than likely, intensive therapy will yield better results rather than low frequency SLT treatments (Zumbansen & Thiel 2014). According to Code and Petheram (2011), the average delivery of SLT for aphasia is 1-5 hours a week, however recent research suggests about 9 hours of intense treatment during a short period is needed to be effective. Their study concluded “there is a significant gap between what the research suggests in the appropriate amount of treatment and actual provision throughout the English speaking world” (Code & Petheram 2011, p.3). The difficulty here is therefore not the lack of research but the lack of provision of services to PWA. This lack of provision is seemingly due to economic limitations in most public health systems and where prioritization of patients’ needs is the current solution to get through a caseload. For example, Rose et al. (2014) found that SLTs in Australia were faced with challenges for treating PWA in the acute phase due to dysphagia being prioritized as a caseload.

**Top 4: Is SLT helpful for more than one year after stroke?**

Moss and Nicholas (2006) found that treating PWA in the chronic stage yield positive outcomes. Their study found an average of 42% change in PWA in the chronic stage. This suggests that there appears to be no upper limit beyond which patients cannot improve if they have access to targeted SLT therapy. The researchers suggested that further research isn’t necessary pertaining to aphasia therapy and time post onset. However their study focused on treatments for verbal expression. Additional research is therefore warranted for PWA with receptive difficulties.

The evidence base for overall effectiveness of SLT & aphasia is limited and research is still indicated as necessary in this area. In a Cochrane review, Brady et al. (2012) found that overall there was insufficient evidence to indicate the best approach to delivering speech and language therapy.
4.2.2. Activity & Participation: Communicating with PWA

Substantial research has been generated in this area and has yielded positive outcomes. Communication partner training is often used as an indirect form of therapy and involves training by giving communication strategies to the conversational partner (carer, volunteer, friend, family member, etc.) and the PWA to increase maximum communication success. A study by Worrall et al. (2011) analyzed PWA goals according to the ICF and found that PWA had a particular focus on the ‘Activity and Participation’ component. This means that social participation is highly important for PWA as part of their recovery goals. 3 RPs relating to communication with PWA figure in the top 10:

**Top 7: Do slowing down, providing written material, allowing time for questions and using conversation partners help improve communication with PWA?**

The later suggestions can be classified as useful communication strategies that are used by a skilled conversational partner. A systematic review by Simmons-Mackie et al. (2010) showed that skilled communication partners are effective at supporting and facilitating communication with a PWA. The researchers state that this should be considered as an approach that offers supportive measure in a PWA’s environment as well as communication access (Simmons-Mackie, 2010). Kagan et al. (2001) concluded in their study that training volunteers as conversation partners was associated with an improvement in the communication of volunteers and their partners with aphasia. According to this study, the lack of skill of untrained conversation partners can pose a barrier to effective communication. Improving skills through communication partner training can therefore help reduce communication barriers and increase social participation opportunities for those affected by aphasia (Kagan et al. 2001).

**Top 6: How can carers be helped to communicate with PWA?**

This RP is similar to the previous one; however it focuses particularly on communication between carers and PWA. Some studies have shown that communication training particularly between carers and PWA is effective. This is important as research shows that carers of PWA experience more difficulty in care related tasks and depressive symptoms than carers of non-aphasic patients (Bakas et al. 2006). Halle and Le Dorze
(2014) proposed that speech and language therapist can help carers re-evaluate their perceptions and prevent carer distress and relationship breakdowns by teaching them how to have a conversation with their partner by teaching them supportive techniques. Achieving successful communication for a PWA depends on the communication partner’s level of support (Nykanen et al. 2013). Nykanen et al. (2013) suggest that studies are still needed for the use of hierarchical strategies in nonverbal communication for both carers and PWA.

**Top 8: Do social communication groups improve confidence in PWA after stroke?**

Research highlights that currently patients with aphasia being discharged from hospital have increased risk of isolation due to lack of expressive, receptive and functional language. According to Worrall et al. (2011), social ease and acceptance are important goals once PWA are at the later stages of recovery. There is some evidence that group participation can benefit social networks and community access. However, Lanyon et al. (2013) indicate that the current evidence isn’t comprehensive. The researchers suggest that further studies should examine activity, participation and contextual factors that are needed to improve aphasia group practice and participation (Lanyon et al. 2013).

**4.2.3. Body structures and Functions: Aphasia and comprehension**

**Top 9: What is the best way to improve understanding after stroke?**

Improving comprehension in aphasia is poorly understood. Comprehension can be viewed 2 ways: verbal (auditory) comprehension or reading comprehension. Auditory comprehension has been a fairly neglected area of study (Morris & Franklin 2013). In spite of the area being under-researched, there are some key findings in impairment based strategies and approaches involving partner training. In reading comprehension, some studies have investigated treatment at a single word level, however Webster et al. (2013) indicate that studies are limited regarding paragraph and connected text reading comprehension.
4.2.4. Specific SLT treatments

Treatment in aphasia that is correctly selected, delivered in the sufficient dosage and carefully targeted to the precise aphasic symptoms does work (Crinion 2012). However, despite some specific interventions in SLT for aphasia, recovery is frequently incomplete and frustratingly slow (Crinion 2012).

**Top 5: Do communication aids and software packages improve communication in aphasia?**

In the current climate, this is likely to be a growing area of research and currently, advances in digital technology have led to the delivery of therapy in aphasia in PWA’s home settings (Dobkin & Dorsch 2013). A study showed that telerehabilitation is valid and reliable tool to delivering speech and language therapy services (Cherney & Van Vuuren 2012), however it also has its limitations, for example in terms of confidentiality of patient information. Nevertheless, the researchers are confident that future research will resolve these problems. This area is still an ongoing and growing area of research and with a doubt future therapy will involve a combination of approaches, both behavioral and technological.

**Top 10: What is the best way to improve the production of structured sentences?**

The production of structured sentences involves taking into account several aspects of production in language, including the conceptual preparations for language, building the predicate argument structure, generating complex forms, verb access and morphology (Marshall 2013). Considerable research has been done in this area and a range of approaches (e.g. mapping therapy) are available and target the various aspects of production in language (Marshall 2013). However, selection of the appropriate treatment is challenging for an SLT, which isn’t helped by the conflicting literature (Marshall 2013). A suggested route for therapy has been to map meaning onto form (structured sentences), bringing the focus to what the PWA is intending to say rather than focusing on structure alone (Marshall 2013). However, further studies are needed to solve the therapy selection dilemma.
4.3. Limitations

We were limited in our study due to the communication difficulties that PWA present with. For some participants, particularly those with severe aphasia, it was challenging at times to guarantee their full understanding of the RPs. The RPs were also challenging for PWA as some of them were language heavy. However, for most participants, with the aid of communication strategies and the ramps, mutual understanding was usually reached. Only one participant could not complete the questionnaire due to having severe difficulties with the understanding the project.

5. CONCLUSION

The top research priorities relating to aphasia have been identified using a rigorous and person centered method. This study highlights that uncertainties currently still exist particularly in relation to SLT treatment in aphasia (in general and specific), communicating with PWA and improving understanding in aphasia. A database research has revealed prevalent gaps in the literature pertaining to SLT treatment in aphasia and improving understanding in aphasia. However, significant research has been conducted on communication with PWA. These RPs will be used in a follow up study to identify a top 10 during a consensus meeting. It would be a greatly welcomed addition to the research as all stakeholders will collaborate together to establish a top 10 in partnership. It is our hope that these will inform and influence prioritization and funding of future research in aphasia following stroke.
Acknowledgements

I would like to express my gratitude to Dr. Alex Pollock and Brigit St. George who made this project possible and helped us immensely throughout, providing valuable advice. I would like to thank my supervisor Pr. Sue Franklin, for her time and patience and who made it all happen. A special thank you to all the people that participated in the study without whom this project would not have been made possible. To my parents Ellen Demos and Ciaran Mc Manus for supporting me and offering their valuable insight. To Aaron Ridgeway for believing in me every step of the way. To Paola Salazar and Claudia Sabato and Calvagh Demos Mc Manus for their reasurance and inspiration. Thanks are also du to my incredible class, blossoming with encouragement and genuine support at all times. Thank you to Michelle and Dearbhla for all their hard work and who have been excellent partners in this project.
APPENDICES

Appendix 1: 34 treatment uncertainties relating to aphasia from Pollock et al.’s (2012) study:

1. Which speech and language therapy treatments work best for aphasia?
2. Do slowing down, providing written material, allowing time for questions and using conversation partners help improve communication with people with aphasia?
3. How can carers be helped to communicate with someone with aphasia?
4. What is the best way to improve understanding (cognition) after stroke?
5. Can playing an instrument help improve communication problems?
6. Can trained volunteers and carers help improve communication after stroke?
7. What stimulation techniques are useful for enhancing the engagement of stroke patients with severe cognition and communication impairments?
8. Is group speech and language therapy better and does it cost less than individual speech and language therapy?
9. Can music or art therapy help people with aphasia?
10. What is the best way for carers to manage depression in people with aphasia following stroke?
11. Do communication aids and software packages improve communication in patients with aphasia?
12. Can cognitive behavioural therapy (CBT) help recovery of speech?
13. What is the best amount and intensity of speech and language therapy for aphasia?
14. When is the best time after stroke to deliver speech and language therapy?
15. Is speech and language therapy helpful for patients more than 1 year after a stroke?
16. What is the best way of giving information about stroke to someone with aphasia?
17. Does a ‘day diary’ to record activities etc., completed by visitors, help people with communication problems share what has been happening?
18. Where is the best place to receive speech and language therapy (community or hospital)?
19. What is the best way to help people with aphasia return to work?
20. What is the best way to treat depression in people with aphasia following a stroke?
21. Can Adult Education improve stroke acquired literacy/numeracy problems?
22. What is the best way to help people with aphasia return to driving after stroke?
23. Can supported communication training for carers help prevent relationship breakdown?
24. What is the best way to improve the production of structured sentences in people with aphasia?
25. What is the best way to help people recover from aphasia?
26. What is the best way to diagnose and assess depression in people with aphasia following a stroke?
27. What is the best way to manage pain in patients with communication problems?
28. Is conversation partner training useful in management of aphasia after stroke?
29. Do social communication groups improve confidence in people with communication problems after stroke?
30. What is the best way to manage feelings of panic due to aphasia?
31. How can stroke survivors and families be helped to cope with speech problems?
32. Can transcranial magnetic stimulation help people with aphasia?
33. Is non-linguistic cognitive training effective for aphasia?
34. Has the HSE National Clinical Programme for Stroke impacted on the provision of services for patients with long term communication problems following stroke?
Appendix 2: Ranking page to facilitate selection and ranking of RPs.

**MY TOP 10 QUESTIONS**

<table>
<thead>
<tr>
<th>Chosen 10 questions ID</th>
<th>Priority 1= most important 10= least important</th>
<th>Full text of question (optional) This may help you rank you 10.</th>
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