IMPLEMENTING EVIDENCE ACROSS THE CONTINUUM OF CARE IN APHASIA REHABILITATION

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CONFLICTS OF INTEREST

Professor Linda Worrall

• Relationships with Commercial Interests: Not Applicable
• No Commercial Support
• Mitigation of Potential Bias: Not Applicable
AIM

To **stimulate discussion** about how to improve outcomes for people with aphasia.

To achieve this I will:

- Argue that aphasia is everyone’s business.
- Show how evidence is not just about therapy.
- Exemplify how implementation needs effort.
OUR TEAMS

Marginalization of aphasia team – Prof Nina Simmons-Mackie, Prof Marian Brady, Winsome Li, Dr Sarah Wallace.

Australian Aphasia Rehabilitation Pathway team – Dr Emma Power, Emma Thomas, Emma Leach, A/Prof Miranda Rose, Prof Leanne Togher, & all of CCRE.

Implementation scientists – Kirstine Shrubsole, Dr Emma Power, Dr Denise O’Connor, Megan Trebilcock
OVERVIEW

1 Aphasia is everyone's business?

**Current research:** Cellar dwellers of stroke outcomes

Marginalization of people with aphasia

2 Evidence isn’t just about SLP therapy

**Current research:** Best practice recommendations for aphasia

Australian Aphasia Rehabilitation Pathway

3 Implementation needs effort

**Current research:** Acute aphasia best practice implementation study
WHY IS APHASIA EVERYONE'S BUSINESS?

Patients with aphasia are the **cellar dwellers** in stroke outcomes

- Highest **costs** in stroke care
- Longer **length of stay** in hospital
- Higher rate of **depression**
- More **social isolation**
- Significantly less success with **return to work**
- More frequent **discharge to higher levels of care**
- Poorer **quality life**
- Greater negative impact on their **caregivers**

- If we improve outcomes for people with aphasia, we improve stroke outcomes overall
WHY IS APHASIA EVERYONE'S BUSINESS?

Is there **marginalization** of people with aphasia in stroke care?

• Staff and visitors **talk to stroke survivors with aphasia significantly less** than stroke survivors without aphasia in acute hospital (Godecke et al., 2014)

• Over half of the patients on a stroke ward were observed to have **difficulty communicating their healthcare needs** (O'Halloran et al., 2012).

• People with aphasia are **less likely to obtain written information** about their stroke and aphasia (Eames et al., 2003)
WHY IS APHASIA EVERYONE'S BUSINESS?

Is there *marginalization* of people with aphasia in stroke research & policy

- People with aphasia not always included in *stroke trials* (Ali et al., 2013)

- **Outcome measures** widely used in stroke research often exclude communication *e.g.* mRS (Li et al., *in prep*)

- **Aphasia organizations** have developed worldwide to meet the special needs of people with aphasia and their need for external support and advocacy
WHY IS APHASIA EVERYONE'S BUSINESS?

Further research agenda

• Are stroke association websites accessible to people with aphasia?
• Is aphasia information provided by stroke associations accessible?
• Do stroke groups accommodate people with aphasia?
• Does aphasia affect your finances?
• How accessible is social security and disability pensions information?
• Are important government legal, financial and health care documents accessible for people with aphasia?
• Do stroke teams routinely collect feedback from people with aphasia?
• Can people with aphasia complain about care?
WHY IS APHASIA EVERYONE'S BUSINESS?

Including people with aphasia

1. All **stroke professionals** should be competent communicators with people with aphasia.

2. All **stroke publications** require justification for non-inclusion of people with aphasia in published research.

3. **Support organizations for stroke and aphasia** should adopt aphasia friendly principles in website design and in all information and policy development communications so that people with aphasia are included in the stroke community.
2. EVIDENCE ISN’T JUST ABOUT THERAPY

Best practice recommendations for aphasia

- Top 10 international best practice recommendations (Simmons-Mackie et al, 2016).

Australian Aphasia Rehabilitation Pathway
13 Recommendations

(Shrubsole, Worrall, Power et al., 2016)

1. All patients should be screened for communication deficits using a screening tool that is valid and reliable.
2. Treatment should be offered as early as tolerated.
3. As much therapy should be provided as can be tolerated.
4. Offer training in communication skills to the conversation partners of people with aphasia.
5. Speech language pathologists should provide direct impairment-based therapy
6. Intervention can include constraint-induced language therapy.
7. Speech language pathologists should teach other methods of communicating
13 Recommendations

8. Speech language pathologists should coach people around the person to develop supportive communication skills.

9. Intervention can include delivery of therapy programs via computer.

10. Tell the person about community-based support groups and encourage them to participate.

11. Aphasia therapy should be led and supervised by a specialist speech language pathologist working collaboratively with other appropriately trained people.

12. Provide opportunities to have conversation and social enrichment with people who have the training, knowledge, skills and behaviours to support communication.

13. All written information on health, aphasia, social and community supports should be available in an aphasia-friendly format.
Top 10 Best Practice Recommendations

(Simmons-Mackie, Worrall, Murray et al., 2016)

Three research phases:

1. Thematic analysis of 9 national clinical guidelines for stroke and aphasia

2. Survey of 500 clinicians internationally to obtain a consensus

3. Language translations at http://www.aphasiaunited.org/
Top 10 Best Practice Recommendations

1. All patients with brain damage or progressive brain disease should be **screened** for communication deficits.

2. People with suspected communication deficits should be **assessed** by a qualified professional; Assessment should extend beyond the use of screening measures to determine the nature, severity and personal consequences of the suspected communication deficit.

3. People with aphasia should **receive information** regarding aphasia, etiologies of aphasia (e.g. stroke) and options for treatment. This applies throughout all stages of health care from acute to chronic stages.

4. No one with aphasia should be discharged from services without some **means of communicating his or her needs and wishes** (e.g. using AAC, supports, trained partners) or a documented plan for how and when this will be achieved.
5. People with aphasia should be offered intensive and individualized aphasia therapy designed to have a meaningful impact on communication and life. This intervention should be designed and delivered under the supervision of a qualified professional.

a) Intervention might consist of impairment-oriented therapy, compensatory training, conversation therapy, functional/participation oriented therapy, environmental intervention and/or training in communication supports or AAC.

b) Modes of delivery might include individual therapy, group therapy, telerehabilitation and/or computer assisted treatment.

c) Individuals with aphasia due to stable (e.g. stroke) as well as progressive forms of brain damage benefit from intervention.

d) Individuals with aphasia due to stroke and other static forms of brain damage can benefit from intervention in both acute and chronic recovery phases.
Top 10 Best Practice Recommendations

6. **Communication partner training** should be provided to improve communication of the person with aphasia.

7. **Families or caregivers** of people with aphasia should be included in the rehabilitation process.
   - Families and caregivers should receive education and support regarding the causes and consequences of aphasia.
   - Families and caregivers should learn to communicate with the person with aphasia.

8. Services for people with aphasia should be **culturally appropriate and personally relevant**.
Top 10 Best Practice Recommendations

9. All **health and social care providers** working with people with aphasia across the continuum of care (i.e. acute care to end-of-life) should be **educated about aphasia** and trained to support communication in aphasia.

10. Information intended for use by people with aphasia should be available in **aphasia-friendly/communicatively accessible formats**.
Consensus-based best practice statements

www.aphasiapathway.com.au

Aphasia Rehabilitation Best Practice Statements 2014
Comprehensive supplement to the Australian Aphasia Rehabilitation Pathway

www.aphasiapathway.com.au
AUSTRALIAN APHASIA REHABILITATION PATHWAY

Best practice for aphasia services across the continuum of care

Home | The Pathway | Best practice statements | About | Contact

Supporting speech pathologists working with people with aphasia.

www.aphasiapathway.com.au
THE EIGHT PARTS OF THE PATHWAY

The Pathway

- Receiving the right referrals
- Optimising initial contact
- Setting goals & measuring outcomes
- Assessing
- Providing intervention
- Enhancing the communicative environment
- Enhancing personal factors
- Planning for transitions
INSIDE THE BOX - MORE DETAILED COMPONENTS

The Pathway

Receiving the right referrals

Aphasia awareness

Aphasia screening

Hospital admission and referrals to speech pathology

Communication training for health professionals

Optimising initial contact

Setting goals & measuring outcomes

Assessing

Providing intervention

Enhancing the communicative environment

Enhancing personal factors

Planning for transitions

Receiving the right referrals

This section aims to support referrals to speech pathology and to ensure that people with aphasia are not missed. Follow the links for best practice statements developed in accordance with the most up-to-date research and expert opinion.

Information that you will find in this section focuses on:

1. **Aphasia awareness** - by increasing aphasia awareness in the community speech pathologists can help to ensure early identification and management of aphasia.

2. **Aphasia screening** - by implementing aphasia screening tools in workplaces, speech pathologists can help to ensure that people with aphasia are not missed.

3. **Hospital admission and referrals to speech pathology services** - by advocating for admission to acute stroke units and referrals to speech pathology for people with aphasia, speech pathologists can provide aphasia rehabilitation in a supportive healthcare setting.

4. **Communication training for health professionals** - this will help other health professionals to identify aphasia characteristics and will provide them with communication strategies to obtain relevant medical and background information from people with aphasia. This will guide appropriate onward referrals and overall management.
FURTHER IN THE BOX – BEST PRACTICE STATEMENTS

The Pathway

Receiving the right referrals
- Aphasia awareness
  - Community awareness
  - Aphasia as a stroke symptom
  - Stroke awareness
- Aphasia screening
- Hospital admission and referrals to speech pathology
- Communication training for health professionals

Optimising initial contact
Setting goals & measuring outcomes
Assessing
Providing intervention
Enhancing the communicative environment
Enhancing personal factors
Planning for transitions

Increasing aphasia awareness

Best Practice Statements

These statements about increasing awareness of aphasia have been developed by the NHMRC CCRE in Aphasia Rehabilitation in accordance with the most up to date research and expert opinion.

Click on the statement for NHMRC level of evidence ratings, supporting rationales, resources and further information.

1. **Community awareness of aphasia should be raised.**
2. **In awareness campaigns, it should be highlighted that aphasia can be an early and persisting symptom of stroke.**
3. **Appropriate stroke information should be given to people with aphasia and their families.**
Community awareness

Community awareness of aphasia should be raised

Reference: N/A
NHMRC level of Evidence: GPP

Rationale: It is well recognised that aphasia is a largely unknown disorder to the public (Code et al., 2001; Elman, Ogar, & Elman, 2000; Mavis, 2007; Simmons-Mackie, Code, Armstrong, Stiegler, & Elman, 2002). A lack of public awareness of aphasia has resulting economic, psychosocial, and political consequences (Elman et al., 2000). Various phone and face-to-face surveys across multiple English speaking counties show that while 9.25% to 18% of people have heard about aphasia, only 1.54% to 11.53% had some basic knowledge of aphasia (Code et al., 2001; Mavis, 2007; Simmons-Mackie et al., 2002). Public awareness needs to be raised by as many people affected by aphasia as possible, including speech pathologists. This can occur in both small and large ways across levels of care and service planning.
How much is known about aphasia?

Aphasia is a largely unknown disorder to the public (Mavis, 2007; Simmon-Mackie et al., 2010; Elman et al., 2000 & Code et al., 2001). A lack of public awareness of aphasia has negative economic, psychosocial, and political consequences (Elman, 2000). Surveys across multiple English speaking countries show that while 9.25% to 18% of people have heard about aphasia, only 1.54% to 11.53% had some basic knowledge of aphasia (Mavis, 2007; Simmon-Mackie et al., 2010 & Code et al., 2001). Many people hear about aphasia at work, so make sure you talk about it with your colleagues (Code et al., 2001).

Figure 1: “How did you hear about aphasia?” taken from Simmon-Mackie, Code and Armstrong et al., 2001.
THE MOST USEFUL BITS - RESOURCES

RESOURCES:

How can I raise awareness of aphasia?

1. View and share the "Understanding Aphasia" video - a free educational resource launched to increase awareness of aphasia for National Stroke Week in Australia (6-14th September 2014).

2. Follow the '7 tips to increase aphasia awareness' - Nina Simmons-Mackie and colleagues (2002) recommend 7 tips for increasing aphasia awareness.

3. Build your own aphasia talk - La Trobe University has developed a 'Build your own aphasia talk' resource to be used by speech pathologists to develop community talks on aphasia for a variety of audiences including nurses, doctors, medical students, government services, community and health services, funding bodies and high school students.

4. Teach others by using aphasia simulations - Aphasia corner.com have developed aphasia simulations that can be used in teaching to help people to understand what it is like to have aphasia.

5. Share Aphasia Information packs with people and their families - UK Connect have developed a free informative information pack for people with aphasia.

6. Display aphasia posters in your workplace - Lingraphica® The Aphasia Company™ created the Aphasia Journey® poster which was used at the ASHA conference in 2013. Lingraphica® The Aphasia Company™ also ran a '30 facts in 30days aphasia awareness campaign' in June 2013. Some examples of their facts sheets can be seen below.

7. Promote 'Aphasia' - the movie. View the trailer.

References:


IMPLEMENTATION NEEDS EFFORT

Guidelines don’t change practice
FEASABILITY IMPLEMENTATION STUDY

(Shrubsole, 2017)

Aim: to evaluate the feasibility, acceptability and potential effectiveness of tailored implementation intervention

- Pilot cluster RCT with 4 acute hospital speech pathology teams
- Sites randomised to:
  - Collaborative Goal Setting (n = 2)
  - Written, Aphasia Friendly Information (n=2)
IMPLEMENTATION INTERVENTION

Workshop addressed the known barriers:

- **Education** - regarding key evidence and feedback of baseline audits

- **Persuasion** – a video presentation, and case studies/quotes.

- **Environmental restructuring** – Teams provided with resources including an interactive PDF information package, and instructions to support the package.

- **Modelling** – modelled examples, provided role-play opportunities
RESULTS

• **Feasible** – low dropout, all sites completed the study

• **Acceptable** – Clinicians were open to feedback on their practice, and participated in all workshop activities

• **Potentially effective** - Most hypothesized changes were significantly different. “It’s made me think differently about what we do”

• **Aspects for improvement** – need for follow-up session & site champion

• **Factors to consider** - Readiness for change
IMPLEMENTATION NEEDS EFFORT

• Tailored theoretically-based behaviour change intervention can improve SLPs’ aphasia management practices

• Speech pathology teams want help to improve service provision for people with aphasia

• Despite environmental barriers, a positive workplace culture and positive beliefs about the benefits of evidence-based aphasia care can close evidence-practice gaps
SUMMARY

1. Aphasia is everyone's business?
   - They have the worst stroke outcomes
   - Is there “aphasia-ism” within stroke care, research and policy?

2. Evidence isn’t just about SLP therapy
   - There are multiple sources of best practice recommendations across the continuum of care
   - Australian Aphasia Rehabilitation Pathway is a resource for speech language pathologists

3. Implementation needs effort
   - Tailored implementation interventions are feasible, acceptable and potentially effective.
To follow our progress....

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