Living Successfully with Aphasia

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The University of Queensland, Australia.

- NHMRC grant #: 631464
The story of this program of research

What does it look like?

How does it develop?

Who gets there?

What can we do about it?
Overview of today

- What does “living successfully with aphasia” mean?
- What happens in the critical first year after the stroke that helps them live successfully (or not) with aphasia?
- What are the factors that determine whether a person successfully lives with aphasia?
- How can we facilitate it?
  - Stepped care
  - ASK trial
What does “living successfully with aphasia” mean?
What does it mean to live successfully with aphasia?

Semi-structured in-depth interviews + participant generated photography  Brown et al., 2013. Aphasiology

- 25 people with aphasia > 2 years post onset
- 25 family members
- 25 speech pathologists

Meta-analysis  - Brown et al, 2012, IJSLP

Dr Kyla Hudson
(nee Brown)
Doing things

Meaningful or important activities to me
  • “You gotta have an interest...like carving or...reading...travel. All that type of thing... It gives you something to work for. It gives something to try and succeed with something.”

Independence in doing things
  • “I like shopping...helps you become independent...I want to buy him [my husband] a birthday present. But I go without him. Thank-you.”

Sense of achievement from doing things
  • “All the things that I’ve managed to do.”
People

Support from family and friends

• “People around you...pulling them [me] up. Come on. You can do it. You can do it.”

Acceptance from family and friends

• “Nothing wrong with Mum. She’s got a stroke, that’s all...To them I’m just Mum.”

Other people with aphasia

• “And it’s just nice to talk with people who...knows what I have... and things flow that way.”
Positive way of living

Absolute recovery – “normal”
- “If I could talk... before the stroke, so, yeah?”

Acceptance
- “I know that that’s not possible, but as... good as I can get and I’m happy.”

Attitude
- “Never giving up... Never—never—never.”
- “Positive... not negative”

Improving – seeing how far I’ve come
- “To see that I am improving. And I think that would be a major thing. And I... know I’ve improved so.”

Getting on with life – looking to future
- “What’s success? It’s living a life. Yeah and having... a vision [for the future].”
Participants’ photos
Living successfully with aphasia means...

- Doing things, having people to support you and having a positive attitude.

- Better communication is part of it, but not all.

- Successfully living with aphasia means different things to different people.

- What does your aphasia service do to help people live successfully with aphasia?
2. How does it develop?

What happens in the critical first year after the stroke that helps them live successfully (or not) with aphasia?
The first three months post stroke
(Grohn et al 2013)

Semi-structured qualitative interviews
Three months post-onset (+/- 2 weeks)

Living Successfully with Aphasia
- Adjustment
- Positive Outlook
- Social Support
- Rehabilitation
- A need to do things

Dr Brooke Ryan (nee Grohn)
# Peter vs Mathew

<table>
<thead>
<tr>
<th></th>
<th>Peter</th>
<th>Mathew</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>M</td>
<td>M</td>
</tr>
<tr>
<td>Age</td>
<td>58</td>
<td>61</td>
</tr>
<tr>
<td>Years of Formal Education</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>WAB AQ at 3mpo</td>
<td>74.9</td>
<td>73.8</td>
</tr>
<tr>
<td>Aphasia Classification at 3mpo</td>
<td>anomic</td>
<td>anomic</td>
</tr>
<tr>
<td>WAB AQ at 12mpo</td>
<td>80</td>
<td>81.9</td>
</tr>
<tr>
<td>Aphasia Classification at 12mpo</td>
<td>anomic</td>
<td>anomic</td>
</tr>
<tr>
<td>Other speech and language difficulties*</td>
<td>mild AOS observed</td>
<td>nil observed</td>
</tr>
<tr>
<td>Self-reported mobility difficulties reported at 3mpo+</td>
<td>moderate difficulty maintaining balance, not able to walk one flight of stairs</td>
<td>no difficulty maintaining balance, no difficulty walking one flight of stairs</td>
</tr>
<tr>
<td>Self-reported mobility difficulties reported at 12mpo+</td>
<td>no difficulty maintaining balance, a little difficulty walking one flight of stairs</td>
<td>a little difficulty maintaining balance, a little difficulty walking one flight of stairs</td>
</tr>
<tr>
<td>Marital status</td>
<td>married</td>
<td>married</td>
</tr>
<tr>
<td>Living Situation after discharge from hospital</td>
<td>living at home with wife</td>
<td>living at home with wife and 3 daughters</td>
</tr>
</tbody>
</table>
Peter’s qualitative results (Grohn et al, submitted)

3m post-onset

I’m not... unsuccessful. I’m successful

6m post-onset

Each day. Each day as it comes

9m post-onset

I couldn’t be any happier

12m post-onset

I can see me coming up to very successful, but that’s next one
Matthew’s qualitative results
(Grohn et al, submitted)

To say, to try and speak is terrible

This talking business is a big thing

Still the same as before

After the year, I keep saying to myself I thought I’d be better than this
1. Emotional distress

Figure 5-3  HADS Depression score

- Mathew: 52.38, 42.86, 42.86, 42.86
- Peter: 0.00, 0.00, 0.00

Transformed score

Timepoints: 3mpo, 6mpo, 9mpo, 12mpo
2. Engagement in meaningful activities

Figure 5-4  ALA Participation score

<table>
<thead>
<tr>
<th></th>
<th>Mathew</th>
<th>Peter</th>
</tr>
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<tbody>
<tr>
<td>3m</td>
<td>57.35</td>
<td>51.47</td>
</tr>
<tr>
<td>6m</td>
<td>58.82</td>
<td></td>
</tr>
<tr>
<td>9m</td>
<td>88.97</td>
<td></td>
</tr>
<tr>
<td>12m</td>
<td>64.71</td>
<td>88.24</td>
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</tbody>
</table>
3. Perceived improvement across time

![Graph showing perceived improvement across time for individuals named Mathew and Peter. The graph indicates a significant increase in scores over time for Mathew, while Peter shows a decrease.](image-url)
How does it develop in the first year?

• Similar themes of doing things, people and a positive approach, but also adjustment and rehabilitation figure prominently.

• People have different trajectories – not all improve on all domains.

• Low mood and depression consistently underlie poorer outcomes.

• How does your aphasia service tailor your services to help each person to live successfully with aphasia in the first year?
What are the factors that determine whether a person successfully lives with aphasia?
Determinants of successfully living with aphasia

Linda Worrall, Kyla Hudson, Brooke Ryan Asaduzzaman Khan
The University of Queensland, Australia.

Nina Simmons-Mackie
South Eastern Louisiana University, USA

• NHMRC grant #: 631464
Aim of study

To determine the factors that contribute to living successfully with aphasia in the first year post stroke

so that

Health professionals can provide the supports and interventions early to facilitate successfully living with aphasia.
Participants

• 58 people with aphasia recruited through speech pathologists in three regions of Australia

• Tested and interviewed at 3, 6, 9 and 12 months post onset.
Test battery

Western Aphasia Battery Revised (WAB-R; Kertesz, 2007)

Demographics (age, gender, socio-economic status, level of education)

Burden of Stroke Scale (BOSS; Doyle et al., 2004)

Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983)

Successfully Living with Aphasia Rating Scale (SLARS; Grohn, Worrall, Simmons-Mackie & Brown, 2012)


Assessment for Living with Aphasia (ALA; Kagan et al., 2011).
Outcome (dependent) variable

Assessment for Living with Aphasia
self-report biopsychosocial measure based on ICF domains
38 items with 5 domains
1. Aphasia (impairment)
2. Participation
3. Environment
4. Personal
5. Life with Aphasia.
Analysis – mixed effects modelling

- Social network size (Social Network Convoy Model)
- Self-rating of living successfully with aphasia
- Psychological distress (HADS)
- Age, gender, socio-economic status, level of education
- Physical functioning (BOSS)

Life with aphasia (ALA)
<table>
<thead>
<tr>
<th>Positive factors</th>
<th>Negative factors</th>
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<tbody>
<tr>
<td>Higher household income</td>
<td>Higher education</td>
</tr>
<tr>
<td>Larger social network*</td>
<td>Low mood*</td>
</tr>
<tr>
<td>Female</td>
<td>Poorer physical functioning*</td>
</tr>
<tr>
<td>Less severe aphasia*</td>
<td></td>
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* potentially modifiable factors
Factors affecting aphasia domain

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* potentially modifiable factors
## Combined results

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* potentially modifiable factors
Conclusion

We may be able to help people with aphasia live more successfully with aphasia in the first year post stroke by:

• Improving mood and preventing depression and anxiety
• Maintaining or increasing their social network
• Helping them adjust and take a positive approach
• Lessening the severity of their aphasia
1. How can we facilitate it?
   1. Stepped care
   2. ASK trial

4. What can we do about it?
PREVENTION AND TREATMENT OF DEPRESSION AFTER APHASIA
A SYSTEMATIC REVIEW

Baker, Caroline ¹ Worrall, Linda ¹ Rose, Miranda ²
Hudson, Kyla ¹ Ryan, Brooke ¹ & O’Byrne, Leana ¹

¹ School of Health and Rehabilitation Sciences, The University of Queensland, Brisbane, Australia.
² School of Allied Health, La Trobe University, Melbourne, Australia.
We know…

- Depression is common in post-stroke aphasia
  - high incidence in post-stroke aphasia (70% at 3 months; 62% at 12 months)
  - major depression increases from 11% to 33% across 12 months post-stroke in aphasia population

- Current Australian stroke outcome sets show lack of psychological care
  - Only 6% in acute care and 32% in rehab had a recommended psychology assessment
  - Only 32% offered counselling
Why a lack of psychological care?

- shortage of psychologists

- SLT’s report reduced confidence in counselling and a need of training in psychological care

Is stepped psychological care the answer?
Stepped psychological care after stroke

- **Level 4**: Severe mood impairment & challenging behaviours
- **Level 3**: Severe & persistent mood impairment
- **Level 2**: Mild to moderate mood impairment
- **Level 1**: Sub-threshold problems in mood
Interventions at Levels 1 to 4 after stroke

**Level 4** Behavioural specialist service

**Levels 3 & 4** Mental health specialists; clinical psychology and if cognition impaired then neuropsychology also; one to one therapy approaches; antidepressant medication

**Level 2** Behavioural activation; cognitive-behavioural therapy; goal setting, relaxation training

**Levels 1 & 2** goal setting, problem solving

**Level 1** Routine assessment; post-stroke psychological information provision and support; prevention strategies
What is the evidence for depression interventions for aphasia?

• Which rehabilitation interventions effectively prevent or treat depression after stroke for people with aphasia and their significant others?

• Which of these interventions may be considered for use within a stepped psychological care model?
Results

Identification
- No. of records identified through database searching n= 4,315
- No. of records identified through other sources n=14
- No. of records after duplicates removed n=3,160

Screening
- No. of records with titles and abstracts screened n=3,160
- No. of records excluded based on inclusion/exclusion criteria n=2,721

Eligibility
- No. of potentially relevant full text articles evaluated n=439
- 43% of studies had no or inadequate detail of individuals with aphasia within stroke sample n=172

Included
- No. of full text articles included for synthesis n= 38
Findings

**Preventive interventions (n=4)**

- improvements in depression outcomes over time in 3 of 4 studies but not statistically significant
Findings

**Treatment interventions**

- strongest evidence found for *behavioural therapy*\(^3\)
- some evidence for *web-based psychosocial program*\(^{14}\)
- some evidence for *telephone-based problem-solving* \(^{15}\)
Findings

Rehabilitation for communicative functioning
• mixed results; positive trends in mood measures but no statistically significant findings
  • biographic-narrative treatment\textsuperscript{16}
  • communication partner training\textsuperscript{17}
  • communication group\textsuperscript{18}

Rehabilitation for psychosocial functioning
• improved mood but not statistically significant in use of
  • self-management book\textsuperscript{19}
• positive qualitative themes from
  • aphasia choir\textsuperscript{20}
  • aphasia carer support group\textsuperscript{21}

Multidisciplinary rehabilitation and transition
• statistically significant less depressive symptoms
  • higher goal achievement score (GAS) \textsuperscript{22}
Translating stepped psychological care for aphasia

**Level 4** Behavioural specialist service

**Levels 3 & 4** Mental health specialists; clinical psychology and if cognition impaired then neuropsychology also; one to one therapy approaches; antidepressant medication

**Level 2** Behaviour therapy; psychological education and problem-solving

**Level 1** Routine assessment; post-stroke psychological information provision and group support; biographic-narrative therapy; communication partner training; aphasia choir; self-management workbook; goal setting.
Clinical implications

- Stepped psychological care is an evidence-based mode of service delivery for people with aphasia after stroke.

- It requires multidisciplinary care including stroke and mental health specialists.

- Stroke staff require support and training to deliver assessment and therapeutic interventions.

- This mode of service delivery has been funded in a national mental health care initiative by the Australian government.
An early psychosocial intervention for people with aphasia and their families
ASK Modules – a package

Before We Begin *compulsory

Set Your Goals *compulsory

My Story
Living the Learning
Not Just Words
Finding the Positive
Stay Connected

Participants will prioritise the order of these modules based on their personal interests and needs

To be completed by all participants before the program
To be completed by all participants as the first module of the program
Tailored approach - Australian Aphasia Rehabilitation Pathway
- an international resource for aphasia therapists
Further information

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