


Written stroke and aphasia information: Preferences of people with aphasia

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Why is aphasia information important?

- One of the most commonly reported goals of people with aphasia was that of obtaining information (n = 50)
- Information about stroke and aphasia was needed to:
 - access services,
 - explain their difficulties to others,
 - enable people with aphasia to begin to take control, and to participate in decisions about their health. (Worrall et al., 2011)
- To bring about a feeling of reassurance, and a sense of being able to understand and accept what has happened. (Parr, Byng, Gilpin, & Ireland, 1997)
- Informational support has also been found to be significantly associated with better health related quality of life (HRQoL) for people with aphasia. (Hilari & Northcott, 2006)



Health information needs of people with aphasia are not currently being met


- 100% of stroke patients without aphasia recalled obtaining information from health professionals. However, only 60% of stroke patients with aphasia reported obtaining information. (Eames, McKenna, Worrall & Read, 2003)
- Health professionals spent less time communicating health information to people who had aphasia compared to people who had a stroke but did not have aphasia. (Knight, Worrall & Rose, 2006)
- Written health materials are not sufficiently modified to suit the reading ability of people with aphasia. (Aleligay, Worrall & Rose, 2008)



Information accessibility:

Multifaceted

- Availability
- Obtainability
- Dialogue between health professionals and people living with aphasia
- Accuracy
- Appropriateness:
 - content
 - timing
 - media
 - format




Study Aims:

- For written stroke and aphasia information to be optimally effective it needs to be:
 - ✓ provided at an appropriate time, and
 - ✓ in a format that the recipient welcomes and can understand.

The aim of this research was to explore these components of health education for people with aphasia.

Participants:



40 adults with aphasia (resulting from a left hemisphere stroke)

Maximum variation sampling:

Age: **32 – 84 years (M = 64; SD = 12)**

Aphasia severity - WAB AQ: **6.58 – 93.1 (M = 75; SD = 20)**

Reading level - RCBA-2: **13 – 98 (M = 78; SD = 19)**

Time post onset: **2 months – 14;8 years (M = 3;1 SD = 3;5)**

Years of education: **2 years – 20 years (M = 12; SD = 4)**

Gender: **16 females, 24 males**

6 participants were bilingual

Overview of four (4) studies and key findings

1 Ten-item face-to-face questionnaire (n = 40)
Audio recorded – spontaneous comments transcribed verbatim

Rose, T.A., Worrall, L.E., McKenna, K.T., Hickson, L.M., & Hoffmann, T.C. (2009). Do people with aphasia receive written stroke and aphasia information? *Aphasiology*, 23(3), 364-392.

1. Did people with aphasia **report receiving** written information about stroke and aphasia?

- 36% (n = 14) of participants reported receiving **both** stroke and aphasia information
- 49% (n = 19) of participants reported receiving written information about **aphasia**
- 67% (n = 26) of participants reported receiving written information about **stroke**







1 Ten-item face-to-face questionnaire (n = 40)
Audio recorded – spontaneous comments transcribed verbatim

Several comments reflected:

- a poor or no understanding of aphasia
 - "No...aphasia I wouldn't know!"
 - "I still don't understand anything about it...I didn't know any of it."
- written information if received was too complex
 - "Oh re ridiculous...Well ah you think you're a ...university student before you can understand them...it's just beyond. Throw it away because I can't understand...too complicated!"

1 Ten-item face-to-face questionnaire (n = 40)
Audio recorded – spontaneous comments transcribed verbatim

2. Where did people with aphasia obtain written information about stroke and aphasia?

	46% (n = 18) Rehabilitation setting e.g., hospital aphasia groups		31% (n = 12) Hospital discharge setting
	26% (n = 10) Community setting e.g., Australian Aphasia Assoc. Stroke Assoc.		26% (n = 10) Internet
	28% (n = 11) Other e.g., family / friends		18% (n = 7) Acute hospital setting

2 21- item face-to-face questionnaire (n = 40)
Audio recorded – spontaneous comments transcribed verbatim

Rose, T.A., Worrall, L.E., Hickson, L.M., & Hoffmann, T.C. (2010). Do people with aphasia want written stroke and aphasia information? A verbal survey exploring preferences for when and how to provide stroke and aphasia information. *Topics in Stroke Rehabilitation*, 17(2), 79-98.

1. Did people with aphasia consider it important to be given written information about stroke and aphasia?

How important is that you are given written information about **stroke**?

Not important ————— **X** ————— Very important
Med = 93 (SD = 21)

How important is that you are given written information about **aphasia**?

Not important ————— **X** ————— Very important
Med = 94 (SD = 12)

Wilcoxon signed ranks test: Participants tended to rate receipt of written aphasia information as more important than written stroke information (z = 1.96, P = 0.05)

2 21- item face-to-face questionnaire (n = 40)
Audio recorded – spontaneous comments transcribed verbatim


2. When do people with aphasia consider it helpful to receive written information about stroke and aphasia?

Time Post Onset	Percentage
At admission	8%
Day after stroke	17%
Within week	31%
Within month	74%
6 months	94%
12 months	89%
More than 12 months	91%


People with aphasia thought it helpful to receive written information at several stages post onset

2 21- item face-to-face questionnaire (n = 40)
Audio recorded – spontaneous comments transcribed verbatim


3. How do people with aphasia prefer to be provided with stroke and aphasia information?




45% - written (brochures / booklets / information sheets)



42% - video/DVD



8% - cassette tape / CD



5% - computer / internet

3

- Semi-structured in-depth interviews (n = 40)
- Transcribed verbatim - qualitative content analysis
- Rank PEMs

Rose, T.A., Worrall, L.E., Hickson, L.M., & Hoffmann, T.C. (2011). Aphasia friendly written health information: Content and design characteristics. *International Journal of Speech-Language Pathology*, 13(4), 335-347.

The majority of participants most liked the "aphasia friendly" PEMs:

- stroke PEM (56%, n = 22)
- aphasia PEM (87%, n = 34)

Several participants demonstrated a clear preference for "aphasia friendly" PEMs:
"Without a doubt...That [aphasia friendly stroke] to me is far better. Far superior..."

Observations:

- greater amount of time looking at the aphasia friendly PEMs
- attempted to read the aphasia friendly PEMs
- emotive reactions e.g., two participants instantly cried
→ appreciated information presented in a way that could be related to and understood

"...my they're. Mine there...That's my people. That's my people."

3 Reasons why "aphasia friendly" PEMs most liked:

1. **Simple:** *"It's the best. It's very simple..."*
2. **Could be understood:** *"It's better. I can understand it. I can understand it."*
3. **Could be read:** *"Yeah very good...I could read this."*
4. **Could be read quickly:** *"Beautiful! ...Tells you everything you within two minute."*
5. **Easy to read:** *"Ah that would be easy to read. Ah yes. I that be really easy."*
6. **Looked appealing:** *"...I like I like this one first...Cause it peals [appeals to] me."*
7. **Well set out:** *"I think it's been formatted right."*
8. **Clear:** *"I mean you can tell it quite clearly...it tell you quite clearly..."*
9. **Looked like they had been developed by someone who understood aphasia:**
"...I can see people...know more about it."

3 What makes everyday documents & PEMs easier / harder to read?

Facilitators and barriers to reading everyday documents and PEMs:

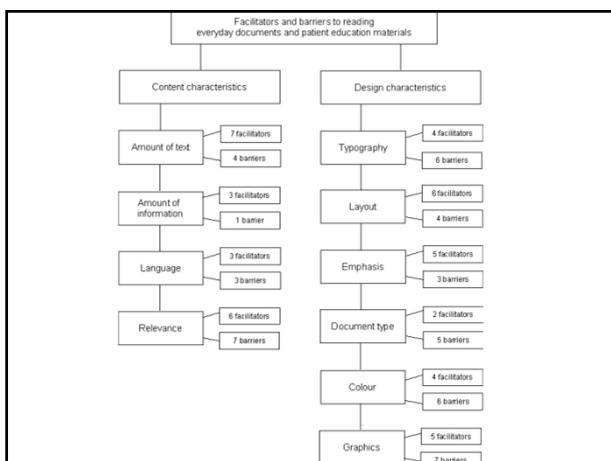
91 codes: 45 facilitator and 46 barrier codes

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10 subcategories

↓

two categories:
1) content characteristics 2) design characteristics



4 Rationale for study: Evidence base needed for text-formatting

Many guidelines based:

- professional opinion (Hoffmann & Worrall, 2004)
- principles from document design, learning theory, advertising, and literacy research (Buxton, 1999)

... rather than consultation with the target audience.

"the production of accessible information is hampered by lack of evidence, research based or otherwise, about 'what works'..."
(p. 40, Townsley, Rodgers, & Folkes, 2003).

4 **37- item face-to-face questionnaire (n = 40)**
Audio recorded - spontaneous comments transcribed verbatim

Rose, T.A., Worrall, L.E., Hickson, L.M., & Hoffmann, T.C. (2012). Design preferences of people with aphasia for written stroke and aphasia information. *International Journal of Speech-Language Pathology*, 14(1), 11-23.

The primary aim was to obtain preferences for specific design characteristics – e.g.,

- 1) the representation of numbers
- 2) font size and type
- 3) line spacing
- 4) graphic type in stroke and aphasia PEMs

4 **Including numerous graphics in written stroke and aphasia information?**

- **Helpful** 87.5 % (n = 35)
- **Offensive** 12.5% (n = 5)
→ participants who were offended by pictures tended to have more severe reading difficulties
- **Childish** 40.0% (n = 16)
→ "Oh well when you get like this it doesn't matter what whether it's childish or not if you can read. If you can work out what it is, if it's childish or otherwise doesn't matter..."
- **Embarrassing** 35.0% (n = 14)
→ "...that be very nice to do [include numerous graphics] but in front of another people showing this would be...yes [embarrassing] because they know...cuckoo."
- Some participants expressed their dislike for the Picture Communication Symbols™ (PCS)
→ "I think the pictures are dreadful...Oh I don't like them!...No I don't think they would be very helpful...I'd feel yuck...as the pictures are I hate them."

4 **Reasons why to include numerous graphics in PEMs**

1. **makes information interesting** "I mean you know the pictures probably liven up."
2. **helps with understanding** "Now this see, I can understand that. It's got pictures."
3. **helps with reading** "I know the photos...I read the photos. I read the photos."
4. **makes information easier to read** "...with this pictures as well then it's much easier..."
5. **makes information quicker to read** "Don't have to read it. All the information is in the pictures so in a way it's quicker to read."
6. **helps orient to the topic** "Each picture gives you an indication of basically what the subject is about...that's the way I would understand it."
7. **helps with remembering** "That's good the cartoons are good it helps you remember things."
8. **adds humour/enjoyment** "There's humour."
9. **graphics linked with the text are helpful** "See um the pictures. Is all click together just like that."
10. **information containing no graphics would not be attempted** "No I wouldn't [read] with not a picture on to me told."

Summary of findings: Guiding principles for the provision of stroke and aphasia PEMs for people with aphasia

- Provide written information about *both* stroke and aphasia
- Do not assume written stroke and aphasia information has previously been provided → even if it has may have been:
→ at time not optimal for the person with aphasia, or
→ in a format that could not be understood
- Do not make assumptions about whether or not people with more severe aphasia and reading difficulties want written stroke and aphasia information
→ no significant relationships were found between importance ratings & reading ability / aphasia severity

Guiding principles for the provision of stroke and aphasia PEMs for people with aphasia


- A systematic approach is needed as some participants reported:
→ receiving mass amounts of written information, but no stroke or aphasia information
→ not knowing who had provided the information → therefore difficult to follow up information needs
- Provide option of written stroke and aphasia information in acute care → individual preferences i.e.,
→ approx 1/3 of participants considered this information helpful in the first week
→ others wanted this information for later reference
→ some wanted this information for their significant others
→ others did not want this information as they were too unwell, and/or were denying their stroke and aphasia.

Guiding principles for the provision of stroke and aphasia PEMs for people with aphasia

- The main source of written stroke and aphasia information was the rehabilitation group setting
→ important to ensure access to such groups throughout the continuum of care, not only several years post stroke
- Ensure people living with aphasia are aware of support associations i.e.,
→ participants commented not being aware of stroke / aphasia associations
- Some people living with aphasia sourced this information from the Internet
→ consider directing people with aphasia and their significant others to appropriately formatted Internet sites for information
- Ensure this information is available in waiting rooms / hospital walls
→ source for some participants

Guiding principles for the provision of stroke and aphasia PEMs for people with aphasia

- Some participants obtained this information from other patients
→ consider connecting people living with aphasia, even in early stages of recovery where appropriate, for the purpose of information sharing
- Ensure this information is available throughout the continuum of care
→ six months post stroke may be a particularly good time to follow up stroke / aphasia information needs
- Ensure a variety of media is available
- Ensure high quality and appropriately developed DVDs about stroke and aphasia are available
→ particularly during the initial 6 months following stroke



Guiding principles for the provision of stroke and aphasia PEMs for people with aphasia

Content and language:

- use small amounts of text and information
- use short, single key words
- use short points, phrases, sentences, and paragraphs
- use simple language that is straight to the point
- use content that is interesting, helpful, important, and relevant
- include contact information for obtaining further information
- ensure the content is well organised
- avoid the use of jargon
- use an appropriate tone i.e., avoid the use of judgmental language
- avoid the use of true and false statements - false statements can be confusing if this is the only text read

Guiding principles for the provision of stroke and aphasia PEMs for people with aphasia

Numbers:

- present smaller numbers as figures
- present larger numbers (e.g., 40 000) in both figures and words
- present fractions in words
- people with aphasia may have a clear preference regarding which representation (i.e., figures or words) they consider easier to read, and should be provided with the option to choose, where possible

Typography and layout:

- use a minimum 14 point font
- use a san serif font (e.g., Verdana or Arial)
- use a font that is clear and bold
- use 1.5 or double line spacing for paragraphs
- ensure white space is included around sections of text
- use bulleted lists where possible

Guiding principles for the provision of stroke and aphasia PEMs for people with aphasia

Emphasis and document type:


- use bold text, headings, and borders to emphasise key points
- use distinctive headings that link to the content
- use documents that are portable
- avoid the use of gloss paper
- be aware that PEMs with multiple fold sections may be difficult for people who have a hemiparesis to open

Colour and graphics:

- use for graphics and to denote sections if possible, but use black for text
- include graphics
- check preferences for the inclusion of graphics and preferences for graphic type, particularly for people with more severe reading difficulties
- ensure all graphics relate to the text and are labeled

When considering these guiding principles...

- no one set of principles will ever fully meet the needs of all people with aphasia
- research findings useful to guide health professionals in the provision and design of stroke and aphasia of PEMs to people with aphasia, but:
→ should not replace the involvement of people with aphasia in the production and evaluation of these documents
- **written information can only truly be considered to be 'aphasia friendly' if the recipient with aphasia deems it so**

Current Research 

Transition Planning Project
Meeting the information needs of people living with aphasia

Survey of family members and friends:
meeting the information needs across transitions throughout the continuum of care
<http://www.surveymonkey.com/s/ccreaphasia>

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Survey of speech pathologists:
What is current practice in aphasia education; recommended resources; barriers & facilitators?
<http://www.surveymonkey.com/s/CCREaphasiasurvey>

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Development of a stroke and aphasia education "toolkit" and does it make a "difference"?

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Publications arising from research:



- Rose, T.A., Worrall, L.E., McKenna, K.T., Hickson, L.M., & Hoffmann, T.C. (2009). Do people with aphasia receive written stroke and aphasia information? *Aphasiology*, 23(3), 364-392
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