
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

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Purpose: Written health information can be better comprehended by people with aphasia if it is provided in an aphasia-friendly format. However, before pursuing research in the area of text-formatting for people with aphasia, it must be determined whether people with aphasia consider it helpful to receive health information in the written media. This study, therefore, aimed to determine the following: whether people with aphasia consider it important to receive written stroke and aphasia information; when people with aphasia prefer to receive this information; and what their preferences are for health information media. **Method:** Surveys were administered in a face-to-face interview with 40 adults with aphasia. Participants were purposefully selected using maximum variation sampling for a variety of variables including aphasia severity, reading ability, and time post stroke. **Results:** Participants thought it important to receive written information about both stroke and aphasia. They considered it helpful to receive written information at several stages post stroke, particularly from 1 month onwards. The largest proportion (97%) of participants identified 6 months post stroke as the most helpful time to receive this information. Written information was the most preferred media at participants' present time post stroke ($M=39$ months; range, 2–178 months). Videos/DVDs were the most preferred media during the 6 months immediately following the stroke. **Conclusion:** Despite reading and language difficulties, participants considered written information to be important, hence people with aphasia should receive written information about both stroke and aphasia. This information should be easily accessible throughout the continuum of care. **Key words:** *aphasia, aphasia friendly, stroke, written health information*

Aphasia can be defined as “the loss or impairment of language function.”^{1(p49)} It is a multimodality disorder that manifests in difficulties with speaking, reading, and writing.¹ Various studies have investigated the prevalence of aphasia resulting from stroke, estimating between 10% to 18% of stroke survivors will have aphasia long term.^{2–4} Given the language difficulties encountered by people with aphasia, there is a growing recognition of the need to produce aphasia-friendly written health information.^{5–9} Aphasia-friendly information incorporates many of the recommendations for how best to format written information for stroke patients^{10,11} but to an exaggerated degree.¹² Preliminary research found that people with aphasia comprehended more health information when standard health information brochures and

booklets were reformatted to contain simple words and short sentences, larger font, white space, and pictures.⁶ Before further pursuing research in the area of aphasia-friendly text formatting, it is fundamental to determine whether people with aphasia wish to receive health information in written formats. “Virtually every variety of aphasia entails some difficulty in oral reading or reading comprehension.”^{13(p60)} Given this, and the wide variety of media available for patient education (eg, DVDs, Websites, verbal information), it should not be assumed that people with aphasia desire to receive health information in a written

format. The primary aim of this research was to determine whether people with aphasia consider it important to receive written stroke and aphasia information.

There is an expanding body of evidence indicating that people with aphasia are not adequately informed about their stroke and aphasia.^{7,10,14-16} People with aphasia have limited access to health care information.¹⁷ Health information access for people with aphasia is recognized to be multifaceted, incorporating features of information availability as well as ease of obtainability.⁸ Information accessibility may also be qualified in terms of accuracy and appropriateness¹⁸ of content, format, and media.⁸ Another attribute of information accessibility may be the timing of health information provision.^{8,18} Additional aims of this study were to explore two specific elements of service delivery by determining the preferences of people with aphasia for when (ie, timing) and how (ie, media) to receive stroke and aphasia information.

Stroke patients generally have expressed their desire for more timely provision of health information.^{19,20} Seventy-five percent of stroke survivors in the study by Eames and colleagues¹⁰ reported that their information needs were not met while in hospital. Participants in the study by Knight and colleagues¹⁶ were also particularly dissatisfied with the timing of health information provision within the acute hospital setting. Both of the aforementioned studies included participants with aphasia. In the study by Rose and colleagues,⁷ 82% of participants with aphasia reported that they did not receive any written information about stroke or aphasia whilst in hospital. Patients who leave the hospital with limited information may lack confidence in how to manage their health.²¹ For people with aphasia, a lack of information about aphasia may also result in a limited awareness of aphasia-specific services.²²

For people with aphasia there can be a disparity between their desire to know more about their health and their inability to absorb information.¹⁴ In the phenomenological research by Parr and colleagues,¹⁴ several participants with aphasia reported being offered information at a time when they could not comprehend it. In addition, stroke patients' desire and need for information,

particularly in the initial stages post stroke, are known to vary according to psychological status.²³ A number of factors including stress,^{24,25} anxiety,²⁶ shock,¹⁹ and physical discomfort^{27,28} have also been identified to affect a patients' ability to absorb and retain information. As Maycock²³ states, "A patient who is overwhelmed by the psychosocial difficulties of living with a chronic illness will probably absorb little of the information offered . . ." (p432) In contrast, Cameron and Gignac²⁹ argue that patients' worry and anxiety may actually increase if stroke information is not immediately available. These arguments highlight the importance surrounding the appropriate timing of information and the need for investigation into the preferences of people with aphasia for receiving written health information in the initial stages post stroke.

The need for stroke information beyond the acute hospital setting is also well supported in the literature^{20,30,31}; researchers identify that the desire for information persists even several years post stroke.^{19,32} Hanger and colleagues³² assert that "the nature of questions change with time but the need for information does not." (p51) In 2007, the National Stroke Foundation in Australia commissioned research that used surveys and in-depth interviews to explore the feelings and experiences of 104 stroke survivors.³³ According to this research, the optimal time to provide stroke survivors with information was after hospital discharge, when the true impact of the stroke had begun to be discovered.

Various studies have also highlighted the importance of repeated information provision.^{30,34-36} In the 2-year follow-up study by Hanger and colleagues,³² nearly one fifth of the participants requested similar information at the various interview times post onset (ie, at 2 weeks, 6 months, and 2 years post onset), highlighting the need for the same information to be repeated several times. Hanger and colleagues³² also identified that requests for basic information such as "What is a stroke?" continued several years post stroke. People with aphasia have also reported a desire for repeated information about "What is aphasia?" several years post stroke.¹⁴

Considerable gaps in the literature exist regarding the most effective and acceptable ways of providing stroke patients with health information.³⁴

In a study by Eames and colleagues,³⁷ 89% of the stroke- and brain injury-specific services surveyed reported providing information in media other than written or verbal formats. Videotapes and/or DVDs were the most commonly used alternative media. Health information may also be obtained by talking with health professionals, friends, acquaintances, and other patients; reading written patient education materials such as brochures, booklets, and posters; and accessing computer-aided information systems and the Internet. Television and phone-in programs may also have a valuable role in the delivery of health information.²⁵ Audiotapes are another alternative media for imparting health information to stroke patients.²⁸ Supplying patients with an audio recording of their health professional providing information may allow the patients to replay the information when stress and anxiety levels may have reduced²⁶ and may remind patients of details that they may have missed during an emotional conversation.³⁸ This media may be particularly useful when bad or distressing information is being provided.²⁶ In addition, stroke patients have reported that they would value a telephone call post discharge³⁹ or a visit from someone who could provide further information.¹⁹ Researchers also assert that it may be necessary to use a variety of media for providing stroke information and to repeat this information in different ways over time.³²

The benefits of using written media to provide health information have been particularly well reported. Written health information, for example, may assist patients with the recall of information^{40,41} and can be accessed at the preferred time and in the location of choice.⁴⁰ Written health information allows the readers to learn at their own pace,^{42,43} is portable, and can provide message consistency and permanency.⁴⁴ There is also evidence that stroke patients value receiving written health information.^{30,45} Evidence, however, that people with aphasia post stroke value written media is lacking. People with aphasia have frequently been excluded from stroke education research^{35,45-49}; in some cases researchers have not reported whether people with aphasia participated.

In summary, this study aimed to (a) determine whether people with aphasia considered it important to receive written stroke and aphasia

information; (b) explore the preferences of people with aphasia regarding when to receive written health information; and (c) investigate the preferred health information media of people with aphasia.

Method

The current study forms part of larger research project that is exploring the preferences of people with aphasia for receiving health information, with a focus on determining text-formatting facilitators and barriers. This study follows on from the study by Rose and colleagues⁷ about whether people with aphasia reported receiving written stroke and aphasia information.

Ethics approval was obtained from the relevant ethics committees. All research information provided to participants contained large text, simplified language, and pictures.⁵⁰ In addition, Kagan and Kimelman's⁵¹ recommendations for obtaining informed consent from research participants who have aphasia were followed.

Participants

Forty adults with aphasia were recruited from university clinics and seven southeast Queensland hospitals in Australia. Inclusion criteria were the following: (a) aged 18 years or older with a diagnosis of aphasia resulting from a left hemisphere stroke (The Western Aphasia Battery⁵² confirmed the diagnosis of aphasia and participants' aphasia typology and severity); (b) ability to participate in an in-depth interview in English using speech, gesture, writing, pictures, and/or drawings, as determined by the researcher (a speech-language pathologist); (c) residence within 2 hour's driving time of Brisbane, Australia; and (d) no significant cognitive, psychiatric, and/or hearing impairment that prevented participation in an in-depth interview, as determined by medical history, self-report, and researcher observation.

Participants were purposefully selected using maximum variation sampling⁵³ for a variety of variables including time post stroke, aphasia severity, and reading ability. Reading ability was assessed using the Reading Comprehension Battery for Aphasia 2 (RCBA-2).⁵⁴ Variations in

characteristics such as age, gender, and years of education were also sought. Participant characteristics are presented in **Table 1**.

Data collection

This descriptive study used a survey design. Surveys were conducted at hospital inpatient or outpatient rehabilitation units, residential aged care facilities, or the participants' usual place of residence within the community. Participants' family members were welcome to be present. The researcher presented questions in a multimodal format (ie, both spoken and written) to maximize comprehension. The written survey was formatted using aphasia-friendly principles.^{6,55} The 21-item

survey (see **Appendix A**) was administered in a face-to-face manner to allow the researcher to repeat and rephrase questions and to clarify and confirm participant responses. In addition, the survey was developed in accordance with recognized methods for design.⁵⁶ A dichotomous (yes/no) response format was most frequently used. Fixed response formats and a 100 mm visual analogue scale, ranging from *not important* to *very important*, were also used to assist participants with aphasia to respond. Participant responses were audio recorded. The survey was piloted on three people with aphasia. This pilot resulted in the inclusion of fewer open-ended questions and minor changes to the wording of some questions.

Table 1. Participant characteristics

Maximum variation sampling variables	Number of participants (n=40) n (%)
<i>Age</i>	
Range, 32 – 84 years; mean \pm SD = 65.9 \pm 12.0	
<70 years	21 (52.5)
\geq 70 years	19 (47.5)
<i>Gender</i>	
Male	24 (60)
Female	16 (40)
<i>Aphasia severity</i>	
Aphasia Quotient [AQ]: range, 6.58 – 93.1; mean \pm SD = 75 \pm 20.5	
Mild (\geq 80 AQ < 93.8 on WAB)	21 (52.5)
Moderate or severe (<80 AQ on WAB)	19 (47.5)
<i>Reading ability</i>	
RCBA-2 score: range, 13–98; mean \pm SD = 77.8 \pm 19.2	
Mild (\geq 85 on RCBA-2)	18 (45)
Moderate or severe (<85 on RCBA-2)	22 (55)
<i>Months since onset of aphasia</i>	
Range, 2–178; mean \pm SD = 39.0 \pm 42.0	
<18 months	15 (37.5)
\geq 18 months to <36 months	12 (30)
\geq 36 months	13 (32.5)
<i>Education</i>	
Range, 2–20 years; mean \pm SD = 11.7 \pm 4.1	
<12 years	23 (57.5)
\geq 12 years	16 (40)
Unable to be determined	1 (2.5)
<i>Other variables</i>	
<i>Number of strokes</i>	
Single	31 (77.5)
More than one	4 (10)
Unable to be determined	5 (12.5)
<i>Able to speak a language other than English</i>	
Monolingual	33 (82.5)
Bilingual	7 (17.5)

Note: WAB=Western Aphasia Battery; RCBA-2=Reading Comprehension Battery for Aphasia-2.

Some questions were not completed by all participants, primarily due to fatigue at the time of interview. In addition, only participants who were more than 6 months post stroke were asked to respond to survey item 21. The number of participants who responded to each question is reported in **Appendix A**.

During the survey, participants were shown examples of written health information (see questions 14 to 16). Written health information has been defined as “written or printed booklets, leaflets, pamphlets, or information sheets whose purpose is to provide information about health . . .”.^{44(p39)} For the purpose of this study, single-sheet documents with fold-out sections were classified as brochures, bound documents with several pages were classified as booklets, while A4 size documents with less than 8 pages were classified as information sheets. Health information was collected in the settings from which participants were recruited, therefore reflecting current practice. The written stroke and aphasia information shown to participants throughout the interview are reported in **Appendix B**.

Data analysis

Descriptive statistics were used to describe participant responses to questionnaire items. Depending on the variable being investigated, a number of nonparametric statistics (Spearman rank correlation, Mann-Whitney *U*, chi-square, and Kruskal-Wallis tests) were used to test for significance between responses and the following participant characteristics: time post stroke, aphasia severity, reading ability, age, years of education, and gender. Relationships between participant characteristics and responses were tested where possible; however, statistical calculations were not completed if responses had cell counts of less than 5. In addition, the Wilcoxon matched-pairs signed rank test was used to determine whether there were any significant differences in participants' importance ratings for receiving stroke and aphasia information and to compare importance ratings for providing this information to significant others. This test compares median scores. Responses to open-ended items and other spontaneous elaborations

were transcribed verbatim and categorized according to the principles of qualitative content analysis.⁵³

Results

Results are presented in the order of the survey questions listed in **Appendix A**. For each question, descriptive statistics are presented, followed by a summary of the qualitative responses including illustrative quotes when appropriate.

Did participants consider it important to receive written stroke and aphasia information?

On the visual analogue scale, 97% of participants (33 of 34 participants) marked above the 50 mm midway point, indicating that the majority of participants considered it important to receive written stroke information. The median importance rating was 92.75, with responses ranging from 2.5 mm to 100 mm ($M=82.4$, $SD=21.49$) (see **Figure 1**).

Participant 23, who was the only participant to mark below the midway point, acknowledged that written information could be important but felt it was important to provide this information to her spouse rather than herself.

ID23: “ . . . I think for myself it was I couldn't care less [about written stroke information]. But it it was important to dad [husband] . . . Oh I hand it all over to [husband].”

For some participants, it seemed written stroke information was not vitally important because they did not consider it to have a role in recovery.

ID12: “ . . . take these books and I know everything about a stroke. What for? It doesn't cure me . . . ”

Using the visual analogue scale, 97% of participants (33 of 34 participants) again marked above the 50 mm midway point, indicating that the majority of participants also considered it important to receive written aphasia information. The median importance rating was 94.25 mm, with responses ranging from 47 mm to 100 mm ($M=87.71$, $SD=14.25$) (see **Figure 1**).

ID12: “It's very important. I didn't know about it . . . is very important.”

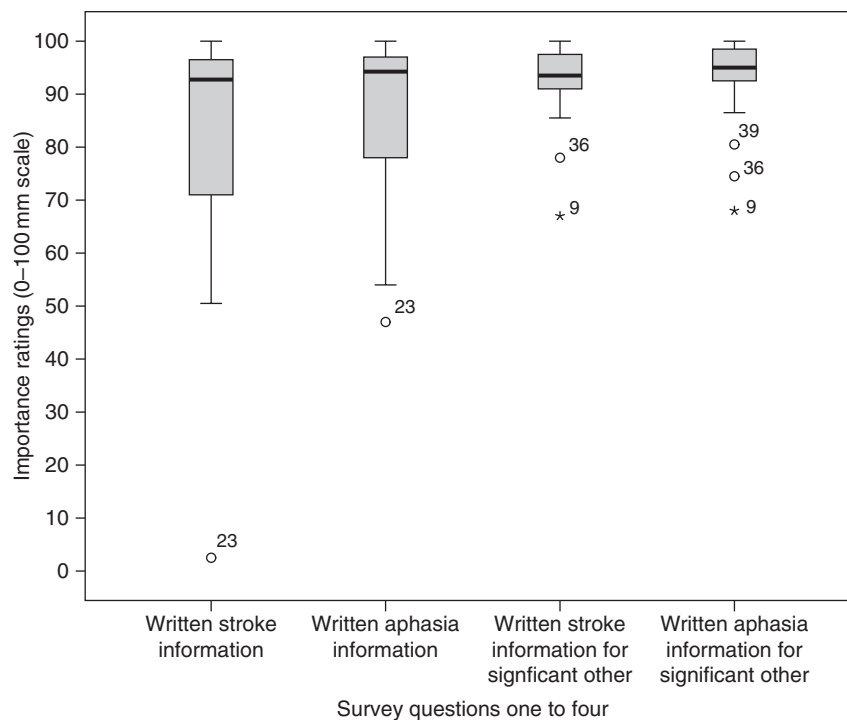


Figure 1. Importance ratings for person with aphasia and significant other to receive written stroke and aphasia information (n=34). The bottom and top of each box represent the 25th and 75th percentile. The band within the box denotes the median (50th percentile). Circles denote outliers more than 1.5 box-lengths from the 25th percentile, while asterisks denote extreme outliers more than 3 box-lengths from the 25th percentile.

For some participants, their importance rating for aphasia information was related to the lack of information they had received.

ID 39: "That's the thing, because I don't know about it [aphasia]. I don't think it's vitally important."

Participant 23, who again was the only participant to mark below the midway point, indicated (at 6 months post stroke) that she had not heard of the word aphasia until being approached to participate in this research.

It was also noted that several participants only considered written stroke and aphasia information to be important if it was provided in an appropriate format.

ID2: "Ah yes yes as long it's ah compiled by some people that know about aphasia, you know."

Despite considering written stroke and aphasia information to be important, a small number of participants also commented negatively about this information.

ID39: "... in hospital ... you're wanting to get out. You don't want ... you find out about that you get a little scared. Oh, is this really the thing for me?"

The Spearman rank correlation and Mann-Whitney *U* tests showed no significant relationships between importance ratings for written stroke or aphasia information and participant characteristics.

The Wilcoxon signed ranks test showed no significant difference between importance ratings for receiving written stroke information (median=92.75) and written aphasia information (median=94.25). There was a trend, however, for participants to rate receipt of written aphasia information as being more important ($z=1.96$, $P=.05$).

ID14: "Well I think it ... is important to you [to receive written aphasia information] because ... you don't know what it's all about at all. And that does give you a reason for why you you are the way you are ... helpful to get the information about the aphasia."

Did participants consider it important for their significant other to receive written stroke and aphasia information?

Using the visual analogue scale, all participants ($n=34$) marked above the 50 mm midway point, indicating that all participants considered it important that their significant other receive written stroke information. The median importance rating was 93.5 mm, with responses ranging from 67 mm to 100 mm ($M=92.82$, $SD=6.73$) (see **Figure 1**).

Participants were then asked how important it is that written aphasia information is provided to their spouse or close family member. All participants ($n=34$) again marked above the 50 mm midway point. The median importance rating was 95 mm, with responses ranging from 68 mm to 100 mm ($M=93.44$, $SD=7.03$) (see **Figure 1**).

Although still above midway, participants 9 and 36 provided the lowest ratings in response to these questions. Participant 9 identified that his family members had independently obtained health information, which may have influenced this participant's importance ratings for providing information to family members.

ID9: "Mum, dad and brother collected from when first had stroke to now."

Participant 36 indicated he had provided lower ratings because he considered it more important that written stroke and aphasia information be provided to the person with aphasia rather than to family members.

ID36: "Yes yes ... yes sir [give it to me – pointed to self]".

Using the Spearman rank correlation and Mann-Whitney U tests, no significant relationships between importance ratings for significant others receiving written stroke or aphasia information and participant characteristics were found.

The Wilcoxon signed ranks test showed no significant difference between importance ratings for significant others receiving written stroke information (median=93.5) and written aphasia information (median=95), indicating that participants considered it equally important for their significant other to receive both written stroke and aphasia information ($z=1.510$, $P=.131$).

Importance ratings for participants receiving written stroke and aphasia information (median = 92.75 and 94.25, respectively) and importance ratings for significant others receiving written stroke and aphasia information (median = 93.5 and 95, respectively) were also compared. The Wilcoxon signed ranks test showed a significant difference in the importance ratings, indicating that although participants considered it important to receive written stroke and aphasia information, the majority considered it more important for their significant others to receive this information ($z=2.912$, $P=.004$, and $z=2.580$, $P=.010$, respectively).

ID14: "I think it's important that they ... [significant other] should get it because they would tell you when you ... are wide you know wide enough awake to understand what was going on I think."

A small number of participants who indicated it was more important that written stroke and aphasia information be provided to their significant other stated they would like to receive this information if it were provided in a simplified format.

ID37: "... without a shadow of a doubt give it to her [spouse] because she's the one that can read it ... only way I can relate to it. ... Well yes if was like that [simplified] ... that's fine. You know that way I can understand as well."

In contrast to the quantitative findings, several participants commented that they considered it equally important for both themselves and their significant other to receive this information.

ID25: "I think that ... both ... because ... otherwise you you tend ... to sit back and let everybody do it for you."

Several other participants commented that it was more important that the person with aphasia receive the written stroke and aphasia information.

ID35: "Give it to me. Yeah give it to me because I try and if I can't I go to [spouse]."

When responding to this question, a small number of participants spontaneously commented that the written information given to people with aphasia and their significant other should be different.

ID1: "The people who had a stroke and the people who care for people who have had a stroke are two totally different things. So they I think you need a a brochure for the people who have had a stroke and a separate one for the people who have had um who care for people who have had a stroke ..."

When did participants consider it helpful to receive written stroke and aphasia information?

Figure 2 shows the majority of participants desired written stroke and aphasia information from 1 month onwards.

ID34: “You can put two ticks for that [6 months] ... three ticks for that one [12 months] ... ah four ticks for that one [after 12 months].”

Only three participants indicated it was not helpful to receive this information when more than 12 months post stroke. The mean time post stroke for these participants was 6 months.

Most participants indicated it would not be helpful to receive written information at admission (91%, n=32) or the day after stroke (86%, n=30) as they would not have been capable of reading or absorbing the information or they wished to deny what had happened.

ID39: “Didn’t want information then [early days]. I wanted to deny it ... I would say about two months. That is when you’ve realized that this takin’ longer than the month to get better ... about six weeks they wake up ah I see it’s going to be for long time ... and that’s when you like to know ... what is ... aphasia ... you accept it.”

For some of these participants it was still important, however, that their significant other receive this information.

ID13: “... give to partner when first admitted, day after stroke, first week but not to person who has had stroke.”

In contrast, others commented it would be helpful to receive this information soon after stroke.

ID14: “... liked to have known by the end of the first week ... I probably would have taken it and held on to it I think. You know um until I was ready to follow it properly ... If I’d have had something there I might have read it you know ... I think it is important to to get it ... That’s what I’m trying to say.”

A chi-square test found a significant relationship between gender and yes responses to receiving information the day after stroke ($\chi^2 (1)=1.600$; $P \leq .001$). Four of the five participants who indicated it would be helpful to receive information at this time were female. No other significant relationships between participant characteristics and preferred times to receive written stroke and aphasia information were found.

Participants were also asked to indicate when they considered it most helpful to receive this

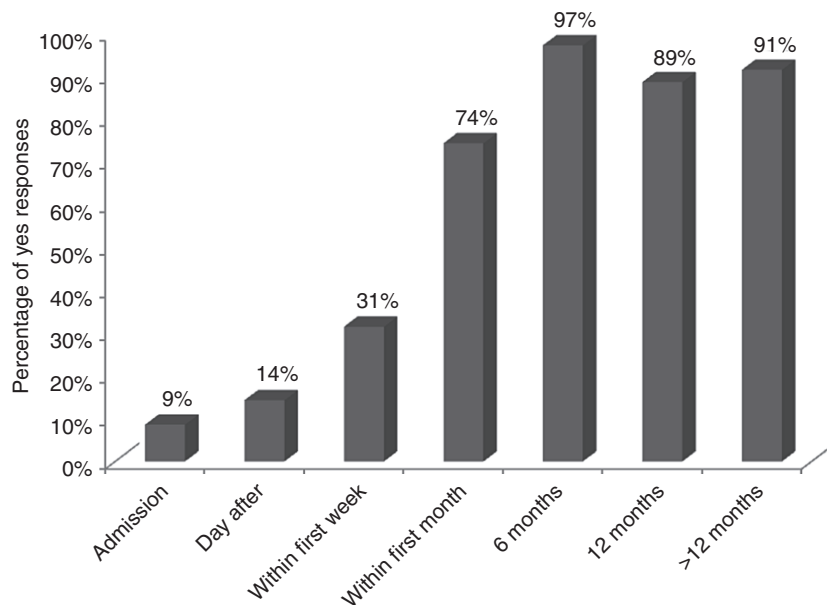


Figure 2. Times post stroke when participants considered it helpful to receive written stroke and aphasia information (n=35).

information (see question 12, **Appendix A**). The largest proportion of participants (32%, $n=12$) indicated that it would be most helpful to receive written stroke and aphasia information at approximately 6 months post onset.

ID23: "It would be now [ie, 7 months post onset] ... it wouldn't be until now that ... I'd try I'd took ... information about it. Before ... I wasn't interested in what came ... in ah information. But it would be now. And I would."

Eleven participants (30%) reported this information would be most helpful if provided at approximately 1 month post onset. Six participants (16%) reported the first week to be the most helpful time. Three participants (8%) indicated it would be most helpful to receive this information the day after stroke, while three participants (8%) considered this information most helpful if provided more than 1 year post stroke. Two participants (6%) considered 1 year post stroke the most helpful time to receive written stroke and aphasia information.

The Spearman rank correlation and Mann-Whitney U tests showed no significant relationships between participant characteristics and most preferred time to receive this information.

In what media should information about stroke and aphasia be provided to people with aphasia?

When questioned about media other than written (see question 13, **Appendix A**), several participants expressed their desire for health professionals to provide verbal information about stroke and aphasia.

ID14: "... doctor or whoever is in charge of your health ... just to talk to you ... they're the most important things."

A small number of participants also commented that it would be helpful to receive information from others in the same situation.

ID5: "Talking to other people who have some [same] problems as you."

Other self-generated responses included sending a letter home from the hospital, providing a stroke and aphasia video, and broadcasting health information about stroke and aphasia on the television and radio. A small number of participants also verbalized their preference for

stroke and aphasia information to be provided in more than one media.

ID1: "Tell me about it and give me a brochure."

ID3: "... talking and video."

Participants were then prompted to consider specific media for the provision of stroke and aphasia information (see questions 14 to 19 in **Appendix A**). Ninety-five percent of participants ($n=37$) thought such information should be provided in brochures, 90% ($n=35$) indicated booklets and information sheets, and 82% ($n=32$) thought this information should be provided in videos/DVDs. Approximately two-thirds (62%) of participants ($n=24$) thought information should be provided on audio tapes/CDs, while just less than half (49%) of the participants ($n=19$) thought this information should be given via computer programs/Internet.

A small number of participants spontaneously indicated that they did not know how to use the Internet; others indicated that although they would not access health information from the Internet, they recognized the value of this information for others.

ID30: "Well that's hard for people ... my husband or something like that can use it."

Relationships between participant characteristics and responses to questions 14 to 16 could not be assessed statistically because of the small number of participants who indicated that stroke and aphasia information should not be provided in brochures ($n=2$), booklets ($n=4$), and information sheets ($n=4$). It was, however, noted that most participants who indicated stroke and aphasia information should not be provided in these media had moderate to severe reading comprehension difficulties. The mean RCBA-2⁵⁴ score for participants who said no to brochures was 40.5. The mean RCBA-2 score for participants who said no to information sheets was 68, while the mean RCBA-2 score for participants who said no to booklets was 72.25.

Using the Mann-Whitney U test, a significant relationship between age and responses for receiving information via videos/DVDs was found [$z(39)=-2.803, P=.005$]. The mean age of participants who said no to this media was

75.7 years compared to the mean age of 63.5 years for participants who said yes. There was also a trend for older participants to indicate that information about stroke and aphasia should not be provided in computer programs/on the Internet [$z(39) = -1.927, P = .054$].

Participants ($n=38$) were then asked to indicate which media they most preferred for stroke and aphasia information at their present stage post stroke (see **Table 2**). The largest proportion of responses was for written media (ie, brochures, booklets, and information sheets) (45%, $n=17$). Several participants spontaneously commented that written information could be retained and accessed when desired.

ID10: "Read it and see it later. A couple of day to get through."

Sixteen participants (42%) identified videos/DVDs as their most preferred media. A small number of participants also commented that it would be important for the video/DVD to be appropriately tailored to meet the communication needs of people with aphasia.

ID2: "Well there again it depends on ah ah the format. Yes. A very good film would be an advantage."

ID9: "If subtitles ... nothing without subtitles, harder."

Only three participants (8%) selected audio tapes/CDs as their preferred media. One participant stated:

ID40: "I don't know whether ... confirmation ... concentration would allow you to listen to a tape for any length of time."

Participants were then asked to think retrospectively and indicate the media they would have most preferred for receiving stroke and aphasia information during their initial 6 months post stroke (see **Table 2**). Although more than one-third of participants (39%, $n=13$) still preferred the written media, more than half of the participants (55%, $n=18$) selected videos/DVDs as their preferred media for receiving this information during the first 6 months post stroke. A small number of participants commented that watching a video about stroke and aphasia while in hospital would provide something to help pass the time.

ID14: "... well if I was in the hospital I wouldn't mind ... would have been something to do."

Table 2 also highlights that brochures were the most preferred written media both at participants' current stage post stroke and within the initial 6 months post stroke. Several participants commented that a brochure format was most preferred because of the smaller size.

ID32: "Go the brochures ... well if the mind's confused it's easier to read something brief."

Participants also commented that it was helpful to initially source information from brochures before looking at other written documents.

ID14: "I'd choose the brochure to start of [off] with."

The Kruskal-Wallis and chi-square tests showed no significant relationships between participant characteristics and preferred media for either the current time or the initial 6 months post stroke.

Table 2. Comparison of preferred media for stroke and aphasia information at present time post stroke and during the initial 6 months post stroke

Media	Preferred media at present time post stroke (n=38) n (%)	Preferred media during initial 6 months post stroke (n=33) n (%)
Written media (all types)	17 (45)	13 (39)
brochures	9 (24)	9 (27)
booklets	5 (13)	2 (6)
information sheets	3 (8)	2 (6)
Videos/DVDs	16 (42)	18 (55)
Tapes/CDs	3 (8)	1 (3)
Computer/Internet	2 (5)	1 (3)

Discussion

Do people with aphasia consider it important to receive written information about stroke and aphasia?

Results from the current study are in accordance with previous findings that stroke patients value receiving written health information.^{20,33,45} In addition, the results expand upon findings within the field of stroke education by specifically highlighting the importance of providing written health information to stroke patients who have aphasia. This is the first known study to specifically investigate whether people with aphasia, post stroke, consider the written media to be important for imparting stroke and aphasia information. The researchers considered this to be a fundamental question to answer before pursuing further research in the area of aphasia-friendly written health information.

Despite the reading difficulties associated with aphasia,¹³ almost all participants considered written information about stroke and aphasia to be important. There were no significant relationships between importance ratings and participants' reading ability or aphasia severity. Even participants with more severe reading comprehension and communication difficulties considered the provision of written stroke and aphasia information to be important.

Although the current findings provide evidence to support the provision of written information to people with aphasia (irrespective of aphasia severity, reading ability, gender, time post stroke, and education level), it is also important to acknowledge that a small number of participants did not consider it especially important to receive this information. These findings support those of Knight et al,¹⁶ who also found that not all stroke patients wanted to receive information. People with aphasia¹⁴ and stroke patients in general have previously been found to have mixed reactions to health information.⁴⁷

For some participants, importance ratings for written stroke and aphasia information were influenced by the view that information could not facilitate recovery. For other participants, importance ratings appeared to be related to denial and feelings of fear. Parr and colleagues¹⁴

also identified that for some people with aphasia, medical information "can confirm their worst fears about their condition, conveying knowledge which they would rather not have." (p90) Health professionals are encouraged to be cognizant and sensitive to these research findings when providing health information and to consider the nature in which information is provided. In the study by Hanger and colleagues³¹ that included participants with aphasia, many of the complaints made in the early stages of recovery related to the disheartening manner in which health information was provided. The importance of maintaining hope has been found to be vitally important when providing information to people with aphasia.⁵⁷ In addition, hope has been positively linked with stroke survival⁵⁸ and is reported to be an important predictor of quality of life in stroke patients generally.⁵⁹ It was also noted that participants did not specifically refer to the written media when expressing the above views about health information. The views expressed may have related to the perceived importance of stroke and aphasia information generally, irrespective of the information media.

For other participants, importance ratings for written aphasia information appeared to be related to their lack of knowledge about aphasia. Several participants in the current study demonstrated poor or no understanding of aphasia.⁷ Limited insight into one's health condition has previously been reported to reduce the need for information.³⁵ Findings from the current study also support that of Knight and colleagues¹⁶ who identified that people with aphasia post stroke who had a poor understanding of aphasia were unsure of what health information they needed. In other words, participants did not know what they did not know. In order for people with aphasia to consider written aphasia information to be important, some initial awareness of aphasia may be required. Health professionals should therefore consider that a reduced desire to receive written aphasia information may potentially reflect poor knowledge of the topic.

It was also noted that participants tended to place more importance on receiving written aphasia information than receiving written stroke information. It seems that people with aphasia

are particularly disadvantaged when it comes to receiving information about aphasia. They may miss out on receiving not only general stroke information but also aphasia-specific written information.⁷ For those who lose the fundamental life skill of effective communication, information on the topic of aphasia may be imperative. The desires of people with aphasia, however, to receive this information are not well documented in the general stroke education literature, as much of the research on providing health information to stroke patients has excluded people with aphasia.^{35,45-49}

Several participants also spontaneously commented that written stroke and aphasia information was only important if it was provided in an appropriate format. The need to develop appropriately formatted written health information for people with aphasia has previously been identified in the literature.^{5-8,14} Aleligay, Worrall, and Rose⁶⁰ for example, analyzed the readability levels of written aphasia information and found this information was not appropriate to the reading abilities of people with aphasia. Participants in the current study echoed the consumer perspectives documented by Parr and colleagues¹⁴ and Rose and colleagues⁷ regarding the importance of providing written stroke and aphasia information in appropriate formats. Further consultation with people with aphasia is needed to determine how best to develop appropriate written stroke and aphasia information.

Did participants consider it important for their significant other to receive written stroke and aphasia information?

The present study has provided preliminary insight into the people from whom participants with aphasia consider it important to receive written stroke and aphasia information. Participants indicated that they felt it more important that their significant others receive written stroke and aphasia information rather than themselves. The need to provide health information to family members and carers has been previously documented.^{20,40,45,47,61} Family members of people with aphasia have rated information about aphasia as their most important informational need post stroke, followed by psychosocial support and hopefulness.⁶² It is

important that health professionals routinely provide written stroke and aphasia information to significant others.

It was interesting to note that participants with more severe aphasia and/or reading difficulties did not rate it significantly more important for their significant others to receive this written information compared to participants who had milder aphasia and/or reading difficulties. Researchers have previously identified that stroke severity³⁰ and patients' communication skills^{30,63} influenced health professionals' decisions to provide written information to stroke patients. The current findings, however, indicate that health professionals should not make assumptions regarding who best to receive written stroke and aphasia information based on aphasia severity and/or reading ability.

There are many factors that may have influenced participants' importance ratings, including participants' experiences receiving poorly formatted written health information. Within the larger scale project, several of the participants commented that the written health information they had received had been too complex for their needs.⁷ People with aphasia may consider it equally important for them and their significant other to receive written stroke and aphasia information if it is provided in an appropriate format.

Relationship status may also be relevant. For example, in the current study, participant 36 who indicated it was more important for written stroke and aphasia information to be provided to the person with aphasia was single and living alone. It is also important to be mindful that the current study focused on written media. People with aphasia may consider it equally important for them and their significant other to receive stroke and aphasia information if it is provided in another format or as a combination of media.

Although the quantitative findings indicate that participants considered it more important that significant others receive written stroke and aphasia information than themselves, not all participants considered it more important. Some participants thought it equally important to receive this information, while a smaller number of participants thought it more important for people with aphasia to receive this written information. The individual wishes and needs of patients must

be considered when providing information.^{14,33,47} The importance of tailoring written health information to meet the needs of stroke patients and their carers has previously been reported in the literature.¹¹

When did participants consider it helpful to receive written stroke and aphasia information?

Participants considered it helpful to be repeatedly provided with written stroke and aphasia information, particularly from 1 month onwards. The need for stroke information to be repeated on a number of occasions has previously been identified within the stroke education literature.^{34,35} Current findings also indicate that the written information needs of people with aphasia are ongoing, with the majority of participants reporting that it would be helpful to receive written stroke and aphasia when more than 1 year post onset. The extent to which stroke patients receive information at greater than 1 year post stroke has not been widely studied, however, in a survey of stroke health professionals by Hoffmann and colleagues,³⁰ only 10% of health professionals were of the belief that written stroke education materials should be provided frequently or routinely at or beyond 6 months post discharge.

It was interesting to note that the three participants who thought that it would not be helpful to receive written stroke and aphasia information when more than 1 year post stroke had had their stroke more recently. Perhaps these participants considered that their health information needs would be met by this time. However, the literature indicates that many stroke patients continue to have information needs even several years post stroke.³²

Based on participants' preferred time to receive written stroke and aphasia information, it seems that 6 months post onset may be a particularly key time for health professionals to provide this information. Comments made by some participants reflected the view that written health information was not considered helpful in the initial stages of recovery as participants thought that their aphasia would go away. Marshall⁶⁴ reports that during the first 6 months after a stroke, people with aphasia have relatively high expectations that life will

return to "normal." It is possible that 6 months was identified as the most helpful time to receive written stroke and aphasia information because it is at this time that the chronicity of aphasia becomes more of a reality.

Given that several participants indicated it was most helpful to receive information at 6 months post stroke or later, there are concerns that people with aphasia may be out of the "health information loop" at the time considered most helpful to receive written information. McKenna and colleagues⁶⁵ identified that the mean length of hospital stay for stroke patients in their Australian study was 97 days (25.7 days mean length of acute hospitalization; 71.3 days mean length of rehabilitation). This mean length of stay was substantially longer than what has been reported in other overseas studies.^{66,67} Although some stroke patients may still be receiving outpatient services at 6 months post stroke, it is likely that some will no longer be in direct contact with rehabilitation health professionals at this time. Stroke patients have previously reported feeling abandoned after hospital discharge, not knowing who to approach for information and support.¹⁹ It has also been argued that health education typically ceases when patients leave hospital, even though the need for information may continue.^{27,30} In addition, the nature of aphasia is likely to impact on health information seeking. As Parr and colleagues¹⁴ identified, to locate information it may be necessary for persons to write down a phone number or an address, make a telephone call, complete a form, write a letter, or request an explanation, all of which require language. To remove the informational barriers faced by people with aphasia,¹⁴ relevant information must be provided in a timely manner. Results from the current study highlight the importance of ensuring written stroke and aphasia information is accessible to people with aphasia at 6 months post stroke and beyond.

Only 14% of participants in the current study reported that they considered it helpful to receive written stroke and aphasia information within the first 24 hours post stroke. In contrast, a study by Wachters-Kaufmann,³⁵ that did not include participants with aphasia, found that the majority of stroke patients (61%) would like to

receive information at this time. Although the aforementioned study did not investigate the desires of stroke patients to specifically receive written information, the contrasting finding may reflect possible differences in information needs between stroke patients with aphasia compared to those without. Several participants in the current study indicated that it would not be helpful to receive written health information soon after stroke because of reading difficulties. Written information may not be the most helpful media for imparting health information to people who have aphasia during the first 24 hours post stroke.

It was interesting to note that four of the five participants who thought it helpful to receive written information within the first 24 hours post stroke were female. Females have previously been reported to attach greater importance to health information²¹ and to desire more information than males.^{68,69} Although the current study found no significant relationships between overall importance ratings for written information and gender, further exploration of the relationship between gender and the desire of people with aphasia to receive written health information at various times post stroke, particularly within the early stages, is warranted.

Although the majority did not consider it helpful to receive written stroke and aphasia information within the first 24 hours post onset, approximately one-third of participants considered it helpful to receive this information within the first week post stroke. This finding reflects a need to provide written health information within the acute stages of recovery. Participants also commented that even if they could not read the written health information at this time, it would still be helpful to receive it so that it could be referred to later. Several Australian hospitals, however, continue to lack a written policy on patient education and have no designated staff member responsible for coordinating patient education in acute care.⁷⁰

In what media should information about stroke and aphasia be provided to people with aphasia?

Approximately half of the participants suggested a media, other than written, for receiving stroke and aphasia information.

Although the nature of aphasia inhibited several participant responses, more than half of the stroke patients in the study by Grevenson and James¹⁹ were also unable to suggest ways of improving services post stroke. Several of the participants who provided a response emphasized the importance of health professionals “talking” to them about their health. “Talk” has been described as the “main ingredient in medical care.”^{71(p3)} In the study by Wachters-Kaufmann and colleagues,³⁵ approximately three-quarters of stroke patients indicated that they preferred to receive health information verbally, as opposed to written or a combination of both written and verbal information. Stroke patients both with and without aphasia, however, have expressed their dissatisfaction with the amount of contact they had with doctors and health professionals.¹⁶ Knight et al¹⁶ observed that health professionals spent little time communicating health information to stroke patients, particularly to those with aphasia. Kagan and LeBlanc⁷² have argued that health care professionals need to be convinced that people with aphasia may be far more competent than they appear. People with aphasia have also identified that verbal information provided by doctors and nurses was too complex for their needs.⁷³ Health professionals need to be provided with resources and tools to enable more effective communication with people who have aphasia.⁷² The current study has highlighted the desire of people with aphasia to receive both verbal and written stroke and aphasia information.

In addition to talking with health professionals, a small number of participants reported it would be helpful to receive stroke and aphasia information from other people with aphasia. Stroke patients have previously reported the value of being in contact with other stroke patients.⁷⁴ This contact, for example, has been found to facilitate problem sharing and the provision of mutual encouragement and to increase awareness of the number and range of difficulties that can result from stroke. Patients with aphasia have also reported feeling that they could “talk” with and be understood by other stroke patients.⁷⁴ People with aphasia may be able to teach others with aphasia in

ways that health professionals cannot.⁷⁵ Despite the implementation of programs for Patients Educating Patients (PEP) in other areas of health care, such as in the renal care field,⁷⁶ no known research has explored this in aphasia.

In addition, a small number of participants suggested that stroke and aphasia information should be provided through television programs. Despite television being the most frequently cited source of health information by the general public,⁷⁷ Pribble and colleagues⁷⁸ found that few health stories about stroke were reported on local television news programs. No known studies, to date, have documented the use of television as a media for conveying health information about aphasia. Considering the comments from participants in the current study and also the positive findings from recent research into aphasia-friendly television viewing,⁷⁹ television programs may well be a helpful and underutilized media for the provision of stroke and aphasia information.

Despite the reading difficulties that can result from aphasia, many participants most preferred to receive stroke and aphasia information in the written media. Participants indicated that brochures were a helpful initial media because they typically required less reading than other written media. Participants also indicated the written media was particularly helpful because information could be retained and re-read at the reader's pace. These latter findings reinforce the benefits of written health information previously documented in the literature.^{42,43}

The majority of participants considered videos/DVDs to be another helpful media for conveying stroke and aphasia information. The benefits of using videos as a media for patient education have previously been documented in the literature.⁸⁰ This media, for example, has been reported to be an economical and entertaining mode of education.⁸¹ Videos offer message consistency, can be viewed in groups or individually, and can be repeated at the viewer's discretion.⁸¹ Audiovisual information has also been found to be effective in increasing patient short-term knowledge⁸¹ and understanding.⁸² Although the efficacy of video use in other areas of health education has been explored,^{80,81} limited assessment of the effectiveness of this media

in the education of stroke patients has been undertaken.³⁴

Weinhardt and Parker⁸³ reported on the development of an educational stroke video that was made available to stroke patients via the hospital's closed-circuit patient television channel. This study reported positive differences in patient's knowledge scores pre and post video viewing. The video developed was specifically designed to use multimodal sensory inputs, containing illustrations and spoken and written narration. Participants in the current study have also emphasized the importance of ensuring videos/DVDs for people with aphasia are appropriately formatted, for example, that they contain written narration (ie, subtitles).

In the current study, videos/DVDs were considered to be a particularly helpful media in the initial 6 months post stroke. Although few participants provided a rationale for this preference, a small number of participants felt that viewing a video/DVD would provide a way of passing the time while in hospital. The setting in which health education videos are viewed, however, has been reported to affect information awareness and recall. Kleemier and Hazzard,⁸⁴ for example, found that videos incidentally viewed in hospital waiting rooms were less conducive to learning compared to videos viewed in a structured learning environment. Given that the current research has identified the desire of people with aphasia to receive stroke and aphasia information in an audiovisual format, research into the effectiveness of this media for people with aphasia and the optimal setting in which to view health education videos is required.

Not all participants, however, considered videos/DVDs helpful for receiving stroke and aphasia information. Six of the seven participants who indicated information should not be provided in this media were over 70 years of age. Similarly, more participants over 70 years of age reported that information about stroke and aphasia should not be provided via computer programs or Internet. This finding is in accordance with Wagner and Wagner⁸⁵ who found that older adults were less likely than other age groups to use computers to access health information.

These researchers hypothesized that rather than being resistant to trying new technologies, older adults may be less likely to self-seek health information as they rely more on health professionals to provide information. It is also important to consider that it was not ascertained whether participants in the current study owned a computer, had Internet access, or were experienced at using computers or the Internet. It was interesting to note that neither severity of aphasia nor reading difficulties were significantly related to whether participants considered computer programs/Internet a helpful media for receiving health information, indicating that this media may have a useful role in providing health education to people with aphasia, particularly those in younger age groups.

Participants in the current study also highlighted the need to provide stroke and aphasia information in more than one media. These findings support professional opinion documented in the literature that it is preferable to provide health information in differing media over time.^{32,39,49,86-88}

Limitations and Further Research

There are many options for stroke education.³⁷ Stroke patients, for example, have previously identified that it would be helpful to receive follow-up visits or follow-up telephone calls from health professionals.¹⁹ People with aphasia have also reported receiving relevant, useful, and easy-to-understand information by attending education programs run by multidisciplinary health care staff.⁷³ It is acknowledged that this preliminary research did not seek the opinions of people with aphasia regarding all available media for health education. The breadth of the participant sample would have been improved by including participants from ethnic minorities and by recruiting participants from rural health facilities.

A small number of participants who were single indicated it was more important that people with aphasia, rather than significant others, receive written stroke and aphasia information.

The impact of relationship status on importance ratings for receiving such information requires further research. Exploration of information needs, particularly with respect to content, across the continuum of care is also required. The preferences of significant others for when and how to receive stroke and aphasia information must also be determined.

Conclusions

People with aphasia have identified that they wish to receive stroke and aphasia information in the written media. They expressed the importance of receiving written aphasia information in addition to written stroke information. People with aphasia also considered it important that their significant others are provided with both written stroke and aphasia information. Written information was considered helpful across the continuum of care, particularly from 1 month onwards. Many participants considered 6 months post stroke to be the most helpful time to receive written stroke and aphasia information. In addition to receiving written information, appropriately formatted videos/DVDs were considered a helpful media by many participants, particularly during the initial stages post stroke. Limited research to date has explored the preferences of people with aphasia for receiving health information. This preliminary research has implications for a patient-centered information pathway for people with aphasia.

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APPENDIX A

Interview Questionnaire

Question number	Question	Response format	Number of participants who responded (n=40)
Did participants consider it important to receive written stroke and aphasia information?			
1	How important is it that you are given written health information about stroke?	visual analogue scale	n=34
2	How important is it that you are given written health information about aphasia?	visual analogue scale	n=34

APPENDIX A. *Continued*

Question number	Question	Response format	Number of participants who responded (n=40)
Did participants consider it important for their significant other to receive written stroke and aphasia information?			
3	How important is it that your spouse or close family member be given written health information about stroke?	visual analogue scale	n=34
4	How important is it that your spouse or close family member be given written health information about aphasia?	visual analogue scale	n=34
When did participants consider it helpful to receive written stroke and aphasia information?			
5	Is it helpful to be given written stroke and aphasia information when first admitted to hospital?	yes / no	n=35
6	Is it helpful to be given written stroke and aphasia information the day after a stroke?	yes / no	n=35
7	Is it helpful to be given written stroke and aphasia information within the first week after a stroke?	yes / no	n=35
8	Is it helpful to be given written stroke and aphasia information within the first month after a stroke?	yes / no	n=35
9	Is it helpful to be given written stroke and aphasia information at about six months after a stroke?	yes / no	n=35
10	Is it helpful to be given written stroke and aphasia information at about twelve months (one year) after a stroke?	yes / no	n=35
11	Is it helpful to be given written stroke and aphasia information more than twelve months (one year) after a stroke?	yes / no	n=35
12	When is it most helpful (from above options) to be given written stroke and aphasia information?	fixed response	n=37
How did participants want to receive stroke and aphasia information?			
13	Other than brochures, how would you like to be given health information?	open ended	n=19
14	Should information about stroke and aphasia be given in brochures? (example of brochure provided)	yes / no	n=39
15	Should information about stroke and aphasia be given in booklets? (example of booklet provided)	yes / no	n=39
16	Should information about stroke and aphasia be given in information sheets? (example of information sheet provided)	yes / no	n=39
17	Should information about stroke and aphasia be given in videos / DVDs?	yes / no	n=39
18	Should information about stroke and aphasia be given in computer programs/ on the Internet?	yes / no	n=39
19	Should information about stroke and aphasia be given in (audio) tapes/CDs?	yes / no	n=39
20	What is your first choice (from above options) for how to be given stroke and aphasia information?	fixed response	n=38
21	What is your first choice (from above options) for how to be given stroke and aphasia information soon after your stroke (i.e., within the first six months)?	fixed response	n=33

APPENDIX B

Examples of Written Stroke and Aphasia Health Information Shown to Participants

Topic	Title of written health information	Format
Stroke	Speech pathology and stroke: general information ⁸⁹	Brochure
Stroke	Stroke attacks the brain: answers to the top ten questions about stroke ⁹⁰	Brochure
Stroke	The brain at risk: understanding and preventing stroke ⁹¹	Booklet
Stroke	What is a stroke? An information paper for persons affected by stroke and their carers ⁹²	A4 information sheet
Aphasia	Speech pathology and dysphasia: difficulty with comprehension and expression ⁹³	Brochure
Aphasia	Speech and communication problems following a stroke ⁹⁴	A4 information sheet
Aphasia	What is aphasia? An interactive booklet for aphasic adults, their families and caregivers ⁹⁵	Booklet