Do people with aphasia want written information? A verbal survey exploring preferences for when and how to provide stroke and aphasia information

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Do people with aphasia receive written stroke and aphasia information?

Running title: Written stroke and aphasia information

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Abstract

Background: Despite the well documented benefits of providing people with written health information, there is a growing body of evidence indicating people who have aphasia are poorly informed about both their stroke and aphasia. Although extensive research has been conducted into stroke education, limited research has specifically investigated the provision of written health information to people with aphasia.

Aims: This study aimed to investigate if people with aphasia recalled receiving written information about stroke and aphasia. Subsequent aims were to determine if reported receipt of stroke and aphasia information was related to participant characteristics such as aphasia severity, reading ability and time post-stroke. This study also aimed to gain insight into where people with aphasia sourced written stroke and aphasia information and which health professionals provided this information.

Methods & Procedures: This article reports on a ten-item verbal questionnaire that was conducted as part of larger project with 40 adults with aphasia following stroke. Participants with a range of aphasia severities, reading abilities and time post-onsets were recruited from university clinics and seven hospitals in Queensland, Australia. Descriptive statistics have been used to describe participant responses to questionnaire items. The relationship between participant responses and participant characteristics were explored using the Mann Whitney U and Person’s Chi Square tests for non parametric data. Participant’s comments have also been categorised.

Outcomes & Results: Only 14 participants (36%) indicated that they received written information about both stroke and aphasia. Findings indicated that receipt of stroke information did not equate to receipt of aphasia information with fewer participants reporting they received written aphasia information (49%) compared to written stroke information (67%). There was no significant relationship between reported receipt of information and
time post-stroke, aphasia severity, reading ability, age, years of education, or gender. Participant comments either reflected the ineffective provision of written information, with many participants commenting about the inappropriate complexity of written health information received, or reflected participants’ poor understanding or no understanding of aphasia. The rehabilitation group setting was the main location for written stroke and aphasia information provision, with speech pathologists most frequently being identified as the health professional to provide this information.

Conclusions: The majority of participants reported receiving no written information about aphasia. Routine provision of appropriately formatted health information and improved access to the health professionals and services which provide information are two strategies for more successful stroke and aphasia education.
Introduction

The benefits of providing health information to stroke patients and their families have been repeatedly documented. Stroke education may increase knowledge (Lomer & McLellan, 1987; 1990; Rodgers et al., 1999), compliance (Philipp et al., 1990), and family functioning (Evans, Matlock, Bishop, Stranahan, & Pederson, 1988). Stroke information may also reduce anxiety (Downes et al., 1993; Hanger & Wilkinson, 2001) and increase satisfaction with stroke services (Rodgers et al., 1999).

According to O’Mahony, Rodgers, Dobson and James (1997), “Provision of good information and advice to stroke patients is an integral part of any high quality service” (p. 68). Stroke survivors and their carers, however, often feel that they have not been provided with enough information about stroke (Forster et al., 2001). There is strong evidence that stroke patients and their families do not receive adequate health information (Hanger & Mulley, 1993; O’Mahony et al., 1997; Pound, Gompertz, & Ebrahim, 1994; Wellwood, Dennis, & Warlow, 1995; Wiles, Pain, Buckland, & McLellan, 1998). In a study by Lomer and McLellan (1987), “93% of patients and 70% of relatives claimed that they received no information about the causes, nature, treatment or prognosis of stroke” (p. 36). Wellwood and colleagues (1995) revealed that 18% of patients and 28.5% of carers reported receiving either too little, far too little or no information. This finding was supported by Rodgers, Bond and Curless (2001) who identified 40% of stroke patients and carers were dissatisfied with the information that they had received during their inpatient stay. More recently, Eames, McKenna, Worrall and Read (2003) reported that 75% of stroke survivors in their study felt that their information needs were not met in hospital.

Many stroke patients and their families consequently lack a clear understanding of stroke (Lomer & McLellan, 1987). In the study by Hanger and Mulley (1993), one quarter of inquiries from stroke patients were requests for simple information such as, “What is a
stroke?" Wellwood, Dennis and Warlow (1994) found that nearly one quarter of stroke patients (22%) and 15% of carers were unable to differentiate between a stroke and a heart attack. When asked if there were any reasons why these people could not find health information, participants stated that staff were too busy to approach, they did not like to ask, and the medical jargon used was not understood. Some patients were also unable to ask because of the difficulties caused by their stroke (Wellwood et al., 1994). Alarmingly, stroke patients have been identified as having many unanswered questions even years after their stroke (Hanger, Walker, Paterson, McBride, & Sainsbury, 1998).

As a result of inadequate information, both stroke patients and their families are left to surmise their own conclusions about recovery (Wiles et al., 1998). Many stroke survivors and their families hold unrealistic views about recovery timeframes, which results in distress when the patient’s disability continues (Wiles et al., 1998). This is especially concerning for people who have aphasia. Various studies have investigated the prevalence of aphasia resulting from stroke, with prevalence statistics ranging from approximately one quarter (Brust, Shafer, Richter, & Bruun, 1976; Lalor & Cranfield, 2004; Lomer & Møller, 1987; Wade, Hewer, David, & Enderby, 1986), to approximately one third (Marquardsen, 1969; Pedersen, Jorgensen, Nakayama, Raaschou, & Olsen, 1995) of patients admitted to hospital with acute stroke. Various studies estimate between 10 to 18% of stroke survivors will have a significant aphasia long-term (Barnes & Ward, 2000; Matsumoto, Whisnant, Kurland, & Okazaki, 1973; Wade et al., 1986).

Despite these prevalence rates, aphasia seems to have remained a relatively unknown disorder to both those affected by it and the general public (Elman, Ogar, & Elman, 2000; Flynn, Cumberland, & Marshall, in press; Simmons-Mackie, Code, Armstrong, Stiegler, & Elman, 2002). Elman and colleagues (2000) argue that many people with aphasia feel isolated, mistakenly believing they have a rare disorder, unaware that there are other people
with aphasia facing the same issues. A delay in providing an aphasia diagnosis can also lead to a delay in aphasia management and general life planning (McNeil & Duffy, 2001). Individuals unaware of their diagnosis may also be unaware of aphasia-specific community and treatment services available to them and their families (Elman et al., 2000). As O’Mahony and colleagues (1997) assert, a patient’s present and future health is influenced by their knowledge and understanding of their health condition.

There is a growing body of evidence to suggest that people who have aphasia are inadequately informed about both stroke and aphasia. In 2005, the National Aphasia Association in the United States, published an Aphasia Bill of Rights which states: “…as a result of their difficulty communicating, people with aphasia may experience great isolation and frustration in their daily lives, which is often made worse by the lack of information that they receive about their condition, and many people are never even told that their difficulty communicating has a name – “aphasia.”

The most compelling evidence to support the Bill of Rights (National Aphasia Association, 2005) stems from the phenomenological study conducted by Parr, Byng, Gilpin and Ireland (1997) in which 50 people with aphasia were interviewed about their experience of aphasia. One of the major themes that emerged from the study was, as one participant stated, “Everything seems a secret” (p. 87). Many people in the study still had information needs many years after their stroke, but a primary concern was “I still don’t understand what wrong with me” (p. 87) and “All I know is that I don’t know what aphasia is” (p. 107). As Parr and colleagues state, “those who have aphasia require information, but the nature of their impairment can mean that their access to it is blocked. The process of locating, selecting and understanding information depends on the very skills which have been weakened” (p. 87).

More recently Eames and colleagues (2003) found that despite similar information needs, people with aphasia post-stroke continue to be less likely to receive information from
health professionals than stroke patients without aphasia. In this study, all stroke patients without aphasia (100%) recalled receiving health information, however only 60% of people with aphasia recalled obtaining information.

Inadequacies in health information provision to people with aphasia were again identified in the ethnographic study by Knight, Worrall and Rose (2006). Using event sampling, seven patients with stroke were observed during their stay in hospital. The time health professionals spent providing information was recorded. Health professionals spent significantly less time communicating information to people with aphasia, than to non-aphasic stroke patients. At the discharge interview, people with aphasia did not recognise the term “aphasia” and demonstrated less knowledge about stroke than stroke patients who did not have aphasia. This small scale study provides further evidence that people with aphasia are not routinely learning about their diagnosis in the acute stroke unit.

Health professionals can use a variety of formats for imparting health information to patients and families. Formats available include: audio and video recordings; follow-up telephone calls; counseling; individual, group and family education sessions; and electronic communication such as computer education software, email and web-based material. Written information in addition to verbal information, however, is reported to be the most common approach for delivering health information at hospital discharge (Johnson, Sandford, & Tyndall, 2003). The literature also repeatedly shows that stroke patients value written information to support the verbal information that is provided (Hanger et al., 1998; Lomer & McLeod, 1987; Mant, Carter, Wade, & Winner, 1998; Pain & McLellan, 1990; Wachters-Kaufmann, Schuling, The, & Meyboom-de Jong, 2005; Wiles et al., 1998).

Several advantages of providing written information in conjunction with verbal information have been identified. Written information can be used to clarify verbal information and may be less easily misinterpreted than verbal information alone (Wiles et al.,
It is reported to be an effective format for enhancing information recall (Patterson & Teale, 1997; Wiles et al., 1998). Written health information allows the reader to learn at their own pace (Farrell-Miller & Gentry, 1989; Myerscough, 1989) is portable (Bernier, 1993) and can be accessed at the time and in the location preferred by the reader (Wiles et al., 1998). Other advantages include message consistency, permanence of information, and reusability (Bernier, 1993).

Despite the documented advantages of providing written health materials, a number of researchers argue that stroke patients and their families are not routinely receiving adequate written information. In the study by Wellwood and colleagues (1994), 88% of stroke patients and 75% of carers reported receiving no literature about stroke. A later study by Hanger and colleagues (1998) also found that only a small proportion of stroke patients recalled receiving written health information, irrespective of their time post-onset. More than two thirds of the stroke survivors stated they had not received written information at two weeks, six months, or two years post-onset. This trend was more recently supported by Eames and colleagues (2003) who found that approximately half of the stroke patients in their study did not recall receiving written health information during their hospital admission.

It is essential that health professionals recognize that all stroke patients, including those with aphasia, have the legal right to access information. As Owens (2006) states, “…people with disabilities require the same information as everyone else” (p.196). There are very few known studies, however, which have specifically investigated the provision of written health information to people with aphasia. Much of the research focusing on the provision of health information to stroke patients and their carers has either excluded people with aphasia (Lomer & McLeod, 1987; Pound et al., 1994; Wachters-Kaufmann et al., 2005; Wellwood et al., 1994, 1995) or did not identify if people with aphasia participated (Anderson, 1988; Greveson & James, 1991; Hanger & Mulley, 1993; O'Mahony et al., 1997;
Wiles et al., 1998). The main aim of this study was to therefore investigate if people with aphasia recalled receiving written information about stroke and aphasia. Subsequent aims were to determine if the receipt of written information was dependent on participant characteristics. Aphasia severity and reading ability were of particular interest as it is possible that health professionals may be reluctant to provide written information to people with more severe language and reading difficulties. It has been reported that health professionals frequently underestimate patients’ desire for and ability to cope with information (Coulter, Entwistle, & Gilbert, 1999). They may believe that older patients, for example, value spoken information more than written because of presumed cognitive, visual, or literacy difficulties (McKenna, 2003; Tooth, Clark, McKenna, & Steinberg, 1999).

This study also aimed to determine if time post-stroke, age, gender, or education level were related to participant’s perceived receipt of written stroke and aphasia information. Age has previously been reported to have a moderate inverse relation with the amount of medical information recalled (Ley et al., 1976). Older stroke patients have also been identified to have less need for information compared to younger stroke patients because it may be easier for them to adjust to their changed and future prospects (Wachters-Kaufmann et al., 2005).

Perceived information needs have also been associated with gender (Ashton, 1997). Females have been reported to attach greater importance to health information (Suhonen, Nenonen, Laukka, & Valimaki, 2005) and may want and require more information than males (Kapral et al., 2006; Stewart, Abbey, Shnek, Irvine, & Grace, 2004). Suhonen and colleagues (2005) identified that women, more often than men, reported receiving information on their illness and treatment. The relationship between gender and receipt of health information for people with aphasia however is largely unexplored.

Patient’s level of education has also been identified in the literature to be related to information needs and perceived receipt of information (Suhonen et al., 2005). Van
Veenendaal, Grinspun and Adriannse (1996) reported that highly educated stroke patients indicated receiving less information and also desired more health information in comparison to stroke patients with less education. A subsequent aim of this study was to therefore determine if the education level of people with aphasia was related to reported receipt of written stroke and aphasia information.

This study also aimed to gain insight into where people with aphasia source written stroke and aphasia information. The Internet in particular has been identified as an information resource for millions of stroke patients and their families (Kuster, 2000). The Internet is available at anytime allowing patients to retrieve information at the time when they are most receptive to learning (Lewis, 1998). The Internet also allows access to health information in a confidential manner in the location of choice, providing an avenue for patients to access health information outside of the less than optimal learning environment of the healthcare setting (Lewis, 1998). Kuster (2000) has identified several stroke and aphasia Internet resources for stroke patients and their families including stroke prevention information, basic information about stroke and aphasia, tips on how to communicate more effectively with people with aphasia, personal accounts from stroke survivors, caregiver activities for promoting language skills and support service information. Internet message boards, mailing lists and chat rooms may also serve as an “important global support lifeline to many stroke survivors and the care providers” (p. 29). Preliminary research by Ghidella and colleagues (2005) has also identified that people with aphasia, when guided to the Internet, have preferences for particular aphasia websites. Given the enormous amount of stroke and aphasia resources available on the Internet, this study aimed to gain insight into whether people with aphasia do obtain stroke and aphasia information from the Internet.

In addition to obtaining information about where people with aphasia source health information, this research also aimed to gain insight into which health professionals provide
written health information. According to Philipp and colleagues (1990), general practitioners (GPs) are perceived to be the principal source of health information. Stroke patients have also previously identified GPs as the most preferred health professional to provide health information (Wachters-Kaufmann et al., 2005). In addition to often being the referring physician, stroke patients have reported they have frequent contact with their GP and they see the GP as a confidant who provides counseling and after-care (Wachters-Kaufmann et al., 2005). Limited research however has focused on who provides written health information to people with aphasia. An aim of this research was to therefore determine which health professionals provide written stroke and aphasia information, particularly, whether people with aphasia obtain written stroke and aphasia information from their GP.

In summary, the main aims of this research were to determine if people with aphasia recalled receiving written stroke and aphasia information, where they obtained this information, and which health professionals provided it.

**Methods**

*Participants*

Forty adults with aphasia resulting from a left hemisphere stroke participated in the larger scale study. This larger scale study explored the preferences of people with aphasia for receiving health information with a focus on determining text formatting facilitators and barriers. Participants were recruited from university clinics and seven southeast Queensland hospitals in Australia. Participants were excluded from the study if there was a medical history documenting cognitively deteriorating conditions. One participant was unable to complete the questionnaire used in this study, primarily due to fatigue at the time of interview.

Participant details (n=39) are reported in Table 1. Twenty-three participants were male and 16 were female. Participant ages ranged from 32 years to 80 years (M = 61 years,
SD = 12.1 years). Time post stroke ranged from 2 months to 14 years 9 months (M = 3.2 years, SD = 3.5 years).

(Table 1 about here)

The Western Aphasia Battery (Kertesz, 1982) confirmed the diagnosis of aphasia and participants’ aphasia typology and severity. Participant aphasia severity ranged from severe (AQ = 6.58) to mild (93.1) (M = 75.3, SD = 20.6). Twenty-seven participants presented with Anomic aphasia, five with Conduction aphasia, three with Broca’s aphasia, two with Transcortical Motor aphasia, one with Wernicke’s aphasia and one with Global aphasia.

Participants with a range of reading abilities were purposefully included. Reading ability was assessed using the Reading Comprehension Battery for Aphasia 2 (RCBA-2) (La Pointe & Horner, 1998). This assessment required the completion of 10 core subtests, with a maximum total score of 100. RCBA-2 scores ranged from 13 to 98 (M = 78.5, SD = 18.9).

Data collection
This descriptive study used a survey design. The study design was similar to that used by Lomer and McLellan (1987) when investigating stroke patients and their relatives’ knowledge of stroke and support services available. A face-to-face interview was conducted with each participant. Sections of this interview were based on questionnaires. This article reports on a ten item questionnaire (see Appendix A). The researcher presented questions in a multimodal format (i.e., both orally and written) to maximize comprehension. The questionnaire was developed in accordance with recognized methods for questionnaire design (Polgar & Thomas, 1995) and included a combination of open and closed questions. However, close-ended questions were predominantly used to assist participants with aphasia.
to respond. A dichotomous response (i.e., yes / no) format was most frequently used. The questionnaire was piloted on three people with aphasia and the number of open-ended questions was reduced as result of this pilot. Minor changes to the wording of some questions were also made. The written questionnaire was formatted using “aphasia-friendly” principles (Brennan, Worrall, & McKenna, 2005; Rose, Worrall, & McKenna, 2003). Administering the questionnaire in a face-to-face interview format allowed the researcher to repeat and rephrase questions and to also clarify and confirm participant responses.

For the purposes of this study written health information was defined as “written or printed booklets, leaflets, pamphlets, or information sheets whose purpose is to provide information about health…” (Bernier, 1993, p.39). Handwritten notes and photocopies from medical texts were also included in the definition of written health information.

**Procedure**

Kagan and Kimelman’s (1995) recommendations for obtaining informed consent from research participants who have aphasia were followed. The majority of interviews were conducted in the participant’s usual place of residence within the community. Participants’ family members were welcome to be present at the time of interview.

**Data analysis**

Descriptive statistics were used to describe participant responses to questionnaire items. The relationships between participants’ responses and participants’ time post-stroke, aphasia severity, reading ability, age, years of education and gender were also explored. Statistical analysis was conducted using the Mann Whitney U and Pearson’s Chi square tests for non-parametric data. Responses to open-ended questionnaire items and other comments were transcribed verbatim. Participants’ comments to each question were categorized and quotes that illustrated a category were used to describe responses.
Results

Did participants recall receiving written information about stroke and aphasia?

See questionnaire items one and two in Appendix A.

Twenty-six participants (67%) reported that they had received written information about stroke, while only 19 (49%) reported receiving written information about aphasia. Only fourteen participants (36%) indicated that they had received both written stroke and aphasia information. Seventeen participants (44%) indicated that they had received either written stroke or aphasia information, while 8 participants (20%) stated that they did not receive any written information about either stroke or aphasia. There was no significant difference in those who reported receiving written stroke and aphasia information according to time post-stroke, aphasia severity, reading ability, age, years of education, or gender.

Comments made by participants when questioned about receipt of written stroke and aphasia information were grouped into two categories. Tables 2 and 3 show participants’ comments in each of these two categories. Comments either reflected the ineffective provision of health information to people with aphasia (see Table 2) or reflected participant’s lack of knowledge about their stroke and aphasia (see Table 3).

(Table 2 about here)

(Table 3 about here)

Participants made comments about the ineffective provision of health information. Several participants felt that they had not received any or enough written information about their stroke and aphasia. In addition, some of the participants who did recall receiving information indicated that it had not been read. Many participants commented about the inappropriate complexity of written health information they had received. As not all
participants received written stroke and aphasia information, some comments were made in reference to general written health information received.

“Oh re ridiculous...Well ah they think you’re a bloody got to be a university student before you can understand them. And it’s just beyond...Some of them I just can’t. Ity bity. Throw it away because I couldn’t understand. You know what I mean. Because it’s just ah too complicated!”

A small number of participants did recall receiving some verbal information about stroke and aphasia, however, this information was not supported with written materials. One participant stated that this spoken information was therefore difficult to remember.

“She (speech pathologist) was talking about aphasia to me. But she didn’t give me any papers or anything, she just talked about it... that’s why that I don’t remember some things...I didn’t have any papers or anything like that...it wasn't written.”

Comments made by a small number of participants also reflected the lack of a systematic approach in the way health information was provided. For example, participants highlighted that they may receive mass amounts of written information without receiving written information specifically addressing stroke or aphasia.

“Yeah...there was lots of bits of paper there (in hospital) and um hard to pull them altogether...it doesn't seem to have sense...”

Another group of comments referred to participants’ lack of knowledge about their stroke and aphasia. Alarmingly a small number of participants clearly believed health professionals had not informed them that they had suffered a stroke. As one participant stated in anger,

“No I was nothing. I wasn’t even told I had stroke…I think everyone else told everybody else had it but I I was not! I didn’t even know I had one until down the track.”
A small number of participants also reported that they still had unanswered questions about their stroke. In addition, several participants indicated they had not been informed of the word “aphasia” and/or its meaning prior to participating in this research. Comments made by several other participants reflected a poor understanding or no understanding of aphasia.

It was suggested by a small number of participants that the poor provision of aphasia information within the hospital setting was related to staff being inadequately informed about aphasia.

“Never told you. Never tell you anything…I think that anybody in the hospital they don’t understand…they have to think about ushageyah (aphasia)...they have to understand that one.”

Where did participants obtain written stroke and aphasia information?

See questionnaire items three to eight in Appendix A.

The main source of written stroke and/or aphasia information was the rehabilitation setting, which included both hospital and university-based aphasia groups. Approximately half (46%) of the participants (n = 18) reported receiving written stroke and/or aphasia information in this setting. Just under one-third (31%) of participants (n = 12) recalled receiving written information when being discharged from the inpatient hospital setting. Less than one-fifth (18%) of participants (n = 7) recalled receiving written information in the acute hospital setting. See Figure 1.

(Figure 1 about here)

Receipt of written stroke and/or aphasia information in the above health settings was not significantly related to aphasia severity, reading ability, age, years of education or gender.
A Mann-Whitney U Test, however, showed a significant difference in the amount of time post-stroke between participants who received information in the rehabilitation setting and those who did not \((z (39) = -2.184, p = 0.029)\). The mean time post-onset for participants who reported receiving written information in the rehabilitation group setting was 4.1 years compared to 2.3 years for participants who stated they did not receive information in this setting.

Participants were asked if they had obtained written stroke or aphasia information from associations in the community setting. A small number of participants made comments indicating that they had no knowledge of aphasia or stroke support associations.

“…are there any? Now I don’t (know) whether there are. Are there any people that um you can go to that ah um might be for um myself…a group of people…I had wonderful friends, but you you do…lose them. You have your good friends but my my outer circle I’ve I’ve stopped going with them because of this. If there was anything…”

Approximately one quarter (26%) of participants \((n = 10)\) reported obtaining information from community associations. The mean time post-onset for participants who stated they had received written stroke and/or aphasia information from community associations was 5.2 years compared to 2.5 years post-onset for participants who reported they had not obtained information from communication associations. This difference was significant \((z(39) = -3.539, p = < 0.001)\). No other significant relationships between reported receipt of information from community associations and other participant characteristics were identified.

Approximately one quarter (26%) of participants reported they had obtained written information about stroke and/or aphasia from the Internet. One participant indicated she
obtained information from the Internet because she had not been provided with adequate information from alternative sources.

“...I did go into the Internet and looking up a big thing on stroke. So that’s the only…but because I haven’t got much.”

From comments made it was also apparent that family members had accessed information for nearly half of those participants who reported obtaining stroke or aphasia information from the Internet.

The mean time post-onset for participants who indicated they had received stroke and/or aphasia information from the Internet was 4.6 years compared to a mean time post-onset of 2.6 years for participants who stated that they had not received information from the Internet. This difference was significant ($z (39) = -2.268, p = 0.023$). No other significant relationships between receipt of information from the Internet and other participant characteristics were identified.

More than one quarter (28%) of participants ($n = 11$) reported that they had obtained information from sources other than those given in the forced choice questions. A small number of participants commented that their family members had collected written stroke and/or aphasia information. A few participants stated they had self-obtained information about stroke and/or aphasia from information displayed on hospital walls.

“...I go and read em meself...it was on the wall.”

A small number of participants commented that they self-obtained information from waiting rooms, while some commented they had obtained written stroke or aphasia information from other patients.

“The lady opposite me (in acute hospital ward)...so I found it and I took it and read it. Tried to read it but I couldn’t read it... she was me, she was the same as me.”
Other sources of written stroke and/or aphasia information identified outside of the hospital setting were the library, newspapers, aphasia conferences, and books. Home medical books were identified as a source of written stroke and/or aphasia information for a small number of participants.

“...our own things here. We’ve got our doctors books and (wife’s name) reads.”

Which health professionals provided participants with written stroke and aphasia information?

See questionnaire items nine and ten in Appendix A.

Participants who reported receiving written stroke and/or aphasia information (n = 31) were asked if they recalled who provided them with this information (see Table 4). Sixteen participants indicated that a speech pathologist or speech pathology student had provided them with written stroke and/or aphasia information. Speech pathologists working in the hospital setting, university setting and private practice setting were identified. Four participants indicated that an occupational therapist had provided written stroke and/or aphasia information. Two participants indicated that a social worker had provided this information, while only one participant reported that a physiotherapist had provided written stroke and/or aphasia information. One example is a participant who showed a folder that her speech pathologist had provided to organize written information obtained during her acute hospital stay. The folder was divided into the following sections: speech, physiotherapy, occupational therapy, social work, and leisure therapy. The participant stated,

“See there’s nothing there. How useless is that hey? (Pointing to the absence of information in all sections other than “speech”.) You don’t know anything...See (pause) they never did nothing. Nothing. Didn’t see anything. How could you use? How good is that?...Nothing at all...Nope... no...no no nothing so useless!”
Four participants stated that a doctor had provided them with written stroke and/or aphasia information. Two of these doctors worked in the hospital setting and two were GPs. An additional participant recalled that a doctor had supplied her spouse with written information.

All participants (n = 39) were specifically asked if their GP had provided them with written stroke and aphasia information. Only two participants (5%) reported receiving written information about stroke or aphasia from their GP. It was also unclear if the GP actually provided the written information to the two participants or whether they self-sought the information available in the patient waiting area. Comments made by these participants suggested the latter.

“I've picked up bits and pieces at the doctor’s surgery. I couldn’t find them now but…yes picked up brochure…lots of brochures.”

“Five years ago picked up (stroke) brochure in GP waiting room…”

A small number of participants commented negatively when asked if their GP had provided them with written stroke and/or aphasia information.

“No not a thing (sarcastically laughing)!“

Other comments made by a small number of participants reflected the view that the GP was too busy to provide written stroke and aphasia information and that the GP was more interested in medications than providing written information.

“No he (referring to GP) didn’t take very much notice. He just said…about the …medication I had, but nothing much else you know.”

Five participants who recalled receiving written stroke and/or aphasia information were unable to identify who had provided them with this information. One participant recalled that hospital nurses had provided health information however this information was presented orally without any written patient education materials.
Did participants recall receiving written information about stroke and aphasia?

Approximately two-thirds of participants recalled receiving written stroke information. This finding is similar to that of Eames and colleagues (2003) who reported 60% of stroke patients with aphasia reported receiving information from health professionals whilst in hospital. The Eames (2003) study however did not distinguish between receipt of stroke and aphasia information. Findings from the current study indicate that receipt of stroke information does not equate to receipt of aphasia information, with even fewer participants (49%) reporting that they received written information about aphasia. It is unclear why fewer participants reported receiving written aphasia information. Perhaps, health professionals require greater knowledge of where and how they can access written health information (Hoffmann, McKenna, Herd, & Wearing, 2007) particularly on the topic of aphasia. Patient communication skills have also been identified as a factor influencing health professionals’ decisions to provide written information (Hoffmann et al., 2007; Sharry, 2002). In addition, Hoffmann (2007) argues that stroke-related characteristics which impact on reading ability may explain why health professionals frequently provide less detailed information to stroke patients. The current findings, however, suggest that information distribution is not significantly influenced by patients’ aphasia severity or reading ability. It appears people with aphasia who have relatively mild reading and communication difficulties are no more likely to receive written stroke or aphasia information.

Other possible explanations for poor patient education are reported in the literature. Attentional narrowing has been found to co-occur when events are viewed as stressful or
Written stroke and aphasia information

emotional (Wessel, Van der Kooy, & Merckelbach, 2000). Consequently patients who receive education in times of stress may not retain the information provided (Hanger et al., 1998). Some stroke patients have also been found to be unwilling or unable to accept information even if provided (Anderson, 1992). Memory for medical information in the general population has also been found to be both poor and inaccurate, with some researchers reporting that 40 to 80% of medical information provided by health professionals is immediately forgotten (Kessels, 2003). In addition, possible memory deficits resulting from stroke may further contribute to the apparent failing in stroke education (Hanger et al., 1998). It is therefore possible that participants in the current study failed to report written health information received. In previous research by Lomer and McLellan (1987) 35% of stroke patients reported that they had not received any written information, despite being given a stroke information leaflet as part of the study. It is acknowledged that the proportion of participants who actually received written information in the current study, as opposed to those who reported receiving written information is unknown. However, the fact that so many participants failed to report receipt of written information casts doubt over its effectiveness even if provided.

Both the qualitative and quantitative data collected in this study provide strong evidence that people with aphasia, even those several years post-onset, continue to be poorly informed about both their stroke and aphasia. This research has identified several contributing factors to the less than optimal provision of written health information to people with aphasia.

First, the low numbers of participants who reported receiving written information and participants’ comments indicate that all health professionals are not routinely using written health information to supplement their spoken message. In the recently published study by Hoffmann (2007), 70% of health professionals surveyed admitted that they provided written
health education materials to 25% or fewer stroke patients in their caseload. The current study provides further evidence that health professionals do not provide written health information to all stroke patients and provides new evidence that people with aphasia may be at a particular disadvantage for receiving such information.

Second, many participants spontaneously commented about the inappropriate complexity of written health information. The readability levels of stroke education materials have repeatedly been found to be too high for both the general public (Hoffmann & McKenna, 2006; Sullivan & O’Conor, 2001) and specifically for people with aphasia (Aleligay, Worrall, & Rose, 2008; Berarducci, Cooper, & Giles, 2007; Eames et al., 2003; Hoffmann & McKenna, 2006). Although the provision of aphasia-friendly written health information has been found to improve comprehension of health information (Rose et al., 2003), it appears that many people with aphasia are still not receiving written health information in appropriate formats. This finding supports that of Parr (2007) who also identified that health providers do not account for the needs of people with aphasia by adapting information so that it easier to understand. There is a need for health professionals to have greater knowledge of how to develop and evaluate written health education materials so that they are appropriate to their patient’s needs, a view also shared by Hoffmann and colleagues (2007).

Third, this study also identified that some people with aphasia did not read the written stroke and aphasia information when it was provided. As Arthur (1995) states, “it cannot be assumed that because a leaflet is available the patient will be educated” (p1084). Although incompatible formatting of health documents may be one explanation for this, other contributing factors may include the patient not perceiving the information as important, inappropriate timing of information provision, and health professionals using an unsuitable medium for health education. Further research exploring whether people with aphasia...
consider written health information to be important, their preferences for timing and also their preferred medium for health education is warranted.

**Where did participants obtain written stroke and aphasia information?**

Hospital and university groups in the rehabilitation setting were the main source of written stroke and aphasia information. The group setting is conducive to both clinician and client-directed health education. Clients attending aphasia groups for example have the opportunity to learn from and be guided by other people living with aphasia (Worrall, Davidson, Howe, & Rose, 2007). Participants who reported receiving information in this setting were approximately four years post-onset. One explanation for this finding is that participants may be more receptive to health information presented in this setting once they are several years post-stroke. It is also possible that stroke and aphasia groups were not available to participants in the early stages of their recovery or they were not made aware of the groups that were available. From the current study it can be inferred that people with aphasia who attend rehabilitation groups are at an advantage for receiving written stroke and aphasia information. There is therefore a need to ensure that all people with aphasia are able to access such groups if desired.

The current findings also provide further evidence that people with aphasia are not receiving adequate health information in the hospital setting. An alarming 82% of participants reported that they had not received written stroke and/or aphasia information during their acute hospital stay. It is argued that education should be a focus during the early phases of aphasia management (Holland & Fridrisksson, 2001; Marshall, 1997). It appears however, that health professionals working in the acute hospital setting spend little time providing health information to stroke patients, particularly to patients who have aphasia (Knight et al., 2006). Knight and colleagues (2006) suggest that health professionals may lack
confidence in communicating with people who have aphasia. Holland and Fridriksson (2001) also hold the view that “training may not adequately prepare clinicians for their earliest encounters with newly aphasic people” (p. 19). It is therefore logical to assume that health professionals may be more reluctant to provide written health information to patients with more severe reading and language difficulties. However, in the current study no significant relationship was found between participants’ aphasia or reading ability and their reported receipt of written information in the acute setting. All people with aphasia, irrespective of the severity of their communication difficulties, appear to be at particular risk for receiving limited or no written health information about their stroke and aphasia in the acute hospital setting.

Community associations have been reported to play a vital role in the continuing education of stroke patients (Hanger et al., 1998). However, the majority of participants (74%) in the current study reported they received no written health information from community associations, with some participants indicating they had no knowledge of such associations. These findings reflect those previously reported in the literature. In the study by Lomer and McLellan (1987), both stroke patients and their families knew very little about stroke assistance available in the community. The majority of patients (89%) and carers (85%) in the Wellwood study (1994) reported that they had received no information about organizations such as stroke associations. Grevenson (1991) also found that despite being able to offer the services and support desired, stroke patients were largely unaware of stroke associations available to them. As Anderson (1988) states, “voluntary services…reach only a small proportion of patients and their families...” (p. 107). It is largely unknown if and why this information is being ineffectively communicated to people with aphasia. Perhaps information about stroke and aphasia associations is only provided to people with aphasia at a time when the chronicity of their condition is not fully understood. Timely provision of
Written stroke and aphasia information

Information about community stroke and aphasia associations may be paramount to the uptake of health information they provide. For example, in the study by Suhonen (2005) only 5% of hospital inpatients considered information about associations to be important. Interestingly, the majority of participants who reported receiving information from community associations in the current study were several years post-stroke. It is unknown if information about available associations was provided to participants and not pursued or whether people with aphasia were not made aware of stroke and aphasia specific associations soon after their stroke. The need for routine provision of information, as well as the need for research into the timing of health information provision to people with aphasia is again highlighted.

Only one quarter (26%) of participants reported obtaining written stroke and/or aphasia information from the Internet. According to Linebarger and colleagues, “aphasic patients…are rarely able to exploit the Internet, due to literacy and attentional issues” (p. 169). The readability levels of stroke and aphasia information available on the Internet have also been shown to be above those recommended for the general public (Ghidella, 2005; Griffin, McKenna, & Worrall, 2004). In the current study, however, receipt of information from the Internet was not significantly influenced by aphasia severity and reading ability. Other explanations for why so few participants reported obtaining stroke and aphasia information from the Internet must therefore be considered. Perhaps participants’ lack of knowledge of the diagnostic term “aphasia” was a barrier for key word searches on the Internet. It is also possible that participants were unaware of the stroke and aphasia information available on the Internet. Health professionals have previously been identified to play a key role in guiding clients to appropriate health information websites (McMullan, 2006), however in the study by Ghidella and colleagues (2005) half of the speech pathologists surveyed reported that they never referred clients to the Internet for aphasia
information. In the current study it is again largely unknown if information about Internet resources was provided and not pursued or whether people with aphasia were not directed to reliable stroke and aphasia information available on the Internet. Many complex issues surround Internet access for people with aphasia (Elman, 2001) and further discussion of this topic is beyond the scope of this paper. Nonetheless, this study has identified that some people with aphasia do rely on the Internet for stroke and aphasia information, particularly when this information is not perceived to have been provided by health professionals. Family members also appear to play a vital role in accessing Internet health information for people with aphasia, even several years post-onset.

In addition to assisting people with aphasia to access Internet health information, a small number of participants also identified family members as a source of information. Stroke patients with aphasia have previously been identified to source more written health information from family members compared to stroke patients without aphasia (Eames et al., 2003). Knight and colleagues (2006) also identified that stroke patients with aphasia relied on their significant others for health information. In the study by Wachters-Kaufmann and colleagues (2005), 44% of stroke patients also identified their partner as a source of health information, while 36% identified other family members as a source. In comparison, fewer participants in the current study identified their family members as source of stroke and aphasia information. Perhaps this was because participants’ family members were also inadequately educated about stroke and aphasia. The recent study by Flynn and colleagues (in press) provides some evidence that family members are also not being adequately informed about aphasia.

This research has also identified that people with aphasia do self-seek written stroke and aphasia information and highlights the need for this information to continue to be available in patient waiting areas and also on hospital walls. The finding that people with
aphasia may self-seek information from other patients in the acute health setting was also of interest. This particular finding can be viewed both positively and negatively. Patients sharing information may facilitate education that is both highly tangible and practical (Worrall et al., 2007) but there is also potential for patients to share incorrect and irrelevant information. Although there is a place for patients to learn from each other, it is concerning that this may have been the only avenue for some participants to obtain written stroke and aphasia information.

**Which health professionals provided participants with written stroke and aphasia information?**

Speech pathologists were the most frequently reported provider of written stroke and aphasia information. In this retrospective study it is acknowledged that potential recall bias in relation to which health professionals provided information must be considered when interpreting results. Speech pathology was the profession of both the primary researcher and also the health professional identified as providing the most written information. This study, however, supports the previous findings of Wachters-Kaufmann (2005) who identified that stroke patients received most of their health information from speech pathologists. Hoffmann and colleagues (2007) also identified speech pathologists to be one of the most frequent providers of written health information. It is possible that the current finding is reflective of the health profession who spends the most time with clients who have aphasia but it may also be that speech pathologists place a greater importance on effective communication. As Tooth and Hoffman report (2004), health professionals who spend more time with patients may be in a better position to ensure that their health information needs are being met.

This research has also identified a potential issue with other health professionals, particularly physiotherapists, not providing written health information to people with aphasia. In contrast, previous research has found physiotherapists to be one of the most frequent
Written stroke and aphasia information

provider of health information to stroke patients (Wachters-Kaufmann et al., 2005). The Wachters-Kaufmann (2005) study however did not specifically consider provision of written information. Although it is generally accepted that verbal education in conjunction with written information is the most effective method of patient education (Hill, 1997), findings from the current study strongly indicate that all health professionals are not routinely providing written information to supplement their spoken message. It is also possible that physiotherapists, as with other health professionals, provided participants with written health information but these materials did not specifically focus on stroke or aphasia. Aleligay and colleagues (2008) reported that the majority of written information received by people with aphasia in their study did not relate to speech pathology topics such as aphasia. Rather, people with aphasia received written health information addressing a variety of topics, ranging from falls prevention, incontinence, to enduring power of attorney information (Aleligay et al., 2008). The quantity of information given to patients should be recognized as a potential barrier to effective health education (Maycock, 1991). Comments made by participants in the current study have again highlighted that people with aphasia may receive mass amounts of written information yet may not receive written information specifically addressing stroke or aphasia.

Comments made have also reflected the need for a more systematic approach to the provision of written health information to people with aphasia. Findings support calls for the health information given by health professionals to be better coordinated (Greveson & James, 1991; Wachters-Kaufmann et al., 2005; Wiles et al., 1998). Health professionals may lack clarity about which team members should provide written stroke and aphasia information to people with aphasia (Knight et al., 2006). As Hoffmann (2007) identified, health professionals are likely to lack knowledge about what health information is provided by other health professionals resulting in an assumption that others have or will provide written health
Written stroke and aphasia information

Ensuring people with aphasia are aware of the health education roles of the various health professionals may also assist in a more coordinated approach. Some participants in this study were unable to identify who provided them with written stroke and aphasia information, a finding also noted by Knight and colleagues (2006). Without this knowledge, people with aphasia may not be aware of the most appropriate health professional to approach for clarification of information provided or to obtain additional information.

Very few participants in the current study reported obtaining written stroke or aphasia information from their GP. Grevenson and James (1991) also identified that although many stroke patients would approach their GP “from previous experience patients and carers had gained the impression that GPs although sympathetic, could offer no help” (p. 162). The current research also supports that of Wachters-Kaufmann (2005) who found GPs provide significantly less stroke information compared to other health professionals.

**Limitations**

In the region of this study, rehabilitation services are provided by both hospital and specialised university aphasia groups. This survey did not distinguish between inpatient and outpatient rehabilitation services. It would have been interesting to determine if written health information was provided within the inpatient rehabilitation setting (i.e., hospital funded aphasia groups) or within the outpatient rehabilitation setting (i.e., university funded aphasia groups). This information however was difficult to ascertain primarily due to the variety of clinical pathways taken by participants. Including participants from ethnic minorities as well as the recruitment of participants from rural hospitals would have improved the breadth of the participant sample.

**Clinical Implications**
This study has highlighted the need for more effective and routine provision of written stroke and aphasia information to people with aphasia. It is important that all health professionals have a clear understanding of the range of communication difficulties that result from aphasia and consequently ensure that written health information provided to people with aphasia is formatted and designed in a manner that facilitates comprehension. The ineffective provision of written information in the acute hospital setting requires particular attention. Speech pathologists working in this setting are encouraged to routinely consider their role in facilitating and overseeing patient-directed learning. Nominating one health professional to provide information may ensure that general stroke and aphasia information is provided and may also provide people with aphasia with more clarity regarding which health professional to approach for additional information. Health professionals also need to be aware that the amount of written information provided on various topics other than stroke and aphasia has the potential to be overwhelming. A more systematic and coordinated approach to the provision of written information is required.

People with aphasia who attend rehabilitation groups appear more likely to receive written stroke and aphasia information. As such, there is a need for group services to be available to all people with aphasia, also challenging speech pathologists to consider whether group education has a role in the initial stages of recovery. There is also a need for health professionals to more effectively communicate information about community stroke and aphasia associations. Clinicians may also need to be more active in referring people with aphasia to reliable stroke and aphasia information available via the Internet.

The majority of participants who reported receiving written information from rehabilitation groups, community associations and the Internet were several years post-stroke. Health professionals must ensure people with aphasia are provided with the necessary
information to access these services as soon as desired after their stroke and that this information is repeatedly provided at various stages along each client’s clinical pathway.

**Conclusion**

Written stroke and aphasia information is not effectively being provided to people with aphasia. The majority of participants reported they had not received both written stroke and aphasia information. No significant relationship between receipt of information and either aphasia severity or reading ability was found. Several participants stated that they were not aware of the term “aphasia” and many participants commented about the inappropriate complexity of the written health information they had received. People with aphasia who attended groups in the rehabilitation setting were more likely to receive written stroke and aphasia information however the majority of these participants were several years post-stroke. Speech pathologists were most frequently identified as the provider of written information. Very few participants reported obtaining written stroke and aphasia information from general practitioners.

It seems inexcusable that people with aphasia continue to be inadequately informed about their stroke and aphasia. Routine provision of appropriately formatted health information and improved access to the health professionals and services which provide information are two strategies for more successful stroke and aphasia education. The basic health rights of people with aphasia will only be met when all people with aphasia have access to education about their life-altering condition.
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<td>87.1</td>
<td>1</td>
<td>2.7</td>
<td>87</td>
<td>10</td>
<td>-</td>
</tr>
<tr>
<td>35</td>
<td>Female</td>
<td>70</td>
<td>Conduction</td>
<td>74.2</td>
<td>1</td>
<td>2.2</td>
<td>72</td>
<td>10</td>
<td>-</td>
</tr>
<tr>
<td>36</td>
<td>Male</td>
<td>61</td>
<td>Broca's</td>
<td>40.9</td>
<td>3</td>
<td>13.0</td>
<td>61</td>
<td>8</td>
<td>-</td>
</tr>
<tr>
<td>37</td>
<td>Male</td>
<td>64</td>
<td>Anomic</td>
<td>84.2</td>
<td>1</td>
<td>0.8</td>
<td>86</td>
<td>10</td>
<td>-</td>
</tr>
<tr>
<td>39</td>
<td>Male</td>
<td>57</td>
<td>Anomic</td>
<td>92.6</td>
<td>1</td>
<td>1.1</td>
<td>98</td>
<td>19</td>
<td>-</td>
</tr>
<tr>
<td>40</td>
<td>Female</td>
<td>61</td>
<td>Conduction</td>
<td>54.7</td>
<td>1</td>
<td>0.2</td>
<td>80</td>
<td>19</td>
<td>-</td>
</tr>
</tbody>
</table>

WAB AQ = Western Aphasia Battery Aphasia Quotient, RCBA-2 = Reading Comprehension Battery for Aphasia - 2
Table 2.
Comments reflecting ineffective provision of stroke and aphasia information for people with aphasia

| Has a health worker ever given you written health information about stroke / aphasia? |
|---------------------------------|---------------------------------------------------------------------------------|
| People with aphasia did          | ID11: “…the girl opposite me…she hadn’t received anything either!... “They never gave me anything.” |
| not receive any or enough        | ID14: “No they (doctors and nurses) haven’t really. You know they just give you your tablets and smile at you and all that (laughs) and yeah no nobody else really has given us anything on it.” |
| written information about stroke and/or aphasia. | ID17: “Nothing given me. No nothing!” |
|                                 | ID28: “I don’t think so because I can’t, I couldn’t read.” |
|                                 | ID29: “I should have had more.” |
|                                 | ID39: “I don’t recollect any health information at all, to be honest.” |
| Written stroke and aphasia       | ID7: “No I don’t think so…I haven’t read anything…I don’t look at any of them.” |
| information was not              | ID9: “…Most of them I didn’t read…because most time I can’t understand…so I didn’t do much reading.” |
| always read if provided.         | ID13: “Ah. I couldn’t read it.” |
|                                 | ID16: “…Some of them like that you could read em. But you get others.” |
|                                 | ID23: “There probably was some pamphlets, but I never read them…I left them there for (husband) to
People with aphasia received written health information that was too complex for their needs. 

<table>
<thead>
<tr>
<th>Participant</th>
<th>Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID3</td>
<td>“…they weren’t in aphasia friendly…”</td>
</tr>
<tr>
<td>ID6</td>
<td>“Too hard!”</td>
</tr>
<tr>
<td>ID10</td>
<td>“Pretty hard to read (referring to information given by social worker). I can think some of it, but not all of it.”</td>
</tr>
<tr>
<td>ID12</td>
<td>“I mean…they are…very important but it’s sort of for doctors not for us as a stroke.”</td>
</tr>
<tr>
<td>ID12</td>
<td>“Those little brochures…on about the stroke they sort sort of not not for us like at a stage I couldn’t read them…they were like for…my companion. They would read about it…I couldn’t.”</td>
</tr>
<tr>
<td>ID13</td>
<td>“Hard to read…I got a right…”</td>
</tr>
<tr>
<td>ID16</td>
<td>“…Oh re ridiculous…Well ah they think you’re a bloody got to be a university student before you can understand them. And it’s just beyond…Some of them I just can’t. Ity bity. Throw it away because I couldn’t under understand. You know what I mean. Because it’s just ah too complicated!”</td>
</tr>
</tbody>
</table>
| ID17        | “…they were medical words… (participant picks up stroke information and begins reading) …ah spine ah cerbel cera cerabreeum cerebellum you know I didn’t know what the word …and antervenious (intravenous) I didn’t know what that meant… Um. They they… think that when they write these things to
the for us general. It’s us! … That a person goes to study medicine to be a doctor to know what that say.

To us it means nothing!

ID23: “They they looked too ah too leafy and too too hard to read…and and they looked too hard and too. I gave them to (husband).”

ID30: “They (referring to a stroke education booklet) were very hard to read!…I mean how can I…how can I? I can’t read it ... I just can't understand that...I would like to know what it means but I can’t.”

ID30: “Here's another one! This is no good! This is. This is not very good...It doesn't understand...

They’re hard! …What am I supposed to do with that?”

ID37: “Far too many words because I just can’t read with speed.”

ID37: “If it was given information wise small print like that, forget it. No because you can’t read so what’s the importance? Do you know what I mean? Sure you like to know that information.”

ID39: “…many I didn’t understand so I don’t know what (why) I had all them.”
<table>
<thead>
<tr>
<th>support of written materials.</th>
<th>ID24: “…well I had ah (the speech pathologist’s name) up at the ah hospital and she took (talk) me a lot about the words yes but I don’t think (written information).”</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>ID39: “No no. The the only you know…The only…information they give you is…um you have had a stroke…brain on the left side switch it…no nothing to read.”</td>
</tr>
<tr>
<td>A systematic approach in the way health information was provided to people with aphasia was lacking.</td>
<td>ID6: “Yeah…there was lots of bits of paper there (in hospital) and um hard to pull them altogether…it doesn’t seem to have sense…I need to put it away and s s set sit my own time and try and make as much out of it I can.”</td>
</tr>
<tr>
<td></td>
<td>ID14: “You know you don’t know what it’s all about at all…just odd little bits that really didn’t um you know make a lot of sense to me at the time I suppose.”</td>
</tr>
<tr>
<td></td>
<td>ID16: “About 40 million of them!” (brochures about stroke)</td>
</tr>
</tbody>
</table>
Table 3.
Comments reflecting participants’ lack of knowledge about stroke and aphasia

<table>
<thead>
<tr>
<th>Has a health worker ever given you written health information about stroke / aphasia?</th>
</tr>
</thead>
<tbody>
<tr>
<td>A small number of participants believed they were not informed of their stroke diagnosis.</td>
</tr>
<tr>
<td>ID12: “…they don’t tell me… Nobody in the…hospitals tolds me I am stroke….They would just you sick…They never tell me something else…you stroke you have that…I never seen the books anywhere that’s written like that…”</td>
</tr>
<tr>
<td>ID40: “No I was nothing. I wasn’t even told I had stroke…I think everyone else told everybody else had it but I I was not. I didn’t even know I had one until down the track.”</td>
</tr>
<tr>
<td>A small number of participants spontaneously indicated their questions about stroke had not been answered.</td>
</tr>
<tr>
<td>ID5: “I wish I had them (examples of stroke information) before…What sort of stroke did I have? …Can I borrow some of that off you?…All of them…!”</td>
</tr>
<tr>
<td>ID39: “I was in the dark as far as my stroke was concerned.”</td>
</tr>
<tr>
<td>ID39: “Never was explained…um…you have a stroke therefore…”</td>
</tr>
<tr>
<td>Several participants indicated they had not</td>
</tr>
<tr>
<td>ID11: “Well I've only only heard that (referring to aphasia) since you.”</td>
</tr>
</tbody>
</table>
| ID17: “It's it’s a new word (referring to aphasia). Where was it? Where did it come from? How long ago
heard the word “aphasia” prior to participating in the current research. 

| ID29: | “I didn't even know about the word (aphasia)...I didn’t know what aphasia was. Never heard of it…” |
| ID14: | “Did say something about it (aphasia) but I it was right at the very beginning and didn’t get it really very clearly… I can't understand it…” |
| ID22: | “I still don't understand anything about it (referring to aphasia)...I didn’t know any of it (referring to aphasia).” |
| ID28: | “No…aphasia I wouldn’t know.” |
| ID30: | “Never told you. Never tell you anything… I think that…in the hospital they don’t understand …about ushfaheyah (aphasia). They have to tell...They didn’t tell me anything about it did they? They didn’t tell.” |

Several comments reflected a poor understanding or no understanding of aphasia.
Table 4.

Health professionals identified as providers of written stroke and/or aphasia information

<table>
<thead>
<tr>
<th>Health professionals</th>
<th>Number of participants who recalled receiving written stroke and/or aphasia information (n = 31*)</th>
</tr>
</thead>
<tbody>
<tr>
<td>speech pathologist / speech pathology student</td>
<td>16</td>
</tr>
<tr>
<td>occupational therapist</td>
<td>4</td>
</tr>
<tr>
<td>doctor working in hospital setting</td>
<td>2</td>
</tr>
<tr>
<td>general practitioner (GP)</td>
<td>2</td>
</tr>
<tr>
<td>social worker</td>
<td>2</td>
</tr>
<tr>
<td>physiotherapist</td>
<td>1</td>
</tr>
<tr>
<td>unable to identify health professional</td>
<td>5</td>
</tr>
</tbody>
</table>

* participants may have obtained written stroke and/or aphasia information from more than one health professional
Figure 1. Where did participants obtain written stroke and aphasia information?
Appendix A.

Interview Questionnaire

<table>
<thead>
<tr>
<th>Question Number</th>
<th>Question</th>
<th>Response Format</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Has a health worker ever given you written health information about stroke?</td>
<td>dichotomous yes / no</td>
</tr>
<tr>
<td>2</td>
<td>Has a health worker ever given you written health information about aphasia?</td>
<td>dichotomous yes / no</td>
</tr>
<tr>
<td>3</td>
<td>Did you receive written health information about stroke/aphasia in the acute hospital setting?</td>
<td>dichotomous yes / no</td>
</tr>
<tr>
<td>4</td>
<td>Did you receive written health information about stroke/aphasia in the hospital discharge setting?</td>
<td>dichotomous yes / no</td>
</tr>
<tr>
<td>5</td>
<td>Did you receive written health information about stroke/aphasia in the rehabilitation setting (e.g., hospital aphasia groups)?</td>
<td>dichotomous yes / no</td>
</tr>
<tr>
<td>6</td>
<td>Did you obtain written health information about stroke/aphasia in the community setting (e.g., stroke associations)?</td>
<td>dichotomous yes / no</td>
</tr>
<tr>
<td>7</td>
<td>Did you obtain written health information about stroke/aphasia from the Internet?</td>
<td>dichotomous yes / no</td>
</tr>
<tr>
<td>8a)</td>
<td>Did you obtain written health information about stroke/aphasia from any other sources?</td>
<td>dichotomous yes / no</td>
</tr>
<tr>
<td>8b)</td>
<td>(If yes response to question 8a) Where did you obtain written information about stroke/aphasia?</td>
<td>open ended</td>
</tr>
<tr>
<td>9</td>
<td>Which health workers gave you written health information about stroke/aphasia?</td>
<td>open ended</td>
</tr>
<tr>
<td>10</td>
<td>Did your general practitioner (GP) give you written stroke/aphasia information?</td>
<td>dichotomous yes / no</td>
</tr>
</tbody>
</table>
References


Written stroke and aphasia information


