Analysis of stroke patients’ and carers’ reading ability and the content and design of written materials: Recommendations for improving written stroke information

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Abstract

Objective: This study (a) evaluated the reading ability of patients following stroke and their carers and the reading level and content and design characteristics of the written information provided to them, (b) explored the influence of sociodemographic and clinical characteristics on patients’ reading ability, and (c) described an education package that provides well-designed information tailored to patients’ and carers’ informational needs.

Methods: Fifty-seven patients and 12 carers were interviewed about their informational needs in an acute stroke unit. Their reading ability was assessed using the Rapid Estimate of Adult Literacy in Medicine (REALM). The written information provided to them in the acute stroke unit was analysed using the SMOG readability formula and the Suitability Assessment of Materials (SAM).

Results: Thirteen (22.8%) patients and 5 (41.7%) carers had received written stroke information. The mean reading level of materials analysed was 11th grade while patients read at a mean of 7–8th grade. Most materials (89%) scored as only adequate in content and design. Patients with combined aphasia read significantly lower (4–6th grade) than other patients (**p = 0.001**).

Conclusion: Only a small proportion of patients and carers received written materials about stroke and the readability level and content and design characteristics of most materials required improvement.

Practice implications: When developing and distributing written materials about stroke, health professionals should consider the reading ability and informational needs of the recipients, and the reading level and content and design characteristics of the written materials. A computer system can be used to generate written materials tailored to the informational needs and literacy skills of patients and carers.

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Keywords: Patient education; Stroke; Written information; Tailored information

1. Introduction

Stroke is a chronic disease with a high risk of recurrence [1] and long-term residual consequences for many patients. The management of chronic diseases requires active participation by the patient [2], and often the carer, and this can only occur when they are well-informed [3]. Patient education aims to improve patients’ health behaviours to enhance their health status. Because knowledge is often a prerequisite to understanding the need for behaviour change, patient education includes interventions to inform patients and enhance their understanding of health conditions and their treatment, increase self-efficacy and enable them to participate in decisions about their care. In relation to stroke, education can assist patients and carers to understand what has happened, to cope with the immediate and ongoing consequences of stroke, and to know what actions they can take to reduce the risk of recurrent stroke. Education therefore is a crucial component of stroke management.

Numerous studies have highlighted the inadequacy of the education provided to stroke patients and their carers [4–7]. Various methods of providing education have been evaluated, yet the ideal method has not been established. The provision of education to stroke patients and their carers can take a number of forms, including written education...
materials [8–10], structured education programs [11–13], education and counselling [14,15], and home visits by a stroke family support organiser [16–18]. The most common medium used in the majority of studies is written information, provided either as part of a multi-component intervention or as a stand-alone intervention.

Written materials offer a number of advantages such as message consistency, reusability, portability, flexibility of delivery [19], and self-paced learning. They are typically provided to increase knowledge so that patients can make informed decisions about their health care and the need for behaviour change. Patients frequently forget information that is conveyed verbally [20]. Written materials can be provided to aid recall and reinforce verbally delivered information [21]. A further benefit of written materials is that patients can choose the amount and type of information that suits their informational needs and level of adjustment [22]. Ideally, written information should be used to supplement and reinforce information that has been provided verbally [23,24]. Despite the benefits of written education materials and reports of patients’ preference to receive more written materials, the frequency with which it is provided is low [7,25]. Studies have reported that 26% [4] and 12% [7] of patients could recall receiving written information while in hospital.

Written information can only be useful if the recipients can read and understand it. Health literacy refers to the ability of individuals to access, understand and use information to promote health [26]. Low levels of health literacy are more prevalent in older people [27,28] and those with low educational attainment [29]. Because most people who have a stroke are older [30], they may be at risk of low health literacy. This may be further compounded by stroke-related impairments such as aphasia, visual and perceptual impairments, which have the potential to impact on reading ability. Health professionals need to be able to identify patients at risk of low literacy so that they can provide written materials appropriate to their reading ability [31].

The literacy demand of written materials can be decreased by careful attention to their reading level and design characteristics. Written materials should be written simply and at the lowest reading level possible while still conveying the information accurately. Consideration of design characteristics such as language, organisation, layout and typography, illustrations and presentation, and learning and motivation can enhance readers’ attention to and understanding and recall of information [32]. None of the studies that have evaluated the use of written materials with stroke patients have addressed the reading level and design characteristics of the information distributed. In the three studies [8–10] that evaluated written information as a stand-alone intervention for stroke patients and their carers, inconclusive results about their effectiveness were reported. Although the results might have been compromised by low statistical power, it is also possible that the reading level and design of the written materials used were inadequate and that the materials did not meet the informational needs of the patients and their carers.

In addition to their reading level and design, the content of written materials should be tailored to the informational needs of patients. Tailoring involves the design and delivery of information that is not only relevant to patients but that will also match their reading ability. Studies have shown that patients prefer tailored information [33,34] and that tailored messages are more likely to be read and remembered [35,36]. One method of providing patients with tailored written materials is by using computer systems to generate information that is relevant to the informational needs and literacy skills of patients. No studies about the development or evaluation of a system for providing computer-generated tailored information to stroke patients and their carers were identified.

The aim of this study was to evaluate current practice in providing stroke patients and carers with written education materials and to make recommendations to overcome identified inadequacies in the provision of written information to this population. The specific objectives were to: evaluate the reading levels and content and design characteristics of the written materials that patients and carers receive; compare the reading level of the written materials to stroke patients’ and carers’ reading ability; determine the effect of age, years of education, previous stroke, and specific impairments (aphasia, perception, vision) on patients’ reading ability; examine the informational needs of stroke patients and carers; and develop a method of providing tailored information of appropriate content and design to stroke patients and their carers.

2. Method

2.1. Participants and procedure

Participants were patients who had been admitted to the stroke unit of a major metropolitan public hospital. Between February and July 2002, 97 consecutive patients with a primary diagnosis of stroke or transient ischaemic attack were admitted. For patients with aphasia, the stroke unit speech pathologist assisted the interviewer in determining their suitability for an interview. Thirty-seven patients did not meet the eligibility criteria and were excluded for the following reasons: communication skills not appropriate for an interview (9), cognitive status not appropriate for interview (7), lived further than 50 km from the hospital (7), poor prognosis (6), died while in hospital (4), did not speak English (3), and severe visual impairment (1). Of the remaining 60 patients, three declined to be involved, leaving 57 patients in the study sample. Twelve carers who were present at the patient’s interview were invited to participate. All carers met the eligibility criteria and consented to participate in the study.
A face-to-face semi-structured interview was conducted with each patient and carer by the first author, up to 2 days before the patient’s discharge. Clinical data were extracted from patients’ medical charts. Information was gathered on the following variables:

1. Sociodemographic variables: age, gender, years of education, living situation, ethnicity.
2. Clinical variables (patients only): type and side of stroke, presence of specific stroke-related impairments (aphasia, perception, vision), and whether this was the patients’ first stroke.
3. Analysis of written materials: Participants indicated the written materials they received while the patient was in hospital and these materials were analysed in terms of their reading level and content and design characteristics:
   a. Reading level: The SMOG readability formula [37] calculates a material’s reading level using the number of long words, defined as words of three or more syllables, in 30 sentences (10 from the beginning, 10 from the middle and 10 from the end of the written material). From the word count, grade levels are then obtained by using the SMOG conversion table.
   b. Content and design characteristics: The Suitability Assessment of Materials (SAM) instrument [32] assesses 22 items, which are grouped into six factors (as shown in Table 1). Each of the 22 items are rated in terms of the degree to which they meet set criteria, on a scale of 2 (superior), 1 (adequate), 0 (not suitable) or not applicable. Applicable scores are summed to yield an overall raw score for the material. This is converted into a percentage (percentage = raw score/possible total score for that written material). The percentages are then interpreted as: 70–100% = superior material; 40–69% = adequate material; 0–39% = not suitable material.
4. Reading ability: Participants’ reading ability was measured according to the Rapid Estimate of Adult Literacy in Medicine (REALM). The REALM is a reading recognition test that measures the reader’s ability to pronounce 66 commonly used medical and lay terms for body parts and illnesses [38]. Raw scores range from 0 to 66 and are converted into four grade range estimates of literacy. The reader’s reading grade level is estimated to be at 3rd grade level or below if the raw score is between 0 and 18 (inclusive), 4–6th grade level if the raw score is between 19 and 44, 7–8th grade level if the raw score is between 45 and 60, and 9th grade level or above if the raw score is between 61 and 66.
5. Informational needs: Participants were asked to identify the stroke-related topics that they would have liked

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Score of 2 (superior) n (%)</th>
<th>Score of 1 (adequate) n (%)</th>
<th>Score of 0 (not adequate) n (%)</th>
<th>Not applicable n (%)</th>
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<tbody>
<tr>
<td>1. Content</td>
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<tr>
<td>a. Purpose is evident</td>
<td>7 (38.9%)</td>
<td>10 (55.5%)</td>
<td>1 (5.6%)</td>
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<tr>
<td>b. Content about behaviours</td>
<td>3 (16.7%)</td>
<td>7 (38.9%)</td>
<td>8 (44.4%)</td>
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<td>c. Scope is limited</td>
<td>13 (72.2%)</td>
<td>5 (27.8%)</td>
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<td>d. Summary or review included</td>
<td>1 (5.6%)</td>
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<td>17 (94.4%)</td>
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<td>2. Literacy demand</td>
<td></td>
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<tr>
<td>a. Reading grade level</td>
<td>4 (22.2%)</td>
<td>14 (77.8%)</td>
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<td>b. Writing style, active voice</td>
<td>5 (27.8%)</td>
<td>13 (72.2%)</td>
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<tr>
<td>c. Vocabulary</td>
<td>5 (27.8%)</td>
<td>12 (66.7%)</td>
<td>1 (5.6%)</td>
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<td>d. Context is given first</td>
<td>5 (27.8%)</td>
<td>13 (72.2%)</td>
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<tr>
<td>e. Advance organisers</td>
<td>18 (100%)</td>
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<td>3. Graphics</td>
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<tr>
<td>a. Cover graphic shows purpose</td>
<td>15 (83.3%)</td>
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<td>3 (16.7%)</td>
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<tr>
<td>b. Type of graphics</td>
<td>6 (33.3%)</td>
<td>8 (44.4%)</td>
<td>2 (11.1%)</td>
<td>2 (11.1%)</td>
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<tr>
<td>c. Relevance of illustrations</td>
<td>10 (55.5%)</td>
<td>7 (38.9%)</td>
<td>1 (5.6%)</td>
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<tr>
<td>d. Lists and tables explained</td>
<td>1 (5.6%)</td>
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<td>17 (94.4%)</td>
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<tr>
<td>e. Captions used for graphics</td>
<td>1 (5.6%)</td>
<td>4 (22.2%)</td>
<td>6 (33.3%)</td>
<td>7 (38.9%)</td>
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<td>4. Layout and typography</td>
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<tr>
<td>a. Layout factors</td>
<td>13 (72.2%)</td>
<td>4 (22.2%)</td>
<td>1 (5.6%)</td>
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<td>b. Typography</td>
<td>6 (33.3%)</td>
<td>12 (66.7%)</td>
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<td>c. Subheadings (‘chunking’) used</td>
<td>3 (16.7%)</td>
<td>5 (27.8%)</td>
<td>8 (44.4%)</td>
<td>2 (11.1%)</td>
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<td>5. Learning stimulation and motivation</td>
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<tr>
<td>a. Interaction used</td>
<td>2 (11.1%)</td>
<td>7 (38.9%)</td>
<td>9 (50.0%)</td>
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<tr>
<td>b. Behaviours are modeled and specific</td>
<td>6 (33.3%)</td>
<td>7 (38.9%)</td>
<td>5 (27.8%)</td>
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<tr>
<td>c. Motivation – self-efficacy</td>
<td>16 (88.9%)</td>
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<td>2 (11.1%)</td>
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<td>6. Cultural appropriateness</td>
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<tr>
<td>a. Match in logic, language, experience</td>
<td>18 (100%)</td>
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<td></td>
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<tr>
<td>b. Cultural image and examples</td>
<td>18 (100%)</td>
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information about and their preferred format for receiving that information. A list of 25 topics identified through earlier pilot studies [39,40] was used as a prompt. The list also contained an open-ended question to encourage participants to identify additional topics of importance to them that were not included on the list.

2.2. Data analysis

Data were entered into the Statistical Program for the Social Sciences, version 11.0.0 and analysed descriptively. To explore the influence of sociodemographic and clinical variables on patients’ reading ability the general linear model (GLM) procedure was used. The dependent variable was REALM score (raw score) and the independent variables were age, years of education, previous stroke (yes, no), presence of aphasia (yes, no), presence of perceptual impairment (yes, no), and presence of visual impairment (yes, no).

3. Results

The mean age of the patients was 72.2 years (range 35–92), 47% were female, and the mean years of education completed was 9.2 (range 2–18). It was the first stroke for 77% of the patients and 34 (59.6%) of the patients had had a left-sided stroke. Fifteen (26.3%) of the patients had aphasia (eight with expressive aphasia and seven with combined expressive and receptive aphasia), 12 (21.1%) had a stroke-related visual impairment, and 8 (14.0%) had a perceptual impairment. The carers’ mean age was 61.3 years (range 42–92), 75% were female, the mean years of education completed was 9.0 (range 6–12), and 58% of the carers were married to the person who had had the stroke. All participants were Caucasian and had English as their primary language.

3.1. Written information received while patient was in hospital

Written information was received by only 13 (22.8%) of the patients and 5 (41.7%) of the carers. Some participants received more than one written material, resulting in 22 different written materials being distributed. Copies of 18 of the materials were obtained for analysis. These consisted of materials from national (38.9%) and state (33.3%) stroke associations, and the hospital’s allied health department (27.8%). The four materials that were not able to be analysed were exercise sheets provided by therapists.

3.2. Reading level of the written materials received

The mean reading level of the written materials was equivalent to an 11th grade reading level (SD = 1.9, range = 8–14).

3.3. Content and design characteristics of the written materials received

Using the SAM, the mean score of the materials was 56% (SD = 9.9, range 38–71). Sixteen (88.8%) of the written materials were rated as adequate, with 1 (5.6%) each rated as superior and not suitable. Table 1 presents the frequency of SAM scores for each evaluation criterion. In the content factor, the criterion related to the content of the materials being about behaviours was scored as unsuitable for just under half (44.4%) of the written materials because they contained nearly all non-behaviour facts, rather than providing information about desirable behaviours that the readers could do to improve their health. The majority (94.4%) of the materials did not contain a summary or review of the content and were scored as unsuitable for that criterion. In the literacy demand factor, the reading grade level was not adequate (ninth grade level or above) in 77.8% of materials, however all of the materials provided advance organisers that informed the reader of the next topic. In the graphics factor, the types of graphics used were adequate in 44.4% of the materials, although 33.3% of the materials did not include captions to explain the graphics. In the layout and typography factor, the layout was superior in 72.2% of the materials, but the typography criterion was only scored as adequate in 66.7% of the materials as many of them used all capitals for headers and a font size less than 12 point. For the criterion of ‘subheadings’ in the layout and typography factor, 44.4% of the materials were rated as unsuitable because they presented more than seven items in a list without a subheading. Considering the learning stimulation and motivation factor, 53% of the materials did not incorporate interaction into the text or graphics, yet 84% of the materials divided complex topics into smaller parts so that readers may be more motivated to understand the content. All materials scored as superior on the cultural match criterion because the central concepts of the materials appeared to be culturally similar to the culture of the intended audience and all materials scored adequate on the culture image criterion as they presented cultural images in a neutral way.

3.4. Participants’ reading ability

The patients’ mean REALM score was 53.5 (SD = 18.2, range = 0–66), which is equivalent to a 7–8th grade reading level. The carers’ mean REALM score was 65.4 (SD = 1.1, range 63–66), which equates to a ninth grade or higher reading level.

3.5. Comparison of participants’ reading ability with the reading level of the written information

Table 2 shows the patients’ and carers’ reading ability compared to the reading level of the written materials. Thirty (52.6%) of the patients could not read beyond an eighth
grade level and therefore may have been unable to read 16 (88.9%) of the materials that had a reading grade level above eighth grade.

3.6. Influence of sociodemographic variables and stroke-related impairments on reading ability

Analysed using GLM, the overall best model was significant $F_{(2,55)} = 6.45$, $p = 0.003$. The only significant influence on REALM score was the presence of aphasia. The 42 patients without aphasia had a mean REALM score of 56.5 (SD = 15.8), the eight patients with expressive aphasia had a mean REALM score of 56.4 (SD = 12.9), and the seven patients with combined expressive and receptive aphasia had a mean REALM score of 32.3 (SD = 24.4). The REALM scores for those with and those without combined expressive and receptive aphasia were significantly different, $t$ (d.f. = 55) = 3.6, $p = 0.001$. The mean REALM scores for the patients without combined aphasia equates to a 7–8th grade reading level. For the patients with combined expressive and receptive aphasia, the mean REALM score equates to a 4–6th grade reading level.

3.7. Desired information and preferred format

The combination of desired additional topics was different for each participant. Some participants wanted to receive information about a few topics, while others wanted to receive information about nearly all of the topics contained on the list of stroke-related topics. Details about patients’ and carers’ informational needs have been published elsewhere [41]. The mean number of topics desired by participants was 10 (SD = 4.79, range = 0–21). Nearly all participants identified written information as their preferred format for receiving additional information.

4. Providing well-designed tailored information

In response to the findings related to current practice in providing stroke patients and their carers with written information, a patient-oriented stroke education package that could provide well-designed information tailored to the expressed informational needs of each patient/carer was developed. The education package that was developed was called the ‘What you need to know about stroke’ education package.

A comprehensive literature review [42] was undertaken to identify the principles that should be followed when designing written health education materials. These principles and the results of this study guided preparation of the package. After the content of the package was written, the principles were converted into a checklist and the education package was assessed according to this checklist, the SAM instrument, and readability formulae. Experts from the fields of neurology, patient education, stroke rehabilitation, and aphasia communication then reviewed the education package. Any necessary alterations were then made to the package.

The supporting database that allows tailored information to be generated was then developed. The intent was to develop a system that could easily be used by health professionals, easily be updated, operate on software and computing systems that are readily available in hospitals, and facilitate communication between health professionals and patients. Full technical details of the system design and results from a pilot study evaluating the usability of the system have been previously described [43].

The content of the package is divided into 34 topics. For some topics there are detailed and shortened versions available. There are also five ‘non-optional’ topics that are incorporated into each booklet as it is generated. These are topics that patients would be unlikely to request if asked, such as the purpose of the booklet and the glossary, however they were considered important to the overall completeness of the booklet. According to the SMOG, the reading grade level of the package is grade 7. An independent rater scored the package using the SAM and the mean score is 79.5% (SD = 5.3, range 74–90), which is in the category of superior material.

There are three tailoring features available. Patients/carers identify which topics they would like about each topic, and the font size that they would like the information to be printed in. The health professional interviews the patient and/or carer, using a checklist to establish their informational needs. The identified needs, along with preferred font size, are then entered into the database and the tailored booklet is automatically generated in Microsoft Word. The health professional can then print the booklet, place it in a folder, personalise the cover page with the patient’s name and the date, distribute the booklet to the patient/carer and provide accompanying verbal education and reinforcement.

5. Discussion and conclusion

5.1. Discussion

In this paper we have investigated inadequacies in the written information that is provided to stroke patients and
their carers. There was a poor match between the reading level of the written materials provided and patients’ reading ability, with the reading level of most of the written materials (89%) higher than the reading ability of over half of the patients (52.6%). Although the mean REALM score for carers indicated a reading ability of ninth grade level or higher, it has been demonstrated that people of all literacy levels find materials with lower reading levels easier to understand [44]. The REALM was designed as a screening instrument to provide reading grade estimates for people who read below a ninth grade level [45]. All of the carers and 27 (47.3%) of the patients could read at the REALM’s highest measurable level (ninth grade), although information about the extent to which these participants’ reading abilities were greater than ninth grade is not provided by the REALM. As 89% of the materials were at or above a grade 9 reading level, it is possible that many of the materials were too difficult for even the participants who read at the REALM’s highest level to comprehend.

The content and design characteristics of written education materials have received far less attention in the literature than the issue of reading levels. However, these features can also influence the comprehension of information [32]. Although 89% of the written materials received an overall rating of adequate on the SAM checklist, there were areas for improvement in most of the written materials. Features of the written materials that were frequently omitted included subheadings, stimulation that encourages reader interaction, summaries of sections or the entire material, font size of at least 12 point, and captions that explain graphics. These features could easily be incorporated into the written materials to enhance their suitability as education materials.

The finding that years of education was not a significant influence on reading ability should serve as a caution for health professionals who may rely on patients’ reported years of education as a proxy for reading ability. Reading ability is not necessarily dependent on educational attainment [31] and relying on reported years of education as an estimate of reading ability may result in an overestimation of reading ability. Studies have shown that a person’s reading ability is generally between 2 and 4 years lower than their reported years of education [46,47]. Reading ability however, has been shown to be a predictor of difficulty understanding written information [31].

Combined expressive and receptive aphasia was the only stroke-related impairment that had a significant influence on reading ability. Although expressive aphasia can cause reading difficulties, the lack of a significant finding regarding its influence on reading ability in this study is most likely reflective of the study’s inclusion criteria, whereby patients with moderate or severe expressive aphasia, who potentially would have had difficulty reading, were not considered, by the stroke unit speech pathologist, to have a communication status sufficient to participate in the study. It is possible that the patients with combined aphasia had a more severe aphasia overall than the patients with only expressive aphasia.

The lack of significant findings regarding the influence of visual and perceptual impairments on reading ability is also likely a result of the inclusion criteria whereby patients with a severe level of impairment that impeded the ability to complete interview tasks were not considered eligible for the study. The small percentage of participants in this sample that had these impairments and the resultant low statistical power, may have also led to non-significant findings. Age was also not found to have a significant effect on reading ability. The small sample size may have reduced the statistical power of the analysis and therefore this result should be considered with caution.

In addition to ensuring that written materials are well-designed, education materials should also provide the information that patients and carers want. Given the inherent variation in the nature of stroke and its effects, it is not surprising that no two participants wanted to receive information about the same combination of topics and this finding reinforces the need to provide patients and carers with information tailored to their needs. A Cochrane review concluded that meeting the expressed informational needs of patients and carers should be the focus of future research [48]. The disparity between what health professionals think patients and their carers want to know and what patients and carers actually want to know has been highlighted by a number of authors [49–51]. The importance of establishing the informational needs of patients and carers and designing an education intervention to meet those needs cannot be underestimated. The provision of computer-generated tailored information is one method of meeting the informational needs of patients and their carers.

5.2. Limitations of the study

Participants in this study were recruited from one metropolitan hospital and only patients who had the communication, cognitive and visual skills necessary to complete interview tasks were included. Therefore, the results of this study may not be generalisable to other settings and all stroke patients. The small sample size restricted the power with which the results could be confidently confirmed.

5.3. Practice implications

Health professionals who work in the area of stroke should routinely assess patients’ and carers’ desire to receive written information. The use of a checklist may ensure that all topics are covered. When deciding whether to use written information, health professionals need to be aware of patients’ reading ability. The administration of a literacy screening instrument such as the REALM can be used to assess reading ability. The presence and severity of stroke-related impairments that may impact on reading ability, particularly aphasia, should also be considered. The provision of written information should be accompanied by supplementary and reinforcing verbal education.
Health professionals need to have access to well-designed written education materials that cover all stroke-related topics. Materials should be assessed using both a readability formula and a broader instrument such as the SAM. The materials should accurately convey information at the lowest reading level possible. Health professionals should provide patients and carers with information that is tailored to their expressed informational needs and reading ability.

References


