Even though providing information after stroke can improve patient and carer knowledge, reduce patient depression, and increase some aspects of patient satisfaction, patients and carers often report a lack of or dissatisfaction with information provided.2–6 Given the importance of education in poststroke care,7 the identification of potential challenges to information provision is crucial for addressing these concerns.

A small number of studies have reported some challenges surrounding the provision of information to this population, but patients’ perspectives have not been explored in detail. The aim of this study was to identify patients’ and carers’ perceived barriers to accessing and understanding information about stroke. Method: Interviews were conducted with patients and their carers prior to and 3 months following discharge from an acute stroke unit. Transcripts were analysed using qualitative content analysis. Results: The three categories of barriers were identified: (1) limited availability and suitability of information, (2) barriers in the hospital environment, and (3) patient and carer barriers. Three themes were also identified, namely, (1) who is responsible, (2) communication, and (3) not knowing. Conclusion: These results have clinical implications for the way in which health professionals coordinate and present stroke information to patients and carers. Addressing these barriers may enhance patients’ and carers’ access to, understanding of, and satisfaction with information about stroke. Key words: stroke, barriers, cerebrovascular accident, health education, health information, patient education, qualitative, written education materials
In summary, barriers to appropriate information provision have been explored in areas outside stroke, but few studies have explored these in detail for the area of stroke. Therefore, to inform best practice in stroke education, there is a need to explore in-depth the perceptions of patients with stroke and their carers. The aim of this study was to identify the barriers to accessing and understanding information as perceived by this population.

Methods

Semi-structured interviews were completed with stroke patients and their carers at two points in time. Responses were analysed using qualitative content analysis.

Recruitment

Participants were patients admitted to a major metropolitan hospital acute stroke unit in Brisbane, Australia, and their carers. Inclusion criteria were the following: (1) being, or caring for, a patient with a current acute stroke unit admission for stroke (first or subsequent); (2) 18 years or older; (3) adequate English, cognition, communication, vision, and hearing to complete consent and questionnaire; and (4) living within 50 km of the hospital (for ease of face-to-face follow-up). Patients were excluded if they had a poor medical prognosis, were admitted from residential care, or had residential care as their planned discharge destination. To incorporate the opinions of as many carers of patients returning to the community as possible, we included the carer if he or she met all the criteria even if a patient was ineligible for the study due to criteria 3. Determination of adequate English, cognition, communication, vision, and hearing was done in consultation with the treating team, and patients with aphasia were invited to participate in the study after consultation with the treating speech pathologist. Aphasia-friendly principles, such as the use of pictures, white space, prompt sheets, gestures, and repeating of information were used throughout the consent process and interviews to maximise the understanding and participation of patients with aphasia.

Data collection and analysis

A brief interview posed two open-ended questions at two times. Prior to discharge, the two questions were “While you or your relative has been in hospital, is there anything that has prevented you from getting the information that you wanted about stroke?” and “While you or your relative has been in hospital, is there anything that has prevented you from getting the help that you have needed to understand the information, access services, learn skills, and/or change behaviours?” Three months following discharge, the two questions were “Since you or your relative were discharged, has there been anything that has prevented you from the getting the information that you wanted or needed about stroke?” and “Since you or your relative were discharged, is there anything that has prevented you from getting the help that you have needed to understand the information, access services, learn skills, and/or change behaviours?”

Data were collected via face-to-face interview and review of the patient’s medical chart. Details were collected about the following demographic and clinical variables: type of stroke, age, gender, living situation, years of education completed, and reading ability (as determined by the Rapid Estimate of Adult Literacy in Medicine [REALM]).

Responses were transcribed online during the interview by the interviewer and checked and revised immediately after the interview. Field notes were used to contextualise the responses. Transcripts were analysed using qualitative content analysis based on the steps described by Graneheim and Lundman. Data were divided into meaning units, which were then condensed while maintaining the core meaning. Subsequently, meaning units were grouped together into codes that were closely related and then labelled (eg, meaning units of “being sick or stuck in hospital” and “you’re so ruddy sick” were grouped under the code of “too sick”). Groups of codes that shared common descriptive content were then grouped together into categories (eg, the codes of “too sick” and “stroke-related impairment” were grouped into the category of “my health gets in the way”). Themes or “. . . thread(s) of underlying meaning through condensed meaning units,
codes or categories, on an interpretive level\textsuperscript{19(p107)}
were also chosen. Transcripts and field notes were read multiple times before meaning units, codes, categories, and themes were allocated by the interviewer (S.E.). They were then reviewed by two researchers (L.W. and an independent researcher) with experience in qualitative analysis and were discussed until consensus was reached.

Procedure

Ethical approval was received from hospital and university ethics committees. Eligible participants were identified by the acute stroke unit team and invited to participate. Initial interviews were completed in the week preceding discharge from the acute stroke unit (mean 11.2, SD 8.6, days post stroke) with follow-up interviews completed approximately 3 months later (mean 102.4, SD 10.4, days post stroke).

All interviews were conducted face-to-face by the first author (S.E.).

Results

Participants

Between November 2007 and June 2008, 132 patients and 44 carers were screened for eligibility. Initial interviews were conducted with 34 stroke patients and 18 carers and follow-up interviews were completed with 27 patients and 16 carers. Figure 1 shows the flow of participants throughout the study. Participants’ demographic and clinical details are presented in Table 1.

Analysis of the data revealed three broad categories of barriers to accessing information, each with numerous subcategories. The three categories were as follows: (1) limited availability and suitability of information, (2) the hospital environment, and (3) patient and carer factors.

\begin{figure}[h]
\centering
\includegraphics[width=\textwidth]{figure1.png}
\caption{Participant flowchart.}
\end{figure}
The amount of information provided by health professionals was a strong focus for both patients and carers. A minority reported too much or an “information overload” (patient, following discharge). A carer (following discharge) stated that at the family meeting the health professionals “told us everything . . . [I felt] absolute terror, but now I want to know a few things.” However, the majority of comments referred to an inadequate quantity of information. Comments such as “no one’s said anything” (patient, prior to discharge) and “I never had anything to read about it” (patient, following discharge), indicated a perception of absence of information, whereas other comments, such as “didn’t have relevant brochures . . . not a lot of detail” (carer, following discharge), “you don’t get much info after leaving hospital” (patient, following discharge), and “isn’t much available” (patient, following discharge), described an incomplete provision of information. Participants also expressed that even though some information had been provided, it often lacked the detail or the specific nature that they desired: “We were told it [shoulder subluxation] wouldn’t get better, but not told what we can do about it” (carer, following discharge) and “doctors and therapists not forthcoming with details, all general” (carer, prior discharge).

### Table 1. Demographic and clinical details of participants at initial interview

<table>
<thead>
<tr>
<th></th>
<th>Patients (n=34)</th>
<th>Carers (n=18)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female, n (%)</td>
<td>14 (41.2%)</td>
<td>13 (72.2%)</td>
</tr>
<tr>
<td>Age, years [mean (SD, range)]</td>
<td>63.3 (16.0, 28–85)</td>
<td>59.5 (14.3, 26–77)</td>
</tr>
<tr>
<td>Years of education [mean (SD, range)]</td>
<td>11.8 (3.9, 7–22)</td>
<td>11.9 (4.3, 7–24)</td>
</tr>
<tr>
<td>Mean REALM score (range)</td>
<td>61 (23–66)</td>
<td>63 (52–66)</td>
</tr>
<tr>
<td>Reading ability</td>
<td>9th grade and above</td>
<td>9th grade and above</td>
</tr>
<tr>
<td>Living situation, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alone</td>
<td>7 (20.6%)</td>
<td>0</td>
</tr>
<tr>
<td>With spouse (with or without other family)</td>
<td>22 (64.7%)</td>
<td>17 (94.4%)</td>
</tr>
<tr>
<td>With family or friend</td>
<td>5 (14.7%)</td>
<td>1 (5.6%)</td>
</tr>
<tr>
<td>Type of stroke, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ischaemic</td>
<td>23 (67.6%)</td>
<td>N/A</td>
</tr>
<tr>
<td>Haemorrhagic</td>
<td>11 (32.4%)</td>
<td>N/A</td>
</tr>
<tr>
<td>Side of stroke, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Left</td>
<td>18 (52.9%)</td>
<td>N/A</td>
</tr>
<tr>
<td>Right</td>
<td>15 (44.1%)</td>
<td>N/A</td>
</tr>
<tr>
<td>Bilateral</td>
<td>1 (2.9%)</td>
<td>N/A</td>
</tr>
</tbody>
</table>

Note: REALM = Rapid Estimate of Adult Literacy in Medicine; N/A = not applicable.

*Two patients were unable to complete the REALM.
to discharge). Two carers described situations of being unable to access information due to hospital regulations “due to confidentiality, they couldn’t tell me over the phone” (carer, prior to discharge) and “they wouldn’t give us documentation and results when he left … had to go through the GP [general practitioner] to request it” (carer, following discharge). Overall this subcategory indicated a perception of lack of information.

**Not in the “right way”**

The third subcategory of barriers specific to the information being provided described inappropriate presentation of information, such as timing, format, and language used. Many participants commented on the timing of provision. One patient described a delay in accessing information, “the first 36–48 hours … I was waiting for something to happen …” (patient, prior to discharge), but participants predominantly described information as being too early: “In hospital, [my] mind [was] too bemused to ask the questions I need to know” (patient, following discharge), and “some of the early days, I can’t remember … may just need to allay fears in early days until I’m over the first hurdle” (patient, following discharge). Still others felt that different information should be provided at different times post stroke. “I’m sure they’ll tell us, when the time comes” (carer, prior to discharge), “it’s only now that I’m taking an interest” (patient, prior to discharge), and “it will be coming as he gets closer to discharge” (carer, following discharge). The potential for patients and carers to have differing timing needs was also acknowledged: “family might need it early” (patient, following discharge).

In addition to the timing of the information, participants described inaccessible formatting of information. Suggestions for improvement included the use of written material to supplement verbal information, “can’t read all that stuff, I need to be told first with written to follow” (patient, following discharge) and “should be written down for them (patients)” (carer, following discharge), and a clearer layout of written information, “need to be written more simply” (patient, following discharge). Additionally the use of technical language or “medical jargon” was disliked, “… they use big words sometimes …” (patient, following discharge) and “they talk in their language. When they’re finished, I think I have an idea, but [I’m] not really certain” (patient, prior to discharge), as was conflicting information, “lots of different answers given” (carer, following discharge), “they do a lot of fence sitting” (patient, following discharge), “one guy said it was the grog [alcohol], another said it wasn’t, so what do you do?” (patient, prior to discharge), “yes … no … still don’t know” (patient, following discharge), and information presented unclearly, “they didn’t explain the dosages properly before discharge, so GP had to explain” (patient, following discharge). In summary, for this category participants described several barriers that relate to a lack of suitable and accessible information, including a lack of provision, an inability to source information, and inappropriate presentation of information.

**Category two: the hospital environment**

The second category of barriers was broadly grouped under those relating to hospital environment, with subcategories of (a) continuity of care and communication and (b) no one has time/ limited access to resources.

**Continuity of care and communication**

Disruption in the continuity of care was also felt to impede access to information. For example, a carer (prior to discharge) reported that a “long weekend [meant] skeleton staff,” and a patient (prior to discharge) noted that public holidays like “Easter [meant that I have] had all the tests [completed], but can’t get results.” In addition to holidays disrupting the flow of normal service delivery, participants felt that changing shifts and rotating staff resulted in a “lack of communication between staff” (carer, prior to discharge), for example, having a “different doctor at follow-up [was] disappointing … [he] wasn’t up to speed, didn’t know anything” (patient, following discharge). This point was also noted in day-to-day follow-up, with a carer (following discharge) observing that a “change in doctors the weekend before the family conference and discharge” was frustrating
and limited effective information sharing. Finally, communication between health professionals was also perceived as limiting access to information: “[there is] not much communication between therapists and nurses” (carer, following discharge), referring to the results of a speech pathology swallowing assessment and the need to update the menu options available to the patient; and “they’re a bit slow in sending information” (patient, following discharge), referring to the completion and transfer of a discharge summary to the general practitioner for follow-up.

No one has time/ limited access to resources

While participants acknowledged limited resources from the health service perspective, for example, “the staff are overworked” (patient, prior to discharge) and “no one has time … staffing is so short” (carer, following discharge), they also reported limited access to medical staff: “doctors are not around when he’s [the patient] alert and wants to ask questions” (carer, prior to discharge), “doctors had little time to explain what happened [which] put more pressure on OTs [occupational therapists] and ST [speech therapist] to answer questions” (patient, following discharge), and “you were lucky to get a doctor to come and speak with [you]” (patient, following discharge).

“Being in hospital all the time [with] no access to internet with printer” (carer, prior to discharge) limited participants’ ability to source information online, and access to stroke-specific information was perceived as limited for those stroke patients who were admitted as outliers to the stroke unit and therefore located in a different ward. For example, “because he wasn’t on [the] stroke floor, [we] didn’t have relevant brochures” (carer, following discharge), and “I was out of mind, out of sight” (patient, following discharge). Consequently a lack of resources in the hospital environment was perceived as a barrier to participants accessing information.

Category three: patient and carer factors

The third category of barriers grouped together patient- and carer-related factors such (a) as lack of time, (b) not asking for information, (c) health “getting in the way,” and (d) poor recall as barriers to accessing and utilising information.

“Haven’t had time”

Being “snowed under” (carer, prior to discharge) or not having “time to pick up a telephone or get on the internet” (carer, prior to discharge) limited participants’ ability to gather information. A carer (prior to discharge) commented, “I know they [health professionals] are all busy, but so are we,” and a carer (prior to discharge) stated, “I haven’t got around to getting it,” indicating a desire for information but an inability to access it due to time restrictions.

“I’ve never asked”

A second patient- and carer-related factor described by participants was their acknowledgment that, for a variety of reasons, they did not seek out information. Patients in particular commented that they “didn’t talk about it much” (patient, prior to discharge), “haven’t asked that much” (patient, prior to discharge), or “haven’t tried to get anything” (patient, following discharge). One reason for this was being uncomfortable approaching staff, “No one is an expert. I wouldn’t think of asking some of them” (carer, prior to discharge), “[I] did try once [but] she [health professional] wasn’t very helpful” (carer, prior to discharge), or feeling intimidated by the hospital environment, “You get the feeling that it’s not your place to badger them” (patient, following discharge), and “I don’t want to be a whinger, so I didn’t tend to ask” (patient, prior to discharge). Some participants didn’t know what to ask: “There could be whole bunch of other things that I don’t know about” (carer, following discharge), and “don’t really know until you go home” (patient, following discharge). A third reason for not seeking out information was being “in denial” (carer, following discharge), and “… denial … the fear … I don’t want to know. I want to run away” (carer, prior to discharge). Being overwhelmed was a fourth reason, “I had myself in such a state (patient, following discharge), or as described by
a carer (following discharge) “try[ing] to get your head around [it].” A fifth reason was assuming that information would be given to them or taking on a passive or “sick” role. For example, “I just haven’t asked, haven’t bothered the doctors” (carer, prior to discharge), “[I] never thought about it. I assumed I would be given the information I needed” (patient, prior to discharge), “[I’ve] gone along with the flow, just waited for people to tell me” (carer, following discharge), and “My problem is [that] I want for it to come to me. If there’s something I need to know I assume that doctor will tell me” (carer, following discharge).

These reasons for participants not seeking information (being uncomfortable approaching staff, not knowing who to approach, being in denial, being overwhelmed, taking on a passive or sick role) were contrasted by a small number of participants who reported to not want or plan to use information: “I put it behind me. I don’t know that I needed information” (patient, following discharge), and “we haven’t tried to get anything . . . didn’t feel we needed more information” (patient, following discharge).

“My health gets in the way”

Poor health impeding access to information was another subcategory of patient- and carer-related factors. This could refer to the acute illness, for example, being “too sick to take advantage of education” (patient, prior to discharge), and “you’re so ruddy sick . . . [It’s too hard] to even think about asking or taking it on board . . . need time to stabilise” (patient, prior to discharge). Alternatively this could refer to a premorbid impairment such as hearing impairment, “[patient] is deaf and he doesn’t always tell people . . . He wouldn’t always get it right” (carer, prior to discharge). Additionally, stroke-related impairments were reported as getting in the way of accessing information, for example, a communication impairment such as aphasia, “one of the jokers [a staff member] has prevented me from understand[ing] . . . he doesn’t understand what I’m saying . . . [which] stops [me from asking questions]” (patient who had aphasia, prior to discharge), or a cognitive impairment such as memory difficulties, “I don’t have intelligence anymore” (patient, following discharge) and “He’s [patient] not going to remember it” (carer, prior to discharge).

“I’d forgotten”

The final patient and carer factor was related to the recall of information provided, for example, “I wasn’t sure . . . if I’d asked. I’d forgotten” (patient, prior to discharge), “[They] may have told me but [the information has] gone in and out . . . didn’t register” (patient, prior to discharge), “[I]did hear the doctor talking to her [patient] but my short-term memory . . . I wasn’t absorbing it” (carer, prior to discharge), and “they did explain it to me but it didn’t sink in, my mind” (patient, following discharge).

Themes

One of the themes to come from these data relates to the question of who is responsible for the provision or access of information. Participants acknowledged that they often did not seek out information, instead waiting for it to come to them or assuming that it would. They appeared dissatisfied with the amount of information provided by health professionals, and this raises the issue of who should be initiating this process.

Another theme found across the categories relates to communication and the role it plays in the sharing of information. Participants commented on the importance of the way information is presented to them by health professionals, for example, using medical jargon or supplementing verbal information with written material. Participants also reported a lack of communication not only between health professionals and participants but also between health professionals. Additionally, the impact of communication impairments such as aphasia and hearing impairment was noted by participants.

A third theme that emerged from these data was the concept of not knowing: of not knowing where to go for information, not knowing who to ask, and of not knowing what information to ask for. Stroke patients and carers may recognise the need (and therefore want) information on some topics but
may not recognise the need for information on other topics (that is, they do not know what to ask about when they do not know what they do not know).

Discussion

This study confirms several of the barriers that have been found elsewhere. These include patient- and carer-related problems such as not knowing what to ask,9,10 the impact of premorbid or stroke-related impairment,9,11,20 the information-related factor of the use of medical jargon,3,9 hospital environment-related issues such as health professionals being too busy,8–10,12,15 and limited communication amongst health professionals.9,11,14 The “knowledge problems” of health professionals that were found in Coulter et al’s15 study, such as doctors not being aware of all the treatment options available, were not specifically reported by participants in this study, but our participants did refer to difficulties that arose from receiving conflicting information.

A unique finding of this study is the impact of carers having limited time available to seek and access information. Previous research has identified limited health professional resources as a potential barrier to patients and carers accessing information, but the current study recognises that limited consumer resources can also be a barrier.

The importance and benefits of presenting information in a suitable manner (eg, by using an active delivery style, repeating or reinforcing information, and making information available in variety of media, including well-designed written material) are well documented in the literature.1,3,21–25 However as patients and carers perceived elements of information presentation as barriers, this suggests that these practices are currently less than optimal. The theme of communication emphasises the need for education to be a two-way, interactive process between individuals and health professionals. By providing suitable information tailored to clients’ and carers’ needs and preferences (including content, format delivery style, and timing), health professionals facilitate the opportunity for clients or carers to participate in their own health care.26

The theme of not knowing raises the concept of information needs versus wants. Tailoring information to an individual’s information needs is an important part of providing stroke information, as needs will differ from person to person.5,27 However patients and carers may not know what they do not know and therefore require guidance from health professional in selecting appropriate information. This is supported by discrepancies that have been found between patients’ and carers’ information needs as perceived by health professionals and by the patients and carers themselves.8,28,29 Answering patients’ and carers’ questions (information “wants”) may be a good starting point in providing information, but facilitating patients’ and carers’ awareness of additional topics, perhaps by providing them with a checklist of topics such as the ones described in Hoffmann et al30 or O’Farrell and Evans,9 may act as a prompt for further information. Supplementing individuals’ information “wants” with newly identified information “needs” in this way may help overcome the barrier of not knowing.

In a recent survey of Australian acute stroke hospital services, gaps were found in the coordination and documentation of stroke education.31 One possible solution to this is the use of a stroke educator. Hoffmann and Cochrane found that 23.5% of acute stroke services surveyed would like to have an educational coordinator position and 23.5% would like to offer their patients postdischarge education and support.31 A dedicated information provider, perhaps based within the stroke unit with the flexibility to provide postdischarge follow-up, who can initiate the provision of information could act as a prompt to patients and carers. Furthermore, this structured approach to information provision could address the issues of patients and carers “not knowing where to go” and health professionals being “too busy.”

Limitations

This study did not explore health professionals’ perceptions of barriers to patients and carers accessing and understanding stroke information, nor did it explore facilitators to the provision of information to patients and carers. Both are potential areas for future research. Replication of this study, with the expanded focus of also
obtaining information about facilitators, at a longer time post stroke would also be of benefit as patients and carers continue to need information many months and years after stroke.32

Conclusion

This qualitative study identified three categories of patient and carer perceived barriers to stroke information provision: (1) limited availability and suitability of information, (2) the hospital environment, and (3) patient and carer factors, with numerous subcategories. Themes of “who is responsible,” “communication,” and “not knowing” were also identified. These results have clinical implications for the way in which health professionals coordinate and present stroke information to patients and carers. Addressing these barriers may enhance patients’ and carers’ access to, understanding of, and satisfaction with information about stroke.

Acknowledgments

Ms. Eames was in receipt of an Australian Postgraduate Award (APA) scholarship during this research. The authors would like to thank Ariane Laplante-Lévesque for assistance with data analysis and acknowledge Associate Professor Kryss McKenna for advice on project design.

REFERENCES


