The Provision of Health Information to Stroke Patients Within an Acute Hospital Setting: What Actually Happens and How Do Patients Feel About It?

Kimberly Knight, Linda Worrall, and Tanya Rose

This preliminary study describes how health information is provided to stroke patients in an acute hospital and describes their perceptions of health information provision. A further aim was to determine if patients with aphasia were disadvantaged in their receipt of information. Seven stroke patients were observed in hospital for an average of 102 minutes each and then interviewed using a semi-structured interview. When communication occurred, only 17.5% of communication time was spent providing information. Patients with aphasia received information for less time and on fewer topics. Implications regarding approaches to information provision for patients with and without aphasia are discussed. **Key words:** aphasia, health information, stroke, stroke unit

In the immediate aftermath of a stroke, stroke patients not only have to deal with the effects of the stroke but also with the sense of bewilderment and confusion about what has happened. In this acute period (the first month after stroke), it is expected that the major goals of health care are the physiological and medical stabilization of patients and assisting patients with the emotional impact of stroke. Patient and family education about the nature of stroke is therefore expected to be a key component of health care within the acute stroke recovery period.

Research has consistently found large gaps in the provision of health information to stroke patients. This is a concern, because the benefits of providing health information are well documented. Health information provision has been linked to increased patient motivation, reduced anxiety, improved patient compliance to treatment programs, improved satisfaction with health care, empowerment of patients in their relationships with health professionals, and greater adjustment to stroke. The benefits of health information provision, however, have not conclusively been found to extend to overall improvements in health and psychological outcomes for stroke patients.

These studies have highlighted the need to consider the specific requirements of patients and their carers in the provision of health information. The World Health Organization states that all patients have a right to receive information about their health condition that is factual, easy to understand, accurate, and appropriate to their needs. It is therefore paramount that research examining the current state of health information provision to stroke patients considers their perceptions of the health information that is provided.

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Stroke patients have consistently requested health information in the acute stroke period on topics such as stroke, stroke prevention, stroke effects, and stroke causes; recovery prognosis and recovery rate; how to cope with self-care activities; and available resources and support. Stroke patients have also shown a preference for a combination of written and verbal health information. Health information specific to patients’ individualized needs is highly desirable amongst stroke patients. Currently the general and specific health information needs of individual patients are not being met satisfactorily.

Stroke patients commonly report high levels of dissatisfaction with health information provided in hospital. A complete absence of information provision regarding their illness has also been reported. Some stroke patients’ knowledge of what a stroke is and its associated symptoms or risk factors is incomplete or inaccurate. In one study, 27% of patients were unaware of their diagnosis 3 weeks after their stroke, and 10% thought they were in hospital due to another health condition. In another study, 22% of patients did not differentiate between a stroke and heart attack, and 70% were not informed about the risk of stroke recurrence. Another study reported that 32% of patients still had questions regarding stroke and its causes on discharge from hospital. These studies highlight the gaps in health information provision to stroke patients in the acute hospital setting.

It is acknowledged that patients may report dissatisfaction with health information and/or may perform poorly on measures of stroke knowledge even when verbal information, written information, or a combination of both has been provided. This has been attributed to the patients’ inability to retain information due to emotional stress or associated impairments; the information provided by health professionals lacking content and quality; or health professionals not accounting for patients’ misunderstanding or misinterpretation of information provided. This highlights the importance of considering both the needs expressed by patients as well as the actual delivery of health information within the acute hospital setting.

It is estimated that one third of stroke patients acquire aphasia as a result of their stroke. Aphasia is a language impairment that may interfere with a person’s ability to express and understand language as well as the ability to read and write. These are the very skills that enable patients to participate effectively in receiving and requesting health information within the hospital setting. A study that provided a comprehensive insight into the lives of people with aphasia, at various stages of recovery, found that “blocked” access to health information was a major issue for people with aphasia. Stroke patients with aphasia were often left with a feeling that “everything [seemed] a secret.”

This is particularly problematic in the acute stroke setting when the potential benefits of health information provision is being considered. The health information needs of people with aphasia are not considerably different from those of stroke patients without aphasia. Furthermore, similar to the needs of stroke patients without aphasia, the health information needs of persons with aphasia can differ from patient to patient. Health information provision therefore needs to take into account individual needs. For stroke patients with aphasia, this means accounting for language difficulties that may be interfering with their ability to access health information. A lack of patient inquiry should not be interpreted as an indication of lack of interest or need. It is also important for health professionals to check patients’ understanding rather than waiting for them to indicate a need for more information. Health information should be clear, accurate, concrete, and consistently made available by using communication strategies that support the language needs of the patient. It has been stated, however, that in the acute hospital setting there is inequality in the access to health care for stroke patients with aphasia, but this inequality has attracted little attention. Many studies that have investigated the needs or perceptions of stroke patients regarding health information provision have excluded stroke patients with aphasia due to their language impairment. Eames et al. highlight the vulnerability of people with aphasia in accessing health information. Despite similar informational needs, stroke patients with aphasia were less likely to report receiving health
information from health professionals and were more likely to report that family and friends were the main providers of health information. They also were more likely to express their need for support from health professionals in accessing and understanding health information.11

The use of the International Classification of Functioning, Disability and Health16 as a framework for service provision encourages a combined medical and social approach. This framework is increasingly calling for health professionals to consider the widespread effects of disability on an individual and to focus on disabling barriers, promoting patients’ equal opportunities, and advocating for patients rights.17 Within a system whereby the provision of health information is already inadequate, stroke patients with aphasia are vulnerable to being left out of the information loop. This study therefore aims

1. (i) To describe how much health information is provided to patients in the acute stroke unit.
   (ii) To determine whether patients with aphasia receive less health information than patients without aphasia.

2. (i) To describe patients’ perceptions of and satisfaction with the provision of health information.
   (ii) To determine whether the perceptions of health information of patients with aphasia are different from patients without aphasia.

3. (i) To describe patients’ knowledge of stroke on discharge from the acute stroke unit.
   (ii) To determine whether patients with aphasia report less knowledge of stroke.

Method

A qualitative approach was used in this study to explore the realities of participants’ time in the acute stroke setting as well as participants’ perspectives during their stay. Both participant observation and qualitative semi-structured interviews were used to obtain insider and outsider perspectives of an acute stroke unit, with the aim of bridging the gap between the two perspectives.18

Participants

A total of seven participants were eligible for participation in the study during the 6-week data collection period; two participants with aphasia (Group A) and five participants without aphasia (Group B). All participants who were approached gave written informed consent to participate in the study. Special considerations were made when gaining consent from participants with aphasia (Group A) to ensure that their decision-making capacity was not masked by their language loss.19 The following guidelines as recommended by Kagan and Kimelman19 were adhered to when gaining consent from this group: (a) proxy decision makers were not used, (b) information regarding the study was given in an aphasia-friendly format in combination with online verification of the participants’ comprehension, and (c) a clear distinction between treatment and research was also made.19 Participants were all patients admitted to the acute stroke unit at the Princess Alexandra Hospital in Brisbane, Australia. Data were collected within a consecutive 6-week period (August 2004–September 2004).

To be eligible to participate in the study, participants admitted to the acute stroke unit required a medical diagnosis of a cerebrovascular accident (CVA) or transient ischaemic attack (TIA). Participants also required a medical and cognitive status conducive to providing informed written consent. Medical and cognitive competency of each participant was advised by the treating speech pathologist on the acute stroke unit. The speech pathologist also identified suitable participants and gained the initial consent in a double consent process. In addition, participants with aphasia (Group A) were required to have reliable yes/no responses. The treating speech pathologist advised the researcher regarding each participant’s eligibility in respect to these criteria.

Table 1 shows the relevant characteristics of each group including participant’s age, gender, type of stroke, length of stay in the acute stroke unit, destination after discharge from the acute stroke unit, presence or absence of hemiparesis, and aphasia typology (where applicable). Ages ranged from 66 to 99 years (M = 78 years, SD =
Provision of Health Information

16.97) in the group of stroke patients with aphasia (Group A) and from 41 to 76 years (M = 56.2 years, SD = 12.9) in the group of stroke patients without aphasia (Group B). All participants spoke English as their first language. The two groups differed according to their average lengths of stay in the acute stroke unit. The average length of stay of stroke patients with aphasia (Group A) was 4.5 days, whereas the average length of stay for the group of stroke patients without aphasia (Group B) was 10 days.

A third group of participants involved in the study was the staff who came into contact with the participants during their time in the acute stroke unit. This group was a convenience sample made up of hospital staff including doctors, student doctors, nurses, speech pathologists, occupational therapists, student occupational therapists, physiotherapists, student physiotherapists, dieticians, pharmacists, and wards people. Written information was provided to the staff regarding the project and, where practical, verbal consent was gained from those staff members observed. Staff members were informed that observations of staff-patient communicative interactions would take place, however, they were not informed of the full nature of the project. Ethical clearance was obtained from the Princess Alexandra Hospital Human Research Ethics Committee and The University of Queensland Human Research Ethics Committee prior to the commencement of this research study.

Table 1. Patient characteristics

<table>
<thead>
<tr>
<th>Group A</th>
<th>Age (years)</th>
<th>Gender</th>
<th>Type of stroke</th>
<th>Length of stay in acute stroke unit (days)</th>
<th>Discharge destination</th>
<th>Hemiparesis</th>
<th>Aphasia typology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant 1</td>
<td>90</td>
<td>F</td>
<td>Left CVA</td>
<td>4</td>
<td>Rehabiliation unit</td>
<td>Absent</td>
<td>Mild expressive</td>
</tr>
<tr>
<td>Participant 2</td>
<td>66</td>
<td>M</td>
<td>Left CVA</td>
<td>5</td>
<td>Cardiology ward</td>
<td>Absent</td>
<td>Mild receptive and expressive</td>
</tr>
<tr>
<td>Group B</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participant 3</td>
<td>58</td>
<td>M</td>
<td>TIA</td>
<td>3</td>
<td>Home</td>
<td>Absent</td>
<td>N/A</td>
</tr>
<tr>
<td>Participant 4</td>
<td>50</td>
<td>F</td>
<td>Right CVA</td>
<td>12</td>
<td>Rehabilitation unit</td>
<td>Present</td>
<td>N/A</td>
</tr>
<tr>
<td>Participant 5</td>
<td>41</td>
<td>F</td>
<td>Cerebellar infarct</td>
<td>8</td>
<td>Rehabilitation unit</td>
<td>Present</td>
<td>N/A</td>
</tr>
<tr>
<td>Participant 6</td>
<td>76</td>
<td>M</td>
<td>Right CVA</td>
<td>9</td>
<td>Medical ward</td>
<td>Present</td>
<td>N/A</td>
</tr>
<tr>
<td>Participant 7</td>
<td>56</td>
<td>F</td>
<td>Right CVA</td>
<td>12</td>
<td>Rehabilitation unit</td>
<td>Present</td>
<td>N/A</td>
</tr>
</tbody>
</table>

Note: F = female; M = male; CVA = cerebrovascular accident; TIA = transient ischaemic attack; N/A = not applicable.

Data collection

The insiders’ (stroke patients’) perceptions of health information provision were obtained via semi-structured interviews. The outsiders’ (researchers’) perspectives of health information provision were obtained via participant observation.

Participant observation

Participant observation is a form of ethnography that enables the researcher to enter into real-life situations and gain an understanding of what happens in that environment. The process of participant observation as described by Spradley is a dual process that involves both observation and participation. It requires the observer to pay explicit attention to the environment, to consider the context in a broad perspective, and to keep and consider observatory records from both an insider’s and outsider’s perspective. Spradley draws a distinction between five levels of participatory observation ranging from high to low degrees of participation. Passive participation is the lowest level of participant observation and was the method used for this study. Passive participation requires the researcher to take on the role of a spectator or bystander who records observations. A recent study used passive participant observation to investigate the everyday communication events that occur within the hospital setting, with
particular respect to the daily communication activities of people with communication disorders. This study highlighted the appropriateness of using passive participant observation in a hospital context due to the obvious inability of the researcher to participate in the care of a patient. Participant observation therefore provided the researcher (an outsider) with a perspective on the provision of health information on the acute stroke unit.

Event sampling and time sampling were used to achieve a more comprehensive insight into information exchanges within the setting. Event sampling involved observing each participant in four common daily events (which varied from doctor's ward rounds, nurse's ward rounds, physiotherapy, occupational therapy or speech therapy sessions, dietician or pharmacist consultations, and discharge meetings). Time sampling involved observing each participant for two 30-minute sessions. Descriptions of the communicative interaction between the participants and health professionals were recorded in an observation log. The observation log required the researcher to note the initiator of the communication exchange, new topics in each exchange, as well as the communication format (i.e., spoken, written). The log also required the researcher to note the duration of the information exchanges during both event and time samples. This measure was used to gather descriptive statistics regarding the amount of time spent observing each participant, the amount of time health professionals spent communicating with participants, and the amount of time health professionals spent communicating health information to participants. The researcher also recorded self-reflections from events and times sampled. The stroke patients with aphasia (Group A) were observed for an average of 94 minutes each, and the stroke patients without aphasia (Group B) were observed for an average of 105 minutes each. As a whole, the groups were observed for an average of 102 minutes each.

**Semi-structured interviews**

Semi-structured interviews were used to gain the participants’ perspectives (insider perspective) regarding health information provided to them during their time in the acute stroke unit. Qualitative interviewing has been described as a useful research method to observe the “unobservable,” that is, to discover what someone’s thoughts are and to collect their story.18 The interviews used in this study were semi-structured. An interview guide (see Appendix 1) was used to ensure that each participant received similar questioning and that the interview time was well utilized.18 Several studies reporting on stroke patients’ satisfaction with health information provision and stroke patients’ informational needs have used a similar approach.7,10,11,23 Qualitative interviewing is thought to allow the researcher to explore issues in a greater depth7 and is preferable when patient satisfaction is an element of exploration.24

Each participant in the study was interviewed for 20 to 30 minutes. All interviews were conducted within 15 days of the onset of CVA or TIA. Interviews were conducted on hospital premises either on the acute stroke unit (Participants 3 and 7), on a rehabilitation ward (Participants 2, 4, 5, and 6), or the cardiology ward (Participant 1). Interviews were held no more than 5 days after participants had been formally discharged from the acute stroke unit. The interviews were structured so that participants initially were asked to describe their time in the acute stroke unit, and then broad topic guides including the amount, types, methods, and timing of information provision were used as prompts, if required (see Appendix 1). All interviews were tape-recorded with the permission of participants and were transcribed verbatim.

To gather additional information on the participants’ satisfaction with different aspects of health information provided and patients’ knowledge of stroke, a predetermined set of questions were asked. First, patients were asked to define stroke and, when appropriate, aphasia. Second, patients were asked close-ended questions that required a yes/no response. These were “Do you feel you received enough information about stroke?” and where appropriate “Do you feel you received enough information about aphasia?” Finally, participants were required to indicate their level of satisfaction with the range of topics on which they
received; information they received regarding stroke, and, where appropriate, aphasia; general health information they received; timing of information provision; methods of information provision; the way staff provided information; and an overall rating on a 4-point scale (see Appendix 2).

Results

Data analysis

Participant observation

Observation logs for four event samples and two 30-minute time samples were collected for each participant. One event sample, a discharge meeting, was missed for Participant 3. Each participant was observed in at least one doctor’s/nurse’s ward round and one therapy/treatment session. The data from the observation logs were analyzed in three ways.

First, the time recordings for each observation were used to calculate the duration that patients and health professionals spent in interactions without communication (no communication time) and communicating (communication time). From the communication time, the time spent communicating information (information time) was calculated. Health information was defined as a communicative exchange where participants were given facts or explanations that contributed to their knowledge of their health condition. Health information may have been requested by the patient or given to the patient by a health professional. A statement such as “I’m going to check your blood pressure now” [field notes] without any further explanation was therefore not counted as a health information exchange by the researcher. A statement such as “The type of stroke you had causes damage to your brain which has affected your co-ordination and balance” [field notes], however, was counted as a health information exchange. Second, the topics of health information were categorized and counted according to topics previously identified in the literature as being topics of information requested by stroke patients. Third, the researchers undertook a qualitative analysis of the descriptions of communicative interactions recorded in the observation logs. The coding process began initially with open or broad coding of the data. This involved allocating and defining categories and then allocating codes within each category for each participant. Cross-checking between the participants then resulted in a cycle of further analysis and coding, which ended once no new categories of codes emerged. Searches for within-group and across-group patterns were then conducted so that themes relevant to stroke patients as a whole as well as stroke patients with aphasia could be determined.

Semi-structured interviews

Interview transcripts were analyzed using the same coding process described above. The answers that participants supplied in response to the knowledge and satisfaction questions were analyzed separately. Participants’ definitions of stroke were analyzed and labeled according to their level of understanding of stroke or aphasia. An ordinal rating scale that contained categories of complete, partial, poor, and no understanding were used to determine their level of understanding (see Table 2). Participants’ responses to the closed-ended question “Do you feel you received enough information about stroke/aphasia?” as well as their level of satisfaction with information provision were tabulated and averaged for each group.

How is health information provided to stroke patients in the acute care setting?

The total length of time spent observing each participant is shown in Table 3. The proportion of time spent without communication (no communication time) or with communication (communication time) is also shown in Table 3. Across all participants, 56% of the observed interaction time between health professionals and participants was spent without any communication. During periods of communication, 18% of time was spent providing health information to the participants (refer to Table 3). Differences in the amount of time spent communicating health information were observed between participants with stroke only (Group B) and participants with aphasia (Group A). Stroke patients with aphasia (Group A) spent slightly less time participating in any com-
munication with health professionals. Of the total communication time observed, only 7% of this time was spent communicating about health information. In comparison, 22% of the communication with stroke patients without aphasia (Group B) was related to health information exchange.

The topics of health information exchange are reported in Table 4. The total number of information exchanges on health topics varied among the group, ranging from 4 to 24 ($M = 9.54$). The number of different health topics discussed with each participant also varied, ranging from a total of two different topics of health information up to a total of nine different topics ($M = 4.71$). The stroke patients with aphasia (Group A) received a lower total number of health information exchanges overall ($M = 4.5$) compared to stroke patients without aphasia ($M = 11.8$). The mean range of health

### Table 2. Stroke knowledge criteria

<table>
<thead>
<tr>
<th>Classification</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complete understanding</td>
<td>The participant indicates that a stroke is both:</td>
</tr>
<tr>
<td></td>
<td>1. damage to the brain</td>
</tr>
<tr>
<td></td>
<td>2. caused by interruption of blood flow (i.e., either hemorrhage and/or infarct). NB: Participant not required to identify both hemorrhage and infarct.</td>
</tr>
<tr>
<td></td>
<td>The participant may detail any specific effects the area of brain damaged has had on them.</td>
</tr>
<tr>
<td>Partial understanding</td>
<td>The participant demonstrates an understanding of only one of the above two pieces of information.</td>
</tr>
<tr>
<td></td>
<td>The participant may mention both of the above two pieces of information, however, appears to misunderstand the relationship between brain damage and blood flow.</td>
</tr>
<tr>
<td>Poor understanding</td>
<td>Participant gives a vague explanation of only one of the above two pieces of information.</td>
</tr>
<tr>
<td></td>
<td>Participant describes the effects of stroke only.</td>
</tr>
<tr>
<td></td>
<td>Patient may provide incorrect or contradictory information, which shows a misunderstanding of what a stroke is.</td>
</tr>
<tr>
<td>No understanding</td>
<td>Participant does not demonstrate any understanding of a stroke. Participant cannot or refuses to give a definition of a stroke.</td>
</tr>
</tbody>
</table>

### Table 3. Total observation times and proportion of no communication, communication, and information times

<table>
<thead>
<tr>
<th>Participants</th>
<th>Total observation time (hr)</th>
<th>No communication time (%)</th>
<th>Communication time (%)</th>
<th>Information time (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Group A</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participant 1</td>
<td>1:49.30</td>
<td>53</td>
<td>47</td>
<td>4</td>
</tr>
<tr>
<td>Participant 2</td>
<td>1:21.15</td>
<td>67</td>
<td>33</td>
<td>11</td>
</tr>
<tr>
<td>Subtotal</td>
<td>3:10:45</td>
<td>59</td>
<td>41</td>
<td>7</td>
</tr>
<tr>
<td><strong>Group B</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participant 3</td>
<td>1:37.34</td>
<td>62</td>
<td>38</td>
<td>57</td>
</tr>
<tr>
<td>Participant 4</td>
<td>1:18.51</td>
<td>70</td>
<td>30</td>
<td>9</td>
</tr>
<tr>
<td>Participant 5</td>
<td>1:38.05</td>
<td>51</td>
<td>49</td>
<td>40</td>
</tr>
<tr>
<td>Participant 6</td>
<td>2:10.04</td>
<td>38</td>
<td>62</td>
<td>2</td>
</tr>
<tr>
<td>Participant 7</td>
<td>1:58.50</td>
<td>59</td>
<td>41</td>
<td>8</td>
</tr>
<tr>
<td>Subtotal</td>
<td>8:43.24</td>
<td>55</td>
<td>45</td>
<td>21</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>11:54:09</td>
<td>56</td>
<td>44</td>
<td>18</td>
</tr>
</tbody>
</table>

*Rounded to the nearest whole number. ¹One event sample missed.
information topics discussed with stroke patients with aphasia (M = 3) was also less compared to stroke patients without aphasia (M = 5.4).

From the analysis of the data, three major themes emerged regarding the nature of health information provision to stroke patients within the acute stroke unit:

- the variability in the quality of health information provided to stroke patients;
- how the frequency of health information exchanges was affected by participants’ role, participants’ characteristics, health professional characteristics, and environmental characteristics; and
- how the frequency and quality of health information provided was affected by the presence of transmission barriers.

The quality (specificity, adequacy, and length) of health information provided was variable within individual event and time samples and across samples for all participants. Health information provided to participants was at times unspecific or specific or brief or more elaborate. No clear patterns emerged that could offer an explanation as to why health information exchanges differed greatly in their level of detail. The level of detail of health information refers to how relevant the health information was to the participants’ particular health condition, how informative it was, and how relevant it was to specific requests from participants (where appropriate) for health information. An example of a detailed explanation is the following:

When explaining the side effects of a medication to one participant, a health professional gave the participant the name of the medication and then explained what the medication did physiologically (“it makes the blood vessels open up”), related this to the particular side effect the patient was experiencing (“the tablets may have therefore given you the headaches”), and then gave an approximate time when the side effects were likely to stop presenting (“but you will only have them for a short while, a day or two, and then they will get better”). [field notes]

A contrasting example observed in a similar situation is the following:

In a discussion regarding the potential effects a medication could have on alleviating presenting symptoms, the health professional gave a definite response (“no, it won’t”), and then gave an arbitrary indication on the likelihood of symptoms being alleviated (“the dizziness will settle but may never go”). There was no explanation of the medication or any further discussion regarding the topic. [field notes]

In this example, neither the name of the medication nor any explanation regarding the function of the medication was given. It is brief and less informative compared to the preceding example.

The frequency of health information exchanges was influenced by four major factors: participants’ role, participants’ characteristics, health professional characteristics, and environmental/contexual characteristics. Each will now be discussed.

1. Participants’ role. Some participants were observed to take an active role in their health care, whereas others took a more passive role. Participants who took on an active role would initiate health information exchanges by spontaneously requesting information, clarifying information, and requesting further information if the initial information was insufficient. Participants who took on a passive role rarely initiated health information or communication exchanges, and no concerted effort was made to continue or extend communicative or health information exchanges. Participants who were more active in an observation saw a higher occurrence of health information exchanges. Participants 3 and 5 were active participants in all samples where communication took place; Participants 2 and 4 fluctuated between active and passive participation levels; and Participants 1, 6, and 7 were always passive participants. Participants’ passive or active behavior did not, however, seem to affect the level of detail in the health information provided.

2. Participants’ characteristics. Participant characteristics that appeared to influence the frequency of health information exchanges were the responsiveness of the participant and the levels of alertness, interest, and cooperation of the participant. In most instances where no health information was exchanged for an entire event or time sample, negative participant characteristics were observed. Participants 6 and 7 frequently displayed negative characteristics such as disinterest, fatigue, limited responsiveness or unresponsiveness, and uncooperativeness across all event and time samples. Participant 4 displayed a number of nega-
Positive characteristics (unresponsiveness, uncooperativeness, and fatigue) in one out of the five samples. No health information exchanges occurred within this sample. The stroke patients with aphasia (Group A) were observed to display negative characteristics of limited responsiveness or unresponsiveness in all samples where no health information was exchanged. Likewise, as participants' responsiveness increased, they were more likely to receive health information. Health information was, however, still provided to participants who displayed negative characteristics, and the negative characteristics did not affect the level of detail in the health information provided.

3. Health professionals' characteristics. Health professionals who checked participants' understanding, repeated information, and offered to follow-up with information were more likely to engage in health information exchanges and provide health information on a number of topics. Event and time samples were often cut short when health professionals appeared to be under time restrictions, and therefore opportunities to exchange health information were decreased, for example:

A health professional is standing at the end of the patient's bed (Participant 3) and the patient has requested some information regarding the medication that he has just been prescribed by the health professional. The health professional responds with a brief but specific explanation. The patient indicates that he requires further clarification/information. The health professional responds hurriedly and while talking to the patient regarding the medication he puts the patients' file in its holder and indicates the need to move on by walking towards the entrance. The patient (more than likely has understood that the health professional needs to leave) asks if he will be able to talk to the doctor later about his medication. The health professional indicates that the patient can discuss it with the doctor and leaves the room. [field notes]

4. Environmental/contextual characteristics. Environmental or contextual characteristics were defined as characteristics of the hospital environment or hospital procedures/activities that had an effect on the occurrence of health information/communication exchanges. Characteristics that resulted in shorter interaction time were the presence of other health professionals or significant others in the room, competing needs of another patient, and health professionals being called away. A participant's involvement in daily activities such as showering or eating a meal appeared to have had an effect on the occurrence of communication and health information exchanges. Some hospital procedures (i.e., ordering medical tests, waiting on transfer from another ward) that involved other hospital departments created uncertainty and made it difficult for some participants to be given information on some topics (i.e., which tests they would be having on a certain day and at what time). The only participant

<table>
<thead>
<tr>
<th>Table 4. Topics of information exchange</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment/therapy/advice</td>
</tr>
<tr>
<td>---------------------------</td>
</tr>
<tr>
<td><strong>Group A</strong></td>
</tr>
<tr>
<td>Participant 1</td>
</tr>
<tr>
<td>Participant 2</td>
</tr>
<tr>
<td><strong>Group B</strong></td>
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<tr>
<td>Participant 3</td>
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<tr>
<td>Participant 4*</td>
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<tr>
<td>Participant 5</td>
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<tr>
<td>Participant 6</td>
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<tr>
<td>Participant 7</td>
</tr>
<tr>
<td><strong>Total</strong></td>
</tr>
</tbody>
</table>

*One event sample missing.
(Participant 3) whose destination post discharge was to their home received the most health information during observations. Participants discharged elsewhere in the hospital (rehabilitation ward or alternate medical ward) varied widely in terms of the amount and type of health information received. Length of stay on the acute ward did not appear to influence the amount or types of health information provided. A pattern that emerged only for stroke patients with aphasia (Group A) was that the occurrence of health information exchanges occurred only when significant others were present.

The presence of transmission barriers had an effect on the occurrence and quality of the health information provided. A transmission barrier refers to a barrier that hindered a participant’s ability to request or receive health information. Observed transmission barriers included poor vision, reduced hearing abilities, and language difficulties. Transmission barriers were observed only for Participants 1, 2, and 6. Participants 1 and 2 (Group A) experienced language-related barriers (aphasia), whereas Participant 6 experienced hearing- and vision-related barriers. Transmission barriers were not present in all event and time samples of these participants; however, when they were present, the health information provided lacked detail.

What are stroke patients’ perceptions and levels of satisfaction with the provision of health information in the acute care setting?

Participants perceived the following topics of health information as being highly desirable on the acute stroke unit: explanations of tests, feedback from test results, prognostic details, the nature of stroke, and future support available. Some participants were unsure of how much or what health information they needed and one participant (Participant 4) stated that she did not require any health information. This participant reported that health information has the potential to confound a stressful situation:

Significant Other: It doesn’t make it any easier does it, even when you know what’s what.

Participant 4: It’s true, it doesn’t. It makes it sometimes in someways harder. [interview transcript]

Five out of the seven participants (Participants 1, 2, 3, 5, and 7) expressed a general level of anxiety regarding a lack of health information provision. These participants perceived that health information provided reassurance. Participant 6 was indifferent regarding the provision of health information.

Patients’ perceived the sources of health information as coming from both within and outside of the acute stroke unit. Most participants (5 out of 7)
identified prior knowledge of stroke as a source of health information and a reliance on significant others as health information providers. Some participants were unsure of who the health professionals were on the stroke unit that provided them with health information or the roles of those health professionals in providing health information. Doctors, nurses, and allied health professionals (physiotherapists, occupational therapists, speech pathologists, dieticians, and social workers) were identified by at least one patient as health information providers. Three out of seven participants identified nurses as predominant health information providers. The two stroke patients with aphasia (Group A), like the rest of the group, identified prior knowledge of stroke and a reliance on significant others as important sources of health information. This group, however, did not identify any health professional from the acute stroke unit who was predominantly involved in providing them with health information. Participant 2 was unsure of who the health professionals were who had provided him with health information.

Participants reported that health information was predominantly given verbally. Two participants (Participant 3 and 4) indicated that they had been given a combination of written and verbal information. Participants’ preferences regarding the provision of written or verbal health information varied. Verbal information was preferred because it was immediate and simpler and reading was not involved. When written information was preferred (by 2 out of 7 participants), it was perceived as being easier to understand. Stroke patients with aphasia (Group A) received only verbal health information. Participant 1 was undecided regarding his preferred format of health information, and Participant 2 showed a preference for written health information.

Participants commonly made assumptions that were influential on their perceptions of their time in the acute stroke unit and their level of satisfaction in the hospital. Participants 4 and 7 did not express any assumptions. Assumptions regarding the busyness of the acute hospital setting and the time restrictions of health professionals were commonly made by participants. An example of this is the statement of Participant 5: “I can appreciate they are all very busy and they have a lot of people to see” [interview transcript]. Three out of the seven participants (Participants 1, 3, and 6) assumed they had a less powerful role within the setting. For example, Participant 6 stated, “You don’t ask questions” [interview transcript], and Participant 3 stated, “As a patient I suppose you may be a little further down the scale than the top of the scale” [interview transcript]. Participant 3, despite being an active participant in his health care, expressed regular feelings of inferiority to explain the gaps in health information provision. Participants 1 and 3 used this assumption of inferiority to make the gaps in health information provision more acceptable. This is reflected in a statement made by the carer of Participant 1 that “we got what we were entitled to” [interview transcript]. No differences were evident amongst the two groups of stroke survivors.

Table 5 summarizes the participants’ satisfaction levels on the different aspects of health information provision within the hospital setting. The group averages indicate that all participants were generally happy with each aspect of health information provision they were questioned about. Participant responses to the interview questions provided some contradictory results compared to the level of satisfaction measured by the scale questions. Six of the seven participants made statements that indicated they were dissatisfied with the health information provided. Particularly participants were dissatisfied with the timing of health information provision and the amount of contact with doctors and, to some degree, with other health professionals. Some participants were also dissatisfied with the adequacy of health information (Participants 3 and 5). When using the scales to assess participants’ satisfaction levels, it was found that participants appeared unwilling to say they were unhappy and many wanted to choose between unhappy and happy. Statements such as “more between unhappy and happy, I’m not incredibly unhappy” [interview transcript] and “just happy, I think they could improve but I don’t think they’re bad” [interview transcript] were often used. Satisfaction levels for stroke patients with aphasia (Group A) were comparable to the group as a whole.
When asked the closed ended question “Do you feel you were given enough information on stroke while in hospital?”, four out of the seven participants (Participants 2, 5, 6, and 7) said no while three out of seven (Participants 1, 3, and 4) said yes. Participant 2, a stroke patient with aphasia, was the only participant in the group to mention transmission barriers as a reason for not receiving any information about stroke. The effect of his aphasia was illustrated in the following statement regarding the lack of stroke information provided: “They told me why but you know it didn’t mean very bloody much to me…see quite a lot of time the doctors had given me information but they haven’t given me any information you know what I mean” [interview transcript].

Participant 1 on the other hand felt enough information was provided about stroke. Due to an absence of any understanding of aphasia by the two participants with aphasia (Group A), the initial question “Do you feel you were given enough information on aphasia while in hospital” was not asked.

### What do stroke patients know about stroke?

Four out of seven participants (Participants 1, 2, 6, and 7) demonstrated no understanding of stroke (refer to Table 2 for stroke knowledge criteria). Of the remaining participants, Participant 5 demonstrated a complete understanding, Participant 3 a partial understanding, and Participant 4 a poor understanding of stroke. Stroke patients with aphasia (Group A) had no understanding of stroke and no understanding of aphasia. Each participant with aphasia (Group A) reported that he or she had not heard the term aphasia.

To summarize, the outsider’s perspective revealed through participant observation that a small proportion of time was spent communicating with patients in the acute stroke unit. Of this communication time, an even smaller proportion of time was spent communicating health information to patients. Of particular interest to researchers, patients with aphasia received less information compared to stroke patients without aphasia. There were several important topics of information that were not observed to be provided to all patients, including information on test procedures and results, stroke and stroke causes, recovery outlook, and available future supports. Thematic analysis of the observational data revealed that the provision of health information is affected by many factors including the roles patients had regarding their care, patient and health professional characteristics, and general environmental characteristics.

### Table 5. Participants’ level of satisfaction on a 4-point scale (1 = very unhappy, 2 = unhappy, 3 = happy, and 4 = very happy)

<table>
<thead>
<tr>
<th>Range of topics</th>
<th>Information on stroke</th>
<th>General health information</th>
<th>Timing of information</th>
<th>Format of information</th>
<th>Staff ability to provide information</th>
<th>Overall satisfaction</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Group A</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Participant 1</td>
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<td>3</td>
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<tr>
<td>Group average</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>3</td>
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<td>3</td>
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<tr>
<td><strong>Group B</strong></td>
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<tr>
<td>Participant 3</td>
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<td>Participant 4</td>
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<td>4</td>
<td>3</td>
<td>4</td>
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<tr>
<td>Participant 5</td>
<td>3</td>
<td>2</td>
<td>3</td>
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<td>3</td>
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<tr>
<td>Participant 6</td>
<td>3</td>
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<td>3</td>
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<tr>
<td>Participant 7</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>3</td>
<td>3</td>
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<tr>
<td>Group average</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>3</td>
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<td><strong>Total average</strong></td>
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<td>3</td>
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<td>3</td>
<td>3</td>
<td>3</td>
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*Rounded to the nearest whole number.*
For speech pathologists, the presence of transmission barriers such as hearing impairment and aphasia had an impact on health information provision. The insider’s perspective revealed through semi-structured interviews that not all stroke patients wanted to receive information and those that did were not willing to directly criticize the lack of health information provision. Sources of information beyond the acute stroke unit were heavily relied upon by most patients; no single health professional was identified as a main provider of health information by all patients. Most patients expressed a need for more information, however they commonly made assumptions about time restrictions of staff and their perceived role as a patient to excuse the perceived lack of information provision. In general, stroke patients’ knowledge of stroke on leaving the acute stroke unit was very poor. Stroke patients with aphasia had no understanding of both stroke and aphasia.

Discussion

How is health information provided to stroke patients in the acute care setting?

Participant observation and semi-structured interviews of seven stroke survivors in the acute stroke unit has allowed for some insights into how health information is provided to patients. The first insight gained was how little time was spent providing health information to stroke patients, particularly to patients with aphasia. Despite four of the six observation samples being event samples where communication-rich exchanges would be expected, as a whole, stroke patients were engaged in communication with health professionals less than 50% of the time. Just over one third of this communication time was spent in health information exchanges. Stroke patients with aphasia experienced less communication and information time. The need for test explanations and feedback as well as more information on prognostic details, the nature of stroke, and available future support were identified by the participants and were similar to those reported in previous studies. Not all participants received information on all topics, in fact, not one information topic was consistently provided to all participants. Only 2 out of 7 participants received test explanations or feedback, 3 out of 7 were given information regarding their recovery outlook, 4 out of 7 received information regarding future supports, and 5 out of 7 received information on stroke and stroke causes. Inequitable provision of health information to stroke patients with aphasia was further evident, with lower group means obtained in relation to the total number of health information exchanges and range of topics each group was given. Previous research has focused on stroke patients’ self-report of the amounts of health information with which they have been provided, as well as self-reports of their informational needs. This is the first known study to focus on what actually happens in the delivery of health information. This preliminary study has shown that the informational needs expressed by participants may indeed reflect a lack of health information provision rather than patients forgetting that health information was given. An extension of this study with a larger sample size would better support these conclusions.

There was large variability in the amount and quality of health information provided to all participants in the study across all observational samples. The pattern of providing health information was erratic, infrequent, and unplanned. The maximum acute hospital stay for participants in this study was 2 weeks, with some participants staying less than 7 days. The short time in which the health professionals have to care for and inform patients is an issue and is likely to continue to be an issue, because shorter lengths of stay are an increasing trend in acute hospital settings. A system that ensures that consistent, timely, and quality health information is provided to patients during this short time is therefore essential. Other studies have highlighted the need for a systematic and individualized approach to health information provision, especially in the acute hospital setting.

This study offers preliminary explanations regarding the lack of or inefficiency in health information provision. From both the researcher’s observations and patients’ perspectives, there appear to be multifaceted reasons for the paucity of health information provision. These include participant,
health professional, and environmental characteristics.

In the present health system, patients who are passive, withdrawn, or exhibit negative patient characteristics such as uncooperativeness, complaining, unresponsiveness and disinterest, or low motivation are often labeled as unpopular or difficult patients. These unpopular or difficult patients in turn receive considerably reduced length of attention and amount of personal interaction compared to popular patients. Popular patients are patients who among other things are cooperative, appreciative, motivated, and uncomplaining. In addition to personality, physical problems such as disfigurement and aphasia contribute to negative labeling of patients. Patients who experience difficulties in communicating are more frequently labeled unpopular. This suggests that within the hospital setting patients with communication disabilities are likely to be disadvantaged from the outset. Stroke patients with aphasia often have passive and unresponsive behavior, because of their difficulties with initiating and participating in communication exchanges. This often means they assume a passive role in their health care even if it is not their intention. This is perhaps best reflected by Parr et al. in this statement regarding information provision and aphasia: “The process of locating, selecting and understanding information depends on the very skills which have been weakened.” Nurse-patient and doctor-patient relationships have for many years encouraged, if not demanded, patients to assume a passive role in their health care. Current emphasis on greater patient independence and collaboration in their health care means passive patients become problematic for health professionals. These patients appear to make little to no effort to become involved in their care; they prefer to just accept whatever advice or instructions they have been given. This means that the inclusion of passive or withdrawn patients requires a more concerted effort and is more demanding for health professionals. The provision of health information to more active patients (presumably more motivated and interested patients) as well as more likeable patients is a result consistent with current health care literature. Certainly in this study, more active participants who demonstrated few negative characteristics received more health information. A chicken-and-egg situation now arises; research tells us that the provision of health information motivates and empowers patients in their relationships with health professionals. However, health professionals may be unlikely to provide health information to patients who are not already exhibiting these characteristics. A routine systematic approach to health information provision may help to counteract the possibility of this situation arising.

This study found that health information was more likely to be provided by health professionals who were actively involved in the provision of health information. The link between health professionals’ active involvement and attitude toward provision of health information should be explored further. Time restrictions and hospital procedures also limited the amount of contact or information that could be provided to participants. An example of a specific contextual factor may be a patient’s discharge destination. This study’s results warrant further investigation into the influence of discharge destination on the amounts and types of health information provided to patients, as it could be possible that the onus for information provision shifts depending on whether patients are to be discharged home or to another hospital department. A larger sample size would be needed to make any conclusions in regard to this. The presence of others (i.e., health professionals, significant others, visitors) within a patient’s environment as well as patient involvement in daily activities are unavoidable realities in the acute stroke setting. It is recommended that factors such as these are taken into consideration and accounted for in the design of more systematic approaches to health information provision. Communication difficulties may be especially challenging for health professionals, because they require increased time and specialized skills and knowledge. Patients who threaten a professional’s feelings of competence are also likely to be viewed as unpopular or difficult patients. It was an interesting finding that health information was only provided to people with aphasia when their significant others were present. This could support
the assumption that health professionals may have a lack of confidence regarding their competence in communicating with patients with aphasia, hence they only provide health information when someone else is present. Also, the health professionals may not see the value in communicating to patients with aphasia or may lack an understanding of their patients’ comprehension abilities and therefore only give health information when someone else is present. Alternatively, it could be a sign that health professionals have recognized that patients with aphasia have an increased reliance on significant others to repeat and re-explain health information because of their language difficulties.

Of the participants who were observed for the full six samples, three participants (Participants 1, 2, and 6) were largely disadvantaged compared to the rest of the group in the amount and in the quality of health information provided. These participants experienced barriers to the transmission of health information and communication in general. Of particular interest to this study, the stroke patients with aphasia experienced inequality in many aspects of health information provision. When their communication difficulties were not taken into account, patients with aphasia (and also Participant 6) received health information that was lacking in detail. It was brief, uninformative, and unspecific.

The inequality experienced by people with aphasia has implications for health professionals, in particular for speech pathologists working within the acute care setting. There is a need for speech pathologists to focus on “building communication ramps” for people with aphasia so that their access to health information is not “blocked.” By being involved in the training of staff on how to facilitate communication with stroke patients with aphasia, the speech pathologist will be able to help break down communication and health information barriers present in the acute hospital setting. This would be a major step in ensuring that equal health service is provided to patients with aphasia. A project trialed in the United Kingdom found positive results in health professionals’ knowledge of aphasia, confidence communicating with patients with aphasia, and knowledge of communication strategies to use with people with aphasia following training by a speech pathologist. This enabled patients with severe aphasia to have greater access to communication and health information.

Stroke patients with aphasia were also not fully informed about their health condition, with both patients with aphasia in this study reporting that they had not received any information about aphasia. Both patients were to be transferred to a rehabilitation unit at the hospital where it may be expected that information would be provided by other members of the rehabilitation team, and this may be why little information was provided to these patients at this stage. It is possible however that the low incidence of health information provision is a result of a lack of clarity about which member of the team should be providing information about stroke-related topics. Further research could attempt to answer questions regarding how health information should be provided, who should be providing it, and when it should be provided.

What are stroke patients’ perceptions and levels of satisfaction with the provision of health information in the acute care setting?

Out of the results reported from the interviews with the participants, we gained an insight into how patients view health information and their time in hospital. Participants placed different importance on the receipt of health information. Most (5 out of 7) believed that the provision of health information provides reassurance and allays anxiety. This finding mirrors those of previous studies. This was not true for all participants, which emphasizes the need to determine participants’ informational needs prior to the provision of health information. Patients’ preferences not to receive information must also be recognized. From the participants’ perspective, previous knowledge, significant others, and health professionals were main sources of health information while in hospital. No single health professional was perceived as being a health information provider by all participants. The reliance on health information sources outside of the acute stroke unit highlights the gaps that are present in the provision of health information to stroke patients. Health information was provided predominantly in a verbal format, with
only 2 out of 7 participants reporting that they had received written health information. This confirms previous studies\textsuperscript{3,11} that indicated between 12\% and 45\% of stroke patients received written information. The strong preference among participants for verbal health information as opposed to written health information due to the perceived simplicity of verbal information suggests that changes to the way written materials are designed and provided to patients may be necessary. Eames et al.\textsuperscript{11} found that stroke patients were given written materials that were often beyond their reading level. This was particularly true of stroke patients with aphasia.\textsuperscript{31} The provision of written information in combination with verbal information may be critical in improving patient knowledge and satisfaction with their health care.\textsuperscript{31}

Despite the findings from observations on the acute stroke unit, measurements of participant satisfaction were reasonably high. Levels of participant satisfaction did not differ between groups. Some methodological issues and prior patient assumptions help to explain this. First, hospital satisfaction measures frequently report high levels of satisfaction. Biases in the timing and mode of data collection are common reasons for this.\textsuperscript{26} In our study, limitations with the rating scale became apparent. The scale was not sensitive enough. The use of ordinal categories such as very happy, happy, unhappy, and very unhappy was not an optimal response format due to value judgments that participants placed on these words. An alternative format recommended for future studies may be the use of an interval format such as a 10-cm visual analogue scale. This may be more sensitive to participants' perceptions and may allow more sensitive comparisons between participants. Interviews of participants, however, may provide a more accurate representation of participants' satisfaction levels than surveys.\textsuperscript{26} This study saw a contrast between interview responses and scaled responses regarding patients satisfaction. All participants were interviewed while still in hospital; this may also explain the high satisfaction ratings despite comments made by participants that contradicted their level of satisfaction. Personal interviews within the hospital setting result in a loss of anonymity, and this raises concerns regarding the potential impact negative responses may have on health care in the minds of patients.\textsuperscript{26} This was certainly a reality for participants in this study. With research showing that patients who complain are often considered unpopular or difficult,\textsuperscript{27–29} patients may have good reason to report high levels of satisfaction. The timing of the interview was also a limitation, because one participant had significant short-term memory problems (a significant other contributed to the interview), and two other participants fatigued quickly during the interview. Participants were asked to rate satisfaction on the scales at the end of the interview, and therefore responses may have been rushed due to fatigue. An additional interview post discharge from hospital would have been helpful. Issues such as anonymity would be less influential, and there is less chance of health issues (i.e., memory loss and fatigue) interfering with the interview. Claims made in this second interview may help to support or refute claims made in the original interview.

An individual's perception of the health information provided was also closely tied to his or her expectations and assumptions regarding the acute hospital setting.\textsuperscript{26} Gaps in health information provided and limited contact from health professionals were considered acceptable by participants because of the perceived busyness and time restrictions of health professionals. Some patients also assumed a hospital hierarchy in which they held the least power as a reason for limitations in health information provision. The acceptance of health professionals as the experts has resulted in similar assumptions being made by patients in other studies.\textsuperscript{30} The measurements of patient satisfaction in this study therefore reflect a multitude of factors that influence patient satisfaction and suggest that the methodology used in this study did not accurately reflect the satisfaction level of patients. Nevertheless, it provided an indication that patients reported overall high levels of satisfaction with the health information provided to them.

**What do stroke patients know about stroke?**

The inefficiency of health information provision within the acute stroke unit is evidenced by only
one of the participants demonstrating a complete understanding of stroke and most participants demonstrating no understanding of stroke at all. The lack of knowledge regarding stroke is similar to previous studies, although it may be a little more marked in this study. Previous studies have taken a more structured approach to determining participants’ knowledge, whereas this study relied on eliciting each participant’s definition of a stroke. This, in turn, relies heavily on each participant’s recall. It is possible, therefore, that this outcome measures disadvantaged participants’ ability to demonstrate their knowledge of stroke/aphasia, because whilst they may have possessed some knowledge of stroke they may have been unable to access this stored knowledge and verbalize it. Of the four patients who demonstrated no understanding of stroke, two were not observed to have been given any information on stroke. Also, many participants expressed a need for further information on stroke and its causes despite a high number of participants being given information on this topic. This supports the view that increased health information provision may lead to increased knowledge of stroke, however, further research is warranted to investigate just how the provision of health information should result in better patient understanding including how and when health information should be provided and who should provide it. The role of written health information may be key, as well as the communication skills of the health professional.

Clinical Implications

Approaching the provision of health information systematically by assessing patients’ individual needs and circumstances and then providing health information that is specific to the patient may improve the efficiency of health information provision. Systems such as nominating a specific team member to provide information on stroke and stroke-related topics to all patients may counteract any “passing the buck” in the system. It could be argued that the speech pathologist on the team has the specialized knowledge and skills in communication to ensure that all patients understand relevant health information. Speech pathologists also have the skills to ensure that patients with aphasia are not left out of the information loop. A systematic approach to health information provision may also ensure that health professional and environmental/contextual characteristics have less influence on the occurrence of health information exchanges. Greater use of appropriate written health information may enhance health information outcomes of stroke patients, as will ensuring that patients have been informed about stroke and are able to ask questions when they are being transferred or discharged from the ward.

Limitations

The limitations of such a small sample size (N = 7) are recognized in this study. Future studies using a larger number of participants as well as a number of different hospitals would be useful in gaining a more comprehensive insight into how health information is provided to stroke patients in the acute care setting. Comparisons between a number of hospitals would be necessary to discount the possibility that this study’s results are hospital specific. Studies that examine larger numbers of participants with aphasia are also necessary to further investigate questions regarding the provision of information about aphasia to this group. A greater number of participants with aphasia in the sample size and more evenly matched groups would have allowed for greater comparisons to be made between this group of stroke patients and stroke patients without aphasia. It may have also been useful to include a nonstroke population to compare the amount and duration of health information provision before reaching conclusions about the limitations with stroke patients. The researchers acknowledge that there is a central limitation to the methodology (participant observation) used in this study. There is a possibility of observer effects (the Hawthorn effect) biasing results, and hence it is not possible to know the extent to which the presence of the researcher influenced the behavior of participants and may have resulted in falsely increased levels of communication between health care professionals and patients. Given that the Hawthorn effect is only temporary, the presence of the participant observer...
over an extended period of time should reduce the effect. Based on the premise of the Hawthorn effect, however, it is unlikely that the researcher’s presence would have resulted in decreased amount of communication between health professionals and patients. The observed gaps in health information provision could in fact be larger than the study reflected. Changes in the way patient satisfaction with health information is captured have also been suggested in this study. Further measures of the reliability of the observational log and the coding of data would add to the rigor of future qualitative studies.

Conclusion

This preliminary study has given some insight into how health information is provided to stroke patients in an acute care setting. Insight into stroke patients’ perceptions regarding the provision of health information has also been gained. Many patients did not receive information on important topics such as stroke, stroke causes and stroke effects, recovery outlook and prognosis, test explanations, test feedback, and available future support. Furthermore, most of the participants demonstrated a poor understanding of stroke, and two participants with aphasia did not know what stroke was. Both participants with aphasia also had no understanding of aphasia. Participants with aphasia were further disadvantaged in that they had the least amount of time dedicated to the provision of health information while in the acute hospital setting. A multitude of reasons explained these general gaps in health information provision to all stroke patients, including passive patients, busy health professionals, and an unstructured approach to health information provision. Despite these findings, however, all participants in the study reported high levels of satisfaction with the provision of health information. The conclusions of this small-scale, preliminary study need to be supported by further research using a more significant number of participants. Further larger scale studies would confirm or refute our finding that the informational needs expressed by participants may indeed reflect a lack of information provision. Whether the information is not being provided or whether the patients have forgotten that information was provided does not detract from the need for intervention studies that determine the effectiveness and efficacy of a systematic individualized approach to information provision. Only when solutions are found to information provision in the acute hospital setting will people who have recently experienced the trauma of stroke be fully informed about their condition.

Acknowledgments

We acknowledge the assistance of the speech pathologist at the Princess Alexandra Hospital, Aimee Turner. Aimee’s contribution to the research as the study’s gatekeeper was invaluable and greatly appreciated.

We also acknowledge the assistance of CDARC doctoral students, Katherine Ives and Robyn OHalloran, and staff, patients, and relatives of the Acute Stroke Unit, Princess Alexandra Hospital, Brisbane, Australia.

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APPENDIX 1

Interview Schedule

- Introduction to interview
- Description of hospital time
  - grand tour
  - e.g., “Can you tell me about the main things that happened while in hospital?”
- mini-tour questions
  - e.g., “Can you tell me about any tests you had?”
- Topic prompts:
  - Amount of information given
  - Type of information given
  - Topics of information provided
  - Who provided information
  - The way staff provided information
  - Timing of information

Mandatory Questions

- Definition of stroke; “Can you tell me what a stroke is?”
- Do you feel you were given enough information about stroke while in hospital?
- If appropriate, definition of aphasia; “Can you tell me what aphasia is?”
- Do you feel you were given enough information about aphasia while in hospital?

APPENDIX 2

Scale Questions

1. How happy are you with the range of topics you were given information on?
2. How happy are you with the information you were given about stroke?
3. How happy are you with the information you were given about aphasia?
4. How happy are you with the general health information you were given while in hospital?
5. How happy are you with the way information was given to you in hospital (i.e., spoken, written)?
6. How happy are you with the timing of the information given while in hospital?
7. How happy are you with the way the staff at the hospital gave you information?
8. Overall how happy are you with information you were given?

Satisfaction Indicator