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“That really shouldn't have happened”: People with aphasia and their spouses narrate adverse events in hospital

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**“That really shouldn't have happened”: People with aphasia and their spouses narrate
adverse events in hospital**

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Abstract

Background: Patients with communication disability are at increased risk of experiencing an adverse event in hospital. Despite forming a particularly vulnerable patient group, little is known about the nature or cause of adverse events experienced by people with aphasia and their spouses in hospital.

Aims: This study aimed to: (a) describe the adverse events experienced by people with aphasia and their spouses in hospital, (b) identify the situations, people, events, and outcomes relevant to the adverse events, and (c) identify commonalities in participant stories of adverse events.

Method: In this narrative inquiry, ten people with chronic aphasia and their spouses participated in in-depth interviews about the adverse events they experienced or witnessed in hospital. A narrative analysis was used to discover common stories of adverse events and common content themes across the stories of experience.

Results: Although a wide variety of adverse event types were identified in the participants' stories, 'undesirable events' were among the most common, along with 'inappropriate discharge home or inadequate discharge plan'. Reliance upon spouses during communicative interactions featured across the stories, with exclusion of spouses from important interactions on the ward representing a barrier to effective communication and a risk for adverse events. Participants suggested strategies for improving the safety of people with aphasia in hospital in the hope of preventing future adverse events in this population.

Conclusions: Adverse events occurring in hospital were distressing to participants and often related to the presence of aphasia. Hospital policies should acknowledge the role that spouses have with patients with aphasia and ensure their inclusion to assist in prevention and management of adverse events in hospitalised patients with aphasia. The need for better discharge planning and information should also be recognised as a means of preventing adverse events.

“That really shouldn’t have happened”: People with aphasia and their spouses narrate adverse events in hospital

The World Health Organization (WHO) (2008) identifies patient safety as a global issue. Throughout the world, millions of disabling injuries and deaths occur each year because of unsafe medical care. The World Health Organization’s Research Priority Setting Working Group (World Health Organization, 2009) calls for a worldwide investment in research to bridge the knowledge gap on patient safety issues. For the developed world, ‘lack of communication and coordination (including coordination across organizations, discontinuity, and hand-overs)’ tops the priority list for research in this field. Indeed, the link between good communication and patient safety is well-established (Bartlett, Blais, Tamblyn, Clermont, & MacGibbon, 2008; Clinical Excellence Commission, 2007; Queensland Health, 2010). Effective communication has been identified as a fundamental skill which influences patient satisfaction (Fleischer, Berg, Zimmermann, Wüste, & Behrens, 2009). Furthermore, communication failures (occurring either between staff or between staff and patients) have been found to account for up to 75% of all harmful patient safety incidents or ‘adverse events’ in hospital (Queensland Health, 2010).

According to the World Health Organization (2009) World Alliance on Patient Safety Drafting Group “a patient safety incident is an event or circumstance that could have resulted, or did result, in unnecessary harm to a patient. A patient safety incident can be a reportable circumstance, a near miss, a no harm incident or a harmful incident (adverse event)” (p.4). Bartlett et al. (2008) conducted a medical record chart review of 2,355 patients in acute care hospitals in Quebec, Canada, and found a significantly increased risk for multiple preventable and harmful adverse events in patients with a range of communication disabilities. The longer mean duration of stay experienced by stroke patients (Somerford, Lee, and Yau, 2004) may further compound this risk, with a positive relationship between longer duration of stay and a

higher incidence of adverse events in hospital identified (Andrews et al., 1997). Given the strong relationship between effective communication and patient safety, people with aphasia form a particularly vulnerable patient group (Blackstone, Ruschke, Wilson-Stronks, & Lee, 2011). To date, there is little information available on patient safety specifically relating to patients with the communication disability of aphasia following stroke.

Research reveals an overlap between patient satisfaction and patient safety, and patients on stroke wards report greater dissatisfaction with hospital care than patients on general wards (Asplund et al., 2009; Atwal et al., 2007; Morris, Payne, & Lambert, 2007). Morris et al. (2007) conducted focus groups with stroke patients, carers and hospital staff following patient discharge to investigate their experiences within a specialist hospital stroke service. Findings revealed that both stroke patients and their spouses wanted more information and explanation about stroke and better discharge planning. Results also included a perceived lack of attention by health care professionals to basic care needs such as toileting and eating which resulted in 'dissatisfaction' with care and a reliance on family members to provide the care (Morris et al., 2007). These findings are supported by Asplund et al. (2009) who reported that the main contributors to dissatisfaction for stroke patients include the amount of information they received regarding stroke, poor discharge planning, and poor communication with health care professionals.

Patient safety is currently one of the highest priorities in health research (WHO, 2009) due to widespread recognition that: (a) 50% of adverse events are preventable; (b) the resulting negative health impacts have widespread negative consequences for patients and healthcare providers; and (c) the costs associated with adverse events are a significant burden to governments and service providers alike (Auditor-General for Western Australia, 2009). Despite being labeled the 'gold standard' in patient safety research, the medical record chart review method is limited, owing to: (a) limitations in information noted in records as to how

and why adverse events or near misses occurred, and (b) underreporting of adverse events – with only a quarter of patient reported adverse events being captured in medical records (Runciman et al., 2008; Weissman et al., 2008). Runciman et al. (2008) stated that the most comprehensive information on adverse events is obtained through combining reviews of medical records (e.g., Bartlett et al., 2008) with qualitative methods such as interviews (e.g., Ebright, Urden, Patterson, & Chalko, 2004) and observations. Despite the advantages of qualitative methods in gaining the participant's perspective or understanding of events (Denzin & Lincoln, 1994), there is no research to date employing qualitative methods examining patient safety in people with aphasia. Therefore, the aims of this study were to: (a) gather the views of people with aphasia and their spouses on their experiences of adverse events in hospital; (b) identify the situations, people, events, and outcomes relevant to any adverse events experienced; and (c) look for commonalities in stories of experiences that would inform the prevention or risk management of adverse events in hospitalised patients with aphasia. It is anticipated that this information could be used to inform policy on the care of people with aphasia in hospital, train hospital staff in improving patient safety (thereby reducing the risk of adverse events for this patient group) and guide future research examining the relationship between aphasia, patient safety and adverse events in hospital.

Method

Ethical approval for this research was granted by The University of Queensland Medical Research Ethics Committee (MREC **Approval number 2009000026**).

Participants

People with aphasia, registered with The University of Queensland's Aphasia Registry were sent information about the study. The Aphasia Registry is a database of people with chronic aphasia in Australia who wish to be invited to participate in research. A checklist of adverse events (Bartlett et al., 2008) was used to determine candidacy for

inclusion in the study. Participants with aphasia were required to have been admitted to hospital and to have experienced at least one adverse event listed on the checklist. In total, fourteen people with aphasia responded to the invitation to participate, and ten met the criteria for inclusion. The ten respondents who met the inclusion criteria were invited to participate and were included in the study. The participants included (a) ten people with aphasia (eight males and two females, ranging in age from 64 to 82 years with an average age of 69.8 years) and (b) ten spouses of the participants with aphasia (two males and eight females, ranging in age from 57 to 74 years, with an average age of 65.3 years). All participants lived in Australia. Nine of the ten participants with aphasia had developed aphasia following stroke. One participant had primary progressive aphasia with an onset in the past decade. The number of hospitalisations following stroke ranged from two to fifteen. Participant information is summarised in Table 1.

(Insert Table 1)

In-depth interviews

Interviews were conducted by a speech pathology researcher experienced in qualitative research interview with people with communication disability and their family members. Each participant pair (participant with aphasia [PA] and their participating spouse [PS]) were interviewed together either at their homes ($n=9$) or in a clinic setting ($n=1$). During the interviews, people with aphasia were given the opportunity to respond to questions, discuss their experiences, and to be the main informant on the adverse events. However, four of the participants with aphasia had limited communication and relied upon their spouse to be the main informant in the interviews. One participant (PA8), with English as his second language, completed the interview in his first language, with English translation provided by his spouse. The duration of each initial interview was between one and two hours. Interviews were digitally audio recorded. Each initial interview commenced with the

researcher using the checklist with participants to identify the types of adverse events experienced. This was followed by the question: “You have indicated that you experienced an adverse event in hospital. Can you tell me about what happened?” The Checklist of Adverse Events was also used to guide the conversational-style interview (see Appendix). Follow-up interviews occurred after analysis of all of the first interviews, to: (a) enable follow-up questions to gain further insights, and (b) give participants and their spouses the opportunity to add, change, remove, or clarify any information or understandings reflected in the researchers’ interpretations (Riessman, 2008). For all but two of the participants, follow-up interviews occurred in person with both the participant with aphasia and their spouse. Two of the participants’ follow-up interviews were with their spouse only (PS3, PS8) and were conducted on the telephone, as preferred by those participants.

Narrative analysis

The interview data was analyzed using narrative inquiry methodology analysis (Polkinghorne, 1995; Riessman, 1993), to form an in-depth understanding of the views of the participants in relation to adverse events in hospital. Each audio recording was transcribed verbatim and de-identified (i.e., removing names, using general descriptors rather than name labels) and potentially identifying information was removed (e.g., specific medical conditions, names of hospitals, information that when combined with other data might identify the person). Field notes detailing the interviewer’s initial perceptions of the data were also made following each of the first interviews and these were added to the transcripts.

Following transcription by the second author and checking by the first, the first two authors read and re-read each transcript and discussed emerging narrative themes before writing a summary story for each participant and spouse pair, that encapsulated events described in hospital. Writing the summary story involved the first two authors looking for narrative elements in the transcript (i.e., characters, settings, events, problems, evaluation,

resolution) and temporally re-ordering events in the story into the common narrative structure of ‘going to’ hospital, ‘being in’ hospital, ‘discharge’, and ‘since discharge’ (Polkinhorne, 1995; Riessman, 1993). Each participant was sent a copy of the summary story by email. This was done to provide them with a written record of their contribution to the research, and for verification and confirmation that the researchers’ interpretations reflected their views of their experiences. Any changes requested by participants were incorporated into the final summary story for each participant prior to further analysis across all 10 participants. The first three authors discussed all narratives and developed the resulting set of common narrative themes across participants’ stories to encapsulate the experiences relating to adverse events.

Results

The context of the stories of adverse events

Just over half ($n = 6$) of the participants reported that the person with aphasia had been admitted to hospital on multiple occasions since acquiring aphasia, for both planned and un-planned admissions (e.g., elective and emergency surgery, medical admissions). When asked about their experiences of adverse events, participants with aphasia and their spouses described events that occurred before, during and after hospitalization, the impact that these adverse events had upon them, and strategies for improving communication in future hospital admissions and reducing negative hospital experiences. Some participants also described adverse events experienced in other health settings, including primary care settings (e.g., general practitioner, ambulatory care clinic) and respite care residential settings. In this paper, only hospital-related adverse events are reported. The number of adverse events reported by participants ranged from two to eight events. The type and number of adverse events reported according to the Checklist of Adverse Events are presented in Table 2.

(Insert Table 2)

The common narrative themes identified in the participants' stories relate to the most common adverse events (i.e., undesirable events, inappropriate discharge), the role of the spouse in hospital, barriers to effective communication, and participants' suggested strategies for preventing future adverse events.

Stories about the most common adverse events: 'undesirable' events.

The most common type of adverse event reported by participants was listed on the checklist of events as 'any other undesirable outcomes not covered in the other categories.' One of these events related to loss of the patient's dentures and pyjamas at the hospital with no explanation from hospital staff. However, most undesirable events pertained to situations where patients with aphasia were unable to gain the attention of the nurse and therefore did not receive assistance in time or what they viewed as a suitable response or resolution to their problems. Situations that participants related to being unable to gain attention and obtain assistance varied widely and included patient falls, wetting the bed, swelling of a limb, and vomiting. PS10 explained a situation in which his wife could not gain the nurses attention when nauseous: "Another time ... you actually were sick because nobody would come, and she was trying to yell and make noises or whatever." Similarly, PS5 described being unable to use the call bell and having no other way of gaining attention:

He could not communicate in the ward; he fell out of bed ... in a ward if you needed help you have to push a button. He couldn't yet do that. So when he needed to go to the toilet he just thought 'well they are never going to come' and of course he couldn't walk so he just fell down.

Although most undesirable events reported by the participants were described as being non-harmful, the manner of their telling and the detail recalled about the incidents suggested that the events were still highly salient, somewhat distressing, and important to the

participants. For example, PA4 provided a detailed description of the events leading up to her undesirable event of ‘wetting the floor’ through not being able to communicate her basic care needs with a nurse, including what she had said and the nurse’s response, and her distress before and after the event. Participants used emotive language to describe these non-harmful events. For example, PA4 described how she “felt very angry and burnt following this incident” and PA9 explained “And that was the worst part of the whole deal because we got the ambulance and then it left us ... for what seemed like an hour ... that’s what hurt.” Other undesirable events related to the exclusion of spouses from interactions between the hospital staff and the patient with aphasia. Patients were therefore left with no way to understand information and/or express their views. These stories are explored in more detail below within the content theme of the role of the spouse in supporting the adult with aphasia in hospital.

Stories about inappropriate discharge to home or inadequate plan for index admission

Just over half of the participants ($n=6$) narrated stories with a common theme of problems relating to the process of discharge from hospital. The participants described problems with discharge planning, rushed or unplanned transfer from the acute care setting to rehabilitation, poor information exchange between hospital staff and spouses regarding discharge, and lack of referral and provision of follow-up therapy services. For example, PS1 was distressed to be called in to assist hospital staff with a videofluoroscopy, which was followed unexpectedly by a prompt discharge:

They made arrangements for me to go in because he was having problems swallowing ... He started refusing it, and they said “please come and help him take it” ... and they were watching it on the machine and they said “right, he swallows, he’s gone” (to discharge). That was a bit of a shock.

PS6 described the lack of information she and her husband received regarding discharge from the acute setting to rehabilitation: “Actually it was appalling. For example, we didn’t know that he was being transferred to the rehab hospital, I think (my husband) was told but there’s no point telling somebody who can’t communicate what’s happening to them.” When it came to the final discharge from hospital, PS6 said:

I have no memories at all of someone saying, “OK this is what’s happened, this is what’s been done, these are your options.” It was just picking up what you could and piecing it together and you know, putting it together, and I read the stroke folder and it clearly said, “before the patient is discharged you will have a meeting with the doctor, this person that person, and they will map out a plan.” There was none of that. You’d think there would have been an opportunity either to have spoken to the doctor, or to have had a message relayed from the doctor via the nurse to us. We had no case conference meeting.

Several of the participants described problems relating to a lack of provision of follow up therapy services after discharge from hospital. This meant that participants had to find their own services, which was often difficult, as PA10 narrated:

They do this thing the OT comes and checks the house out and we got a couple of rails in and that sort of thing, fine, but no plan of where to go, what to do, who to see, you know, find your own physio, find your own speech, find your own whatever.

PS6 described the difficulty **she** and her husband had in locating speech pathology services:

And that was probably the most disappointing of everything, that that had not been arranged, because that was totally left up to us to do. He was hardly speaking at all when he left hospital ... so I went into a panic mode.

Stories about less commonly reported adverse events

In their stories of adverse events, participants also narrated problems with (i) unplanned admission (including readmission) as a result of health care management within 12 months prior to the admission ($n = 3$), (ii) adverse drug reaction ($n = 3$), (iii) unplanned transfer from general care to intensive care ($n = 3$), and (iv) hospital-acquired infection or sepsis ($n = 3$). PS5 viewed that communication breakdown between her husband and the hospital staff had contributed in part to the event, as PA5 was unable to understand instructions relating to his follow-up care after heart surgery:

Following my husband's heart surgery, he got an infection in the wound ... The hospital staff tried to explain to him that when he needed to cough, he should hug a rolled towel tightly to his chest, to prevent his wound from opening. However, he couldn't follow the instructions.

Apart from PA5's story, other participants' stories of the less common, and potentially more serious adverse events, did not reflect participants making any association between the communication difficulty and the adverse event.

The important role of spouses in supporting the patient with aphasia in hospital

People with aphasia reported that during their time in hospital they relied on their spouse to communicate with health professionals, particularly to remember detail and instructions regarding their health care and medication. As PA3 noted: "When I'm in hospital, I communicate through my wife and rely so much on [my wife] it's not funny, particularly in the hospital side of things, and that's why she always comes with me, always, because I can't remember." The spouses in this study also narrated that they felt they needed to be present to ask important questions regarding their partner's health care and to keep them safe. PS3 and PS7 explained:

PS3: I agree that I need to be present in hospital to help PA3 remember what the doctor has said and also to ask the doctors questions to gain important information about my husband's care. I also feel I need to be present in the hospital to ensure that he is given his medication.

PS7 said: "My role was to help with the communication and oversee things, to protect him a bit. I felt I needed to be there in case he became upset about not being able to tell them what he needed." However, participants' narratives also reflected that spouses were sometimes excluded during ward rounds or specialist appointments and that this barrier to communication was an undesirable event. Excluding the spouse caused distress for people with aphasia, who had difficulty understanding or remembering information, and for spouses, who missed important information regarding medical care, as illustrated by the following quotes:

PA2: I told the surgeon that I would prefer to have my wife with me, but he just ignored me ... [he] was talking too fast and I couldn't keep up, so I asked him to repeat what he had said, but he just kept going ... I felt frustrated and angry. I just need extra time to speak and my wife with me to get the detail, so she can then tell me the information later.

PS5: In the beginning the ICU would lock me out whenever anyone was attending to my husband, saying you have to leave now, we're doing the rounds. Eventually, I persuaded them that I should be present, especially if they wanted to ask him questions or tell him anything.

PS10: I got sent out to the waiting room, again, leaving (my wife) distraught and angry, and I'm trying to say "at least give me time to settle her back down and I'll go or whatever", but no "rules are rules" and I'm trying to explain about (wife) and

communication and she's upset and she's angry about all of this happening, and all that sort of thing - that's a big episode that will not leave our minds.

As well as with stories of spouses staying to protect the patient, eight of the ten participants relayed stories of adverse events arising when the spouse was not present. Participants described the patient being left alone and unable to gain the nurse's attention or get their message across as leading to problem situations. PS1 recounted being notified by nurses that PA1 had fallen while left alone in the toilet. She said: "He couldn't walk, they would have had to take him to the toilet, but they obviously left him there alone." Narratives reflected spouses returning to the hospital after having a break or being at home overnight to observe a near miss even or intervening to prevent an adverse event. PS7 explained:

I was told one day that he could get up the next day and they would take him to the shower and shave him. When I arrived the next day, he had taken his white stockings off and was gathering his things together to go to the shower himself. I said "I don't think you're supposed to be doing that, you need to wait until the nurse comes." He's a bit independent and he said "no no no" because he wanted to go himself. I asked him how he had got his stockings off. There was a cleaning lady in the ward, and she said "oh I helped him off with his stockings; he wanted to have a shower." I told her he was not supposed to go alone. I felt that really shouldn't have happened.

Barriers to effective communication in stories of adverse events

A common theme across participants' stories was the patient with aphasia not being able to understand the hospital staff. Some participants viewed this as occurring because the staff did not consider the patients' aphasia when talking to them. In some cases, the patients were also expected to pass on information to their spouse, as illustrated by PS6:

After six weeks I think he was allowed home on the weekend, and on the morning, the hospital rang and said “oh, where are you?” and I said “what do you mean?” and they said, “oh well, PA6 is sitting here waiting for you to pick him up – he is allowed home for the weekend” ... Well it would have been good if we could have been told ... I think they just assumed that he would pass the information about the weekend visit on to me.

PS7 viewed communication as being more difficult for her husband with aphasia on the cardiac ward than on the stroke ward, as staff on the cardiac ward had less experience and knowledge of how to communicate with a patient with aphasia:

I just felt because they were concentrating on his heart and the associated problems, they didn’t take much notice that he couldn’t communicate very well. I don’t know when they hand over any shift whether any information was passed on, and they’d come in and talk to him as if he could understand everything.

Participants’ stories also reflected that people with aphasia often experienced difficulty gaining attention and communicating their needs to hospital staff, which resulted in them experiencing a range of adverse events, including patient falls, wetting the bed and vomiting. As PA5 described:

I remember one situation while I was alone in hospital and I was trying to gain the attention of the nurses. I was shouting out at the nurse because I wanted my food, you know. They didn’t come. I got tangled up in the sheets and I wasn’t able to press the buzzer. And I fell out of bed.

Stories also reflected hospital staff not understanding the person with aphasia who was trying to communicate basic care needs. PA4 described problems arising when the nurse caring for her did not understand that she needed to go to the toilet:

I said I wanted to go to the toilet, and I really wanted to go so I tried and tried and tried to tell her (the nurse) and she just sort of wouldn't understand or didn't understand. I just went back to sleep ... the next morning well I got up, and I just lost it everywhere, it just went everywhere over the floor and I could, I was really angry with that woman [the nurse], really terribly angry with her because she just didn't understand what I was talking about and that's really what got to me.

Participants' views on strategies for the future

Participants suggested strategies that they viewed might help to prevent or overcome the communication barriers in future hospital admissions. Strategies included strengthening the 'advocacy' role of the spouse and highlighting the importance of the 'relationship' between spouses and hospital staff to improve information exchange:

PS10: I would advise people to get onto the right side of somebody in charge, like at the nurses' station or a nurse and just talk reasonably with your knowledge of aphasia what would make your partner feel the most comfortable. Try to make the point that you need to be there at that time when the doctor is there. And when you are there show by practical example that you are there to help.

PA6: Stand your ground about that discharge meeting, definitely that's something you have to have "what now", okay you've been in hospital, so what's now, what's the future, you've got to have that in place I think, that's really important.

PS6: You've got to go and get organised, like for (follow up) appointments. You need to know where to go...These are the places, this is what they offer, this is how much it costs or if it is free. If people have that (information), it is reassuring and also you know that the treatment hasn't stopped as soon as you leave hospital.

Strategies suggested for the patients with aphasia focused on ensuring that the hospital staff were aware of the patient's aphasia and how this affected their ability to communicate. As PA10 and her husband explained:

PS10: Try and get the talking one to be there. If you can't do that, take a card from the Aphasia organisation. On the card it would say, "I am intelligent, I can hear and see, give me time to talk to you. Talk in small sentences." Download a brochure on the Triple A website (Aphasia Association of Australia) on what is aphasia.

PA10: If my husband couldn't be there I would try and explain about my aphasia, when I go to hospital I say "I have aphasia and ask them if they know what it is and ask them to explain it back to me" because otherwise I get upset and uptight, so, easy for me if you understand me.

Half of the participants also provided an example of how a 'good' communicator had facilitated their understanding and thus improved the healthcare interaction. These stories were examined for potential strategies to help communication in hospital. Stories about good communication included hospital staff using simple, clear explanations, objects as 'props' such as models for medical explanations, or asking the spouse about how to communicate with the patient with aphasia. PS7 noted a positive experience of one hospital staff member realising her husband's difficulties and making adaptations:

I mean some people realised, a nurse came to speak to (PA7) about what had happened to him what they were going to do for him and his care afterwards. When she realised what the situation was, she took, my son, who was with me at the time, and me to another room and with a three dimensional heart she explained everything in detail. She then went back and explained things very simply to him PA7 that was really good.

Further strategies for hospital staff suggested to improve communication with patients with aphasia during hospital included giving the patient time to communicate (see Hemsley, Balandin & Worrall, 2012), using communication aids (e.g., pictures depicting basic needs), and knowing more about aphasia and how it affects a person's ability to communicate. PS2 suggested that to improve their experiences, hospital staff needed to take the time to listen, and know that PA2 needs his wife with him to help in understanding all the information and ask the necessary questions. PS2 said that in future she would let hospital staff know that PA2 feels more comfortable with her in the room and request that she be included in discussions about his care. PS8 also suggested using communication aids to help her husband communicate with staff in her absence:

What they – both patients and staff - need are A4 laminated sheets with only a few, say 6-10 different pictures, clearly designed and easy to see - a symbol for pain, a symbol for toilet, food, water, and just to turn to the one needed at that moment. The basic things. Beyond that is the information about “what is wrong with me, and what will happen to me, and when am I going home?” “When am I going home?” is the big question, as far as my husband is concerned.

Discussion

The link between poor communication and adverse events is well established in the literature (Bartlett et al., 2008; Clinical Excellence Commission, 2007; Queensland Health, 2010), and results from this study have provided insight into the types of adverse events reported by people with aphasia and their spouses. The most common adverse events experienced by the participants featured communication breakdowns between the patient with aphasia, their spouse, and the health professional. Communication breakdown led to ‘undesirable’ adverse events as defined by Bartlett et al. (2008) which were distressing to patients and their spouses and prompted a protective role of the spouse in hospital. The types

of events reported in this study as undesirable were similar to sources of dissatisfaction reported previously in the literature on the satisfactions of stroke patients in hospital (Asplund et al., 2009; Morris et al., 2007). Previously reported contributors to stroke patients' dissatisfaction include patients receiving little information regarding stroke, problems with discharge planning, and a lack of attention by health care professionals to basic care needs such as toileting and eating (Asplund et al., 2009; Morris et al., 2007).

The findings of this study also support previous reports on hospital satisfaction of older patients in hospital, with dissatisfaction in this population pertaining to unmet needs and difficulty gaining the nurses attention (Atwal et al., 2007). However, participants in this study also highlighted adverse consequences as being reasons for 'dissatisfaction' including falls and patient distress. Over half of the participants in this study described problems related to inadequate discharge planning prior to leaving the hospital. Thus, while discharge planning might already be limited for stroke patients or older patients in general, patients with aphasia and their spouses might be particularly prone to problems with discharge when the spouse is not included as an important communication support in discussions about the patient's care.

In this study, patients with aphasia and their spouses encountered barriers to effective communication that resulted in the patient experiencing an adverse event in hospital. These barriers and their association with adverse events in hospital are reflected in the World Health Organisation's World Report on Disability (WHO 2011). The WHO (2011) noted that problems with care often arise when people with disabilities have difficulty understanding explanations about diagnosis and management of health conditions. The exclusion of the spouse from ward rounds and the consequence of missing out on important information that the patient could not relay, has also been reported by family carers of adults with lifelong disabilities (Hemsley, Balandin, & Togher, 2008a, 2008b). This may indicate that hospital

policies do not yet recognise the important role of ‘communication supporters’ or interpreters for people with communication disability. The findings of this study support recent research by Perry and Middleton (2011), who found that carers of stroke patients perceived that they should be included in the service provision process and receive information about stroke and health services. Indeed, a patient’s right to be included in information and decisions about care, to having information available in easy-to-understand formats, and to have a support person present during consultations, is reflected in charters of patients’ healthcare rights and responsibilities (e.g., Australian Commission on Safety and Quality in Healthcare, 2008; Department of Health, 2010; Joint Commission, 2010; State of Queensland, 2002).

The finding that spouses have a central role in supporting people with aphasia in hospital also echoes reports of family carers of adults with other forms of communication disability in hospital (Hemsley, Balandin, & Togher, 2007). Patients with lifelong disability and little or no speech also rely heavily on family members, who are often older parents, to provide communication support in hospitals (Hemsley et al., 2007). While not suggesting that spouses of people with aphasia take on parental caring roles in hospital, results of this study suggest that there might be similarities in the types of communication support provided by family members across populations of patients with different types of communication disability. The implications of this are that (i) interventions designed to improve communication for one population might also need to consider the needs of other populations in the same setting, and (ii) that interventions found to improve the hospital communication experiences of one population might also benefit another population of patients with communication disability.

Clinical Implications

Speech pathologists working with people with aphasia need to consider how this population might be supported to prepare for better communication in hospital to reduce their

risk for adverse events. This may include (i) preparing information for the person with aphasia to give to hospital staff about their aphasia and communication methods (Rose, Worrall, McKenna, Hickson, & Hoffman, 2009), (ii) working on the situation-specific communication skills of the person with aphasia that might be helpful in hospital (e.g., gaining attention, answering yes/no questions, responding to questions about pain and other basic needs) (Hemsley, Balandin, & Worrall, 2011; O'Halloran, Worrall, & Hickson, 2011), (iii) selecting materials to support communication in hospital (e.g., picture supports, photographs, yes/no symbols), and (iv) supporting family members (e.g., spouses) in their roles supporting successful communication between the person with aphasia and hospital staff. Hospital staff education on (i) allowing enough time to communicate with the patient with aphasia, (ii) seeking information on the patient's method of communication and level of understanding of language, (iii) being aware of the patient's communication skills and adapting their communication to suit the individual, (iv) including a familiar communication partner in interactions where information is exchanged with the patient, and (v) using available strategies for supporting communication (e.g., gesturing, picture displays) might work to reduce the incidents of the types of adverse events highlighted in this study. These strategies might also contribute to the formation of a more communicatively accessible environment and help other communicatively vulnerable patients on the stroke ward to communicate in hospital (O'Halloran et al., 2011).

Limitations and directions for future research

This was a small study involving only 10 people with aphasia of diverse aetiology. As such, the findings may not apply to other people with aphasia and their spouses. In this study, no attempt was made to assess the participants for type or degree of aphasia and it is not possible to determine any causal relationship between the type or degree of aphasia and

the adverse events described. Only six of the people with aphasia were able to participate as main informants to the interviews and it is possible that had all participants with aphasia been the main informant, further insights would have been gained. Future research could examine the most common adverse events described in this study in a larger group of people with aphasia immediately after discharge and using other patient safety research methods. Further investigation of (a) the relationship between patient satisfaction, patient safety, and hospital experiences for patients with aphasia and their spouses; (b) causes or contributing factors of specific adverse events is needed to guide policy and practice in improving patient safety for people with aphasia, (c) the impact of strategies suggested in this report on reducing the occurrence of adverse events in hospitalised adults with aphasia, and (d) the patient safety experiences of adults with and without aphasia following stroke.

Conclusions

The results of this study offer unique insight into the perspectives of people with aphasia and their spouses in relation to adverse events experienced in hospital since stroke. The participants in this study reported a wide range of adverse events occurring in hospital admissions subsequent to stroke. Participants perceived that the most common undesirable events arose when the patient's communication disability had not been taken into account during interactions with hospital staff. The exclusion of the spouse from interactions represented a barrier to communication and led to the patient's loss of communication support and subsequent difficulties. Commonly, the occurrence of adverse events in the absence of a spouse was met with increased vigilance from spouses who attended the hospital for long periods, took on protective and advocacy roles, and spoke on behalf of their husband or wife with aphasia.

Participants suggested a range of strategies designed to avoid adverse events **for** adults with aphasia in hospital in the future. These strategies have policy and practical

implications for hospitals and speech pathologists. Participants indicated the need for improved communication between hospital staff and people with aphasia. This can be achieved through (a) educating hospital staff on the impact of stroke and aphasia on a person's ability to communicate, and (b) providing hospital staff with specific strategies to aid communication with these patients.

Hospital policies must be updated to reflect the important role that spouses of people with aphasia play in providing protection, advocacy and communication support. Policies that enable a spouse to be present to provide communication support to the patient with aphasia might also improve communication between the patient with aphasia, the spouse and hospital staff. There is also a need for new policies that reflect the need to increase the amount of information available to patients and their spouses regarding discharge planning and follow up therapy services. Such policies may assist in better management of patient safety in stroke patients with aphasia while in hospital in the future.

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Table 1

Participant Information

Participant code	Sex	Age of adult with aphasia	Years post stroke	Spouse participant code	Age of spouse	Main informant in the interview
PA1	Male	71	5	PS1	69	PS1
PA2	Male	64	11	PS2	62	PA2
PA3	Male	70	5	PS3	66	PA3
PA4	Female	73	9	PS4	74	PA4
PA5	Male	82	n/a	PS5	66	PS5
PA6	Male	69	1	PS6	59	PA6 / PS6
PA7	Male	66	1	PS7	69	PS7
PA8	Male	66	7	PS8	67	PS8
PA9	Male	69	3	PS9	57	PA9
PA10	Female	68	7	PS10	64	PA10

Table 2

Adverse Events Reported By Participants on the Checklist of Adverse Events (Bartlett et al., 2008)

Type of adverse event	No. of participants	Participants reporting the event
Unplanned admission (including readmission) as a result of health care management within 12 months prior to the admission.	3	PA3, PA5, PA10
Unplanned admission to any hospital within the 12 months after discharge from the admission.	2	PA3, PA10
Adverse drug reaction.	3	PA1, PA5, PA9
Unplanned transfer from general care to intensive care.	3	PA1, PA3, PA10
Unplanned transfer to another acute care hospital (excluding transfers for tests, procedures or specialized care that was not available at referring hospital.	2	PA3, PA9
Unplanned return to the operating room	2	PA3, PA5
Other patient complications (e.g. acute myocardial infarction, cerebrovascular accident, pulmonary embolism.	1	PA10
Development of neurological deficit not present at the time of admission but present at the time of discharge from the admission	1	PA5
Inappropriate discharge to home or inadequate discharge plan for	6	PA1, PA2,

index admission (excluding discharges 'against medical advice').		PA4, PA6, PA8, PA10
Cardiac arrest or respiratory failure.	2	PA5, PA10
Hospital-acquired infection or sepsis.	3	PA2, PA3, PA5
Dissatisfaction with care documented in the medical record or evidence of complaint lodged.	1	PA10
Any other undesirable outcomes not covered above.	9	PA1, PA2, PA4, PA5, PA6, PA7, PA8, PA9, PA10

Appendix

Checklist of Adverse Events

Checklist of adverse events to determine candidacy for inclusions in an in-depth interview (Bartlett et al., 2008). The following screening items were used to detect potential adverse events among patients admitted to hospital. If the participant reported any of the following, they were asked for more detail about each event:

- o Unplanned admission (including readmission) as a result of health care management within the 12 months before the admission.
- o Unplanned admission to any hospital within the 12 months after discharge from the admission.
- o Hospital-incurred patient injury (including any harm, injury or trauma occurring during the admission).
- o Adverse drug reaction.
- o Unplanned transfer from general care to intensive care.
- o Unplanned transfer to another acute care hospital (excluding transfers for tests, procedures or specialized care that was not available at referring hospital).
- o Unplanned return to the operating room.
- o Unplanned removal, injury or repair of organ or structure during surgery or invasive procedure.
- o Other patient complications (e.g., acute myocardial infarction, cerebrovascular accident, pulmonary embolism)*.
- o Development of neurological deficit not present at the time of admission but present at the time of discharge from the admission†.

- o Inappropriate discharge to home or inadequate discharge plan for index admission (excluding discharges “against medical advice”).
- o Cardiac arrest or respiratory failure.
- o Injury related to abortion or to labour and delivery.
- o Hospital-acquired infection or sepsis‡.
- o Dissatisfaction with care documented in the medical record or evidence of complaint lodged.
- o Documentation or correspondence indicating litigation, either contemplated or actual.
- o Any other undesirable outcomes not covered above.

*Includes any unexpected complication occurring during the admission that is not a natural progression of the patient’s disease or an expected outcome of treatment.

†Includes neurological deficits related to procedures, treatments or investigations.

‡Excludes infections or sepsis occurring less than 72 hours after admission.