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Hospital staff and stroke patient perceptions of barriers and facilitators to communication on acute and rehabilitation hospital wards.

| Manuscript ID bmjopen-2020-043897 Article Type: Original research Date Submitted by the Author: 19-Aug-2020 Complete List of Authors: D'Souza, Sarah; Edith Cowan University, School of Medical and Health Sciences Godecke, Erin; Edith Cowan University, School of Medical and Health Sciences; La Trobe University, Centre for Aphasia Recovery and Rehabilitation Research Ciccone, Natalie; Edith Cowan University, School of Medical and Health Sciences Hersh, Deborah; Edith Cowan University, School of Medical and Health Sciences Janssen, Heidi; The University of Newcastle Hunter Medical Research Institute Armstrong, Elizabeth; Edith Cowan University, School of Medical and Health Sciences Stroke < NEUROLOGY, Adult neurology < NEUROLOGY, QUALITATIVE |
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| Keywords: RESEARCH |

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Title page

Title

Hospital staff and stroke patient perceptions of barriers and facilitators to communication on acute and rehabilitation hospital wards.

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Key words: stroke, adult neurology, qualitative research

Competing interests statement: This research was funded by The Hollywood Private Hospital Research Grant (RF087). SD received an Australian Post Graduate Award Scholarship for the first year of this study, and received an ECU Research Travel Grant. The authors have no other competing interests to declare.

Author contributions: All authors designed the study and the protocol. EG reviewed the final copies of the protocol documents. SD conducted the semi-structured interviews and focus groups. SD performed data analysis. DH conducted the critical review of the categories and review of themes. All authors contributed to the manuscript and approved the manuscript.

Reporting guidelines checklist: The consolidated criteria for reporting qualitative studies (COREQ)²¹ was used to guide reporting this study.

Funding statement: This work was supported by the Hollywood Private Hospital Research Foundation grant number RF087. SD received an Australian Post Graduate Award Scholarship for the first year of this study, and received an ECU Research Travel Grant.

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All authors have completed the <u>Unified Competing Interest form</u>) and declare: This research was funded by The Hollywood Private Hospital Research Grant (RF087). SD received an Australian Post Graduate Award Scholarship for the first year of this study, and received an ECU Research Travel Grant. No other support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years, no other relationships or activities that could appear to have influenced the submitted work.

The lead author (the manuscript's guarantor) affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned have been explained.

This study has Ethics approval from the Edith Cowan University Human Research Ethics Committee (ECU HREC 12149) and The Hollywood Private Hospital Research Ethics Committee (HPH431).

Abstract

Objectives: To explore hospital staff, volunteer and stroke survivor perceived barriers and facilitators to stroke survivor communication in an acute and a rehabilitation ward setting.

Design: A qualitative descriptive sub-study within a larger study which aimed to develop and test a Communication Enhanced Environment in an acute and a rehabilitation ward.

Setting: A metropolitan Australian private hospital.

Participants: Acute and rehabilitation doctors, nurses, allied health staff and volunteers were purposively recruited. Seven stroke inpatients, including three with aphasia, were consecutively recruited.

Results: Hospital staff and volunteer focus groups and interviews, and patient interviews were conducted. The key themes related to barriers and facilitators to communication, contained sub-categories related to hospital, staff and patient factors. Hospital related barriers to communication were private rooms, mixed wards, the physical hospital environment, hospital policies, the power imbalance between staff and patients, and task specific communication. Staff related barriers to communication were staff's perception of time pressures, underutilisation of available resources, staff individual factors such as personality, role perception and lack of knowledge and skills regarding communication strategies. The patient related barrier to communication involved patients' functional and medical status. Hospital related facilitators to communication were shared rooms/colocation of patients, visitors and volunteers. Staff related facilitators to communication were utilisation of resources, speech pathology support, staff knowledge and utilisation of communication strategies and individual staff factors such as personality.

Conclusions: Barriers and facilitators to communication appeared to be interconnected and likely to influence one another suggesting that the level of communication access may vary from patient to patient within the same setting.

Study strengths

- This study involved a large number of staff in comparison to previous studies^{12, 13} and included volunteers working within the acute and rehabilitation wards as well stroke in-patients.
- Data saturation was reached within the staff focus groups.

Study limitations

- Small numbers of medical (n=2) and nursing staff (n= 11) were recruited
 compared to allied health staff (N= 32) which may be reflected in the results.
- This study involved a small number of stroke participants; a broader range of perspectives may have been expressed with a larger number of participants.
- This study was conducted at a private hospital involving a mixed acute and a
 mixed rehabilitation ward. These results reflect this context and may not be
 directly generalisable to hospitals in the public sector.

Background

Stroke survivors in hospital spend on average 65-94% of their day inactive.¹ Despite improvements in functional independence during their hospital admission, stroke survivors' engagement in cognitive and social activity remains largely unchanged.² Stroke survivors with aphasia spend two thirds less time engaged in social interactions with family and friends compared to stroke survivors without aphasia.³

Stroke survivors have described time outside therapy as "dead" and "wasted", reporting a lack of stimulation and inactivity in hospital impacting their ability to self-direct their rehabilitation outside of therapy.⁴ A lack of social and cognitive activity early after stroke for stroke patients with aphasia has the potential to contribute to: i) the development of maladaptive compensatory communication behaviours, and ii) the learned non-use of language, which may ultimately impact on their quality of life and overall language recovery.³

This study aimed to explore hospital staff and volunteer, and stroke patient perceptions of barriers and facilitators to stroke patient communication in an acute and a rehabilitation hospital ward. Identifying barriers and facilitators to stroke inpatient communication will inform the development of a Communication Enhanced Environment (CEE) for the purposes of increasing stroke survivor engagement in language activity within a hospital ward to maximise post-stroke aphasia language recovery.

Methods

Design

This was a sub-study of a larger study which aimed to develop and test a CEE within an acute and a rehabilitation ward (see supplementary file for study protocol and procedure). This sub-study contributed to the baseline phase of the larger study outlined below:

- i) Baseline phase: observe and quantify stroke patients' engagement in language activity in the acute and rehabilitation ward environments and explore hospital staff and volunteer, and stroke patients' perceptions of barriers and facilitators to communication in hospital;
- ii) Implementation phase: develop and implement the CEE on the acute and rehabilitation wards;

Post-implementation phase: assess the impact of the CEE on stroke patient engagement in language activity, and hospital staff and patients' perceptions of barriers to communication in hospital.

Research authors' relationship with participants

The first author who was external to the hospital conducted focus groups and interviews. The first author engaged key hospital team members for the duration of the study to inform the study design to ensure it aligned with the hospital policies and priorities.

Public and patient involvement

The public and patients were not involved in the design of this study however this data informed the development of the CEE model in the larger study. A working group consisting of key members of the stroke multidisciplinary team provided feedback on this study's findings and were involved in the development of the CEE model and embedding approach, which was based on the outcomes of this sub-study. Dissemination of the final results of this sub-study will be provided on completion of the larger study.

Setting

This study was conducted on an acute and a rehabilitation ward at a private hospital in Perth, Western Australia. The acute ward was a 26- bed unit with acute stroke and medical patients. The acute ward had four individual rooms and nine shared rooms, two rooms with four beds per room, and seven rooms with two beds per room. Patients ate meals in their rooms and had access to an outdoor balcony area. The rehabilitation ward was a 44-bed mixed rehabilitation unit for medical, orthopaedic, post-surgical and stroke patients. There were thirty-six individual rooms, and four shared rooms with two beds in each room. Patients had breakfast in their rooms but were encouraged to eat lunch and dinner in one of two communal dining areas.

Participants

Hospital staff participants: Purposeful sampling of acute and rehabilitation hospital staff was conducted to include at least one representative from each acute and rehabilitation staff group including medical, nursing, volunteers, and allied health staff members who were over 18 years of age. A total of 51 staff and volunteers were recruited (Table 1.) by contacting staff department managers who identified staff currently working or had previously worked with stroke patients on the acute or rehabilitation wards.

Table 1. Staff participants

| Staff/volunteer groups | | | | | | | | |
|------------------------------|---|---------------------------------------|---|----------------|---|--|--|--|
| Medical & Nursing | N | Allied Health | N | Volunteer | N | | | |
| Acute nurses (AN) | 2 | Dietitian (DT) | 1 | Volunteers (V) | 6 | | | |
| Clinical nurse manager (CNM) | 1 | Occupational therapy manager (OTM) | 1 | | | | | |
| Medical consultants (MC) | 2 | Occupational therapists (OT) | 5 | | | | | |
| Rehabilitation nurses (RN) | 8 | Occupational therapy assistants (OTA) | 3 | | | | | |
| | | Physiotherapists (PT) | 8 | | | | | |
| | | Physiotherapy assistants (PTA) | 2 | | | | | |
| | | Social workers (SW) | 5 | | | | | |
| | | Speech pathology manager (SPM) | 1 | | | | | |
| | | Speech pathologists (SP) | 4 | 7 | | | | |
| | | Speech pathology assistant (SPA) | 1 | | | | | |
| | | Volunteer manager (VM) | 1 | | | | | |

Stroke patient participants: All consecutively admitted stroke patients from January to February 2016, and June 2016 to July 2017 were screened for eligibility to participate in the study. Inclusion criteria: i) admitted to the acute or rehabilitation ward with an acute stroke, ii) less than 21 days post-stroke during data collection, iii) able to provide informed consent based on the judgement of the medical team responsible for the medical management of the patient, iv) Glasgow Coma Scale⁶ greater than 10, v) estimated total length of hospital stay greater than 14 days, vi) adequate English proficiency to participate in interviews as determined by managing speech pathologist or medical team. Exclusion criteria: i) uncorrected hearing or vision (for example hearing impairment without the use of hearing aids or vision impairment without the use of glasses), ii) medically unstable, iii) documented diagnosis of current untreated depression, documented diagnosis of dementia, previous aphasia or traumatic brain injury. The diagnosis of aphasia was confirmed for those who achieved a Western Aphasia Battery-Revised Aphasia Quotient score less than 93.7. A total of 9 stroke participants were recruited, however 2 stroke participants were withdrawn as they became medically unwell. Data collection was completed for 4 stroke patients without aphasia and 3 stroke patients with aphasia. See Figure 1. for the summary of stroke participant screening and recruitment. Stroke participant details and demographics are detailed in Table 2.

No staff or stroke participants withdrew from participating in this study.

Data collection

The first author, a female speech pathologist (Bachelor of Speech Pathology, First Class Honours) and PhD student with seven years clinical experience working in the hospital setting and five years research experience, including conducting interviews and focus groups, completed all semi-structured interviews and focus groups. Staff were informed that the researchers wanted to investigate their perceptions of the hospital ward environment in regards to communication opportunities to inform the development of a Communication Enhanced Environment (see supplementary file for staff and volunteer information and consent forms). Stroke patients were informed that the researchers wanted to explore how the hospital environment influenced patient activity (see supplementary file for stroke patient information and consent forms).

All interviews and focus groups were conducted using interview and focus group guides (staff focus groups and interview guide Appendix A., patient interview guide

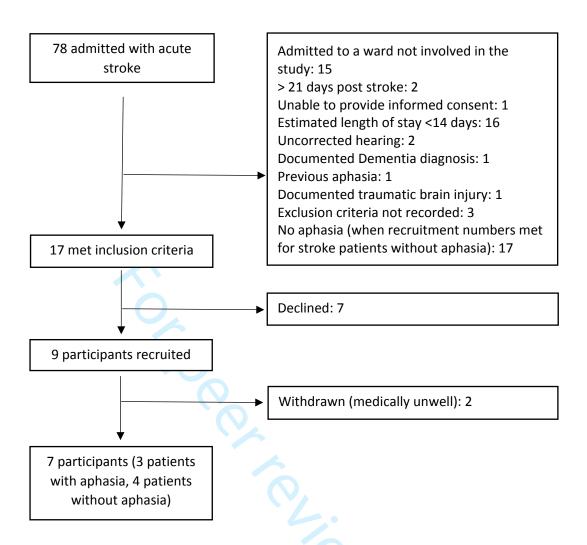


Figure 1. Summary of stroke participant screening and recruitment

Table 2. Stroke participant characteristics

| | Premorbid mobility | Age | Gender | Language/s spoken at home | Type of stroke ^a | NIHSS ^b score (days post stroke) | MoCA ^c (days post stroke) | WAB-R AQ ^d score (days post stroke) | Days post-stroke interview conducted | |
|--|---|-----|--------|---------------------------------|-----------------------------|---|---|---|--------------------------------------|--|
| Stroke patients with aphasia (PWA) | | | | | | | | | | |
| PWA1 | Independent | 78 | М | English | L MCA infarct | 1 (7) | 18/30 (7) | 84.6, mild Broca's aphasia | 11 | |
| PWA2 | Independent | 78 | М | English | L thalamic infarct | 4 (10) | 9/30 (11) | 72.3, moderate Broca's aphasia (10) | 13 | |
| PWA3 | Walking stick for distance, independent otherwise | 87 | F | English | L MCA infarct | 9 (20) | 16/30 (20) | 74.8, moderate Broca's aphasia (20) | 25 | |
| Stroke patients without aphasia (PWOA) | | | | | | | | | | |
| PWOA1 | Independent | 76 | F | English | L lacunar infarct | 5 (13) | 21/30 (13) | | 17 | |

| PWOA2 | Independent | 88 | F | Polish, Russian, English | R cerebellar infarct | 2 (21) | 17/30 (21) | 24 |
|-------|-------------|----|---|--------------------------------|---------------------------|--------|------------|--------|
| PWOA3 | Independent | 93 | F | English | R parenchymal haemorrhage | 8 (16) | 18/30 (16) | 21 |
| PWOA4 | Independent | 78 | M | English | R MCA and R ACA infarcts | 0 (9) | 22/30 (9) | 21 |

Notes: ^aR= right hemisphere, L= left hemisphere, MCA= middle cerebral artery, ACA= anterior cerebral artery; ^bNIHSS=National Institute of Health Stroke Scale⁸; ^cMoCA= Montreal Cognitive Assessment⁹; ^dWABAQ=Western Aphasia Battery-Revised⁶⁷ Aphasia Quotient score.

Appendix B.) and were audio recorded. Field notes were completed by the first author during data collection. Seven staff focus groups were conducted with two to eight participants in each focus group. One-on-one interviews were conducted with two staff members. All staff focus groups were completed on the hospital site in various locations that were private and quiet. Six out of seven stroke patient interviews were conducted in person during their inpatient admission in their hospital room, and one was completed over the phone (stroke patient without aphasia) one day following discharge from hospital. All patient interviews were conducted within fifteen days post-stroke. Interview and focus groups were 20-60 minutes long, often varying based on the number of participants.

Supported conversation strategies were used during interviews with PWA to facilitate their participation in the interview. One PWA had two family members present during the interview. Member checking was conducted during the interviews through clarifying questions and paraphrasing comments for confirmation by participants.

Data analysis

Focus groups and interviews were transcribed verbatim. Responses to any leading questions were removed from the data set.¹¹

The theoretical framework for this research was a qualitative description approach.¹² This approach involves describing patient experiences, with minimal interpretation of the data to minimise potential bias of the researchers. ¹² Participant experiences were analysed using NVivo¹⁰ computer software to manage the data. Data were grouped into themes according to content.¹¹ The first level of coding identified the broad content of the data then sub-categories were identified.¹¹ Single lines of data were not removed from their 'story' during data analysis to maintain the context and help ensure meaning was not lost or misinterpreted.¹¹ Ongoing critical review of the categories were conducted and themes were reviewed by a second researcher.¹²

Results

The key themes from the focus group and interviews related to barriers and facilitators to communication, with sub-categories identified which related to hospital, staff and patient factors (Figure 2.).

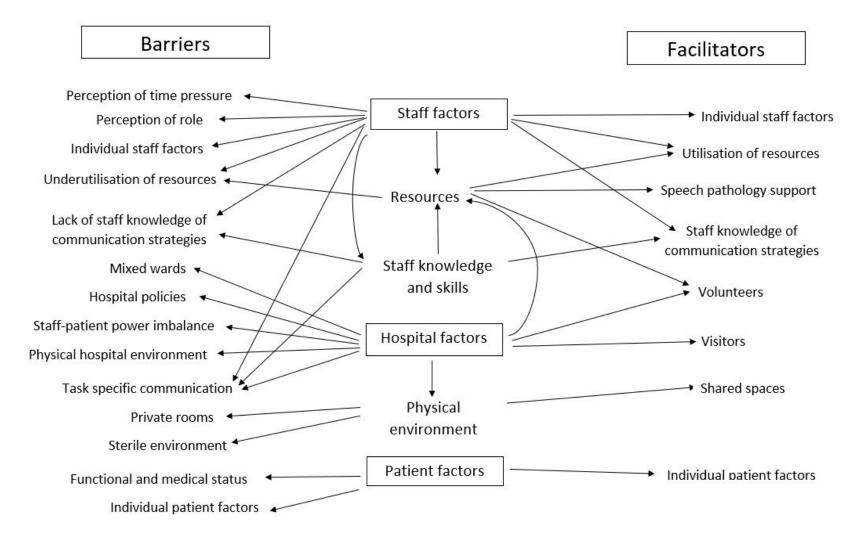


Figure 2. Summary of themes and subthemes of staff and patient perceptions to barriers and facilitators to stroke inpatient communication and language activities.

Barriers to Communication

Hospital related factors

Private rooms reduce opportunities for social interaction

Staff and patients described the impact of single rooms which limited incidental socialisation with other patients and their visitors.

We used to co-locate our stroke patients and often using our shared rooms. That's when people had more opportunities for interacting with one another. (MedC1)

Mixed wards affect staff acquisition of specialist skills

Staff described their perception of the negative effect a mixed hospital ward had on the acquisition of stroke specific specialist skills.

Having a stroke specific ward... everybody on the ward would be trained...and that's the only thing they'd have to focus on rather than having lots of other patients with lots of medical conditions. (OT4)

Hospital environment does not encourage socialising

Staff talked about the physical hospital ward environment affecting social interaction as it contributed to a sterile atmosphere rather than one that promoted social activity. Staff also talked about the consequence of background noise and environmental distractors in large shared rooms on the acute ward which reduced their ability to communicate with stroke patients with communication impairments.

My general feeling of rehab [rehabilitation] is that they come to their sessions and then they go back to their lonely dark room... I don't really see the rooms as a particularly happy, busy place where they are getting a lot out of being in there... the dining rooms... they're not a particularly pleasant place to be either. (PT2)

Hospital policies restrict the development of communication-promoting ideas and initiatives

Hospital policies were perceived by staff as a barrier to communication, negatively influencing their ability to develop ideas and initiatives to increase patients' opportunities for social interaction.

It's just every time you try and do something you hit a barrier... you do try and think outside the box what more can you do for this patient and you get another hospital rule. (PT2)

Power imbalance of staff and patients in hospital controls patients' ability to access communication opportunities

Staff and patients discussed the influence of the power imbalance for patients in hospital, and patient perceptions that they have to do what is expected in the hospital environment. This appeared to limit the patients' ability to freely engage and explore the environment resulting in patients retreating to their rooms and limiting their opportunities to engage in activities.

I think most males like to account for their time um and I felt like I haven't been able to do that and that's, that's the bit that I'm really, really lacking. (PWA2)

I was in the hospital so I think I had to stick into the room, to the rules. (PWOA2)

Very often when you're in a hospital you do what you think you're expected to do. (SP4)

Task specific communication reduces patients' communication opportunities

Staff talked about the nature of interactions with patients as often being driven by the patient's care, restricting opportunities for communication beyond this context.

I know we aim to be very holistic... but very often care is very[sic] directed from a medical health care perspective (SP4)

Staff related factors

Staff's perception of time pressures limiting opportunities for communication

Both patients and staff perceived staff time pressures as a barrier negatively effecting communication on the wards. Some staff reported that they felt interactions with patients with communication impairments required extra time which was challenging in a time pressured hospital environment. Time pressures were also perceived to restrict the staff's ability to facilitate opportunities for patients to socialise with other patients. For example, nurses appeared to deprioritise transferring patients to the communal area for lunch in busier times.

If they're hoist patients it might not be as easy for staff to get them to the dining room, that wouldn't totally prevent someone from going, it would just depend on the time that people had on the day. (SW3)

Staff and patient's underutilisation of available resources

Staff described the lack of accessible resources as a factor negatively affecting staffpatient communication. They described the need for resources when communicating with patients with aphasia and other communication impairments. They also described a number of resources that they felt patients were not aware of and therefore did not utilise.

There are all of these opportunities but I don't think a lot of the patients access them so it sounds like great communicative opportunities for them but the reality is that a lot of them are sitting in their rooms most of the times by themselves watching television and most of the interactions they have is with the nurses or just whoever comes in to see them. (SP4)

Individual staff factors leading to restricted opportunities for communication

Staff described individual staff factors such as personality, values and attitudes influencing communication opportunities for stroke patients, such as staff providing patients with opportunities for incidental social interaction during routine tasks.

Often if people need to go in and see the patient let's just say to take obs [observations] or to do a wash... they don't always use that opportunity as an opportunity to chat... there could be more opportunity to chat at those times whilst they are doing what they need to get done and you know that varies from person to person, personality as well and how busy people are, what else is going on. (SP3)

Staff's perception their role does not include communication tasks

Some staff perceived communication as a task separate from the responsibility of their role therefore limiting their facilitation of communication opportunities for stroke patients.

They [speech pathologists] do their bit and we do ours... we don't have time to practice speech with them because we really do have to get all of our jobs filled in the time and it's specifically rostered for us to do our work, not to help with someone else's. (RehabN1)

Lack of staff knowledge and skills resulting in unsuccessful communication interactions or avoiding communication interactions

Staff described a lack of knowledge and skills in communicating with stroke patients with communication impairments. Some staff reported feeling anxious about encouraging patients to communicate as communication breakdowns may cause stress and anxiety for the patient, and the staff member. Staff reported a lack of confidence in their ability to repair communication breakdowns which resulted in increased time pressures in their sessions, often leading them to avoid encouraging communication interactions within their treatment sessions.

I find it challenging... knowing how the best way to communicate with that person [with aphasia]... then [they] become very frustrated and not have the tools themselves to communicate back to me and you would never want to leave someone in that space. So that's something that I struggle with. (SW2)

Patient related factors

Patients' functional and medical status limiting their ability to seek out and engage in activities

Staff and patients perceived patients' medical status as a barrier to communication by limiting their ability to engage with their environment including independently seeking out activities and being able to utilise communal areas.

If someone is bed bound, you know the interaction is very minimal... you often walk past and you see them alone in their room... you wonder what happens during those periods of time where they're just in their room and they don't have family. (OT2) Well I can't do anything cos I can't go off by myself and do anything. (PWOA2)

Individual patient factors limiting opportunities for communication

Staff described individual patient factors such as personality, mood and motivation communication opportunities for stroke patients such as independent practice of communication therapy tasks, and social opportunities with patients and hospital staff.

We have to recognise some patients who have had strokes ... they're fed up with having people poking and prodding them then have a volunteer and go "do you want to do your exercises for speech?" (VM)

Facilitators to Communication Hospital related factors

Shared rooms/co-location encourages incidental social interactions

Staff talked about use of communal areas at other hospitals which facilitated socialisation and communication during non-therapy times and during group therapy. Staff described the importance of the use of communal areas given the large number of private rooms on the ward. Patients also described the need to be co-located to promote social interaction.

I think that, put the [sic] whole lot of people together and ah and they [sic] something collective, that's what human beings are put together for ... sitting around talking... over the proverbial cuppa. (PWA2)

Visitors provide patients opportunities for socialisation

Staff identified visitors as a facilitator to communication interaction for stroke patients outside of therapy times during their inpatient admission.

Interaction with the family... it's not therapy based but it's their [stroke patients'] opportunity to practice. (PT1)

Volunteers facilitate opportunities for patients to engage in social activities

Staff discussed the benefit of volunteers in facilitating opportunities for patients to engage in social interactions including programs involving therapy dogs, book loaning, hand massages, and taking patients off the ward.

If we see people that are lonely, are not getting visitors, there's many volunteers... to go and visit them and if they're well enough they can take them out... the volunteers, we do rely on them. (OTA)

Staff related factors

Staff utilisation of resources promote communication exchange

Staff identified access to resources such as chat books and alternative and augmentative communication boards often facilitated communication interactions with stroke patients with communication impairments on the ward.

Sometimes with the ... signs... "do you want to drink? some water?" or something, so they can just point because ... they want to say something and maybe the right words are not coming out... that also helps. (RehabN3)

Speech pathology support and education facilitates staff's use of communication promoting strategies

Staff reported support and education from speech pathology staff facilitated their ability to interact successfully with stroke patients with aphasia.

I had a patient who had word finding difficulties... I just was observing the speechie [speech pathologist], she would just be like "no, what do you mean?" and he'll be like [pointing] and she'll be like "tell me what's the word"... it's something I could have just added to my session. (PT4)

Staff knowledge and utilisation of communication strategies promotes communication activities

Staff and volunteers discussed the use of communication strategies and resources to facilitate communication on the ward for patients with a variety of communication impairments.

We use communication boards, pictures, writing things down, talking slowly. (MedC2)

If they are having trouble, I will say to them "it's okay you don't need to hurry, that's fine". (V1)

Individual staff factors promote communication opportunities for patients

Staff and patients talked about how individual characteristics of staff, including rapport building and being friendly, facilitated communication for patients with communication difficulties.

Sometimes they [stroke patients] look for that specific person... the more they get confident, the more they get relaxed, the more their speech enhances as well. (RehabN3)

Discussion

This study aimed to explore hospital staff, volunteers and stroke patients' perceptions of barriers and facilitators to communication on an acute and a rehabilitation ward. A wide range of factors were perceived to act as potential barriers or facilitators to communication. Additionally, a number of factors influencing patient access to communication opportunities appeared to influence one another.

The co-location of patients in therapy spaces, dining areas or in shared rooms were perceived as facilitators to communication for stroke inpatients providing opportunities for incidental social interactions with other patients and their visitors. However, background noise in these shared spaces was also perceived to act as a barrier to patients' ability to engage in communication. Patient access to communal spaces was influenced by a number of factors including patients' sense of autonomy to freely explore the hospital ward environment, and their medical and mobility status, and staff's perception of their available time, which influenced staff's perception of whether they transferred patients to these spaces. Rosbergen et al¹⁴ reported that in an acute stroke ward enriched environment communal mealtimes and group activities were perceived to facilitate social activity. The study by Rosbergen et al¹⁴ found that staff reported perceptions that shared rooms limited

staff and patients' ability to engage in private conversations, consistent with O'Halloran et al's¹⁵ findings. It may be that access to both private and communal spaces available within the hospital environment play critical roles in regards to providing opportunities for social interactions with other patients and their visitors and opportunities for privacy when required.

The predominance of single rooms and limited opportunities to access shared spaces may have increased the effect of other barriers on communication opportunities for patients. For example, a patient with poor autonomy may be more likely to remain alone in their single room when they are not attending therapy, as they perceive they are not 'allowed' to freely explore the hospital environment. This may reduce the likelihood of the individual independently seeking out social interactions beyond their room. If they also have reduced mobility, they may be more reliant on staff to facilitate transfers to communal spaces which may be impacted by staff time constraints. The person's functional status may also limit their ability to initiate and engage in activities while they are in their room. Therefore, the combined effect of these barriers may significantly limit this patient's communication opportunities.

These communication barriers may be mitigated by having regular visitors to provide opportunities for communication and socialisation within their room, and facilitate patient access to shared spaces, such as helping mobilise wheelchair bound patients into communal dining areas or education to patients that they are allowed to explore the hospital ward environment. Rosbergen et al¹⁴ identified patient and family autonomy to initiate and direct activity as a factor enriching the acute ward environment. Therefore, increasing patient autonomy within this setting may facilitate their ability to seek out interactions within the environment and increase engagement in communication activity, which may then reduce the effect of being in a single room with reduced mobility and time poor staff.

A potential lack of opportunities to access social interactions with other patients means staff, including volunteers, and visitors may become the main communication partner for stroke inpatients. Godecke et al's³ observation study found that nurses are the most frequent communication partner for patients with aphasia, after their family members, therefore patient-staff interactions may play a significant role for those patients with minimal or no visitors. Within the current study, communication between staff and patients appeared to be dependent on a number of factors including staff perception of

their role, their knowledge and skills in facilitating communication, their values and attitudes towards communication and whether supporting language and communication for stroke patients with aphasia is part of their 'role', their willingness to be flexible with their time, and their knowledge of and access to resources which may be used to facilitate communication. This also highlights the potential impact of the perceived power imbalance between staff and patients and the significance of interactions that are task directed. Hersh et al¹⁶ reported stroke patients with aphasia felt disempowered in communicative interactions with nurses, where nurses tended to talk to the task and controlled the interactions. This highlights the need for communication partner training which may provide staff with the knowledge and skills required to support effective communication with patients with aphasia.¹⁷

Time pressure was perceived as a major barrier to communication impacting on staff's ability to support successful communication within their interactions with patients, and facilitate patients' opportunities to engage in interactions in social or communal areas. Time constraints have been reported to limit communicative opportunities between stroke in-patients and nurses. Ball et al found that 86% of surveyed nurses reported one or more activities had been "left undone" in their last shift as a result of lack of time. The study found that activities most likely to be missed by nurses as a result of time constraints were comforting and talking to patients (66%) and patient education (52%). This has also been identified by patients who "did not like to bother the busy nurse". Time limitations and pressures on the wards may be facilitated by developing staff knowledge of and skills in using communication promoting strategies. Effective and efficient nurse patient communication as a result of nurse training has been found to save time, reduce frustration and reduce the burden associated with caring for PWA.

This study included a small number of medical and nursing staff in comparison to compared to allied health staff which may be reflected in the reported results. This study also involved a small number of stroke participants and a broader range of perspectives may have been expressed with a larger number of participants. The results of this study may reflect the context of a private metropolitan hospital therefore further exploration of stroke patient and staff perspectives in the public sector may be warranted.

Conclusions

The barriers and facilitators to communication appear to be interconnected and likely to influence one another, suggesting that the level of communication access may vary from patient to patient within the same setting. The identification of factors that support inpatient communication may reduce the risk of stroke patients with aphasia and other communication impairments developing maladaptive communication behaviours such as learned non-use of communication. A CEE has the potential to benefit stroke patients with and without communication impairments by increasing communication access, improving patient well-being, promoting overall engagement in stroke rehabilitation and improving post-stroke recovery.

Acknowledgements

The authors would like to thank the hospital and staff for supporting this study and assisting in participant recruitment. We would also like to thank all the participants in this study for sharing their experiences and insights.

Data sharing statement

Data is stored to NHMRC standards and will be available (in a de-identified manner) on request.

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Table 1. Staff participants

| Staff/volunteer groups | | | | | | | | |
|------------------------------|-----------------|---------------------------------------|---|----------------|---|--|--|--|
| Medical & Nursing | N Allied Health | | | Volunteer | N | | | |
| Acute nurses (AN) | 2 | Dietitian (DT) | 1 | Volunteers (V) | 6 | | | |
| Clinical nurse manager (CNM) | 1 | Occupational therapy manager (OTM) | 1 | | | | | |
| Medical consultants (MC) | 2 | Occupational therapists (OT) | 5 | | | | | |
| Rehabilitation nurses (RN) | 8 | Occupational therapy assistants (OTA) | 3 | | | | | |
| | | Physiotherapists (PT) | 8 | | | | | |
| | | Physiotherapy assistants (PTA) | 2 | | | | | |
| | | Social workers (SW) | 5 | | | | | |
| | | Speech pathology manager (SPM) | 1 | | | | | |
| | | Speech pathologists (SP) | 4 | 7 | | | | |
| | | Speech pathology assistant (SPA) | 1 | | | | | |
| | | Volunteer manager (VM) | 1 | | | | | |



Table 2. Stroke participant characteristics

| | Premorbid mobility | Age | Gender | Language/s spoken at home | Type of stroke ^a | NIHSS ^b score (days post stroke) | MoCA ^c (days post stroke) | WAB-R AQ ^d score (days post stroke) | Days post-stroke interview conducted | |
|--|---|-----|--------|---------------------------------|-----------------------------|---|---|---|--------------------------------------|--|
| Stroke patients with aphasia (PWA) | | | | | | | | | | |
| PWA1 | Independent | 78 | М | English | L MCA infarct | 1 (7) | 18/30 (7) | 84.6, mild Broca's aphasia (7) | 11 | |
| PWA2 | Independent | 78 | М | English | L thalamic infarct | 4 (10) | 9/30 (11) | 72.3, moderate Broca's aphasia (10) | 13 | |
| PWA3 | Walking stick for distance, independent otherwise | 87 | F | English | L MCA infarct | 9 (20) | 16/30 (20) | 74.8, moderate Broca's aphasia (20) | 25 | |
| Stroke patients without aphasia (PWOA) | | | | | | | | | | |
| PWOA1 | Independent | 76 | F | English | L lacunar infarct | 5 (13) | 21/30 (13) | | 17 | |

| PWOA2 | Independent | 88 | F | Polish, Russian, English | R cerebellar infarct | 2 (21) | 17/30 (21) | 24 |
|-------|-------------|----|---|--------------------------------|---------------------------|--------|------------|--------|
| PWOA3 | Independent | 93 | F | English | R parenchymal haemorrhage | 8 (16) | 18/30 (16) | 21 |
| PWOA4 | Independent | 78 | М | English | R MCA and R ACA infarcts | 0 (9) | 22/30 (9) | 21 |

Notes: ^aR= right hemisphere, L= left hemisphere, MCA= middle cerebral artery, ACA= anterior cerebral artery; ^bNIHSS=National Institute of Health Stroke Scale⁸; ^cMoCA= Montreal Cognitive Assessment⁹; ^dWABAQ=Western Aphasia Battery-Revised⁶⁷ Aphasia Quotient score.

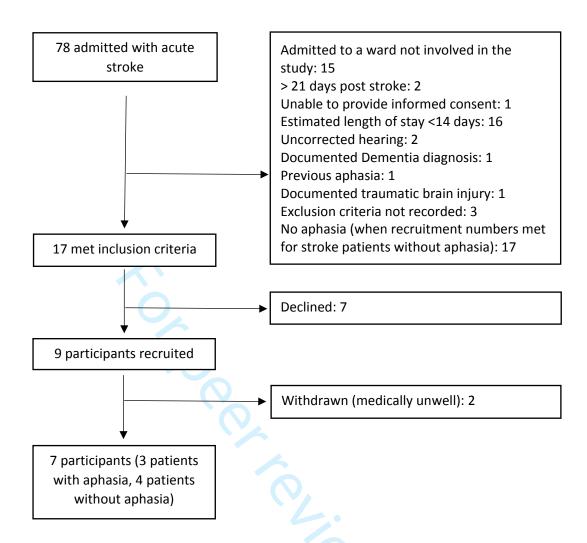


Figure 1. Summary of stroke participant screening and recruitment

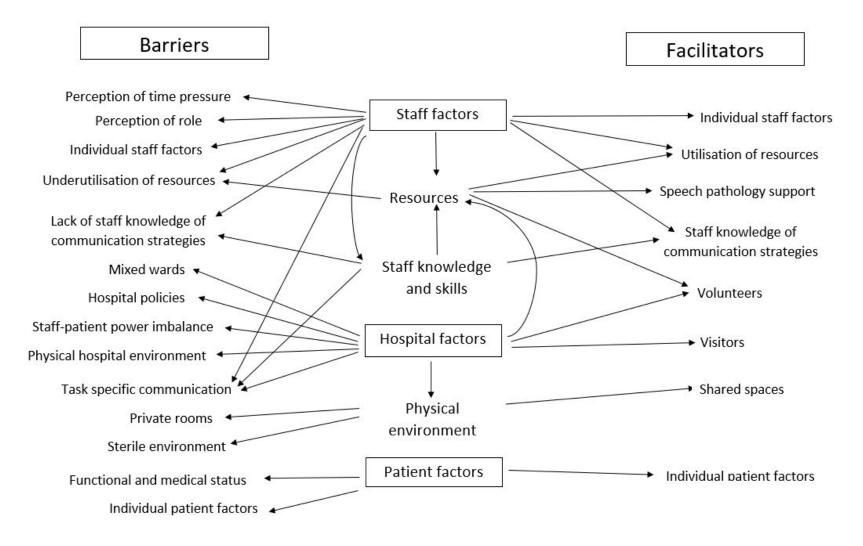


Figure 2. Summary of themes and subthemes of staff and patient perceptions to barriers and facilitators to stroke inpatient communication and language activities.

Appendix A.

Investigating Communication Enhanced Environments after stroke: Staff focus group guide

What kind of language activities or language tasks do stroke patients currently participate in on the ward?

What kind of language activities or language tasks would you like see stroke patients have access to on the wards?

Describe your experience of communicating with stroke patients at the moment.

Can you tell me about anything that facilitates your ability to communicate with stroke patients on the ward?

Can you tell me about any barriers you experience that impact your ability to communicate with stroke patients on the ward?

What changes would you like to see to enhance communication between staff and stroke patients on the ward?

What changes would you like to see to enhance communication between visitors and stroke patients on the ward?

How could we enhance or optimise communication and language tasks and activities for stroke patients on the ward?

What do you think a communication and language enhanced stroke ward environment might look like?

Appendix B.

Investigating Communication Enhanced Environments after stroke: Patient interview guide

Tell me about what kind of activities you do while you are here (in hospital).

Describe your experience of communicating with people on the ward.

What makes it easier to communicate with people on the ward?

What makes it hard to communicate with people on the ward?

What can we do to make communicating with people easier?

Investigating Communication Enhanced Environments (CEE) early after stroke: A before-after non-randomised controlled pilot study.

Study protocol version 1 19.05.20

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1 Abbreviations and Definitions of Terms

CEE: Communication Enhanced Environment, an adapted model of an Enriched Environment, an environment that provides stroke patients opportunities to engage in language activities during inpatient rehabilitation.

PWA: Stroke patients with aphasia.

PWOA: Stroke patients without aphasia.

Language activities: Language tasks that consist of solitary or interactive language activities.

Solitary language activities: Activities that may promote aphasia recovery such as reading, writing, listening to the radio, and the use of iPad applications.

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The are be involving tall. Interactive language activities: activities which are based in communicative interactions that involve an exchange of information with a communication partner involving talking, gesture and/or facial expression, reading, writing or drawing to communicate.

EE: Enriched Environment, an environment that promotes physical, cognitive and social activity.

2. Protocol Synopsis

| Study Title: | Investigating Communication Enhanced Environments on acute and rehabilitation wards early after stroke: A before-after non-randomised |
|---------------------|--|
| | controlled pilot study |
| Study type: | Interventional |
| Study Intervention: | A Communication Enhanced Environment (CEE) model will be developed from pre-intervention observations of inpatient language activities and investigations of barriers and facilitators to communication together through focus groups with hospital staff and interviews with patients on the acute and rehabilitation wards. |
| | Sixteen stroke patients will be recruited in this prospective before-after non-randomised controlled pilot study set in an acute and a rehabilitation ward of a metropolitan private hospital. The study includes: i) The baseline phase which involves observation of stroke patients (n=8, 4 stroke patients with aphasia (PWA) and 4 stroke patient without aphasia (PWOA)); the collection of qualitative data through focus groups and semi-structured interviews to determine patient and staff perceived barriers and facilitators to communication; ii) the implementation phase where a model of CEE will be developed and embedded into usual care; iii) the post-implementation phase which will involve repeated baseline data collection on a different cohort of patients (n=8, 4 PWA and 4 PWOA) to determine i) how solitary and interactive language activity levels changed following implementation of the CEE model, ii) the differences post CEE implementation in hospital staff's use of communication promoting strategies when interacting with stroke patients, iii) the differences post CEE implementation in staff and patient perceptions of the barriers and facilitators to inpatient language activities. |
| | The CEE model will include the provision of: i) CEE equipment, for example reading materials such as books and magazines, and access and encouragement to reside in a communal dining area; ii) CEE education, support and training for staff with the aim to develop the ability to facilitate language activities for patients after stroke. The training program will be guided by research evidence, expert opinion and baseline data. Staff will complete a questionnaire pre and post training to determine changes in their knowledge, skills and attitudes regarding communication and aphasia. |
| | Control treatment: Stroke patients with and without aphasia will be observed and video recorded over two week days and one weekend day pre (n=8) and post (n=8) implementation of a CEE model. Behavioural mapping will record patient interactive and solitary language activity observed within the first minute of 5-minute intervals in 4-hour time periods between 7am and 7pm. Solitary language activities are activities that may promote aphasia recovery such as reading, writing, listening to the radio, and the use of iPad applications. Interactive language activities are activities which are based in communicative interactions that involve an exchange of information with a communication partner involving talking, gesture and/or facial expression, reading, writing or drawing to communicate. |

| This study aims to investigate a CEE on an acute and rehabilitation ward and if stakeholders perceive a CEE within the rehabilitation stroke unit as valuable by addressing the following research questions: - Does a CEE increase the amount of time PWA and PWOA spend in participating in solitary and interactive language activities on acute and rehabilitation wards during the early post-stroke period? - What are the differences in stroke patients' experience of communication in a CEE compared to stroke patients' experience of communication in a standard environment on in-patient acute and rehabilitation wards? - What is the experience of implementing a CEE for staff working with PWA and PWOA within in-patient acute and rehabilitation wards? - Do staffs' perceptions of their knowledge of, skills with, and attitude towards communication and aphasia change following implementation of a CEE? Number of Centres: 1 Study Hypothesis: A CEE will increase stroke patient solitary and interactive language activities and improve staff and patient experiences of communication compared to a standard ward environment. Primary outcomes: The primary outcome is the change in the proportion of solitary and interactive language activities as a percentage of total observed activity after the implementation of the CEE model. Timepoint: Stroke patient observations completed within 21 days post stroke. Secondary outcomes: The differences post CEE implementation in staff and patient perceptions of the barriers and facilitators to inpatient language activities. Timepoint: Within 18 months of embedding the CEE model. T1-T2 before-after non-randomised pilot study Stroke patients will be eligible for inclusion if they have/are: admitted to the acute or rehabilitation ward for a stroke, less than 21 days post |
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| the acute or renabilitation ward for a stroke, less than 21 days nost |
| stroke during baseline phase or post-implementation phase, the ability |
| to provide informed consent as determined by the medical team, a |
| Glasgow Coma Scale ¹ score greater than 10 at the time of screening, an |
| estimated length of hospital stay greater than 14 days, adequate English |
| proficiency to participate in semi-structured interviews and are above 18 |
| years of age. Patients with aphasia will also have an Aphasia Quotient |
| below 93.7 on the Western Aphasia Battery-Revised. ² |
| Staff participants: One representative from each acute and rehabilitation |
| staff group including medical, nursing, volunteers, and allied health staff |
| members (n=17), who are over 18 years old. |
| Key exclusion criteria: Patients will be excluded if they have/are: uncorrected hearing or vision, |
| not medically stable, a documented diagnosis of dementia, traumatic |
| brain injury or previous aphasia, a documented current untreated |
| depression at the time of acute admission or are a participant in another |
| research trial which may affect this study's outcome measures. |
| |
| Study Procedures: Baseline phase: Eligible stroke participants during the baseline phase |
| will be observed and video recorded for 4 hours on 3 consecutive days |
| (one weekend and two weekdays) and will complete a semi-structured |
| interview to explore their experiences of communication, and their |

| | perceptions of barriers and facilitators to inpatient language activities | | | |
|---------------------|--|--|--|--|
| | during their inpatient admission. Staff will participate in a one-hour focus group to explore their | | | |
| | perceptions of barriers and facilitators to inpatient language activities. A | | | |
| | focus group interview schedule will be used across all focus groups. | | | |
| | focus group interview schedule will be used across all focus groups. Implementation phase: The CEE model will be implemented within the | | | |
| | Implementation phase: The CEE model will be implemented within the acute and rehabilitation wards. | | | |
| | | | | |
| | Post-implementation phase: Intervention group patient observations | | | |
| | and interviews, and staff focus groups will replicate baseline data | | | |
| | collection. | | | |
| Safety parameters | Stroke participants and/or their significant others may experience | | | |
| | increased levels of distress during recruitment and/or data collection. | | | |
| | This may be the result of adjustment following stroke and/or diagnosis | | | |
| | of aphasia and increased awareness of impairment. No other risks | | | |
| | known regarding participation in this project. The baseline assessments | | | |
| | and interview will be conducted by the Chief Investigator who has | | | |
| | experience in supporting stroke patients during this early stage of stroke | | | |
| | recovery. If a stroke participant or significant others becomes upset or | | | |
| | distressed, the assessment or interview will be paused with the option to | | | |
| | discontinue and counselling strategies will be provided. | | | |
| Statistical methods | Patient demographic and stroke characteristics will be presented using | | | |
| /analysis | descriptive statistics. One-way ANOVA or the Kruskal-Wallis and chi- | | | |
| | square tests will examine differences in characteristics between groups. | | | |
| | Time spent observed in interactive and solitary language activities will be | | | |
| | expressed as a percentage of total observations. A mixed design ANOVA | | | |
| | will be used to calculate the within-subjects variable of presence of | | | |
| | aphasia and the between-subjects variable of a CEE on language activity | | | |
| | levels of participants by comparing baseline to intervention phase | | | |
| | observations. A qualitative description research approach will be used | | | |
| | for the qualitative component of this research. The mixed methods | | | |
| | design will enable the triangulation of the qualitative and quantitative | | | |
| | data. | | | |
| Sample size | The stroke participant sample size was selected for this pilot study to | | | |
| determination: | collect data across each observation period for each patient group in the | | | |
| | baseline and intervention phases (see document: | | | |
| | Observation_protocol_SD_version 3_23-02-16). The sample size for staff | | | |
| | participants was selected to capture a sufficient breadth of professional | | | |
| | perspectives. | | | |
| I | | | | |

3. Introduction

Aphasia is an acquired communication disorder that affects approximately 30% of first ever ischaemic stroke survivors³ and persists in up to 61% of survivors one-year post stroke.⁴ Aphasia impacts all communication modalities with significant negative consequences for social participation, interpersonal relationships, autonomy, capacity to work and quality of life.⁵

Stroke patients with aphasia (PWA) have been observed to spend less than 28% of their day communicating and 44% of their day alone during their first weeks of inpatient rehabilitation.⁶ Inadequate opportunities for communication places PWA at risk of developing maladaptive behaviours such as learned non-use of language.⁷

Environmental Enrichment (EE) refers to conditions which promote physical, cognitive and social activity and has been shown in animal models of stroke to enhance neuroplasticity⁸, promote better learning and memory and contribute to significant improvements in motor function.⁹ The human equivalent model¹⁰ in a rehabilitation unit results in stroke patients spending more time engaged in activity and less time sleeping and alone.¹¹

4. Objectives

Aphasia is a complex language impairment and PWA may need additional support within an Enriched Environment. This pilot study seeks to develop and test an adapted model of an Enriched Environment, a Communication Enhanced Environment (CEE), as a strategy to provide PWA and stroke patients without aphasia (PWOA) more opportunities to engage in language activities during inpatient rehabilitation. Within this study language activities include both *solitary activities* that may promote aphasia recovery such as reading, writing, listening to the radio, and the use of iPad applications, and *interactive activities* which are based in communicative interactions that involve an exchange of information with a communication partner involving talking, gesture and/or facial expression, reading, writing or drawing to communicate.

4.1 Hypotheses

A CEE will increase stroke patient solitary and interactive language activities and improve staff and patient experiences of communication compared to a standard ward environment.

5. Study design

This mixed methods pilot study is a prospective before-after non-randomised controlled design in an acute and a rehabilitation ward of a metropolitan private hospital. The study involves three phases:

- i) Baseline: observe and quantify the current ward environment;
- ii) Implementation of the CEE model;
- iii) Post-implementation: assess the impact of the CEE model.

6. Study Population

- i) Stroke patients: The baseline group (n=8, 4 PWA, 4 PWOA) recruited within the baseline phase, and the intervention group (n=8, 4 PWA, 4 PWOA) recruited during the post-implementation phase.
- ii) Staff participants: One representative from each acute and rehabilitation staff group including medical, nursing, volunteers, and allied health staff members (n=17), who are over 18 years old.

6.1 inclusion and exclusion criteria

Stroke patients will be eligible for inclusion if they have/are: admitted to the acute or rehabilitation ward for a stroke, less than 21 days post stroke during baseline phase or intervention phase, the ability to provide informed consent as determined by the medical team, a Glasgow Coma Scale¹ score greater than 10 at the time of screening, an estimated length of hospital stay greater than 14 days, adequate English proficiency to participate in semi-structured interviews and are above 18 years of age. Patients with aphasia will also have an Aphasia Quotient below 93.7 on the Western Aphasia Battery-Revised.²

Stroke patients will be excluded if they have/are: uncorrected hearing or vision, not medically stable, a documented diagnosis of dementia, traumatic brain injury or previous aphasia, a documented current untreated depression at the time of acute admission or are a participant in another research trial which may affect any of this study's outcome measures.

Staff and volunteers who are over 18 years old will be eligible to participate in this study.

7. Study Assessments and Procedures

Baseline

All recruited stroke participants will complete the Montreal Cognitive Assessment,¹¹ and The NIH Stroke Scale.¹² PWA will also complete the Western Aphasia Battery-Revised.² Stroke participants' behaviour will be observed and video recorded for four hours per day on a Sunday, Monday and Tuesday between 7am to 7pm. A behaviour mapping tool (Appendix A) developed for this study will record stroke participant engagement in language activities in the first minute of each five-minute interval across each four-hour observation period. Semi-structured interviews will explore stroke participants' perceptions of barriers and facilitators to inpatient language activities. An interview schedule will be used across all interviews (Appendix B.). Supportive communication strategies will be used to facilitate PWA participation in interviews with transcriptions annotated to capture any non-verbal responses.

Staff will participate in a one-hour focus group to explore their perceptions of barriers and facilitators to inpatient language activities. A focus group/interview schedule (Appendix C.) will be used across all focus groups.

Implementation

The CEE model will be implemented within the acute and rehabilitation wards.

Post implementation

Intervention group patient observations and interviews, and staff focus groups will replicate baseline data collection.

8. Study Treatment

The CEE model incorporates the following strategies to encourage engagement in language activities:

- Staff training to facilitate stroke patients' communication and provide opportunities to engage in language activities;
- ii) Patient access to:
 - a) Communication enhancement resources such as iPads and audiobooks;
 - b) Communal areas to facilitate engagement amongst patients.

9. Participant Completion and Discontinuation

9.1 Participant Completion

Participants will have completed the study when they have completed the semi-structured interview.

9.2 Participant withdrawal

Participation in this study is voluntary. The participant can withdraw from taking part in the study at any time without giving a reason for withdrawing.

10. Data analysis

10.1 Primary Analysis

The proportion of observed episodes where PWA and PWOA are engaged in language activities at baseline and post implementation will be analysed using a mixed design ANOVA.

10.2 Secondary Analysis

The differences in staff and patient perceptions of the barriers and facilitators to inpatient language activities and communication post CEE implementation will be analysed through a qualitative description approach. Triangulation of the qualitative and quantitative data will be conducted.

11. Data management

The data collected will be confidential. No identifying information will be attached to the data and any information that may reveal participant's identity will be removed. The master list of participant names and codes will be kept in a locked filing cabinet at the hospital site which will only be accessible by the research team. All data will be accessed, used and stored in accordance with Commonwealth Privacy Laws. The de-identified data will be stored on a password-controlled computer and/or in a locked cabinet at Edith Cowan University. Electronic data will be backed up on a password controlled hard drive only accessible by the Chief Investigator.

The data collected from this study will have a significant contribution to the aphasia research area and therefore will be stored for 15 years following the completion of this study. Data may be accessed for future studies by the study investigators or higher degrees by research (HDR). In the case of HDR use of the data, the use of the data will be bound by a two-way confidentiality agreement. The data may be used for teaching purposes only with the additional written permission from participants. The data may be made accessible to consumer groups (for example the Australian Aphasia Association) and information may be made available through the National Stroke Foundation and scientific journals. Confidentiality will be maintained in all circumstances. Non-identifiable data will be accessible by researchers through data sharing archives. This data will be governed by an overarching body to ensure data are only used for approved purposes. Researchers who access this data from the data bank will not have access to the participant keys that attach participants to codes therefore data will only be re-identifiable by the Chief Investigator. Data will be deleted from electronic storage and hard copy data will be shredded by the chief investigator after 15 years completion of the research study (with Ethics Committee approval, Ethics approval numbers: HPH431 and ECU HREC 12149). Non-identifiable data will be added to data archives for data sharing.

12. Study Report

This study will be published in a PhD thesis as part of the Chief Investigator's Higher Research Degree. Outcomes from this study will be published in peer review journals and at conferences.

13. Administration Procedures

13.1 Ethical Considerations

This research is likely to have a significant impact on aphasia recovery following stroke and will form the basis for future study designs. This study will develop a teaching and learning package that can be used in the future to facilitate and promote increased levels of communication activity during early stroke recovery. The implementation of a CEE may address missed opportunities for language stimulation, harness increased levels of neuroplasticity and optimise aphasia language recovery after stroke. The benefit of a CEE may extend beyond patients with aphasia and may improve health care experience and communication access for all stroke in-patients. Additionally, these benefits may extend beyond patients involved in the study as trained staff may use skills and knowledge obtained in the training program to enhance the communication environment of all patients they care for.

13.2 Ethical Review Committee

All processes and documentation used within this study will be reviewed and approved by the Edith Cowan University Research Ethics Committee and the site Ethics Committee. The Chief Investigator will complete the annual ethics reports and will be responsible for reporting any adverse events to the Ethics Committees.

13.3 Informed Consent

Participants will be excluded if they do not have adequate English proficiency to participate in semi-structured interviews and focus groups. Any participants that require an interpreter will be excluded from inclusion in this study as determined by the medical team.

Patients with aphasia will be provided with aphasia friendly information sheets and consent forms with simple language, bold key words and pictorial support. This will be read and explained by the researcher. Supported conversation strategies will be used to support and facilitate patients with aphasia's involvement and understanding of the research process, informed consent and their rights to withdraw at any time. This will be provided by the Chief Investigator who is a qualified speech pathologist with experience in communicating with patients with aphasia using supported conversation techniques to facilitate and support communication. A detailed information will also be provided to the 'person responsible' for all stroke patients.

13.4 Protocol Amendments

All protocol amendments will be reviewed and accepted by the Edith Cowan University Research Ethics Committee and the site research Ethics Committee.

14. References

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| Time (5 min): | NO LANGUAGE ACTIVITIES OBSERVED (describe) | | | COMMENTS |
|---|---|--|---|----------|
| Location (select one) | People present | INTERACTIVE LANGUAGE ACTIVITIES | 'OTHER' FUNCTIONAL LANGUAGE ACTIVITIES | |
| Amenities Bedroom Hall Therapy area Family Mtg Room Activity room ON WARD Doctor's room Dining room Communal area (describe) | Nurse Personal care assistant Doctor Physio OT SP DT Social worker Family/Friend Other patient Alone | In person Telephone Therapy session/ward round Other (describe) Patient Verbal communication Non-verbal gesture/facial expression (describe) Written aids (writing or reading (circle)) Pictorial aids (describe) | Typing/writing Reading (describe) Texting (mobile phone) Listening to radio/music Watching TV Internet use (describe) Word games with a partner Other (describe) | |
| OFF WARD Outside Off-unit (describe) Other (describe) | Other (describe) | Other communication aid (describe) Communication partner/s Verbal communication Non-verbal gesture/facial expression(describe) Written aids Pictorial aids Other communication aid (describe) | NON-FUNCTIONAL/ NON-PROPOSITIONAL LANGUAGE ACTIVITIES Singing Word games (alone) Language apps (alone) Copying written letters, words, sentences (alone). OTHER Talking to observer Talking to self: appropriate/inappropriate (describe) | |
| Time (5 min): | NO LANGUAGE ACTIVITIES OBSERVED (describe) | | COMMENTS | |
| Location (select one) | People present | INTERACTIVE LANGUAGE ACTIVITIES | 'OTHER' FUNCTIONAL LANGUAGE ACTIVITIES | |
| Amenities Bedroom Hall Therapy area Family Mtg Room Activity room ON WARD Doctor's room Dining room Communal area (describe) OFF WARD Outside Off-unit (describe) | Nurse Personal care assistant Doctor Physio OT SP DT Social worker Family/Friend Other patient Alone Other (describe) | In person Telephone Therapy session/ward round Other (describe) Patient Verbal communication Non-verbal gesture/facial expression (describe) Written aids (writing or reading (circle)) Pictorial aids (describe) Other communication aid (describe) Communication partner/s Verbal communication | Typing/writing Reading (describe) Texting (mobile phone) Listening to radio/music Watching TV Internet use (describe) Word games with a partner Other (describe) NON-FUNCTIONAL/ NON-PROPOSITIONAL LANGUAGE ACTIVITIES Singing Word games (alone) | |
| Other <i>(describe)</i> | | Non-verbal gesture/facial expression(describe) Written aids Pictorial aids Other communication aid (describe) | Language apps (alone) Copying written letters, words, sentences (alone). OTHER Talking to observer Talking to self: appropriate/inappropriate (describe) | |

Appendix B. Patient interview guide

Investigating Communication Enhanced Environments after stroke Patient Interview guide, version 1_11-8-15

Tell me about what kind of activities you do while you are here (in hospital).

Describe your experience of communicating with people on the ward.

What makes it easier to communicate with people on the ward?

What makes it hard to communicate with people on the ward?

What can we do to make communicating with people easier?



Investigating Communication Enhanced Environments after stroke

Staff focus group guide, version 1 27-7-15

STAFF FOCUS GROUP GUIDE BASELINE PHASE

Appendix C. Staff focus group guide.

What kind of language activities or language tasks do stroke patients currently participate in on the ward?

What kind of language activities or language tasks would you like see stroke patients have access to on the wards?

Describe your experience of communicating with stroke patients at the moment.

Can you tell me about anything that facilitates your ability to communicate with stroke patients on the ward?

Can you tell me about any barriers you experience that impact your ability to communicate with stroke patients on

the ward?

What changes would you like to see to enhance communication between staff and stroke patients on the ward?

What changes would you like to see to enhance communication between visitors and stroke patients on the ward?

How could we enhance or optimise communication and language tasks and activities for stroke patients on the

ward?

What do you think a communication and language enhanced stroke ward environment might look like?

STAFF FOCUS GROUP GUIDE POST-IMPLEMENTATION PHASE

Describe your experience of communicating with stroke patients at the moment.

Can you tell me about any barriers you experience that impact your ability to communicate with stroke patients on

the ward?

Describe the differences in the communication environment since implementing the model.

What changes did you see to enhance communication between staff and stroke patients on the ward?

What changes did you see to enhance communication between visitors and stroke patients on the ward?

What was it like to use the model?

How do you feel about the model?

Can you tell me about anything that helped you use the model with stroke patients on the ward?

Can you tell me about any barriers you experienced while implementing the model?

How can we improve the model?

Communication Enhanced Environments after Stroke

Study procedure version 2_23-02-16

BASELINE:

Staff recruitment: The Chief Investigator will recruit staff participants through a verbal explanation of the study and the provision of the information sheets and written consent forms. Staff will be provided 48 hours to discuss the study and ask questions before consenting to participate. Staff interviews and focus groups will commence as staff participants are recruited. Staff will participate in a one-hour focus group or a one-hour semi-structured interview (in person or via telephone) to explore staff perceptions of environmental barriers and facilitators to language activity and communication on in-patient acute and rehabilitation wards.

Patient recruitment: All consecutively admitted stroke patients during the baseline period will be screened for eligibility to participate in the study. The hospital site investigators will identify potential stroke participants that meet the inclusion and exclusion criteria. Stroke participants with aphasia will be identified by the hospital speech pathology or medical team as having a diagnosis of aphasia (aphasia diagnosis will be confirmed via Western Aphasia Battery-Revised (WAB-R)¹ Aphasia Quotient score <93.7 during data collection). The site investigators will approach potential participants and gain verbal consent from the patient to be approached by a member of the research team and have their 3-point identification released to the research team. This will be documented in the patient's integrated medical progress notes. Once verbal consent has been gained and documented, the site investigators will email the Chief Investigator the patient alert proforma identifying the patient as meeting the inclusion/exclusion criteria. The research team will liaise with the medical team to confirm the potential stroke participant meets the inclusion criteria: (i) admitted to the in-patient rehabilitation stroke unit for recent stroke, (ii) are less than 21 days post stroke and during baseline phase or intervention phase, (iii) have the ability to provide informed consent as determined by the medical team iv) Glasgow Coma Scale² greater than 10 at the time of screening, (v) have an estimated length of stay greater than 14 days and (vi) have adequate English proficiency to participate in semi-structured interviews. Patients will be excluded if they (i) have uncorrected hearing or vision (for example hearing impairment without hearing aids, vision impairment without glasses), (ii) are not medically stable, (iii) have a documented diagnosis of major depression or (iv) have a documented history of dementia or significant cognitive decline, traumatic brain injury or previous aphasia at the time of admission for the acute event, (v) or are a participant in a research study that will influence this study's outcomes. Stroke participant recruitment will follow the stroke participant consent procedure (see document: SD_Communication Enhanced Environments after Stroke consent procedure version 1_3-2-15). A record of identifying participant details attached to patient codes will be kept at the hospital site in a locked filing cabinet. An email summary of the baseline assessment results will be sent to the hospital speech pathology generic email address. The patient will be identified by patient code and ward/room number. The hospital speech pathology team will write a summary of the assessment results in the patient's integrated medical progress notes.

Patient data collection: All recruited stroke participants will complete the NIH Stroke Scale³ (by someone trained in using this tool) and the Montreal Cognitive Assessment (MoCA).⁴ Participants with aphasia will also complete an assessment of aphasia, the WAB-R¹ and provide a personal narrative language sample on their reason for admission to confirm a diagnosis of aphasia. After patient recruitment has been completed, the Chief Investigator and/or trained medical team members will recruit the patient's family, friends and significant others to consent to video recording and observations of their interactions with stroke participants.

Observations of stroke participants will commence 1-3 days after obtaining written consent. Patients' behaviour will be observed by the Chief Investigator or a Research Assistant, and video recorded for a total of 12 hours to enable behaviour mapping of video data (see document: Observation_protocol_SD_version 3_23-02-16). Patients will be observed and video recorded for 4 hours per day on weekend day and two consecutive weekdays between 7am to 7pm. The observation periods will be grouped into 4-hour observation intervals (e.g. 7am-11am, 11am-3pm and 3pm-7pm). Each day the patient will be observed and video recorded for one observation interval. The participant will be observed and video recorded during a different observation interval each day to gain a general insight into the patients' activities (see Figure 1. below). Patients who do not consent to video recording will be provided with the option of audio recording and manual observation conducted by the researcher to enable the collection of case notes regarding patient behaviour. An observational protocol developed for this study will be used to measure the frequency stroke participants engage in language activities. These will be categorised into solitary language activities for example reading, writing, listening to the radio, use of iPad applications, and interactive language activities defined as i) an interaction involving an exchange of information, ii) with a communication partner including gesture and/or facial expression, reading, writing or drawing for the purpose of communication and use of technology including talking on the telephone. The observational protocol will be based on the behavioural mapping techniques of Janssen et al.⁵ Stroke patients' solitary and interactive language activities will be recorded in 5-minute intervals and activity observed within the first minute of the observation interval will be recorded on a checklist of the predetermined behaviours. Semi-structured supported conversation interviews for stroke participants will be conducted within 5 days of the last observation. The interviews will explore stroke patients' perceptions of environmental barriers and facilitators to language activities and communication and their experience of communication on the acute and rehabilitation wards.

IMPLEMENTATION:

A model of a CEE will be implemented within the acute and rehabilitation wards. The model will be developed as part of the research project. We hypothesise that our model of CEE will include the provision of:

- i) CEE equipment, for example reading materials such as books and magazines, access to a computer with internet and access to a communal dining area,
- ii) CEE education, support and training for staff, patients and their family, friends and significant others with the aim to develop the ability to support and facilitate 'language activity' and 'communication activity' for patients after stroke. This will be accessible via multiple modalities including one-on-one training and group training sessions, as

well as through the provision of video and written resources. A questionnaire will be administered pre and post training in order to determine staffs' perceptions of changes in their knowledge, skills and attitude towards communication and aphasia. Additionally, feedback regarding the content and format of the training program will be obtained through questionnaires administered after the completion of the training program. Training and support provided in the implementation phase will be continued until the end of the intervention phase.

POST-IMPLEMENTATION:

Staff participant semi-structured interviews and focus groups will be conducted. Staff will participate in a one-hour semi-structured interview or a one-hour focus group to explore staff perceptions of environmental barriers and facilitators to language activities and communication.

The procedures for participant recruitment and data collection during the post-implementation phase will replicate those used in the baseline phase.

There is no travel commitment for all participants as all data collection and training will be conducted at the hospital.

| Observation | Observation | Day 1: | Day 2: | Day 3: |
|-------------|-------------|--------|--------|---------|
| interval | time | Sunday | Monday | Tuesday |
| | | | | |
| 1 | 7am-8am | PWA1 | PWA3 | PWA2 |
| | 8am-9am | PWOA1 | PWOA3 | PWOA2 |
| | 9am-10am | | | |
| | 10am-11am | | | |
| 2 | 11am-12pm | PWA2 | PWA1 | PWOA |
| | 12pm-1pm | PWOA2 | PWOA1 | PWOA3 |
| | 1pm-2pm | | | |
| | 2pm-3pm | | | |
| 3 | 3pm-4pm | PWA3 | PWA2 | PWA1 |
| | 4pm-5pm | PWOA3 | PWOA2 | PWOA1 |
| | 5pm-6pm | | | |
| | 6pm-7pm | | | |

Figure 1. CEE Observation schedule

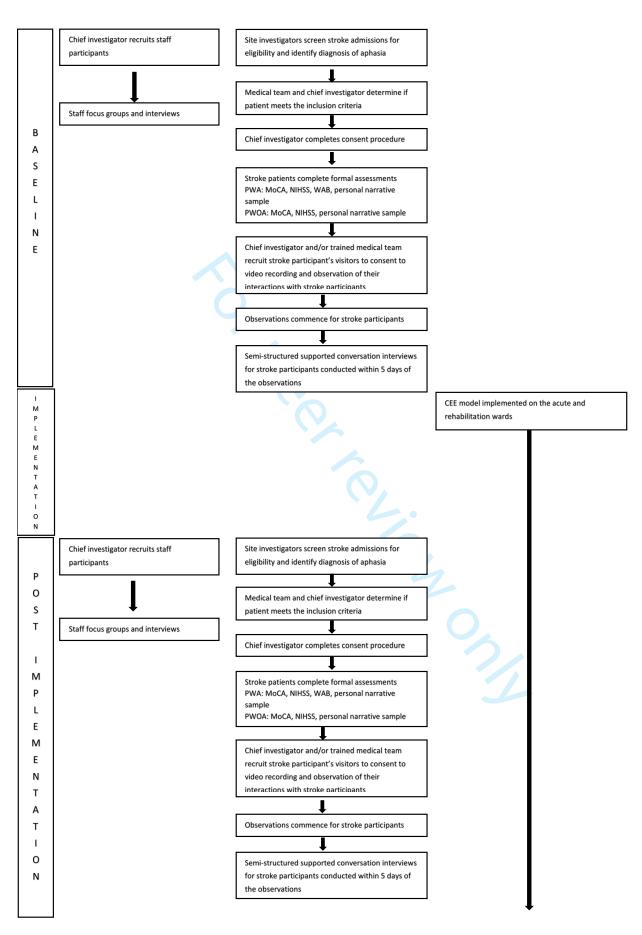


Figure 2. Study flow diagram

References

- 1. Kertesz A. Western Aphasia Battery- Revised. San Antonio, TX, Harcourt Assessment; 2006.
- 2. Teasdale G, Jennett B. Assessment of coma and impaired consciousness. A practical scale. Lancet. 1974;2(7872): 81–4.
- 3. NIH stroke scale [Internet]. Bethesda, Md, National Institute of Neurological Disorders and Stroke (U.S.). 2011 [cited 2016 Feb 10]. Available from https://www.ninds.nih.gov/sites/default/files/NIH_Stroke_Scale.pdf
- 4. Nasreddine ZS, Phillips NA, Bédirian, V, et al. The Montreal Cognitive Assessment, MoCA: A brief screening tool for mild cognitive impairment. J Am Geriatr Soc. 2005;53(4); 695-9.
- 5. Janssen H, Ada L, Bernhardt J, et al. An enriched environment increases activity in stroke patients undergoing rehabilitation in a mixed rehabilitation unit: A pilot non-randomized controlled trial. Disabil Rehab, 2014; 36(3), 255–262. doi: 10.3109/09638288.2013.788218

Communication Enhanced Environments after Stroke consent procedure

Version 1_3-2-15

Stroke participants

The following consenting procedure will be used for all participants who are identified as potential research participants. Recruitment will only be completed by the Chief Investigator.

- 1. Check the stroke participant meets the inclusion criteria and exclusion criteria.
- 2. Read the participant information sheet to the participant. Use the pictures on the participant consent form to support the patient's comprehension of verbal information. Use gesture, written and pictorial support to facilitate verbal communication as required.
- 3. Provide the person responsible with the person responsible information sheet and consent form.
- 4. Provide time for the stroke patient and the person responsible to discuss the study and ask questions to their satisfaction.
- 5. Ask the stroke participant if they consent to the study using simple closed questions (e.g. "Do you understand what the study is about?", "Do you have any questions about the study?", "Do you want to be in the study?", "Will you sign the form?". Use multi-modal communication strategies and repeat information/questions as required. Use the pictures on the participant consent form to support patient comprehension of verbal information.
- 6. If the stroke patient agrees to participate in the study, ensure they sign the consent form witnessed by someone independent of the study.
- 7. Provide the stroke participant with a copy of the information sheet and consent form for their own records.
- 8. Add the participant study number to the consent form
- 9. Store the signed consent forms in a locked cabinet at the hospital site. This cabinet will only be accessible by the research investigators.

Investigating Communication Enhanced Environments after stroke Observation Protocol version 3_ 23-2-16

During the baseline and intervention period, patients' behaviour will be observed and video recorded for a total of 12 hours. Patients who do not consent to video recording will be provided with the option of audio recording and manual observation. This will enable the collection of relevant notes about factors that might influence the interactions that may not be captured in the video or behavioural mapping, for example the context of the interactions or details about the environment.

Patients will be manually observed <u>and</u> video recorded for four hours per day on two weekdays and one weekend day between 7am to 7pm. The observations will be grouped into three x 4-hour observation intervals (e.g. 7am-11am, 11am-3pm, 3pm-7pm). Each day the patient will be observed and video recorded for one of the 4-hour observation intervals. The 4- hour observation period will be split into 5-minute intervals. All language and communication activity observed within the first minute of the 5-minute interval will be recorded on the behavioural mapping sheet with predetermined behaviours (Appendix 1). The free smart phone app 'Impetus' can be used to time 1-minute observations. You can set the timer to vibrate briefly when the 1-minute observation interval begins and ends.

Observation times (see Figure 1.) will be randomly selected by drawing out of an envelope. This will be conducted by the primary investigator prior to commencing patient observations. It may not be possible to observe the patient during the planned observation time, for example as a result of scheduled testing or home visits. If this occurs, patients can be observed during the next available observation interval. Changing or modifying the observation schedule should be avoided where possible.

| Observation interval | Observation time | Day 1: Sunday | Day 2: Monday | Day 3: Tuesday |
|----------------------|---|------------------|------------------|-------------------|
| 1 | 7am-8am 8am-9am 9am-10am 10am-11am | *PWA1 **PWOA1 | PWA3 PWOA3 | PWA2 PWOA2 |
| 2 | 11am-12pm 12pm-1pm 1pm-2pm 2pm-3pm | PWA2 PWOA2 | PWA1 PWOA1 | PWA3 PWOA3 |
| 3 | 3pm-4pm 4pm-5pm 5pm-6pm 6pm-7pm | PWA3 PWOA3 | PWA2 PWOA2 | PWA1 PWOA1 |

Figure 1. Observation schedule *PWA: stroke patient with aphasia

^{**}PWOA: stroke patient without aphasia

DISCOURSE SAMPLE

You must collect a personal narrative discourse sample for each participant at the beginning of the first observation. Once you have set up the video camera and have started recording, ask the patient "what has brought you into hospital?". Once the patient has finished telling you their personal narrative, tell the patient you will now start the observations.

VIDEO RECORDING SET-UP

Place the video camera facing the patient approximately 1-2 metres away from them. Ensure the camera is placed in an area where it is unlikely to be moved for the duration of the observation time (for example at the end of the patient's bed). Ensure the camera frame is capturing the patient as well as their surroundings (e.g. potential communication partners, visitors, etc). If the patient relocates, reposition the camera to ensure the patient and their surroundings remain in frame. Observe and manually record the patient's behaviour and their environment according to the procedure for behavioural mapping.

Do not record the patient in the bathroom or shower or during any other inappropriate circumstances (this may include sensitive conversations, culturally sensitive situations or if the patient requests). If the patient indicates that they don't want to be recorded or becomes agitated, upset or distressed, use the 'withdrawal from observations visual resource' (if appropriate) and ask the patient:

- 1. Do they want you to stop video recording?
- Do they want to be manually observed and audio recorded instead?If the patient responds 'no', ask the patient-
- 3. Can you come back another time to observe them?

If the patient asks you to stop recording you must cease recording immediately. The patient may allow you to continue with manual observations or come back another time to complete the observations. If the patient allows you to complete manual observations and audio recording, follow the audio-recording set-up and protocol below.

AUDIO RECORDING SET-UP AND PROTOCOL

This protocol is to be followed if the patient or their family indicate they do not want to be video recorded however agree to audio recording and manual observations. Place the cap on the video camera and continue recording in order to capture audio. If using a battery-operated audio recorder, place it on a table close to the patient (within 1

metre). Ensure the audio recorder is placed in a location where it will not be touched or moved throughout the observation time. Observe and manually record the patient's behaviour and their environment according to the procedure for behavioural mapping. Ensure spare batteries for the audio recorder are available if required.

COMMUNICATION PARTNERS AND VISITORS

Take note of all communication partners and visitors who have provided consent to video recording and/or observations of their patient interactions. If someone enters the room during recording politely interrupt the interaction, introduce yourself and inform the person that the patient is being video recorder recorded as a part of the study the patient has agreed to participate in. Ask the visitor if they would like to go out of the room with the researcher to find out about the study and the video recording. Provide a verbal explanation of the study and provide the 'Visitors/communication partners' information and consent form'. Offer the visitor the option of no video or manual recoding during their interaction with the patient. If the person chooses not to participate in manual or video observations inform the person that any incidental recordings of them will be deleted and will not be included in the study. The researcher will step out of the room for the duration of their visit.

PROCEDURE FOR BEHAVIOURAL MAPPING

- Position self where the patient can be clearly observed
- Remain inconspicuous as possible
- Circle ALL appropriate components on the observation schedule in regards to location, activity, people
 present and details of language and communication observed within the first minute of each five-minute
 interval.
- You can circle more than one key per section if required (except for location).
- If you require a toilet break, leave the camera recording while you take a break. If you miss a 1-minute observation, place a line through the observation interval on the behavioural mapping sheet and write 'unobserved-toilet break'.

TIME

Write the time at the beginning of the 1-minute observation interval

LOCATION

- Circle only one location
- If the patient is moving between two locations, circle the location the patient is moving towards

AMENITIES: Toilet, shower.

BEDROOM: Around the patient's room or bed. If the patient is outside of their doorway this is considered 'hall'.

HALL: Any hallway within the hospital ward.

THERAPY AREA: In an allied health therapy session, including occupational therapy, physiotherapy, speech pathology, nursing.

FAMILY MEETING ROOM: Family meeting room.

DOCTOR'S ROOM: Doctor's office.

DINING ROOM: Dining room during meal times or any other time.

COMMUNAL AREA: Communal dining area.

OUTSIDE: Outside areas including the garden, car park.

OFF UNIT: Off-site locations, home visits, testing off site.

OTHER: Anything that doesn't fit into the above categories-provide description of location.

PEOPLE PRESENT

People present include any person that is near the patient and is able to have an interaction with the patient. If you do not know how to classify the person make a note to check with staff at a later time and complete the observation schedule.

Exceptions: People who are near the patient but are unable to interact with the patient, e.g. cognitive or behavioural issues, barriers between person and the patient preventing them from interacting- e.g. curtain drawn, people in the way. If an interaction is occurring despite objects in the way, the communication partner is considered as a 'person present'.

PEOPLE PRESENT: Nurse, nurse assistant, doctor, physio (physiotherapist), OT (occupational therapist), SP (speech pathologist), DT (dietician), SW (social worker), family/friend, other patient, alone (no-one present that is conducive to interactions), other (describe).

ACTIVITIES

UNOBSERVED: If you are unable to observe the patient. Place a line through the observation

interval and write unobserved.

NO LANGUAGE ACTIVITY: If the patient is observed not engaged in any communication activity.

- Circle 'no activity' on the checklist
- Write what the patient is doing, e.g. 'sleeping'

INTERACTIVE LANGUAGE ACTIVITIES: Defined as an interaction involving an immediate communicative exchange with a communication partner. Interactive language activities may include talking, gesture and/or facial expression, reading, writing or drawing for the purpose of communication, use of communication aids or AAC devices and use of technology including talking on the telephone. Non-verbal gesture or facial expression includes eye contact to

initiate interactions, hand gestures (e.g. waving, thumbs up), body movements for the purpose of conveying a communicative message (e.g. shrugging) and/or facial expressions for the purpose of communication.

Communication aids or AAC devices includes any use of alternative and augmentative devices for the purpose of communication, e.g. high-tech or low-tech AAC devices such as letter boards, pictures/photos, whiteboard, writing or drawing, smart phones, iPad. Please describe communication aids observed.

OTHER FUNCTIONAL COMMUNICATION ACTIVITIES: All other communication activities that do not involve a direct immediate communicative exchange with a communication partner. Functional communication activity may include reading, typing/writing, emailing, internet use, watching TV, listening to talking on the radio. Note the patient must be looking directly at the TV to be considered 'watching TV'. If the TV is on in the background, do not include this as 'watching TV'.

NON-FUNCTIONAL/NON-PROPOSITIONAL LANGUAGE ACTIVITIES: Singing, word games (carried out alone), language apps (used alone), copying written letters, words or sentences (carried out alone).

OTHER: Communication or language activities that do not fit the criteria of interactive language activity, 'other' functional communication activities, non-functional/non-propositional language activities or may be a confounding variable (for example, talking to self and talking to the observer). If a patient is talking to themself, note if this is appropriate (for example, saying 'excuse me' after burping) or inappropriate (for example, an extensive monologue) and describe the context. If the patient's verbal output is inaudible, write this is in the space underneath 'talking to self'.

Note: If the patient is using a computer, phone, smart device, or iPad where the activity they are engaged in (e.g. texting, emailing, playing a game, etc) cannot be accurately determined, note this in the comments section. After the 1-minute observation interval has been completed ask the patient if they mind sharing if what activity they were completing on their device and record this in the relevant section. If the patient does not wish to share this information with you, record this in the 'other' section.

COMMENTS

Describe the context of the interactions or details about the environment in the comments section. This will provide information regarding factors that may influence the interactions, for example 'background noise'. Additionally, write down any information that may be missed in the video data, for example, people out of the camera frame, interactions that may be overheard in the room that might impact on the current interactions.

Draw a line under the final comment after the one-minute observation had been completed. Write any additional observations within the final 4 minutes below this line (see example).

If you have any queries or questions regarding this observation protocol or the observation protocol please contact chief investigator Sarah D'Souza.

Stroke participant information and consent form Communication activity in hospital

This research project is being undertaken as **part of** the **requirements** of a **PhD at Edith Cowan University**.

Researchers' contact details

| Edith Cowan University | | | | |
|---|---------------------|------------------|--|--|
| Chief Investigator/ | Sarah D'Souza | Ph: 0439 982 451 | | |
| PhD student | | | | |
| Principal Supervisor | Professor Beth | Ph: 08 6304 2769 | | |
| | Armstrong | | | |
| Co-Supervisor | Associate Professor | Ph: 08 6304 2047 | | |
| | Natalie Ciccone | | | |
| Co-Supervisor | Associate Professor | Ph: 08 6304 5901 | | |
| | Erin Godecke | | | |
| Co-Supervisor | Associate Professor | Ph: 08 6304 2563 | | |
| | Deborah Hersh | | | |
| Hunter Stroke Service, University of Newcastle and Hunter | | | | |
| Medical Research Institute | | | | |
| Adjunct Supervisor Dr Heidi Janssen Ph: 02 40420417 | | | | |

You are **invited** to participate in a research project. Sarah D'Souza, a speech pathologist and PhD student is leading the study as Chief Investigator. This study has received ethical **approval** from **ECU** Human Research **Ethics Committee** and the Hollywood Private Hospital Research Ethics Committee.

This project is investigating the **hospital environment** to see how this **influences** patient **communication activity**. Communication activity involves communication, such as **talking** with other patients, **socialising**, **reading** the paper, using the **telephone**, talking to staff, or engaging in group activities including **therapy**.

You have been selected to participate as you have had a stroke and are receiving treatment at Hollywood Private Hospital. We are interested in seeing how the hospital surroundings affect what you do throughout the day.

What would you have to do?

You will be **asked** to provide **consent** to **agree to participate** in the study.

You will be **asked to consent** to:

Complete three tests to see how your stroke has affected you
including your language, concentration and memory. These tests
will be conducted at the beginning of the project. The tests will take
approximately 1 hour to complete with an option to complete the tests

over **two separate 30 minute sessions** and with as many **breaks** as you may need.

- A researcher spending approximately 1 hour discussing with you
 your opinion regarding how your rehabilitation surroundings affect
 your stay in hospital and your communication activity levels.
- A researcher video recording, observing and writing down what is happening in your environment including your activities. You will be observed and recorded for a total of 12 hours over 3 days.

You may **not want** to be **video recorded**. If you **request**, you will **not** be **video recorded**. You can ask not to be video recorded at **any time**. In this case the researcher will **only observe**, **audio record** and **write down** what is **happening in your** environment **including** your activities.

- A researcher looking at your hospital medical file to collect information regarding:
 - Your details (such as your age, your living arrangements, your occupation and your level of functioning before your stroke)
 - Any conditions or diseases you may have
 - Information about your stroke (for example when it happened, the area of the brain affected, how it has affected your functioning and abilities)
 - Details about how long you have been in hospital since your stroke

If you decide to participate in this study, you will not miss out on any treatment. Participation will not cost you anything and after completing the tests and the interview you will be asked to continue participating in your normal activities.

We will **not record** if you are **behind closed curtains** or completing sensitive tasks such as when you are in the **toilet** or **shower**.

We may use the **recordings** of **you** to make a **training package** (including a video). You can have **your face blurred out** if you want. If you **do not want** to be in the training package we will **not include you** in the training package or video.

Your hospital **discharge** will **not be affected** because you are in this study. **You** will be **discharged** from hospital when the hospital **medical team decides** that you are **ready**.

There are **no known risks** of participating in this study. If you feel uncomfortable at any time, you are free to **tell the researcher** and **observations** within your room will **stop immediately**. You may become **upset** during the **tests** or the **interview**. If this happens you can **ask** to take a **break or stop** the interview.

There will be **no immediate benefit** to you from participating in this research; however your participation will allow the collection of

information that may **help improve** stroke **hospital wards** which may **benefit** future stroke survivors.

Participating in this study is completely voluntary. You do not have to participate if you don't want to. If you decide to participate you may withdraw at any time without giving a reason and withdrawing will not disadvantage you in any way and will not affect your hospital treatment. If you decide that you do not want to participate in the study, you can ask to remove all of your information from the study.

All the **information** you give will be **confidential**. You will **not be identified** by name. You will be **assigned** a unique **code** and any information that may reveal your **identity** will be **removed**.

All personal health information will be accessed, used and stored in accordance with Commonwealth Privacy Laws. **Information** from all the people in the study is **combined** and **summarised.**

We will **store** all your electronic **information** on a **password locked computer** and **password locked hard drive only accessible by the Chief Investigator**. Your hard copy information will be **kept** in a **locked cabinet** at Edith Cowan University. You information will **only** be **accessible to researchers** named on **this study**.

The **results** of this study may be **published** in research **journals** or presented at **conferences**. Your **name** will **not** be **used**.

Data may be **used** in higher degree by **research studies** in the **future**. **Confidentiality** will be **maintained** and no identifying information will be used.

Data will be **accessible by researchers** through data sharing archives. This data will be governed by an overarching body to ensure data is **only used for approved research** purposes. Researchers who access this data from the data bank will not have access to participant information and therefore **will not know your identity**.

Read this information and be sure you **understand** its content **before** you **agree** to participate in this study.

If **you** would **like** to **participate** in this study, please **sign the form** below and **return** it to a **staff** member or a member of the **research team**.

Questions or further information?

You may wish to discuss this information with your doctor, a relative or friend before agreeing to take part in this study.

If you are interested in participating, please tell the researchers. If you have any questions or require any further information about the research project, please contact: Sarah D'Souza [Ph: 0439 982 451].

Thank you for considering the invitation to take part in this research project.

Yours sincerely,

Sarah D'Souza

If you have any **concerns or complaints** about the research project and wish to **talk to an independent person**, you may contact:

Kim Gifkins

Senior Research Ethics Advisor

Edith Cowan University

270 Joondalup Drive

JOONDALUP WA 6027

Phone: (08) 6304 2170

Email: research.ethics@ecu.edu.au

This project has been approved by the ECU Human Research Ethics Committee and the Hollywood Private Hospital Research Ethics Committee.

You have been asked to participate in a research study.

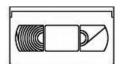






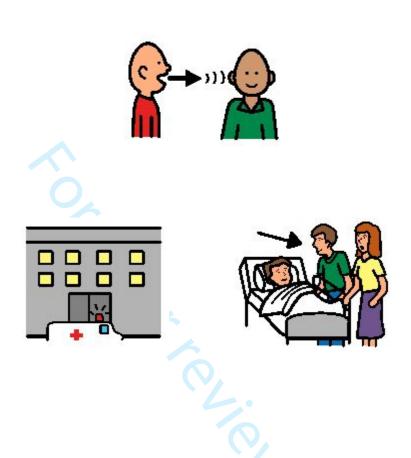
A researcher will record you with a tape recorder or a video camera, watch and write down what is happening in your environment including your activities.







A researcher will discuss with you your opinion regarding how your hospital surroundings affect your stay in hospital and your communication activity levels.



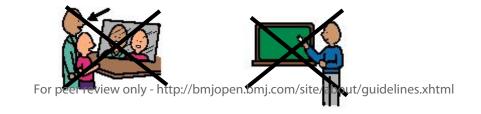
Your name and personal details will be kept private.



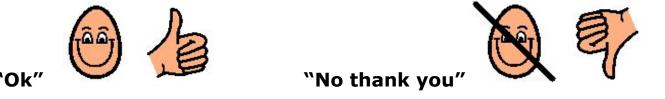




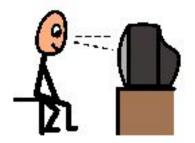




You can say no at any time.



We may use the **recordings** of **you** to make a **training package** (including a video).





You can have your face blurred out if you want.





If you **do not want** to be in the training package we will **not include you** in the training package or video.



I agree to take part in the above research project and give my consent freely.





I have been **given a copy** of the **Information Statement** and I understand that the **project** will be **carried out** as **explained**.



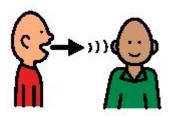


I understand and agree to:

 Complete three tests to assess how the stroke has affected me, my language, concentration and memory, at the beginning of the project.



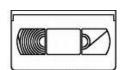
 A researcher spending approximately 1 hour discussing with me my opinion regarding how my hospital environment affects my stay in hospital and what I do.





 A researcher video recording, observing and writing down what is happening in my environment including my activities.





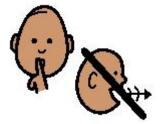


 A researcher looking at my hospital medical file to collect information for the study.



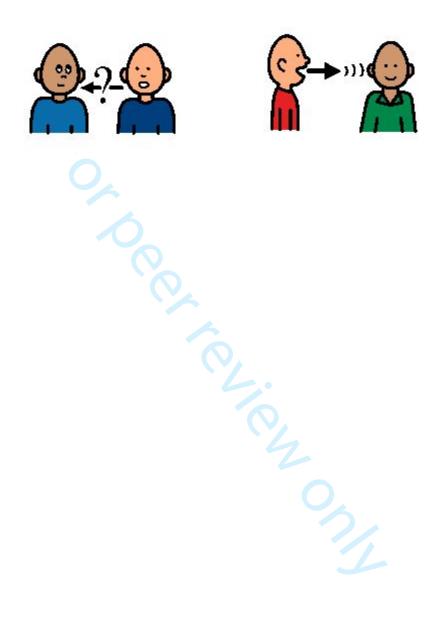


I understand that my identity, personal information and data will remain confidential.





I have had the **opportunity** to **ask questions** about the study and am **satisfied** with the **responses** that have been provided.



| Would you li | ike to be involved? | Yes | No |
|-----------------------|---|-----|----|
| _ | e recordings of me nining package video). | Yes | No |
| I would like n | ny face blurred out. | Yes | No |
| | | | |
| Your Signatu | ıre | | |
| | Signature: | 70 | |
| | Print name: | - 3 | |
| | Date: | | |
| Witness | Signature: | | |
| | Print name: | | |
| | Date | | |

Person responsible information sheet Stroke patients' communication activity in hospital

This research project is being undertaken as part of the requirements of a PhD at Edith Cowan University.

Researchers' contact details

| Edith Cowan University | | | | |
|--|-----------------------------|------------------|--|--|
| Chief Investigator/ | Sarah D'Souza | Ph: 0439 982 451 | | |
| PhD student | | | | |
| Principal Supervisor | Professor Beth Armstrong | Ph: 08 6304 2769 | | |
| Co-Supervisor | Associate Professor Natalie | Ph: 08 6304 2047 | | |
| | Ciccone | | | |
| Co-Supervisor | Associate Professor Erin | Ph: 08 6304 5901 | | |
| | Godecke | | | |
| Co-Supervisor | Associate Professor Deborah | Ph: 08 6304 2563 | | |
| | Hersh | | | |
| Hunter Stroke Service, University of Newcastle and Hunter Medical Research Institute | | | | |
| Adjunct Supervisor | Dr Heidi Janssen | Ph: 02 40420417 | | |

The participant is invited to take part in a research project. Sarah D'Souza, a Speech Pathologist and PhD student, is leading the study as Chief Investigator. This study has received ethical approval from ECU Human Research Ethics Committee and Hollywood Private Hospital Research Ethics Committee.

This project is investigating the hospital environment to see how this influences patient activity.

The participant has been selected to take part in this study as they have had a stroke and are receiving treatment at Hollywood Private Hospital. We are interested in

seeing how the hospital surroundings affect their communication activity throughout the day. Communication activity involves communication, such as talking with other patients, socialising, reading the paper, using the telephone, talking to staff, or engaging group activities including therapy.

This information sheet will explain the research project and will detail what is involved in the study. You will be given a copy of this information to keep for your reference.

Please read through all of the information carefully. You can ask the researcher questions about the study at any time.

Purpose of the research

Little is known about the impact of the hospital rehabilitation environment on patient communication activity levels during stroke recovery. This study will investigate how the hospital stroke ward environment influences patient communication activity levels. The information gathered from this study will assist in improving the Hollywood Private Hospital stroke ward environment to help the recovery of stroke survivors in the future.

What does the stroke patient have to do?

- Complete three tests and a recording of them talking to see how their stroke has
 affected their functioning including their language, concentration and memory. These
 tests will be conducted at the beginning of the project. The tests will take
 approximately 1 hour to complete with an option to complete the tests over two
 separate 30 minute sessions and with as many breaks as the participant needs.
- Spend approximately 1 hour discussing with the researcher their opinion regarding how their rehabilitation surroundings affect their stay in hospital and activity levels.
- Allow the researcher to video record, observe and write down what is happening in the
 participant's environment including their activities for a total of 12 hours over a 3 day
 period. Video recording is a useful way of capturing the details of everyday activities on

the ward. Often, people forget that the camera is there. Obviously, personal or private activity such as toileting would not be filmed. The participant may not want to be video recorded. If they request, they will not be video recorded. In this case the researcher will only observe, audio record and write down what is happening in their environment including their activities.

- A researcher will look at the participant's hospital medical file to collect information regarding:
 - The participant's details (such as their age, living arrangements, occupation and level of functioning before stroke)
 - Any relevant conditions or diseases the participant may have
 - Information about the participant's stroke (for example when it happened, the area of the brain affected, how it has affected their functioning and abilities)
 - Details about how long the participant has been in hospital since their stroke

The participant will not miss out on any treatment. Participation will not cost anything. After completing the tests and the interview the participant will be asked to continue their normal activities.

The participant's hospital discharge will not be affected because they are in this study. The participant will be discharged from hospital when the hospital medical team decides that they are ready.

There are no known risks of participating in this study. If the participant feels uncomfortable at any time, you or the participant are free to tell the researcher and observations within their room will stop immediately. The participant may become upset during the tests or the interview. If this happens you or the participant can ask to take a break or stop the interview.

There will be no immediate benefit to you or the participant from taking part in this research; however their participation will allow the collection of information that may help improve stroke hospital wards which may benefit future stroke survivors.

Participating in this study is completely voluntary. The participant can withdraw from taking part in the study at any time without giving a reason for withdrawing.

The participant can request access to their research data at any time. They can request any of the information collected to be amended or removed if it is incorrect or they disagree with it. Please contact Sarah D'Souza (phone: 0439 982 451) if you would like to discuss accessing the participant's information.

The video, audio and written data will be identified by code. The information you provide will remain completely confidential. There will be no identifying information attached to the data and any information that may reveal the participant's identity will be removed. A list of participant names and codes will be kept in a locked filing cabinet at Hollywood Private Hospital and will only be accessible by the research team. All personal health information will be accessed, used and stored in accordance with Commonwealth Privacy Laws. The data will be stored on a password controlled computer or in a locked cabinet at Edith Cowan University. Electronic data will be backed-up on a password controlled hard drive only accessible by the Chief Investigator. Data will be stored for a maximum of 15 years after completion of the study. Video and audio recordings will then be permanently deleted and hard copy data will be shredded.

Non-identifiable data will be accessible by researchers through data sharing archives. This data will be governed by an overarching body to ensure data is only used for approved research purposes. Researchers who access this data from the data bank will not have access to participant information therefore data will not be re-identifiable.

The results of this study may be published in research journals or presented at conferences. The results will not include any information that may identify participants. Data may be used in higher degree by research studies in the future. In this circumstance, confidentiality will be maintained and no identifying information will be used.

Data collected from this study (including videos) may be used to develop training packages to improve future stroke survivors' communication activity levels in the future. We can blur out

the participant's face if they want. If they do not want to be in the training package we will not include them in the training package.

At the end of the research project a summary of the results will be provided to you and the participant.

If you have any questions or require any further information about the research project, please contact: Sarah D'Souza [Ph: 0439 982 451].

Yours sincerely,

Sarah D'Souza

If you have any concerns or complaints about the research project and wish to talk to an independent person, you may contact:

Kim Gifkins

Senior Research Ethics Advisor

Edith Cowan University

270 Joondalup Drive

JOONDALUP WA 6027

Phone: (08) 6304 2170

Email: research.ethics@ecu.edu.au

This project has been approved by the ECU Human Research Ethics Committee and the Hollywood Private Hospital Research Ethics Committee.

Visitors and communication partners information and consent form Investigating Enhanced Environments after stroke

This research project is being undertaken as part of the requirements of a PhD at Edith Cowan University.

Researchers' contact details

| Edith Cowan University | | | | |
|--|-------------------------------------|------------------|--|--|
| Chief Investigator/ | Sarah D'Souza | Ph: 0439 982 451 | | |
| PhD student | | | | |
| Principal Supervisor | Professor Beth Armstrong | Ph: 08 6304 2769 | | |
| Co-Supervisor | Associate Professor Natalie Ciccone | Ph: 08 6304 2047 | | |
| Co-Supervisor | Associate Professor Erin Godecke | Ph: 08 6304 5901 | | |
| Co-Supervisor | Associate Professor Deborah Hersh | Ph: 08 6304 2563 | | |
| Hunter Stroke Service, University of Newcastle and Hunter Medical Research Institute | | | | |
| Adjunct Supervisor | Dr Heidi Janssen | Ph: 02 40420417 | | |

Description of the research project

This study is exploring stroke patient's experiences in regards to the environment of an in-patient stroke rehabilitation unit. We want to explore stroke patient communication activity, which includes activities such as talking with other patients and visitors, socialising, reading the paper, using the telephone, talking to staff, or engaging group activities including therapy.

The participant has agreed to take part in this study. They have agreed to be video recorded for a total of 12 hours over a three day period.

Your interactions with the patient will be video recorded and manually recorded by the chief investigator to explore patient communication activity levels. You can choose to be observed by the researcher only if you do not want to be video recorded. You do not need to do anything other than complete your usual tasks and activities. We will not record if you are having sensitive conversations with the participant, if they are behind closed curtains or completing sensitive tasks such as toileting or showering.

We may use the recordings of you to make a training package (including a video). You can have your face blurred if you want. If you do not want to be in the training package we will not include you in the training package.

There will be no cost to you associated with the investigation. Participation is completely voluntary. You do not have to participate if you don't want to. If you decide to participate you may withdraw at any time without giving a reason and withdrawing will not disadvantage you or the participant in any way.

You may also benefit from the knowledge that you are helping future stroke survivors. It is possible that you may not benefit from participating in this study. There are no known risks associated with participating in this study.

Confidentiality of information

The video, audio and written data will be identified by code. There will be no identifying information attached to the data and any information that may reveal your identity will be removed. A list of participant names and codes will be kept in a locked filing cabinet at Hollywood Private Hospital and will only be accessible by the research team. All data will be accessed, used and stored in accordance with Commonwealth Privacy Laws. The data will be stored on a password controlled computer or in a locked cabinet at Edith Cowan University. Electronic data will be backed-up on password controlled hard drive only accessible by the Chief Investigator. Data will be stored for a maximum of 15 years after completion of the study. Video and audio recordings will then be permanently deleted and hard copy data will be shredded.

Non-identifiable data will be accessible by researchers through data sharing archives. This data will be governed by an overarching body to ensure data is only used for approved research purposes. Researchers who access this data from the data bank will not have access to participant information therefore data will not be re-identifiable.

The results of this study may be published in research journals or presented at conferences. The results will not include any information that may identify participants. Data may be used in higher degree by research studies in the future. In this circumstance, confidentiality will be maintained and no identifying information will be used.

Please read this Information Statement and be sure you understand its content before you consent to take part.

If you would like to take part, please complete the consent form and return it to Sarah D'Souza or a member of the research team.

Questions or further information?

If you have any questions or require any further information about the research project, please contact: Sarah D'Souza [Ph: 0439 982 451]

Thank you for considering the invitation to take part in this research project.

Yours sincerely,

Sarah D'Souza

If you have any concerns or complaints about the research project and wish to talk to an independent person, you may contact: Kim Gifkins

Research Ethics Officer

Edith Cowan University

270 Joondalup Drive

JOONDALUP WA 6027

Phone: (08) 6304 2170

Email: research.ethics@ecu.edu.au

This project has been approved by the ECU Human Research Ethics Committee and the Hollywood Private Hospital Research Ethics Committee.

| I | | (print name), give my consent freely and |
|-----------------|--------------|--|
| agree to | o participat | e in observations of my interactions with the participant. |
| Yes | No | (please circle) |
| I agree | to the rese | archer video recording my interactions with the participant |
| Yes | No | (please circle) |
| I agree | to be inclu | ded in a training package (including a video). |
| Yes | No | (please circle) |
| If I am i | ncluded in | the video training package I would like my face blurred out. |
| Yes | No | (please circle) |
| I unders | | roject will be conducted as stated in the information letter, a copy of which I have |
| I unders | stand I can | withdraw from the project at any time and do not have to give a reason for withdrawing |
| I unders | stand pers | onal information will remain confidential to the researchers. |
| I have b | een given | the opportunity to raise any questions or concerns I have and am satisfied with the |
| | ses I was g | |
| · | _ | |
| <u>Particip</u> | <u>oant</u> | |
| Print na | ame: | |
| Signatu | ıre: | |
| Phone | number: _ | |
| Email a | ddress: _ | |
| | | |
| Witnes | | |
| Print na | ame: | |
| | | |
| Date: _ | | |

Staff information and consent form Investigating Enriched Environments after stroke

This research project is being undertaken as part of the requirements of a PhD at Edith Cowan University.

Researchers' contact details

| Edith Cowan University | | | | |
|--|-------------------------------------|------------------|--|--|
| Chief Investigator/ | Sarah D'Souza | Ph: 0439 982 451 | | |
| PhD student | | | | |
| Principal Supervisor | Professor Beth Armstrong | Ph: 08 6304 2769 | | |
| Co-Supervisor | Associate Professor Natalie Ciccone | Ph: 08 6304 2047 | | |
| Co-Supervisor | Associate Professor Erin Godecke | Ph: 08 6304 5901 | | |
| Co-Supervisor | Associate Professor Deborah Hersh | Ph: 08 6304 2563 | | |
| Hunter Stroke Service, University of Newcastle and Hunter Medical Research Institute | | | | |
| Adjunct Supervisor | Dr Heidi Janssen | Ph: 02 40420417 | | |

Description of the research project

This study is exploring staff and stroke patient's experiences in regards to the environment of the Edwards and Woods wards at Hollywood Private Hospital. We want to explore stroke patient communication activity, which includes activities such as talking with other patients, socialising, reading the paper, using the telephone, talking to staff, or engaging group activities including therapy. We would like to explore staffs' perceptions of barriers and facilitators to communication activity on the wards and address these in order to enhance the ward environment.

Staff have been selected to participate in order to gain a range of perspectives in regards to the day to day operations, procedures, policies and interactions that influence the environment of the Edwards and Woods wards. A training program for staff will be designed to address barriers and facilitators identified on the wards.

There are two components of this research study that involve staff. You may wish to consent to participate in one or both parts of this study.

<u>Part 1:</u> Stroke in-patients will be video recorded for a total of 12 hours over a three day period. Your interactions with the patient will be video recorded and manually recorded by a member of the research team to explore patient communication activity levels. You can choose to be observed by the researcher only if you do not want to be video recorded. You do not need to do anything other than complete your usual daily tasks and activities. We will not record if you are behind closed curtains or completing sensitive tasks such as toileting or showering the patient.

We may want use the recordings of you to make a training package (including a video). We will show you the video we want to use and explain exactly how this will be used before we do anything. You can have your face blurred out if you want. If you don't want to be included in the training package we will not include any videos of you in the training package.

Part 2: You will be asked to take part in the following:

edited or have your comments erased.

- A focus group with the researcher and your co-workers for approximately 1 hour to explore your perceptions of environmental barriers and facilitators to activity.
- Attend a training program for approximately 1.5 hours. This will focus on training staff to promote
 patient communication on the ward. This session will be located at Hollywood Private Hospital and
 will be offered over several dates to facilitate your ability to attend. If you are unable to attend the
 training program we may provide training and video resources to facilitate your participation in
 training.
- Complete an anonymous short questionnaire before and after attending the training program to gain feedback on training and explore your perception of changes in your knowledge, skills and attitudes towards communication and aphasia.
- A final focus group with the researcher for approximately 1 hour to again explore your perceptions
 of environmental barriers and facilitators to activity.
 The focus groups will be tape recorded however at any stage you may ask for the tape to stopped,

There will be no cost to you associated with the investigation. Participation is completely voluntary. You do not have to participate if you don't want to. If you decide to participate you may withdraw at any time without giving a reason and withdrawing will not disadvantage you in any way.

You may benefit from gaining knowledge and skills regarding communication from attending the training program. Additionally, you may also benefit from the knowledge that you are helping future stroke

survivors. It is possible that you may not benefit from participating in this study. There are no known risks associated with participating in this study.

Confidentiality of information

The information you provide during the interviews will be audio recorded by the Chief Investigator. Your perspectives and opinions will be analysed and grouped into common 'themes' and 'stories'. This will be used to inform the development and review of the training program.

The video, audio and written data will be identified by code. The information you provide will remain completely confidential. There will be no identifying information attached to the data and any information that may reveal your identity will be removed. A list of participant names and codes will be kept in a locked filing cabinet at Hollywood Private Hospital and will only be accessible by the research team. All data will be accessed, used and stored in accordance with Commonwealth Privacy Laws. The data will be stored on a password controlled computer or in a locked cabinet at Edith Cowan University. Electronic data will be backed-up on a password controlled hard drive only accessible by the Chief Investigator. Data will be stored for a maximum of 15 years after completion of the study. Video and audio recordings will then be permanently deleted and hard copy data will be shredded.

Non-identifiable data will be accessible by researchers through data sharing archives. This data will be governed by an overarching body to ensure data is only used for approved research purposes. Researchers who access this data from the data bank will not have access to participant information therefore data will not be re-identifiable.

The results of this study may be published in research journals or presented at conferences. The results will not include any information that may identify participants. Data may be used in higher degree by research studies in the future. In this circumstance, confidentiality will be maintained and no identifying information will be used.

A summary of the results will be provided through Hollywood Private Hospital 18 months after the completion of the study.

Please read this Information Statement and be sure you understand its content before you consent to take part.

If you would like to take part, please complete the consent form and return it to Sarah D'Souza, Claire Tucak or a member of the research team.

Questions or further information?

You may wish to consult with your manager before agreeing to take part in this study.

If you have any questions or require any further information about the research project, please contact: Sarah D'Souza [Ph: 0439 982 451]

Thank you for considering the invitation to take part in this research project.

Yours sincerely,

Sarah D'Souza

If you have any concerns or complaints about the research project and wish to talk to an independent person, you may contact: Kim Gifkins

Research Ethics Officer

Edith Cowan University

270 Joondalup Drive

JOONDALUP WA 6027

Phone: (08) 6304 2170

Email: research.ethics@ecu.edu.au

This project has been approved by the ECU Human Research Ethics Committee and the Hollywood Private Hospital Research Ethics Committee.

| I | | (print name), give my consent freely and |
|--------------------|---------------------|---|
| agree to partici | pate in (please c | ircle): |
| <u>Part 1:</u> | | |
| Yes | No | Observations of your |
| | | interactions with stroke patients. |
| Yes | No | Video recording of your |
| | | interactions with stroke patients. |
| <u>Part 2:</u> | | |
| Yes | No | Complete two focus groups with the researcher, complete two short questionnaires and attend a training program. |
| I understand th | e project will be o | conducted as stated in the information letter, a copy of which I have |
| I understand I | can withdraw fron | n the project at any time and do not have to give a reason for withdrawing |
| I understand pe | ersonal informatio | on will remain confidential to the researchers. |
| I have been giv | en the opportuni | ty to raise any questions or concerns I have and am satisfied with the |
| responses I wa | as given. | |
| <u>Participant</u> | | |
| Print name: _ | | |
| Signature: | | |
| Phone numbe | r: | |
| Email address | s: | |
| Date: | | |
| <u>Witness</u> | | |
| Print name: _ | | |
| Signature: | | |
| | | |

Volunteer information and consent form Investigating Enriched Environments after stroke

This research project is being undertaken as part of the requirements of a PhD at Edith Cowan University.

Researchers' contact details

| Edith Cowan University | | | | |
|--|-------------------------------------|------------------|--|--|
| Chief Investigator/ | Sarah D'Souza | Ph: 0439 982 451 | | |
| PhD student | | | | |
| Principal Supervisor | Professor Beth Armstrong | Ph: 08 6304 2769 | | |
| Co-Supervisor | Associate Professor Natalie Ciccone | Ph: 08 6304 2047 | | |
| Co-Supervisor | Associate Professor Erin Godecke | Ph: 08 6304 5901 | | |
| Co-Supervisor | Associate Professor Deborah Hersh | Ph: 08 6304 2563 | | |
| Hunter Stroke Service, University of Newcastle and Hunter Medical Research Institute | | | | |
| Adjunct Supervisor | Dr Heidi Janssen | Ph: 02 40420417 | | |

Description of the research project

This study is a Communication Enhanced Environment (CEE) at Hollywood Private Hospital. A CEE involves several initiatives that aim to provide more opportunities for communication for stroke survivors on the ward. One of these initiatives involves the participation of volunteers.

As a volunteer participant, you will be asked to take part in the following:

- Attend a training program for approximately 1.5 hours. This will focus on training volunteers in
 communicating with stroke patients with communication difficulties. This session will be located at
 Hollywood Private Hospital and will be offered over several dates to facilitate your ability to attend. If
 you are unable to attend the training program we may provide training and video resources to
 facilitate your participation in training.
- Complete an anonymous short questionnaire before and after attending the training program to obtain your feedback on the training session.

- A focus group with the researcher and other volunteers for approximately 1 hour to explore your
 perceptions of communicating with stroke patients. The focus group will be tape recorded however
 at any stage you may ask for the tape to stopped, edited or have your comments erased.
- Host a communal dining and lounge area once a week to offer tea and coffee and provide social companionship for stroke patients.
- Your interactions with the patient may be video recorded and manually recorded by a member of
 the research team to explore patient communication activity levels. You can choose to be observed
 by the researcher only if you do not want to be video recorded. We will not record if you are having
 sensitive conversations with the stroke patient/s.

There will be no cost to you associated with participating in this study. Participation is completely voluntary. You do not have to participate if you don't want to. If you decide to participate you may withdraw at any time without giving a reason and withdrawing will not disadvantage you in any way.

You may benefit from gaining knowledge and skills regarding communication from attending the training program. Additionally, you may also benefit from the knowledge that you are helping future stroke survivors. It is possible that you may not benefit from participating in this study. There are no known risks associated with participating in this study.

Confidentiality of information

The information you provide during the interviews will be audio recorded by the Chief Investigator. Your perspectives and opinions will be analysed and grouped into common 'themes' and 'stories'.

The video, audio and written data will be identified by code. The information you provide will remain completely confidential. There will be no identifying information attached to the data and any information that may reveal your identity will be removed. A list of participant names and codes will be kept in a locked filing cabinet at Hollywood Private Hospital and will only be accessible by the research team. All data will be accessed, used and stored in accordance with Commonwealth Privacy Laws. The data will be stored on a password controlled computer or in a locked cabinet at Edith Cowan University. Electronic data will be backed-up on a password controlled hard drive only accessible by the Chief Investigator. Data will be stored for a maximum of 15 years after completion of the study. Video and audio recordings will then be permanently deleted and hard copy data will be shredded.

Non-identifiable data will be accessible by researchers through data sharing archives. This data will be governed by an overarching body to ensure data is only used for approved research purposes.

Researchers who access this data from the data bank will not have access to participant information therefore data will not be re-identifiable.

The results of this study may be published in research journals or presented at conferences. The results will not include any information that may identify participants. Data may be used in higher degree by research studies in the future. In this circumstance, confidentiality will be maintained and no identifying information will be used.

A summary of the results will be provided through Hollywood Private Hospital 18 months after the completion of the study.

Please read this Information Statement and be sure you understand its content before you consent to take part.

If you would like to take part, please complete the consent form and return it to Sarah D'Souza, Claire Tucak or a member of the research team.

Questions or further information?

If you have any questions or require any further information about the research project, please contact: Sarah D'Souza [Ph: 0439 982 451]

Thank you for considering the invitation to take part in this research project.

Yours sincerely,

Sarah D'Souza

If you have any concerns or complaints about the research project and wish to talk to an independent person, you may contact: Kim Gifkins

Research Ethics Officer

Edith Cowan University

270 Joondalup Drive

JOONDALUP WA 6027

Phone: (08) 6304 2170

Email: research.ethics@ecu.edu.au

This project has been approved by the ECU Human Research Ethics Committee and the Hollywood Private Hospital Research Ethics Committee.

| I (print name), give my consent freely and |
|--|
| agree to participate in (please circle) this study as described in this information and consent form. |
| I understand the project will be conducted as stated in the information letter, a copy of which I have retained. |
| I understand I can withdraw from the project at any time and do not have to give a reason for withdrawing. |
| I understand personal information will remain confidential to the researchers. |
| I have been given the opportunity to raise any questions or concerns I have and am satisfied with the responses I was given. |
| <u>Participant</u> |
| Print name: |
| Signature: |
| Phone number: |
| Email address: |
| Date: |
| Witness Print name: |
| Signature: |
| Date: |
| Date: |
| |

BMJ Open

Hospital staff, volunteers, and patients' perceptions of barriers and facilitators to communication following stroke in an acute and rehabilitation private hospital ward: A qualitative description sub-study.

| Journal: | BMJ Open |
|----------------------------------|--|
| Manuscript ID | bmjopen-2020-043897.R1 |
| Article Type: | Original research |
| Date Submitted by the Author: | 04-Feb-2021 |
| Complete List of Authors: | D'Souza, Sarah; Edith Cowan University, School of Medical and Health Sciences; Centre for Aphasia Recovery and Rehabilitation Research, La Trobe University Godecke, Erin; Edith Cowan University, School of Medical and Health Sciences; Centre for Aphasia Recovery and Rehabilitation Research, La Trobe University Ciccone, Natalie; Edith Cowan University, School of Medical and Health Sciences Hersh, Deborah; Edith Cowan University, School of Medical and Health Sciences Janssen, Heidi; The University of Newcastle Hunter Medical Research Institute Armstrong, Elizabeth; Edith Cowan University, School of Medical and Health Sciences |
| Primary Subject Heading : | Neurology |
| Secondary Subject Heading: | Qualitative research, Rehabilitation medicine |
| Keywords: | Stroke < NEUROLOGY, Adult neurology < NEUROLOGY, QUALITATIVE RESEARCH |
| | |

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Title page

Title

Hospital staff, volunteers, and patients' perceptions of barriers and facilitators to communication following stroke in an acute and rehabilitation private hospital ward: A qualitative description sub-study.

Authors

Sarah D'Souza^{1,2}, Erin Godecke^{1,2}, Natalie Ciccone¹, Deborah Hersh¹, Heidi Janssen³, Elizabeth Armstrong¹

Affiliations

- 1. Edith Cowan University, Perth, Western Australia, Australia
- Centre for Aphasia Recovery and Rehabilitation Research, La Trobe University,
 Melbourne, Victoria, Australia
- 3. Hunter New England Local Health District, NSW Health, New South Wales, Australia

Addresses of all authors

Sarah D'Souza

School of Medical and Health Sciences, Edith Cowan University 270 Joondalup Drive, Joondalup 6027, Australia s.dsouza@ecu.edu.au

Associate Professor Erin Godecke

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Associate Professor Natalie Ciccone

School of Medical and Health Sciences, Edith Cowan University

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Associate Professor Deborah Hersh

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Dr Heidi Janssen

Hunter Medical Research Institute

Lot 1, Kookaburra Circuit, New Lambton Heights NSW 2305

Heidi.Janssen@health.nsw.gov.au

Professor Elizabeth Armstrong

School of Medical and Health Sciences, Edith Cowan University

270 Joondalup Drive, Joondalup, WA 6027, Australia

b.armstrong@ecu.edu.au

Key words: stroke, adult neurology, qualitative research

Reporting guidelines checklist: The consolidated criteria for reporting qualitative studies (COREQ)²¹ was used to guide reporting this study.

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All authors have completed the <u>Unified Competing Interest form</u>) and declare: This research was funded by The Hollywood Private Hospital Research Grant (RF087). SD received an Australian Post Graduate Award Scholarship for the first year of this study, and received an ECU Research Travel Grant. No other support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years, no other relationships or activities that could appear to have influenced the submitted work.

The lead author (the manuscript's guarantor) affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned have been explained.

This study has Ethics approval from the Edith Cowan University Human Research Ethics Committee (ECU HREC 12149) and The Hollywood Private Hospital Research Ethics Committee (HPH431).

Abstract

Objectives: To explore barriers and facilitators to patient communication in an acute and rehabilitation ward setting from the perspectives of hospital staff, volunteers and patients following stroke.

Design: A qualitative descriptive sub-study within a larger study which aimed to develop and test a Communication Enhanced Environment in an acute and a rehabilitation ward.

Setting: A metropolitan Australian private hospital.

Participants: Focus groups with acute and rehabilitation doctors, nurses, allied health staff and volunteers (n=51) and interviews with patients following stroke (n=7), including three with aphasia, were conducted

Results: The key themes related to barriers and facilitators to communication, contained sub-categories related to hospital, staff and patient factors. Hospital related barriers to communication were private rooms, mixed wards, the physical hospital environment, hospital policies, the power imbalance between staff and patients, and task specific communication. Staff related barriers to communication were staff's perception of time pressures, underutilisation of available resources, staff individual factors such as personality, role perception and lack of knowledge and skills regarding communication strategies. The patient related barrier to communication involved patients' functional and medical status. Hospital related facilitators to communication were shared rooms/colocation of patients, visitors and volunteers. Staff related facilitators to communication were utilisation of resources, speech pathology support, staff knowledge and utilisation of communication strategies and individual staff factors such as personality. No patient related facilitators to communication were reported by staff, volunteers or patients.

Conclusions: Barriers and facilitators to communication appeared to be interconnected and likely to influence one another suggests communication access may vary between patients within the same setting. Practical changes may promote communication opportunities for patients in hospital early after stroke such as access to areas for patient co-location as well as areas for privacy, encouraging visitors, enhancing patient autonomy, and providing communication trained health staff and volunteers.

Study strengths

- This study involved a large number of staff in comparison to previous studies and included volunteers working within the acute and rehabilitation wards as well patients following stroke with and without aphasia.
- Data saturation was reached within the staff focus groups.

Study limitations

- The results in this study reflect the perceptions of a small number of medical (n=2) and nursing staff (n= 11) compared to allied health staff (N= 32) which may be reflected in the results.
- This study involved exploring the perceptions a small number of patients; a broader range of perspectives may have been expressed with a larger number of participants.
- This study was conducted at a private hospital involving a mixed acute and a
 mixed rehabilitation ward, and a relatively homogenous groups of
 participants linguistically and ethnically, therefore these results reflect this
 context and may not be directly generalisable to hospitals in the public
 sector, nor did they explore cultural factors contributing to communication.

Background

Aphasia research supports the theory that commencing aphasia rehabilitation in the early phase post-stroke (<1-month post-stroke) results in better outcomes than therapy commenced in the chronic phase (>6-months post stroke).^{1,2} However, patients in hospital following stroke spend on average 65-94% of their day inactive.³ Despite improvements in functional independence during their hospital admission following stroke, patients' engagement in cognitive and social activity remains largely unchanged. ⁴ Patients with aphasia spend two thirds less time engaged in social interactions with family and friends compared to those without aphasia.⁵ A lack of social and cognitive activity early after stroke for patients with aphasia has the potential to contribute to: i) the development of maladaptive compensatory communication behaviours, and ii) the learned non-use of language, which may ultimately impact on their quality of life and overall language recovery.⁵

Patients following stroke with and without aphasia have described time outside therapy as "dead" and "wasted", reporting a lack of stimulation and inactivity in hospital impacting their ability to self-direct their rehabilitation outside of therapy. They report the experience of boredom is worse in the evenings and weekends when there are less structured activities. They also perceive that boredom negatively influences their mood, motivation, and contributes to their experience of post-stroke fatigue. Boredom is associated with a loss of autonomy and sense of control and contributes to patients becoming passive recipients of care, which may have negative implications for stroke recovery.

This study aimed to explore hospital staff and volunteer, and patient perceptions of barriers and facilitators to patient communication in an acute and a rehabilitation hospital ward. Identifying barriers and facilitators to patients' communication will inform the development of a Communication Enhanced Environment (CEE) for the purposes of increasing their engagement in language activity within a hospital ward to maximise post-stroke aphasia language recovery.

Methods

Design

This was a sub-study of a larger study which aimed to develop and test a CEE model within an acute and a rehabilitation ward (see supplementary file for study protocol and

procedure). This sub-study contributed to the baseline phase of the larger study outlined below:

- i) Baseline phase: observe and quantify levels of engagement in language activity in the acute and rehabilitation ward environment for patients following stroke, and explore hospital staff, volunteers, and patients' perceptions of barriers and facilitators to communication in hospital;
- ii) Implementation phase: develop and implement the CEE model on the acute and rehabilitation wards;
- *Post-implementation phase:* assess the impact of the CEE mode on patient engagement in language activity, and hospital staff, volunteers and patients' perceptions of barriers to communication in hospital.

Reporting guidelines

The consolidated criteria for reporting qualitative studies (COREQ)⁸ was used to guide reporting this study (Appendix C.).

Research authors' relationship with participants

The first author who was external to the hospital conducted focus groups and interviews. The first author engaged key hospital team members for the duration of the study to inform the study design to ensure it aligned with the hospital policies and priorities.

Patient and public involvement

Patients and the public were not involved in the design of this study however this data informed the development of the CEE model in the larger study. A working group consisting of key members of the stroke multidisciplinary team provided feedback on this study's findings and were involved in the development of the CEE model and embedding approach, which was based on the outcomes of this sub-study.

Setting

This study was conducted on an acute and a rehabilitation ward at a private hospital in Perth, Western Australia. The acute ward was a 26- bed unit with patients following acute stroke as well as other medical conditions. The acute ward had four individual rooms and nine shared rooms, two rooms with four beds per room, and seven rooms with two beds per room. Patients ate meals in their rooms and had access to an outdoor balcony area. The rehabilitation ward was a 44-bed mixed rehabilitation unit for patients following stroke and

other medical, orthopaedic and post-surgical conditions. There were thirty-six individual rooms, and four shared rooms with two beds in each room. Patients had breakfast in their rooms but were encouraged to eat lunch and dinner in one of two communal dining areas.

Participants

Hospital staff participants: Purposeful sampling of acute and rehabilitation hospital staff was conducted to include at least one representative from each acute and rehabilitation staff group including medical, nursing, volunteers, and allied health staff members who were over 18 years of age. A total of 51 staff and volunteers were recruited (Table 1.) by contacting staff department managers who identified staff currently working or had previously worked with patients following stroke on the acute or rehabilitation wards.

Table 1. Staff participants

| Staff/volunteer groups | | | | | |
|------------------------------|---|---------------------------------------|---|----------------|---|
| Medical & Nursing | N | Allied Health | N | Volunteer | N |
| Acute nurses (AN) | 2 | Dietitian (DT) | 1 | Volunteers (V) | 6 |
| Clinical nurse manager (CNM) | 1 | Occupational therapy manager (OTM) | 1 | | |
| Medical consultants (MC) | 2 | Occupational therapists (OT) | 5 | | |
| Rehabilitation nurses (RN) | 8 | Occupational therapy assistants (OTA) | 3 | | |
| | | Physiotherapists (PT) | 8 | | |
| | | Physiotherapy assistants (PTA) | 2 | | |
| | | Social workers (SW) | 5 | | |

Speech pathology manager (SPM) Speech pathologists (SP) Speech pathology assistant (SPA) Volunteer manager (VM)

Patient participants: All patients consecutively admitted following stroke from January to February 2016, and June 2016 to July 2017 were screened for eligibility to participate in the study. Inclusion criteria: i) admitted to the acute or rehabilitation ward with an acute stroke, ii) less than 21 days post-stroke during data collection, iii) able to provide informed consent based on the judgement of the medical team responsible for the medical management of the patient, iv) Glasgow Coma Scale⁹ greater than 10, v) estimated total length of hospital stay greater than 14 days, vi) adequate English proficiency to participate in interviews as determined by managing speech pathologist or medical team. Exclusion criteria: i) uncorrected hearing or vision (for example hearing impairment without the use of hearing aids or vision impairment without the use of glasses), ii) medically unstable, iii) documented diagnosis of current untreated depression, documented diagnosis of dementia, previous aphasia or traumatic brain injury. The diagnosis of aphasia was confirmed for those who achieved a Western Aphasia Battery-Revised¹⁰ Aphasia Quotient score less than 93.7. A total of 9 patients were recruited, however 2 patients were withdrawn as they became medically unwell. Data collection was completed for 4 patients without aphasia and 3 patients with aphasia. See Figure 1. for the summary of patient screening and recruitment. Patient details and demographics are detailed in Table 2.

No staff or patients withdrew from participating in this study.

Data collection

The first author, a female speech pathologist (Bachelor of Speech Pathology, Honours) and PhD student with seven years clinical experience working in the hospital setting and five years research experience, including conducting interviews and focus groups, completed all semi-structured interviews and focus groups. Staff were informed that the researchers wanted to investigate their perceptions of the hospital ward environment in regards to communication opportunities to inform the development of a Communication Enhanced Environment (see supplementary file for staff and volunteer information and consent forms). Patients were informed that the researchers wanted to explore how the hospital environment influenced patient activity (see supplementary file for patient information and consent forms).

All interviews and focus groups were conducted using interview and focus group guides (staff focus groups and interview guide Appendix A., patient interview guide Appendix B.) and were audio recorded. Field notes were completed by the first author

during data collection. Seven staff focus groups were conducted with two to eight participants in each focus group. One-on-one interviews were conducted with two staff members. All staff focus groups were completed on the hospital site in various locations that were private and quiet. Six out of seven patient interviews were conducted in person during their inpatient admission in their hospital room, and one was completed over the phone (patient without aphasia) one day following discharge from hospital. All patient interviews were conducted within fifteen days post-stroke. Interview and focus groups were 20-60 minutes long, often varying based on the number of participants. Supported conversation strategies¹¹ were used during interviews with patients with aphasia to facilitate their participation in the interview. One patients with aphasia had two family members present during the interview. During the interviews and focus groups, clarifying questions and paraphrasing participant comments were used to confirm and clarify their perspectives and insights.

[Figure 1. inserted here]



Table 2. Patient characteristics

| | Group | PWA | PWOA |
|---|-----------|-----------|------------|
| | (n=7) | (n = 3) | (n = 4) |
| Participants | | | |
| Age (yr), mean (SD) | 83 (7) | 81 (5) | 84 (8.10) |
| Sex, n females | 4 | 1 | 3 |
| Pre-morbid mobility, n needing aids | 1 | 1 | 0 |
| Pre-morbid living arrangement, n alone | 3 | 1 | 2 |
| Time since stroke (d), mean (SD) | 14 (5) | 13 (7) | 15 (5) |
| Stroke severity (NIHSS ¹² 0-42), mean (SD) | 4 (3) | 5 (4) | 5 (3) |
| Mild, n score < 8 | 5 | 2 | 3 |
| Moderate, n score 8-15 | 2 | 1 | 1 |
| Severe, n score > 15 | 0 | 0 | 0 |
| Mobility status at time of data collection | | | |
| Independent +/- walking aid | 1 | 0 | 1 |
| Stand-by assistance | 3 | 1 | 2 |
| 1-2 person assistance | 2 | 1 | 1 |
| Hoist/wheelchair | 1 | 1 | 0 |
| Cognition (MOCA ¹³), median (range) | 18 (9-22) | 16 (9-18) | 20 (17-22) |
| Aphasia severity, WAB-R ¹⁰ AQ mean, (SD) | | 77 (6.50) | |
| Ward (d) | | | |
| Acute (%) | 4 (17) | 4 (40) | 0 (0) |
| Rehabilitation (%) | 19 (83) | 6 (60) | 13 (100) |
| Average number of days in single room per participant (%) | 3.1 (96) | 3 (90) | 3.3 (100) |

Notes: PWA= patient with aphasia; PWOA= patient without aphasia; NIHSS=National Institute of Health Stroke Scale¹²; MoCA= Montreal Cognitive Assessment¹³; WABAQ=Western Aphasia Battery-Revised¹⁰ Aphasia Quotient score.

Data analysis

Focus groups and interviews were transcribed verbatim. Responses to any leading questions were removed from the data set.¹⁴

The theoretical framework for this research was a qualitative description approach.¹⁵ This approach involves describing patient experiences, with minimal interpretation of the data to minimise potential bias of the researchers. ¹⁵ Participant experiences were analysed using NVivo¹⁶ computer software to manage the data. Data were grouped into themes according to content.¹⁵ The first level of coding identified the broad content of the data then sub-categories were identified.¹⁵ Single lines of data were not removed from their 'story' during data analysis to maintain the context and help ensure meaning was not lost or misinterpreted.¹⁵ Ongoing critical review of the categories were conducted and themes were reviewed by a second researcher.¹⁵ Staff were provided feedback on the findings.

Results

The key themes from the focus group and interviews related to barriers and facilitators to communication, with sub-categories identified which related to hospital, staff and patient factors (Figure 2.).

[Figure 2. inserted here]



Barriers to Communication

Hospital related factors

Private rooms reduce opportunities for social interaction

Staff and patients described the impact of single rooms which limited incidental socialisation with other patients and their visitors.

We used to co-locate our stroke patients and often using our shared rooms. That's when people had more opportunities for interacting with one another. (MedC1)

Mixed wards affect staff acquisition of specialist skills

Staff described their perception of the negative effect a mixed hospital ward had on the acquisition of stroke specific specialist skills.

Having a stroke specific ward... everybody on the ward would be trained...and that's the only thing they'd have to focus on rather than having lots of other patients with lots of medical conditions. (OT4)

Hospital environment does not encourage socialising

Staff talked about the physical hospital ward environment affecting social interaction as it contributed to a sterile atmosphere rather than one that promoted social activity. Staff also talked about the consequence of background noise and environmental distractors in large shared rooms on the acute ward which reduced their ability to communicate with patients with communication impairments.

My general feeling of rehab [rehabilitation] is that they come to their sessions and then they go back to their lonely dark room... I don't really see the rooms as a particularly happy, busy place where they are getting a lot out of being in there... the dining rooms... they're not a particularly pleasant place to be either. (PT2)

They [patients] can hear other people talking... there is [sic] a lot of voices going on which is going to impact on their understanding as well. (PT3)

Hospital policies restrict the development of communication-promoting ideas and initiatives

Hospital policies were perceived by staff as a barrier to communication, negatively influencing their ability to develop ideas and initiatives to increase patients' opportunities for social interaction. This included policies regarding leaving patients unattended in dining areas without patient care assistants supervising them, and requiring nurses to supervise

patients if they are eating; and reported limitations around food related activities as a result of food hygiene policies and occupational health and safety.

It's just every time you try and do something you hit a barrier... you do try and think outside the box what more can you do for this patient and you get another hospital rule. (PT2)

Power imbalance of staff and patients in hospital controls patients' ability to access communication opportunities

Staff and patients discussed the influence of the power imbalance for patients in hospital, and patient perceptions that they have to do what is expected in the hospital environment. This appeared to limit the patients' ability to freely engage and explore the environment resulting in patients retreating to their rooms and limiting their opportunities to engage in activities.

I think most males like to account for their time um and I felt like I haven't been able to do that and that's, that's the bit that I'm really, really lacking. (PWA2)

I was in the hospital so I think I had to stick into the room, to the rules. (PWOA2)

Very often when you're in a hospital you do what you think you're expected to do. (SP4)

Task specific communication reduces patients' communication opportunities

Staff talked about the nature of interactions with patients as often being driven by the patient's care, restricting opportunities for communication beyond this context.

I know we aim to be very holistic... but very often care is very[sic] directed from a medical health care perspective (SP4)

Staff related factors

Staff's perception of time pressures limiting opportunities for communication

Both patients and staff perceived staff time pressures as a barrier negatively effecting communication on the wards. This may be the reflection of actual time pressures, or staff perceptions of their available time. Some staff reported that they felt interactions with patients with communication impairments required extra time which was challenging in a time pressured hospital environment. Time pressures were also perceived to restrict the staff's ability to facilitate opportunities for patients to socialise with other patients. For example, nurses appeared to deprioritise transferring patients to the communal area for lunch in busier times.

If they're hoist patients it might not be as easy for staff to get them to the dining room, that wouldn't totally prevent someone from going, it would just depend on the time that people had on the day. (SW3)

Staff and patient's underutilisation of available resources

Staff described the lack of accessible resources as a factor negatively affecting staff-patient communication. They described the need for resources when communicating with patients with aphasia and other communication impairments but felt unsure about what these were or how to access them. They also described a number of resources that they felt patients were not aware of and therefore did not utilise such as volunteer services that promote communication opportunities and facilitate patient access to outdoor areas.

I feel like I don't know where else to go. I don't know if other things that [sic] could help us, maybe there's things out there that I don't know about that would help us communicate with these patients. (PT2)

There are all of these opportunities but I don't think a lot of the patients access them so it sounds like great communicative opportunities for them but the reality is that a lot of them are sitting in their rooms most of the times by themselves watching television and most of the interactions they have is with the nurses or just whoever comes in to see them. (SP4)

Individual staff factors leading to restricted opportunities for communication

Staff described individual staff factors such as personality, values and attitudes influencing communication opportunities for patients, such as staff providing patients with opportunities for incidental social interaction during routine tasks.

Often if people need to go in and see the patient let's just say to take obs [observations] or to do a wash... they don't always use that opportunity as an opportunity to chat... there could be more opportunity to chat at those times whilst they are doing what they need to get done and you know that varies from person to person, personality as well and how busy people are, what else is going on. (SP3)

Staff's perception their role does not include communication tasks

Some staff perceived communication as a task separate from the responsibility of their role therefore limiting their facilitation of communication opportunities for patients.

They [speech pathologists] do their bit and we do ours... we don't have time to practice speech with them because we really do have to get all of our jobs filled in the time and it's specifically rostered for us to do our work, not to help with someone else's. (RehabN1)

Lack of staff knowledge and skills resulting in unsuccessful communication interactions or avoiding communication interactions

Staff described a lack of knowledge and skills in communicating with patients with communication impairments. Some staff reported feeling anxious about encouraging patients to communicate as communication breakdowns may cause stress and anxiety for the patient, and the staff member. Staff reported a lack of confidence in their ability to repair communication breakdowns which resulted in increased time pressures in their sessions, often leading them to avoid encouraging communication interactions within their treatment sessions.

I find it challenging... knowing how the best way to communicate with that person [with aphasia]... then [they] become very frustrated and not have the tools themselves to communicate back to me and you would never want to leave someone in that space. So that's something that I struggle with. (SW2)

Patient related factors

Patient related factors reflected their functional and medical status, personality, mood and motivation, which were perceived by staff and patients to often act as a barrier to engaging in communication interactions during their hospital admission early after stroke.

Patients' functional and medical status limiting their ability to seek out and engage in activities

Staff and patients perceived patients' medical status as a barrier to communication by limiting their ability to engage with their environment including independently seeking out activities and being able to utilise communal areas.

If someone is bed bound, you know the interaction is very minimal... you often walk past and you see them alone in their room... you wonder what happens during those periods of time where they're just in their room and they don't have family. (OT2) Well, I can't do anything cos I can't go off by myself and do anything. (PWOA2)

Individual patient factors limiting opportunities for communication

Staff described individual patient factors such as personality, mood and motivation communication opportunities for patients such as independent practice of communication therapy tasks, and social opportunities with patients and hospital staff.

We have to recognise some patients who have had strokes... they're fed up with having people poking and prodding them then have a volunteer and go "do you want to do your exercises for speech?" (VM)

They need a break after OT [the occupational therapist] has done a shower. If they don't get that break then the physio isn't going the be as good for them because they're so tired, so we also have to look at break times in between each sessions... (OTA1)

Facilitators to Communication

Hospital related factors

Shared rooms/co-location encourages incidental social interactions

Staff talked about use of communal areas at other hospitals which facilitated socialisation and communication during non-therapy times and during group therapy. Staff described the importance of the use of communal areas given the large number of private rooms on the ward. Patients also described the need to be co-located to promote social interaction.

I think that, put the [sic] whole lot of people together and ah and they [sic] something collective, that's what human beings are put together for ... sitting around talking... over the proverbial cuppa. (PWA2)

Visitors provide patients opportunities for socialisation

Staff identified visitors as a facilitator to communication interaction for patients outside of therapy times during their inpatient admission.

Interaction with the family... it's not therapy based but it's their [patients'] opportunity to practice. (PT1)

Volunteers facilitate opportunities for patients to engage in social activities

Staff discussed the benefit of volunteers in facilitating opportunities for patients to engage in social interactions including programs involving therapy dogs, book loaning, hand massages, and taking patients off the ward.

If we see people that are lonely, are not getting visitors, there's many volunteers... to go and visit them and if they're well enough they can take them out... the volunteers, we do rely on them. (OTA1)

Staff related factors

Staff utilisation of resources promote communication exchange

Staff identified access to resources such as chat books and alternative and augmentative communication boards often facilitated communication interactions with patients with communication impairments on the ward.

Sometimes with the ... signs... "do you want to drink? some water?" or something, so they can just point because ... they want to say something and maybe the right words are not coming out... that also helps. (RehabN3)

Speech pathology support and education facilitates staff's use of communication promoting strategies

Staff reported support and education from speech pathology staff facilitated their ability to interact successfully with patients with aphasia.

I had a patient who had word finding difficulties... I just was observing the speechie [speech pathologist], she would just be like "no, what do you mean?" and he'll be like [pointing] and she'll be like "tell me what's the word"... it's something I could have just added to my session. (PT4)

Staff knowledge and utilisation of communication strategies promotes communication activities

Staff and volunteers discussed the use of communication strategies and resources to facilitate communication on the ward for patients with a variety of communication impairments.

We use communication boards, pictures, writing things down, talking slowly. (MedC2)

If they are having trouble, I will say to them "it's okay you don't need to hurry, that's fine". (V1)

Individual staff factors promote communication opportunities for patients

Staff and patients talked about how individual characteristics of staff, including rapport building and being friendly, facilitated communication for patients with communication difficulties.

Sometimes they [patients] look for that specific person... the more they get confident, the more they get relaxed, the more their speech enhances as well. (RehabN3)

Discussion

This study aimed to explore hospital staff, volunteers and patients' perceptions of barriers and facilitators to communication on an acute and a rehabilitation ward. A wide range of factors were perceived to act as potential barriers or facilitators to communication. Additionally, a number of factors influencing patient access to communication opportunities appeared to influence one another.

The co-location of patients in therapy spaces, dining areas or in shared rooms were perceived as facilitators to communication for patients, providing opportunities for incidental social interactions with other patients and their visitors. However, background noise in these shared spaces was also perceived to act as a barrier to their ability to engage in communication. Patient access to communal spaces was influenced by a number of factors including patients' sense of autonomy to freely explore the hospital ward environment, and their medical and mobility status, and staff's perception of their available time, which influenced staff's perception of whether they transferred patients to these spaces. Rosbergen et al¹⁷ reported that in an acute stroke ward enriched environment communal mealtimes and group activities were perceived to facilitate social activity. The study by Rosbergen et al¹⁷ found that staff reported perceptions that shared rooms limited staff and patients' ability to engage in private conversations, consistent with O'Halloran et al's¹⁸ findings. It may be that access to both private and communal spaces available within the hospital environment play critical roles in regards to providing opportunities for social interactions with other patients and their visitors and opportunities for privacy when required.

The acute and rehabilitation wards had a large proportion of single rooms, which could have been considered the result of this study being conducted at a private hospital.

However, there has been a perceived trend towards increased proportions of single rooms

in newly built public hospitals to promote infection control and patient privacy which may have a detrimental effect on communication. ^{19,20} The predominance of single rooms and limited opportunities to access shared spaces may have increased the effect of other barriers on communication opportunities for patients. For example, a patient with poor autonomy may be more likely to remain alone in their single room when they are not attending therapy, as they perceive they are not 'allowed' to freely explore the hospital environment. This may reduce the likelihood of the individual independently seeking out social interactions beyond their room. If they also have reduced mobility, they may be more reliant on staff to facilitate transfers to communal spaces which may be impacted by staff time constraints. The patient's functional status and levels of fatigue may also limit their ability to initiate and engage in activities while they are in their room. Therefore, the combined effect of these barriers may significantly limit this patient's communication opportunities.

These communication barriers may be mitigated by having scheduled rest periods, and periods allocated to encouraging visitors to provide opportunities for communication and socialisation within their room, and facilitate patient access to shared spaces, such as helping mobilise wheelchair users into communal dining areas or education to patients that they are allowed to explore the hospital ward environment. Rosbergen et al¹⁷ identified patient and family autonomy to initiate and direct activity as a factor enriching the acute ward environment. Therefore, increasing patient autonomy within this setting may facilitate their ability to seek out interactions within the environment and increase engagement in communication activity, which may then reduce the effect of being in a single room with reduced mobility and time poor staff.

A potential lack of opportunities to access social interactions with other patients means staff, including volunteers, and visitors may become the main communication partner for patients. Godecke et al's⁵ observation study found that nurses are the most frequent communication partner for patients following stroke with aphasia, after their family members, therefore patient-staff interactions may play a significant role for those patients with minimal or no visitors. It is interesting to note that this study recruited a limited number of acute nurses in comparison to rehabilitation nurses. This could be interpreted as a reflection of differences in nurses' capacity for additional activities within the demands and time restrictions of the acute ward context in comparison to the

rehabilitation ward context. Within the current study, communication between staff and patients appeared to be dependent on a number of factors including staff perception of their role, their knowledge and skills in facilitating communication, their values and attitudes towards communication and whether supporting language and communication for patients with aphasia is part of their 'role', their willingness to be flexible with their time, and their knowledge of and access to resources which may be used to facilitate communication. This also highlights the potential impact of the perceived power imbalance between staff and patients and the significance of interactions that are task directed. Hersh et al²¹ reported patients with aphasia felt disempowered in communicative interactions with nurses, where nurses tended to talk to the task and controlled the interactions. This highlights the need for communication partner training which may provide staff with the knowledge and skills required to support effective communication with patients with aphasia.²² Implementation strategies will need to be considered to promote behaviour change as well as the uptake and maintenance of training including involvement of management and ward champions, and ensuring trained communication strategies are easy to learn, apply and audit in order to be applicable in this busy context.²³

Time pressure was perceived as a major barrier to communication impacting on staff's ability to support successful communication within their interactions with patients, and facilitate patients' opportunities to engage in interactions in social or communal areas. Time constraints have been reported to limit communicative opportunities between patients following stroke and nurses.²⁴ Ball et al²⁴ found that 86% of surveyed nurses reported one or more activities had been "left undone" in their last shift as a result of lack of time. The study found that activities most likely to be missed by nurses as a result of time constraints were comforting and talking to patients (66%) and patient education (52%).²⁴ This has also been identified by patients who "did not like to bother the busy nurse".²⁵ Time limitations and pressures on the wards may be facilitated by developing staff knowledge of and skills in using communication promoting strategies. Effective and efficient nurse patient communication as a result of nurse training has been found to save time, reduce frustration and reduce the burden associated with caring for patients following stroke with aphasia.²⁶ Additionally, time limitations reported by staff may lend to an argument for additional nursing allocation for patients with communication impairments.

This study included a small number of medical and nursing staff in comparison to compared to allied health staff which may be reflected in the reported results. This study also involved a small number of patients and a broader range of perspectives may have been expressed with a larger number of participants. The results of this study may reflect the context of a private metropolitan hospital therefore further exploration of patient and staff perspectives in the public sector may be warranted.

Conclusions

The barriers and facilitators to communication appear to be interconnected and likely to influence one another, suggesting that the level of communication access may vary from patient to patient within the same setting. Results of this study highlight a number of practical changes that could be implemented to promote communication opportunities for patients admitted to hospital early after stroke. However, implementation of behaviour and cultural change strategies may be pertinent to promote meaningful and sustainable change within the hospital setting. Consideration of areas for co-location for patients such as therapy spaces, dining areas or shared rooms as well as access to private spaces may potentially address the need for social opportunities with other patients as well as access to privacy when required. The promotion of visitors attending the wards may facilitate communication opportunities for patients between therapy times by providing socialisation in patients' rooms as well as facilitating and advocating for patient access to communal areas. This has the potential to mitigate the effect of social isolation in single rooms, staff time restraints and limitations as a result of patients' medical status. Strategies to promote patient autonomy in hospital may promote their ability to freely explore the environment beyond their room may help address the power imbalance that can occur between patients and hospital staff. Additionally, health staff and volunteer education in using communication promoting strategies may increase opportunities for interactions between patients, and staff or volunteers and promote communication exchange within those interactions. These factors will be explored in a Communication Enhanced Environment, which aims to increase patients' opportunities to engage in language activities during early stroke recovery in hospital.

Acknowledgements

The authors would like to thank the hospital and staff for supporting this study and assisting in participant recruitment. We would also like to thank all the participants in this study for sharing their experiences and insights.

Author contributions

SD, EG, NC, DH, HJ and EA designed the study and the protocol. EG reviewed the final copies of the protocol documents. SD conducted the semi-structured interviews and focus groups. SD performed data analysis. DH conducted the critical review of the categories and review of themes. SD, EG, NC, DH, HJ and EA contributed to the manuscript and approved the manuscript.

Competing interests statement

This research was funded by The Hollywood Private Hospital Research Grant (RF087). SD received an Australian Post Graduate Award Scholarship for the first year of this study, and received an ECU Research Travel Grant. The authors have no other competing interests to declare.

Funding statement

This work was supported by the Hollywood Private Hospital Research Foundation grant number RF087. SD received an Australian Post Graduate Award Scholarship for the first year of this study, and received an ECU Research Travel Grant.

Data sharing statement

Data is stored to NHMRC standards and will be available (in a de-identified manner) on request.

Figures

Figure 1. Summary of patient screening and recruitment.

Figure 2. Summary of themes and subthemes of staff and patient perceptions to barriers and facilitators to patient following stroke.

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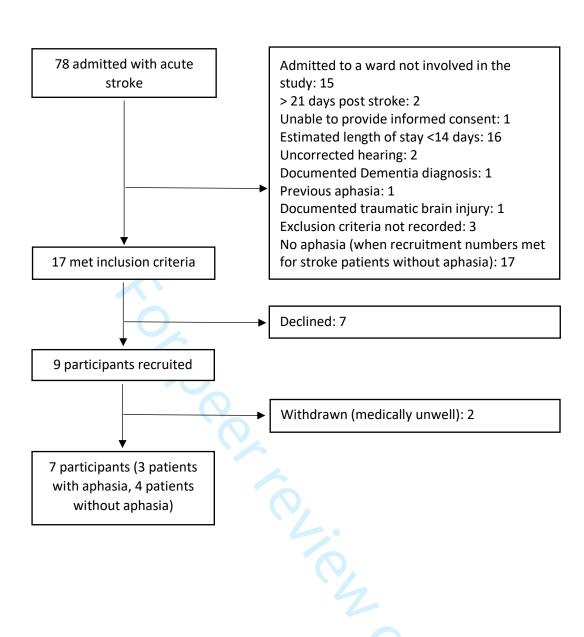


Figure 1. Summary of patient screening and recruitment

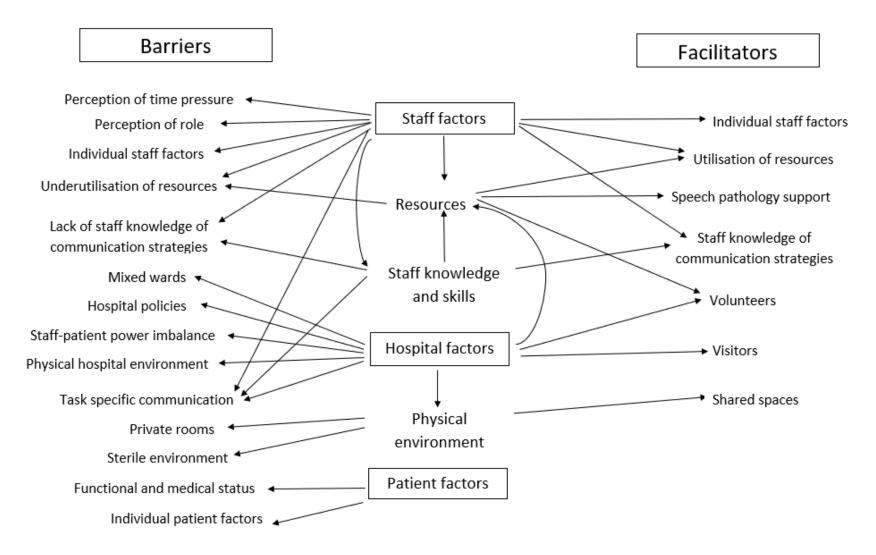


Figure 2. Summary of themes and subthemes of staff and patient perceptions to barriers and facilitators to patient following stroke.

Appendix A.

Investigating Communication Enhanced Environments after stroke: Staff focus group guide

What kind of language activities or language tasks do stroke patients currently participate in on the ward?

What kind of language activities or language tasks would you like see stroke patients have access to on the wards?

Describe your experience of communicating with stroke patients at the moment.

Can you tell me about anything that facilitates your ability to communicate with stroke patients on the ward?

Can you tell me about any barriers you experience that impact your ability to communicate with stroke patients on the ward?

What changes would you like to see to enhance communication between staff and stroke patients on the ward?

What changes would you like to see to enhance communication between visitors and stroke patients on the ward?

How could we enhance or optimise communication and language tasks and activities for stroke patients on the ward?

What do you think a communication and language enhanced stroke ward environment might look like?

Appendix B.

Investigating Communication Enhanced Environments after stroke: Patient interview guide

Tell me about what kind of activities you do while you are here (in hospital).

Describe your experience of communicating with people on the ward.

What makes it easier to communicate with people on the ward?

What makes it hard to communicate with people on the ward?

What can we do to make communicating with people easier?

Appendix C.

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

| No Item | Guide questions/description | Location within paper |
|---|---|---|
| Domain 1: Research team and reflexivity | | |
| Personal Characteristics | | |
| 1. Interviewer/facilitator | Which author/s conducted the interview or focus group? | Page 10 |
| 2. Credentials | What were the researcher's credentials? E.g. PhD, MD | Page 10 |
| 3. Occupation | What was their occupation at the time of the study? | Page 10 |
| 4. Gender | Was the researcher male or female? | Page 10 |
| 5. Experience and training | What experience or training did the researcher have? | Page 10 |
| Relationship with participants | 10h. | Page 7 |
| 6. Relationship established | Was a relationship established prior to study commencement? | Page 7 |
| 7. Participant knowledge of the interviewer | What did the participants know about the researcher? e.g. personal goals, reasons for doing the research | Supplementary files, participant information and consent forms, page 10 |
| 8. Interviewer characteristics | What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic | Page 10 |
| Domain 2: study design | · | |
| Theoretical framework | | |

| 9. Methodological orientation and Theory | What methodological orientation was stated | Page 13 |
|--|---|------------------------|
| | to underpin the study? e.g. grounded theory, | |
| | discourse analysis, ethnography, | |
| | phenomenology, content analysis | |
| Participant selection | | |
| 10. Sampling | How were participants selected? e.g. | Page 8, 10 |
| | purposive, convenience, consecutive, | |
| | snowball | |
| 11. Method of approach | How were participants approached? e.g. | Page 8, 10 |
| | face-to-face, telephone, mail, email | |
| 12. Sample size | How many participants were in the study? | Page 8, 10 |
| 13. Non-participation | How many people refused to participate or | Figure 1, page 8 |
| | dropped out? Reasons? | |
| 14. Setting | Setting of data collection Where was the | Page 7-8 |
| | data collected? e.g. home, clinic, workplace | |
| 15. Presence of non-participants | Was anyone else present besides the | Page 11 |
| | participants and researchers? | |
| 16. Description of sample | What are the important characteristics of the | Table 2, page 12 |
| | sample? e.g. demographic data, date | |
| Data collection | | 4 |
| 17. Interview guide | Were questions, prompts, guides provided | Appendix A, Appendix B |
| | by the authors? Was it pilot tested? | |
| 18. Repeat interviews | Were repeat interviews carried out? If yes, | NA |
| | how many? | |
| 19. Audio/visual recording | Did the research use audio or visual | Page 10 |
| | recording to collect the data? | |
| 20. Field notes | Were field notes made during and/or after | Page 10 |
| | the interview or focus group? | |
| 21. Duration | What was the duration of the interviews or | Page 11 |
| | focus group? | |

| 22. Data saturation | Was data saturation discussed? | Page 5 |
|------------------------------------|---|------------|
| 23. Transcripts returned | Were transcripts returned to participants for | No |
| | comment and/or correction? | |
| Domain 3: analysis and findings | | |
| Data analysis | | |
| 24. Number of data coders | How many data coders coded the data? | Page 13 |
| 25. Description of the coding tree | Did authors provide a description of the | Figure 2 |
| | coding tree? | |
| 26. Derivation of themes | Were themes identified in advance or | Page 13 |
| | derived from the data? | |
| 27. Software | What software, if applicable, was used to | Page 13 |
| | manage the data? | |
| 28. Participant checking | Did participants provide feedback on the | Page 13 |
| | findings? | |
| Reporting | 10 | |
| 29. Quotations presented | Were participant quotations presented to | Page 14-20 |
| | illustrate the themes / findings? Was each | |
| | quotation identified? e.g. participant number | |
| 30. Data and findings consistent | Was there consistency between the data | Page 14-20 |
| | presented and the findings? | 6 |
| 31. Clarity of major themes | Were major themes clearly presented in the | Figure 2 |
| | findings? | |
| 32. Clarity of minor themes | Is there a description of diverse cases or | Page 14-20 |
| | discussion of minor themes? | |

Investigating a Communication Enhanced Environment (CEE) model early after stroke: A before-after non-

randomised controlled pilot study.

Study protocol version 1 19.05.20

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1 Abbreviations and Definitions of Terms

CEE model: Communication Enhanced Environment model, an adapted model of an Enriched Environment, an environment that provides stroke patients opportunities to engage in language activities during inpatient rehabilitation.

PWA: Patients following stroke with aphasia.

PWOA: Patients following stroke without aphasia.

Language activities: Language tasks that consist of solitary or interactive language activities.

Solitary language activities: Activities that may promote aphasia recovery such as reading, writing, listening to the radio, and the use of iPad applications.

Interactive language activities: activities which are based in communicative interactions that involve an exchange of information with a communication partner involving talking, gesture and/or facial expression, reading, writing or drawing to communicate.

EE: Enriched Environment, an environment that promotes physical, cognitive and social activity.

2. Protocol Synopsis

| Study Title: | Investigating a Communication Enhanced Environment model on acute and rehabilitation wards early after stroke: A before-after non-randomised controlled pilot study |
|---------------------|--|
| Study type: | Interventional |
| Study Intervention: | A Communication Enhanced Environment (CEE) model will be developed from pre-intervention observations of inpatient language activities and investigations of barriers and facilitators to communication together through focus groups with hospital staff and interviews with patients on the acute and rehabilitation wards. |
| | Sixteen patients following stroke will be recruited in this prospective before-after non-randomised controlled pilot study set in an acute and a rehabilitation ward of a metropolitan private hospital. The study includes: i) The baseline phase which involves observation of patients following stoke (n=8, 4 patients with aphasia (PWA) and 4 patients without aphasia (PWOA)); the collection of qualitative data through focus groups and semi-structured interviews to determine patient and staff perceived barriers and facilitators to communication; ii) the implementation phase where a CEE model will be developed and embedded in usual care; iii) the post-implementation phase which will involve repeated baseline data collection on a different cohort of patients (n=8, 4 PWA and 4 PWOA) to determine i) how solitary and interactive language activity levels changed following implementation of the CEE model, ii) the differences post CEE implementation in hospital staff's use of communication promoting strategies when interacting with patients, iii) the differences post CEE implementation in staff and patient perceptions of the barriers and facilitators to inpatient language activities. |
| | The CEE model will include the provision of: i) CEE model equipment, for example reading materials such as books and magazines, and access and encouragement to reside in a communal dining area; ii) CEE model education, support and training for staff with the aim to develop the ability to facilitate language activities for patients after stroke. The training program will be guided by research evidence, expert opinion and baseline data. Staff will complete a questionnaire pre and post training to determine changes in their knowledge, skills and attitudes regarding communication and aphasia. |
| | Control treatment: Patients following stroke with and without aphasia will be observed and video recorded over two week days and one weekend day pre (n=8) and post (n=8) implementation of a CEE model. Behavioural mapping will record patient interactive and solitary language activity observed within the first minute of 5-minute intervals in 4-hour time periods between 7am and 7pm. Solitary language activities are activities that may promote aphasia recovery such as reading, writing, listening to the radio, and the use of iPad applications. Interactive language activities are activities which are based in communicative interactions that involve an exchange of information with a communication partner involving talking, gesture and/or facial expression, reading, writing or drawing to communicate. |

| Objectives of the | This study aims to investigate a CEE model on an acute and rehabilitation |
|---------------------------|--|
| Study: | ward and if stakeholders perceive a CEE model as valuable by addressing |
| Study. | the following research questions: |
| | - Does a CEE model increase the amount of time PWA and PWOA spend |
| | in participating in solitary and interactive language activities on acute |
| | |
| | and rehabilitation wards during the early post-stroke period? |
| | - What are the differences in patients' experience of communication in a |
| | CEE model compared to patients' experience of communication in a |
| | standard environment on in-patient acute and rehabilitation wards? |
| | - What is the experience of implementing a CEE model for staff working |
| | with PWA and PWOA within in-patient acute and rehabilitation wards? |
| | - Do staffs' perceptions of their knowledge of, skills with, and attitude |
| | towards communication and aphasia change following implementation |
| | of a CEE model? |
| Number of Centres: | 1 |
| Study duration: | 5 years |
| Study Hypothesis: | A CEE model will increase patient engagement in solitary and interactive |
| ' '' | language activities and improve staff and patient experiences of |
| | communication compared to a standard ward environment. |
| Primary outcomes: | The primary outcome is the change in the proportion of solitary and |
| , | interactive language activities as a percentage of total observed activity |
| | after the implementation of the CEE model. |
| | |
| | Timepoint: Patient observations completed within 21 days post stroke. |
| Secondary outcomes: | The differences post CEE model implementation in staff and patient |
| Secondary outcomes. | perceptions of the barriers and facilitators to inpatient language |
| | activities. |
| | Timepoint: Within 18 months of embedding the CEE model. |
| Study docions | |
| | |
| Study design: | Before-after non-randomised pilot study |
| Key inclusion criteria: | Patients will be eligible for inclusion if they have/are: admitted to the |
| | Patients will be eligible for inclusion if they have/are: admitted to the acute or rehabilitation ward for a stroke, less than 21 days post stroke |
| | Patients will be eligible for inclusion if they have/are: admitted to the acute or rehabilitation ward for a stroke, less than 21 days post stroke during baseline phase or post-implementation phase, the ability to |
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| Key inclusion criteria: | Patients will be eligible for inclusion if they have/are: admitted to the acute or rehabilitation ward for a stroke, less than 21 days post stroke during baseline phase or post-implementation phase, the ability to provide informed consent as determined by the medical team, a Glasgow Coma Scale¹ score greater than 10 at the time of screening, an estimated length of hospital stay greater than 14 days, adequate English proficiency to participate in semi-structured interviews and are above 18 years of age. Patients with aphasia will also have an Aphasia Quotient below 93.7 on the Western Aphasia Battery-Revised.² Staff participants: One representative from each acute and rehabilitation staff group including medical, nursing, volunteers, and allied health staff members (n=17), who are over 18 years old. Patients will be excluded if they have/are: uncorrected hearing or vision, not medically stable, a documented diagnosis of dementia, traumatic brain injury or previous aphasia, a documented current untreated depression at the time of acute admission or are a participant in another research trial which may affect this study's outcome measures. Baseline phase: Eligible patients during the baseline phase will be observed and video recorded for 4 hours on 3 consecutive days (one |
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| _ | , |
|---------------------|--|
| | Staff will participate in a one-hour focus group to explore their |
| | perceptions of barriers and facilitators to inpatient language activities. A |
| | focus group interview schedule will be used across all focus groups. |
| | Implementation phase: The CEE model will be implemented within the |
| | acute and rehabilitation wards. |
| | Post-implementation phase: Intervention group patient observations |
| | and interviews, and staff focus groups will replicate baseline data |
| | collection. |
| Safety parameters | Patients and/or their significant others may experience increased levels |
| | of distress during recruitment and/or data collection. This may be the |
| | result of adjustment following stroke and/or diagnosis of aphasia and |
| | increased awareness of impairment. No other risks known regarding |
| | participation in this project. The baseline assessments and interview will |
| | be conducted by the Chief Investigator who has experience in supporting |
| | patients during this early stage of stroke recovery. If a patient or any |
| | significant others becomes upset or distressed, the assessment or |
| | interview will be paused with the option to |
| | discontinue and counselling strategies will be provided. |
| Statistical methods | Patient demographic and stroke characteristics will be presented using |
| /analysis | descriptive statistics. One-way ANOVA or the Kruskal-Wallis and chi- |
| • | square tests will examine differences in characteristics between groups. |
| | Time spent observed in interactive and solitary language activities will be |
| | expressed as a percentage of total observations. A mixed design ANOVA |
| | will be used to calculate the within-subjects variable of presence of |
| | aphasia and the between-subjects variable of a CEE on language activity |
| | levels of patients by comparing baseline to intervention phase |
| | observations. A qualitative description research approach will be used |
| | for the qualitative component of this research. The mixed methods |
| | design will enable the triangulation of the qualitative and quantitative |
| | data. |
| Sample size | The patient sample size was selected for this pilot study to collect data |
| determination: | across each observation period for each patient group in the baseline |
| | and intervention phases (see document: |
| | Observation_protocol_SD_version 3_23-02-16). The sample size for staff |
| | participants was selected to capture a sufficient breadth of professional |
| | perspectives. |

3. Introduction

Aphasia is an acquired communication disorder that affects approximately 30% of first ever ischaemic stroke survivors³ and persists in up to 61% of survivors one-year post stroke.⁴ Aphasia impacts all communication modalities with significant negative consequences for social participation, interpersonal relationships, autonomy, capacity to work and quality of life.⁵

Patients following stroke with aphasia (PWA) have been observed to spend less than 28% of their day communicating and 44% of their day alone during their first weeks of inpatient rehabilitation.⁶ Inadequate opportunities for communication places PWA at risk of developing maladaptive behaviours such as learned non-use of language.⁷

Environmental Enrichment (EE) refers to conditions which promote physical, cognitive and social activity and has been shown in animal models of stroke to enhance neuroplasticity⁸, promote better learning and memory and contribute to significant improvements in motor function.⁹ The human equivalent model¹⁰ in a rehabilitation unit results in patients spending more time engaged in activity and less time sleeping and alone.¹¹

4. Objectives

Aphasia is a complex language impairment and PWA may need additional support within an Enriched Environment. This pilot study seeks to develop and test an adapted model of an Enriched Environment, a Communication Enhanced Environment (CEE), as a strategy to provide PWA and patients following stroke without aphasia (PWOA) more opportunities to engage in language activities during inpatient rehabilitation. Within this study language activities include both *solitary activities* that may promote aphasia recovery such as reading, writing, listening to the radio, and the use of iPad applications, and *interactive activities* which are based in communicative interactions that involve an exchange of information with a communication partner involving talking, gesture and/or facial expression, reading, writing or drawing to communicate.

4.1 Hypotheses

A CEE will increase patient solitary and interactive language activities and improve staff and patient experiences of communication compared to a standard ward environment.

5. Study design

This mixed methods pilot study is a prospective before-after non-randomised controlled design in an acute and a rehabilitation ward of a metropolitan private hospital. The study involves three phases:

- i) Baseline: observe and quantify the current ward environment;
- ii) Implementation of the CEE model;
- iii) Post-implementation: assess the impact of the CEE model.

6. Study Population

i) Patients: The baseline group (n=8, 4 PWA, 4 PWOA) recruited within the baseline phase, and the intervention group (n=8, 4 PWA, 4 PWOA) recruited during the post-implementation phase.

ii) Staff participants: One representative from each acute and rehabilitation staff group including medical, nursing, volunteers, and allied health staff members (n=17), who are over 18 years old.

6.1 inclusion and exclusion criteria

Patients will be eligible for inclusion if they have/are: admitted to the acute or rehabilitation ward for a stroke, less than 21 days post stroke during baseline phase or intervention phase, the ability to provide informed consent as determined by the medical team, a Glasgow Coma Scale¹ score greater than 10 at the time of screening, an estimated length of hospital stay greater than 14 days, adequate English proficiency to participate in semi-structured interviews and are above 18 years of age. Patients with aphasia will also have an Aphasia Quotient below 93.7 on the Western Aphasia Battery-Revised.²

Patients will be excluded if they have/are: uncorrected hearing or vision, not medically stable, a documented diagnosis of dementia, traumatic brain injury or previous aphasia, a documented current untreated depression at the time of acute admission or are a participant in another research trial which may affect any of this study's outcome measures.

Staff and volunteers who are over 18 years old will be eligible to participate in this study.

7. Study Assessments and Procedures

Baseline

All recruited patients will complete the Montreal Cognitive Assessment, ¹¹ and The NIH Stroke Scale. ¹² PWA will also complete the Western Aphasia Battery-Revised. ² Patients' behaviour will be observed and video recorded for four hours per day on a Sunday, Monday and Tuesday between 7am to 7pm. A behaviour mapping tool (Appendix A) developed for this study will record patient engagement in language activities in the first minute of each five-minute interval across each four-hour observation period. Semi-structured interviews will explore patients' perceptions of barriers and facilitators to inpatient language activities. An interview schedule will be used across all interviews (Appendix B.). Supportive communication strategies will be used to facilitate PWA participation in interviews with transcriptions annotated to capture any non-verbal responses.

Staff will participate in a one-hour focus group to explore their perceptions of barriers and facilitators to inpatient language activities. A focus group/interview schedule (Appendix C.) will be used across all focus groups.

Implementation

The CEE model will be implemented within the acute and rehabilitation wards.

Post implementation

Intervention group patient observations and interviews, and staff focus groups will replicate baseline data collection.

8. Study Treatment

The CEE model incorporates the following strategies to encourage engagement in language activities:

- Staff training to facilitate patients' communication and provide opportunities to engage in language activities;
- ii) Patient access to:

- a) Communication enhancement resources such as iPads and audiobooks;
- b) Communal areas to facilitate engagement amongst patients.

9. Participant Completion and Discontinuation

9.1 Participant Completion

Participants will have completed the study when they have completed the semi-structured interview.

9.2 Participant withdrawal

Participation in this study is voluntary. The participant can withdraw from taking part in the study at any time without giving a reason for withdrawing.

10. Data analysis

10.1 Primary Analysis

The proportion of observed episodes where PWA and PWOA are engaged in language activities at baseline and post implementation will be analysed using a mixed design ANOVA.

10.2 Secondary Analysis

The differences in staff and patient perceptions of the barriers and facilitators to inpatient language activities and communication post CEE implementation will be analysed through a qualitative description approach. Triangulation of the qualitative and quantitative data will be conducted.

11. Data management

The data collected will be confidential. No identifying information will be attached to the data and any information that may reveal participant's identity will be removed. The master list of participant names and codes will be kept in a locked filing cabinet at the hospital site which will only be accessible by the research team. All data will be accessed, used and stored in accordance with Commonwealth Privacy Laws. The de-identified data will be stored on a password-controlled computer and/or in a locked cabinet at Edith Cowan University. Electronic data will be backed up on a password controlled hard drive only accessible by the Chief Investigator.

The data collected from this study will have a significant contribution to the aphasia research area and therefore will be stored for 15 years following the completion of this study. Data may be accessed for future studies by the study investigators or higher degrees by research (HDR). In the case of HDR use of the data, the use of the data will be bound by a two-way confidentiality agreement. The data may be used for teaching purposes only with the additional written permission from participants. The data may be made accessible to consumer groups (for example the Australian Aphasia Association) and information may be made available through the National Stroke Foundation and scientific journals. Confidentiality will be maintained in all circumstances. Non-identifiable data will be accessible by researchers through data sharing archives. This data will be governed by an overarching body to ensure data are only used for approved purposes. Researchers who access this data from the data bank will not have access to the participant keys that attach participants to codes therefore data will only be re-identifiable by the Chief Investigator. Data will be deleted from electronic storage and hard copy data will be shredded by the chief

investigator after 15 years completion of the research study (with Ethics Committee approval, Ethics approval numbers: HPH431 and ECU HREC 12149). Non-identifiable data will be added to data archives for data sharing. Researchers who access data archives will not have access to information attaching participants to coded data.

12. Study Report

This study will be published in a PhD thesis as part of the Chief Investigator's Higher Research Degree. Outcomes from this study will be published in peer review journals and at conferences.

13. Administration Procedures

13.1 Ethical Considerations

This research is likely to have a significant impact on aphasia recovery following stroke and will form the basis for future study designs. This study will develop a teaching and learning package that can be used in the future to facilitate and promote increased levels of communication activity during early stroke recovery. The implementation of a CEE may address missed opportunities for language stimulation, harness increased levels of neuroplasticity and optimise aphasia language recovery after stroke. The benefit of a CEE may extend beyond patients with aphasia and may improve health care experience and communication access for all patients following stroke. Additionally, these benefits may extend beyond patients involved in the study as trained staff may use skills and knowledge obtained in the training program to enhance the communication environment of all patients they care for.

13.2 Ethical Review Committee

All processes and documentation used within this study will be reviewed and approved by the Edith Cowan University Research Ethics Committee and the site Ethics Committee. The Chief Investigator will complete the annual ethics reports and will be responsible for reporting any adverse events to the Ethics Committees.

13.3 Informed Consent

Participants will be excluded if they do not have adequate English proficiency to participate in semi-structured interviews and focus groups. Any participants that require an interpreter will be excluded from inclusion in this study as determined by the medical team.

Patients with aphasia will be provided with aphasia friendly information sheets and consent forms with simple language, bold key words and pictorial support. This will be read and explained by the researcher. Supported conversation strategies will be used to support and facilitate patients with aphasia's involvement and understanding of the research process, informed consent and their rights to withdraw at any time. This will be provided by the Chief Investigator who is a qualified speech pathologist with experience in communicating with patients with aphasia using supported conversation techniques to facilitate and support communication. A detailed information will also be provided to the 'person responsible' for all patients.

13.4 Protocol Amendments

All protocol amendments will be reviewed and accepted by the Edith Cowan University Research Ethics Committee and the site research Ethics Committee.

14. References

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- 5. Kruithof WJ, van Mierlo ML, Visser-Meily JM, van Heugten CM, Post MW. Associations between social support and stroke survivors' health-related quality of life a systematic review. Patient Educ Couns. 2013;93(2): 169–76.
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- 7. Nithianantharajah J, Hannan AJ. Enriched environments, experience dependent plasticity and disorders of the nervous system. Nat Rev Neuroscience. 2006;7(9): 697-709.
- 8. Janssen H, Bernhardt J, Collier JM, et al. An enriched environment improves sensorimotor function post–ischemic stroke. Neurorehab Neural Re, 2010;24(9), 802–813.
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- 10. Janssen H, Ada L, Bernhardt J, et al. An enriched environment increases activity in stroke patients undergoing rehabilitation in a mixed rehabilitation unit: A pilot non-randomized controlled trial. Disabil Rehabil. 2014;36(3), 255–262.
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| Гіте (5 min): | NO LANGUAGE ACTIVITIES OBSERVED (describe) | | | COMMENTS |
|--|--|--|---|----------|
| Location (select one) | People present | INTERACTIVE LANGUAGE ACTIVITIES | 'OTHER' FUNCTIONAL LANGUAGE ACTIVITIES | |
| Amenities | Nurse | In person | Typing/writing | |
| sedroom | Personal care assistant | Telephone | Reading (describe) | |
| Hall | Doctor | Therapy session/ward round | , , , , , , , , , , , , , , , , , , , | |
| herapy area | Physio | Other (describe) | Texting (mobile phone) | |
| amily Mtg Room | OT | Carlot (addende) | Listening to radio/music | |
| Activity room | SP | Patient | Watching TV | |
| totivity room | DT | Verbal communication | Internet use (describe) | |
| ON WARD | Social worker | Non-verbal gesture/facial expression (describe) | internet use (describe) | |
| Doctor's room | Family/Friend | Non-verbai gestare/raciai expression (describe) | Word games with a partner | |
| Dining room | Other patient | Written aids (writing or reading (circle)) | Other (describe) | |
| o . | • | | Other (describe) | |
| Communal area (describe) | Alone | Pictorial aids (describe) | | |
| OFF WARD | Other (describe) | Other communication aid (describe) | NON FUNCTIONAL / NON PROPOSITIONAL | |
| OFF WARD Outside | | Communication partner/s | NON-FUNCTIONAL/ NON-PROPOSITIONAL LANGUAGE ACTIVITIES | |
| Off-unit <i>(describe)</i> | | Verbal communication | | |
| on-unit (describe) | | Non-verbal gesture/facial expression (describe) | Singing Word games (alone) | |
| Other (december) | | Non-verbai gesture/raciai expression(describe) | , | |
| Other (describe) | | Main an aide | Language apps (alone) | |
| | | Written aids | Copying written letters, words, sentences (alone). | |
| | | Pictorial aids | OTHER | |
| | | Other communication aid (describe) | Talking to observer | |
| | | | Talking to self: appropriate/inappropriate (describe) | |
| | | | | |
| Гіте (5 min): | NO LANGUAGE ACTIVIT | TIES OBSERVED (describe) | 10. | COMMENTS |
| Location (select one) | People present | INTERACTIVE LANGUAGE ACTIVITIES | 'OTHER' FUNCTIONAL LANGUAGE ACTIVITIES | |
| Amenities | Nurse | In person | Typing/writing | |
| Bedroom | Personal care assistant | Telephone | Reading (describe) | |
| Hall | Doctor | Therapy session/ward round | | |
| herapy area | Physio | Other (describe) | Texting (mobile phone) | |
| amily Mtg Room | OT | . | Listening to radio/music | |
| Activity room | SP | Patient | Watching TV | |
| NI WADD | DT Conint worker | Verbal communication | Internet use (describe) | |
| ON WARD Ooctor's room | Social worker | Non-verbal gesture/facial expression (describe) | Word games with a partner | |
| Doctor's room Dining room | Family/Friend Other patient | Writton aids (writing or reading (sirele)) | Word games with a partner Other (describe) | |
| Dining room Communal area <i>(describe)</i> | Alone | Written aids (writing or reading (circle)) Pictorial aids (describe) | Other (describe) | |
| ommunai area (uescribe) | Other (describe) | Other communication aid (describe) | NON-FUNCTIONAL/ NON-PROPOSITIONAL | |
| OFF WARD | Cities (describe) | Other communication aid (describe) | LANGUAGE ACTIVITIES | |
| Outside | | Communication partner/s | Singing | |
| Off-unit <i>(describe)</i> | | Verbal communication | Word games (alone) | |
| u.m (4000/100) | | Non-verbal gesture/facial expression(describe) | Language apps (alone) | |
| Other (describe) | | (orbai gootaro/radiai expression(accombe) | Copying written letters, words, sentences (alone). | |
| (10000) | | Written aids | OTHER | |
| | | Pictorial aids | | |
| | | Other communication aid (describe) | Talking to observer | |
| | 1 | - 1 | Talking to self: appropriate/inappropriate (describe) | 1 |

Appendix B. Patient interview guide

Investigating Communication Enhanced Environments after stroke Patient Interview guide, version 1_11-8-15

Tell me about what kind of activities you do while you are here (in hospital).

Describe your experience of communicating with people on the ward.

What makes it easier to communicate with people on the ward?

What makes it hard to communicate with people on the ward?

What can we do to make communicating with people easier?



Appendix C. Staff focus group guide.

Investigating Communication Enhanced Environments after stroke Staff focus group guide, version 1_27-7-15

STAFF FOCUS GROUP GUIDE BASELINE PHASE

What kind of language activities or language tasks do stroke patients currently participate in on the ward?

What kind of language activities or language tasks would you like see stroke patients have access to on the wards?

Describe your experience of communicating with stroke patients at the moment.

Can you tell me about anything that facilitates your ability to communicate with stroke patients on the ward?

Can you tell me about any barriers you experience that impact your ability to communicate with stroke patients on

the ward?

What changes would you like to see to enhance communication between staff and stroke patients on the ward?

What changes would you like to see to enhance communication between visitors and stroke patients on the ward?

How could we enhance or optimise communication and language tasks and activities for stroke patients on the

ward?

What do you think a communication and language enhanced stroke ward environment might look like?

STAFF FOCUS GROUP GUIDE POST-IMPLEMENTATION PHASE

Describe your experience of communicating with stroke patients at the moment.

Can you tell me about any barriers you experience that impact your ability to communicate with stroke patients on

the ward?

Describe the differences in the communication environment since implementing the model.

What changes did you see to enhance communication between staff and stroke patients on the ward?

What changes did you see to enhance communication between visitors and stroke patients on the ward?

What was it like to use the model?

How do you feel about the model?

Can you tell me about anything that helped you use the model with stroke patients on the ward?

Can you tell me about any barriers you experienced while implementing the model?

How can we improve the model?

Communication Enhanced Environments after Stroke

Study procedure version 2_23-02-16

BASELINE:

Staff recruitment: The Chief Investigator will recruit staff participants through a verbal explanation of the study and the provision of the information sheets and written consent forms. Staff will be provided 48 hours to discuss the study and ask questions before consenting to participate. Staff interviews and focus groups will commence as staff participants are recruited. Staff will participate in a one-hour focus group or a one-hour semi-structured interview (in person or via telephone) to explore staff perceptions of environmental barriers and facilitators to language activity and communication on in-patient acute and rehabilitation wards.

Patient recruitment: All consecutively admitted patients following stroke during the baseline period will be screened for eligibility to participate in the study. The hospital site investigators will identify potential stroke participants that meet the inclusion and exclusion criteria. Stroke participants with aphasia will be identified by the hospital speech pathology or medical team as having a diagnosis of aphasia (aphasia diagnosis will be confirmed via Western Aphasia Battery-Revised (WAB-R)¹ Aphasia Quotient score <93.7 during data collection). The site investigators will approach potential participants and gain verbal consent from the patient to be approached by a member of the research team and have their 3-point identification released to the research team. This will be documented in the patient's integrated medical progress notes. Once verbal consent has been gained and documented, the site investigators will email the Chief Investigator the patient alert proforma identifying the patient as meeting the inclusion/exclusion criteria. The research team will liaise with the medical team to confirm the potential stroke participant meets the inclusion criteria: (i) admitted to the in-patient rehabilitation stroke unit for recent stroke, (ii) are less than 21 days post stroke and during baseline phase or intervention phase, (iii) have the ability to provide informed consent as determined by the medical team iv) Glasgow Coma Scale² greater than 10 at the time of screening, (v) have an estimated length of stay greater than 14 days and (vi) have adequate English proficiency to participate in semi-structured interviews. Patients will be excluded if they (i) have uncorrected hearing or vision (for example hearing impairment without hearing aids, vision impairment without glasses), (ii) are not medically stable, (iii) have a documented diagnosis of major depression or (iv) have a documented history of dementia or significant cognitive decline, traumatic brain injury or previous aphasia at the time of admission for the acute event, (v) or are a participant in a research study that will influence this study's outcomes. Stroke participant recruitment will follow the stroke participant consent procedure (see document: SD_Communication Enhanced Environments after Stroke consent procedure version 1_3-2-15). A record of identifying participant details attached to patient codes will be kept at the hospital site in a locked filing cabinet. An email summary of the baseline assessment results will be sent to the hospital speech pathology generic email address. The patient will be identified by patient code and ward/room number. The hospital speech pathology team will write a summary of the assessment results in the patient's integrated medical progress notes.

Patient data collection: All recruited stroke participants will complete the NIH Stroke Scale³ (by someone trained in using this tool) and the Montreal Cognitive Assessment (MoCA).⁴ Participants with aphasia will also complete an assessment of aphasia, the WAB-R¹ and provide a personal narrative language sample on their reason for admission to confirm a diagnosis of aphasia. After patient recruitment has been completed, the Chief Investigator and/or trained medical team members will recruit the patient's family, friends and significant others to consent to video recording and observations of their interactions with stroke participants.

Observations of stroke participants will commence 1-3 days after obtaining written consent. Patients' behaviour will be observed by the Chief Investigator or a Research Assistant, and video recorded for a total of 12 hours to enable behaviour mapping of video data (see document: Observation_protocol_SD_version 3_23-02-16). Patients will be observed and video recorded for 4 hours per day on weekend day and two consecutive weekdays between 7am to 7pm. The observation periods will be grouped into 4-hour observation intervals (e.g. 7am-11am, 11am-3pm and 3pm-7pm). Each day the patient will be observed and video recorded for one observation interval. The participant will be observed and video recorded during a different observation interval each day to gain a general insight into the patients' activities (see Figure 1. below). Patients who do not consent to video recording will be provided with the option of audio recording and manual observation conducted by the researcher to enable the collection of case notes regarding patient behaviour. An observational protocol developed for this study will be used to measure the frequency stroke participants engage in language activities. These will be categorised into solitary language activities for example reading, writing, listening to the radio, use of iPad applications, and interactive language activities defined as i) an interaction involving an exchange of information, ii) with a communication partner including gesture and/or facial expression, reading, writing or drawing for the purpose of communication and use of technology including talking on the telephone. The observational protocol will be based on the behavioural mapping techniques of Janssen et al.⁵ Patients' solitary and interactive language activities will be recorded in 5-minute intervals and activity observed within the first minute of the observation interval will be recorded on a checklist of the predetermined behaviours. Semi-structured supported conversation interviews for stroke participants will be conducted within 5 days of the last observation. The interviews will explore patients' perceptions of environmental barriers and facilitators to language activities and communication and their experience of communication on the acute and rehabilitation wards.

IMPLEMENTATION:

A model of a CEE will be implemented within the acute and rehabilitation wards. The model will be developed as part of the research project. We hypothesise that our model of CEE will include the provision of:

- i) CEE equipment, for example reading materials such as books and magazines, access to a computer with internet and access to a communal dining area,
- ii) CEE education, support and training for staff, patients and their family, friends and significant others with the aim to develop the ability to support and facilitate 'language activity' and 'communication activity' for patients after stroke. This will be accessible via multiple modalities including one-on-one training and group training sessions, as

well as through the provision of video and written resources. A questionnaire will be administered pre and post training in order to determine staffs' perceptions of changes in their knowledge, skills and attitude towards communication and aphasia. Additionally, feedback regarding the content and format of the training program will be obtained through questionnaires administered after the completion of the training program. Training and support provided in the implementation phase will be continued until the end of the intervention phase.

POST-IMPLEMENTATION:

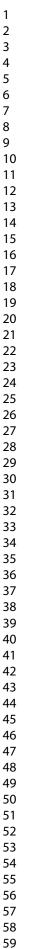
Staff participant semi-structured interviews and focus groups will be conducted. Staff will participate in a one-hour semi-structured interview or a one-hour focus group to explore staff perceptions of environmental barriers and facilitators to language activities and communication.

The procedures for participant recruitment and data collection during the post-implementation phase will replicate those used in the baseline phase.

There is no travel commitment for all participants as all data collection and training will be conducted at the hospital.

| Observation | Observation | Day 1: | Day 2: | Day 3: |
|----------------------|-----------------------------------|--------|--------|---------|
| interval | time | Sunday | Monday | Tuesday |
| | | | | |
| 1 | 7am-8am | PWA1 | PWA3 | PWA2 |
| | 8am-9am | PWOA1 | PWOA3 | PWOA2 |
| | 9am-10am | | | |
| | 10am-11am | | | |
| 2 | 11am-12pm | PWA2 | PWA1 | PWOA |
| | 12pm-1pm | PWOA2 | PWOA1 | PWOA3 |
| | 1pm-2pm | | | |
| | 2pm-3pm | | | |
| 3 | 3pm-4pm | PWA3 | PWA2 | PWA1 |
| | 4pm-5pm | PWOA3 | PWOA2 | PWOA1 |
| | 5pm-6pm | | | |
| | 6pm-7pm | | | |
| igure 1. CEE Observa | igure 1. CEE Observation schedule | | | |
| | | | | |
| | | | | |
| | | | | |

Figure 1. CEE Observation schedule



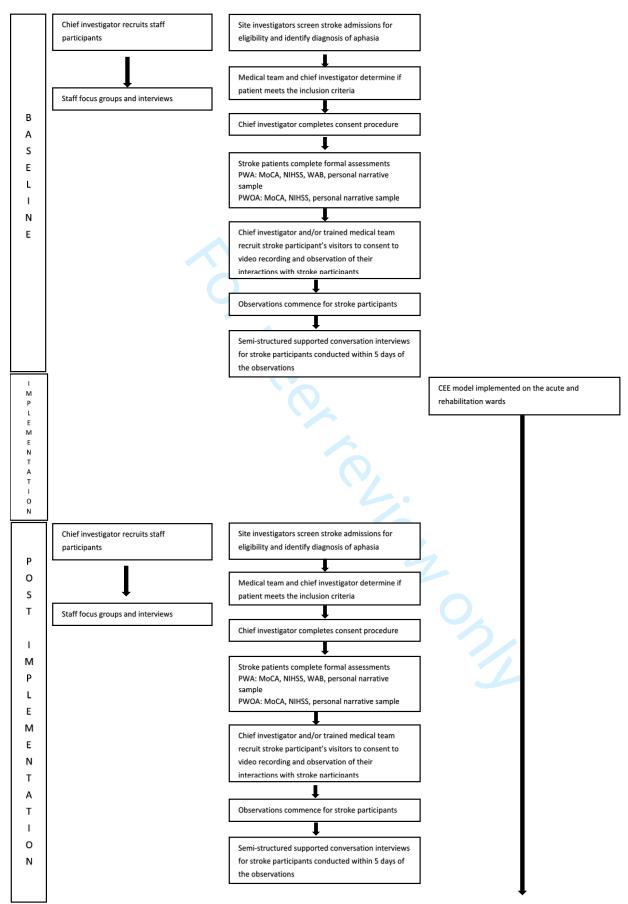


Figure 2. Study flow diagram

References

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- 2. Teasdale G, Jennett B. Assessment of coma and impaired consciousness. A practical scale. Lancet. 1974;2(7872): 81–4.
- 3. NIH stroke scale [Internet]. Bethesda, Md, National Institute of Neurological Disorders and Stroke (U.S.). 2011 [cited 2016 Feb 10]. Available from https://www.ninds.nih.gov/sites/default/files/NIH_Stroke_Scale.pdf
- 4. Nasreddine ZS, Phillips NA, Bédirian, V, et al. The Montreal Cognitive Assessment, MoCA: A brief screening tool for mild cognitive impairment. J Am Geriatr Soc. 2005;53(4); 695-9.
- 5. Janssen H, Ada L, Bernhardt J, et al. An enriched environment increases activity in stroke patients undergoing rehabilitation in a mixed rehabilitation unit: A pilot non-randomized controlled trial. Disabil Rehab, 2014; 36(3), 255–262. doi: 10.3109/09638288.2013.788218

Communication Enhanced Environments after Stroke consent procedure

Version 1_3-2-15

Stroke participants

The following consenting procedure will be used for all participants who are identified as potential research participants. Recruitment will only be completed by the Chief Investigator.

- 1. Check the stroke participant meets the inclusion criteria and exclusion criteria.
- 2. Read the participant information sheet to the participant. Use the pictures on the participant consent form to support the patient's comprehension of verbal information. Use gesture, written and pictorial support to facilitate verbal communication as required.
- 3. Provide the person responsible with the person responsible information sheet and consent form.
- 4. Provide time for the stroke patient and the person responsible to discuss the study and ask questions to their satisfaction.
- 5. Ask the stroke participant if they consent to the study using simple closed questions (e.g. "Do you understand what the study is about?", "Do you have any questions about the study?", "Do you want to be in the study?", "Will you sign the form?". Use multi-modal communication strategies and repeat information/questions as required. Use the pictures on the participant consent form to support patient comprehension of verbal information.
- 6. If the stroke patient agrees to participate in the study, ensure they sign the consent form witnessed by someone independent of the study.
- 7. Provide the stroke participant with a copy of the information sheet and consent form for their own records.
- 8. Add the participant study number to the consent form
- 9. Store the signed consent forms in a locked cabinet at the hospital site. This cabinet will only be accessible by the research investigators.

Investigating Communication Enhanced Environments after stroke Observation Protocol version 3_ 23-2-16

During the baseline and intervention period, patients' behaviour will be observed and video recorded for a total of 12 hours. Patients who do not consent to video recording will be provided with the option of audio recording and manual observation. This will enable the collection of relevant notes about factors that might influence the interactions that may not be captured in the video or behavioural mapping, for example the context of the interactions or details about the environment.

Patients will be manually observed <u>and</u> video recorded for four hours per day on two weekdays and one weekend day between 7am to 7pm. The observations will be grouped into three x 4-hour observation intervals (e.g. 7am-11am, 11am-3pm, 3pm-7pm). Each day the patient will be observed and video recorded for one of the 4-hour observation intervals. The 4- hour observation period will be split into 5-minute intervals. All language and communication activity observed within the first minute of the 5-minute interval will be recorded on the behavioural mapping sheet with predetermined behaviours (Appendix 1). The free smart phone app 'Impetus' can be used to time 1-minute observations. You can set the timer to vibrate briefly when the 1-minute observation interval begins and ends.

Observation times (see Figure 1.) will be randomly selected by drawing out of an envelope. This will be conducted by the primary investigator prior to commencing patient observations. It may not be possible to observe the patient during the planned observation time, for example as a result of scheduled testing or home visits. If this occurs, patients can be observed during the next available observation interval. Changing or modifying the observation schedule should be avoided where possible.

| Observation | Observation | Day 1: | Day 2: | Day 3: |
|-------------|-------------|---------|--------|---------|
| interval | time | Sunday | Monday | Tuesday |
| | | | | |
| 1 | 7am-8am | *PWA1 | PWA3 | PWA2 |
| | 8am-9am | **PWOA1 | PWOA3 | PWOA2 |
| | 9am-10am | | | |
| | 10am-11am | | | |
| 2 | 11am-12pm | PWA2 | PWA1 | PWA3 |
| | 12pm-1pm | PWOA2 | PWOA1 | PWOA3 |
| | 1pm-2pm | | | |
| | 2pm-3pm | | | |
| 3 | 3pm-4pm | PWA3 | PWA2 | PWA1 |
| | 4pm-5pm | PWOA3 | PWOA2 | PWOA1 |
| | 5pm-6pm | | | |
| | 6pm-7pm | | | |

Figure 1. Observation schedule *PWA: patient with aphasia

^{**}PWOA: patient without aphasia

DISCOURSE SAMPLE

You must collect a personal narrative discourse sample for each participant at the beginning of the first observation. Once you have set up the video camera and have started recording, ask the patient "what has brought you into hospital?". Once the patient has finished telling you their personal narrative, tell the patient you will now start the observations.

VIDEO RECORDING SET-UP

Place the video camera facing the patient approximately 1-2 metres away from them. Ensure the camera is placed in an area where it is unlikely to be moved for the duration of the observation time (for example at the end of the patient's bed). Ensure the camera frame is capturing the patient as well as their surroundings (e.g. potential communication partners, visitors, etc). If the patient relocates, reposition the camera to ensure the patient and their surroundings remain in frame. Observe and manually record the patient's behaviour and their environment according to the procedure for behavioural mapping.

Do not record the patient in the bathroom or shower or during any other inappropriate circumstances (this may include sensitive conversations, culturally sensitive situations or if the patient requests). If the patient indicates that they don't want to be recorded or becomes agitated, upset or distressed, use the 'withdrawal from observations visual resource' (if appropriate) and ask the patient:

- 1. Do they want you to stop video recording?
- Do they want to be manually observed and audio recorded instead?If the patient responds 'no', ask the patient-
- 3. Can you come back another time to observe them?

If the patient asks you to stop recording you must cease recording immediately. The patient may allow you to continue with manual observations or come back another time to complete the observations. If the patient allows you to complete manual observations and audio recording, follow the audio-recording set-up and protocol below.

AUDIO RECORDING SET-UP AND PROTOCOL

This protocol is to be followed if the patient or their family indicate they do not want to be video recorded however agree to audio recording and manual observations. Place the cap on the video camera and continue recording in order to capture audio. If using a battery-operated audio recorder, place it on a table close to the patient (within 1 metre). Ensure the audio recorder is placed in a location where it will not be touched or moved throughout the

observation time. Observe and manually record the patient's behaviour and their environment according to the procedure for behavioural mapping. Ensure spare batteries for the audio recorder are available if required.

COMMUNICATION PARTNERS AND VISITORS

Take note of all communication partners and visitors who have provided consent to video recording and/or observations of their patient interactions. If someone enters the room during recording politely interrupt the interaction, introduce yourself and inform the person that the patient is being video recorder recorded as a part of the study the patient has agreed to participate in. Ask the visitor if they would like to go out of the room with the researcher to find out about the study and the video recording. Provide a verbal explanation of the study and provide the 'Visitors/communication partners' information and consent form'. Offer the visitor the option of no video or manual recoding during their interaction with the patient. If the person chooses not to participate in manual or video observations inform the person that any incidental recordings of them will be deleted and will not be included in the study. The researcher will step out of the room for the duration of their visit.

PROCEDURE FOR BEHAVIOURAL MAPPING

- Position self where the patient can be clearly observed
- Remain inconspicuous as possible
- Circle ALL appropriate components on the observation schedule in regards to location, activity, people
 present and details of language and communication observed within the first minute of each five-minute
 interval.
- You can circle more than one key per section if required (except for location).
- If you require a toilet break, leave the camera recording while you take a break. If you miss a 1-minute
 observation, place a line through the observation interval on the behavioural mapping sheet and write
 'unobserved-toilet break'.

TIME

Write the time at the beginning of the 1-minute observation interval

LOCATION

- Circle only one location
- If the patient is moving between two locations, circle the location the patient is moving towards

AMENITIES: Toilet, shower.

BEDROOM: Around the patient's room or bed. If the patient is outside of their doorway this is considered 'hall'.

HALL: Any hallway within the hospital ward.

THERAPY AREA: In an allied health therapy session, including occupational therapy, physiotherapy, speech pathology, nursing.

FAMILY MEETING ROOM: Family meeting room.

DOCTOR'S ROOM: Doctor's office.

DINING ROOM: Dining room during meal times or any other time.

COMMUNAL AREA: Communal dining area.

OUTSIDE: Outside areas including the garden, car park.

OFF UNIT: Off-site locations, home visits, testing off site.

OTHER: Anything that doesn't fit into the above categories-provide description of location.

PEOPLE PRESENT

People present include any person that is near the patient and is able to have an interaction with the patient. If you do not know how to classify the person make a note to check with staff at a later time and complete the observation schedule.

Exceptions: People who are near the patient but are unable to interact with the patient, e.g. cognitive or behavioural issues, barriers between person and the patient preventing them from interacting- e.g. curtain drawn, people in the way. If an interaction is occurring despite objects in the way, the communication partner is considered as a 'person present'.

PEOPLE PRESENT: Nurse, nurse assistant, doctor, physio (physiotherapist), OT (occupational therapist), SP (speech pathologist), DT (dietician), SW (social worker), family/friend, other patient, alone (no-one present that is conducive to interactions), other (describe).

ACTIVITIES

UNOBSERVED: If you are unable to observe the patient. Place a line through the observation

interval and write unobserved.

NO LANGUAGE ACTIVITY: If the patient is observed not engaged in any communication activity.

- Circle 'no activity' on the checklist
- Write what the patient is doing, e.g. 'sleeping'

INTERACTIVE LANGUAGE ACTIVITIES: Defined as an interaction involving an immediate communicative exchange with a communication partner. Interactive language activities may include talking, gesture and/or facial expression, reading, writing or drawing for the purpose of communication, use of communication aids or AAC devices and use of technology including talking on the telephone. Non-verbal gesture or facial expression includes eye contact to

initiate interactions, hand gestures (e.g. waving, thumbs up), body movements for the purpose of conveying a communicative message (e.g. shrugging) and/or facial expressions for the purpose of communication.

Communication aids or AAC devices includes any use of alternative and augmentative devices for the purpose of communication, e.g. high-tech or low-tech AAC devices such as letter boards, pictures/photos, whiteboard, writing or drawing, smart phones, iPad. Please describe communication aids observed.

OTHER FUNCTIONAL COMMUNICATION ACTIVITIES: All other communication activities that do not involve a direct immediate communicative exchange with a communication partner. Functional communication activity may include reading, typing/writing, emailing, internet use, watching TV, listening to talking on the radio. Note the patient must be looking directly at the TV to be considered 'watching TV'. If the TV is on in the background, do not include this as 'watching TV'.

NON-FUNCTIONAL/NON-PROPOSITIONAL LANGUAGE ACTIVITIES: Singing, word games (carried out alone), language apps (used alone), copying written letters, words or sentences (carried out alone).

OTHER: Communication or language activities that do not fit the criteria of interactive language activity, 'other' functional communication activities, non-functional/non-propositional language activities or may be a confounding variable (for example, talking to self and talking to the observer). If a patient is talking to themself, note if this is appropriate (for example, saying 'excuse me' after burping) or inappropriate (for example, an extensive monologue) and describe the context. If the patient's verbal output is inaudible, write this is in the space underneath 'talking to self'.

Note: If the patient is using a computer, phone, smart device, or iPad where the activity they are engaged in (e.g. texting, emailing, playing a game, etc) cannot be accurately determined, note this in the comments section. After the 1-minute observation interval has been completed ask the patient if they mind sharing if what activity they were completing on their device and record this in the relevant section. If the patient does not wish to share this information with you, record this in the 'other' section.

COMMENTS

Describe the context of the interactions or details about the environment in the comments section. This will provide information regarding factors that may influence the interactions, for example 'background noise'. Additionally, write down any information that may be missed in the video data, for example, people out of the camera frame, interactions that may be overheard in the room that might impact on the current interactions.

Draw a line under the final comment after the one-minute observation had been completed. Write any additional observations within the final 4 minutes below this line (see example).

If you have any queries or questions regarding this observation protocol or the observation protocol please contact chief investigator Sarah D'Souza.

Stroke participant information and consent form Communication activity in hospital

This research project is being undertaken as **part of** the **requirements** of a **PhD at Edith Cowan University**.

Researchers' contact details

| Edith Cowan University | | | |
|---|---------------------|------------------|--|
| Chief Investigator/ | Sarah D'Souza | Ph: 0439 982 451 | |
| PhD student | | | |
| Principal Supervisor | Professor Beth | Ph: 08 6304 2769 | |
| | Armstrong | | |
| Co-Supervisor | Associate Professor | Ph: 08 6304 2047 | |
| | Natalie Ciccone | | |
| Co-Supervisor | Associate Professor | Ph: 08 6304 5901 | |
| | Erin Godecke | | |
| Co-Supervisor | Associate Professor | Ph: 08 6304 2563 | |
| | Deborah Hersh | | |
| Hunter Stroke Service, University of Newcastle and Hunter | | | |
| Medical Research Institute | | | |
| Adjunct Supervisor | Dr Heidi Janssen | Ph: 02 40420417 | |

You are **invited** to participate in a research project. Sarah D'Souza, a speech pathologist and PhD student is leading the study as Chief Investigator. This study has received ethical **approval** from **ECU** Human Research **Ethics Committee** and the Hollywood Private Hospital Research Ethics Committee.

This project is investigating the **hospital environment** to see how this **influences** patient **communication activity**. Communication activity involves communication, such as **talking** with other patients, **socialising**, **reading** the paper, using the **telephone**, talking to staff, or engaging in group activities including **therapy**.

You have been selected to participate as you have had a stroke and are receiving treatment at Hollywood Private Hospital. We are interested in seeing how the hospital surroundings affect what you do throughout the day.

What would you have to do?

You will be **asked** to provide **consent** to **agree to participate** in the study.

You will be asked to consent to:

Complete three tests to see how your stroke has affected you
including your language, concentration and memory. These tests
will be conducted at the beginning of the project. The tests will take
approximately 1 hour to complete with an option to complete the tests

over **two separate 30 minute sessions** and with as many **breaks** as you may need.

- A researcher spending approximately 1 hour discussing with you
 your opinion regarding how your rehabilitation surroundings affect
 your stay in hospital and your communication activity levels.
- A researcher video recording, observing and writing down what is happening in your environment including your activities. You will be observed and recorded for a total of 12 hours over 3 days.

You may **not want** to be **video recorded**. If you **request**, you will **not** be **video recorded**. You can ask not to be video recorded at **any time**. In this case the researcher will **only observe**, **audio record** and **write down** what is **happening in your** environment **including** your activities.

- A researcher looking at your hospital medical file to collect information regarding:
 - Your details (such as your age, your living arrangements, your occupation and your level of functioning before your stroke)
 - Any conditions or diseases you may have
 - Information about your stroke (for example when it happened, the area of the brain affected, how it has affected your functioning and abilities)
 - Details about how long you have been in hospital since your stroke

If you decide to participate in this study, you will not miss out on any treatment. Participation will not cost you anything and after completing the tests and the interview you will be asked to continue participating in your normal activities.

We will **not record** if you are **behind closed curtains** or completing sensitive tasks such as when you are in the **toilet** or **shower**.

We may use the **recordings** of **you** to make a **training package** (including a video). You can have **your face blurred out** if you want. If you **do not want** to be in the training package we will **not include you** in the training package or video.

Your hospital **discharge** will **not be affected** because you are in this study. **You** will be **discharged** from hospital when the hospital **medical team decides** that you are **ready**.

There are **no known risks** of participating in this study. If you feel uncomfortable at any time, you are free to **tell the researcher** and **observations** within your room will **stop immediately**. You may become **upset** during the **tests** or the **interview**. If this happens you can **ask** to take a **break or stop** the interview.

There will be **no immediate benefit** to you from participating in this research; however your participation will allow the collection of

information that may **help improve** stroke **hospital wards** which may **benefit** future stroke survivors.

Participating in this study is completely voluntary. You do not have to participate if you don't want to. If you decide to participate you may withdraw at any time without giving a reason and withdrawing will not disadvantage you in any way and will not affect your hospital treatment. If you decide that you do not want to participate in the study, you can ask to remove all of your information from the study.

All the **information** you give will be **confidential**. You will **not be identified** by name. You will be **assigned** a unique **code** and any information that may reveal your **identity** will be **removed**.

All personal health information will be accessed, used and stored in accordance with Commonwealth Privacy Laws. **Information** from all the people in the study is **combined** and **summarised**.

We will store all your electronic information on a password locked computer and password locked hard drive only accessible by the Chief Investigator. Your hard copy information will be kept in a locked cabinet at Edith Cowan University. You information will only be accessible to researchers named on this study.

The **results** of this study may be **published** in research **journals** or presented at **conferences**. Your **name** will **not** be **used**.

Data may be **used** in higher degree by **research studies** in the **future**. **Confidentiality** will be **maintained** and no identifying information will be used.

Data will be **accessible by researchers** through data sharing archives. This data will be governed by an overarching body to ensure data is **only used for approved research** purposes. Researchers who access this data from the data bank will not have access to participant information and therefore **will not know your identity**.

Read this information and be sure you **understand** its content **before** you **agree** to participate in this study.

If you would like to participate in this study, please sign the form below and return it to a staff member or a member of the research team.

Questions or further information?

You may wish to discuss this information with your doctor, a relative or friend before agreeing to take part in this study.

If you are interested in participating, please tell the researchers. If you have any questions or require any further information about the research project, please contact: Sarah D'Souza [Ph: 0439 982 451].

Thank you for considering the invitation to take part in this research project.

Yours sincerely,

Sarah D'Souza

If you have any **concerns or complaints** about the research project and wish to **talk to an independent person**, you may contact:

Kim Gifkins

Senior Research Ethics Advisor

Edith Cowan University

270 Joondalup Drive

JOONDALUP WA 6027

Phone: **(08) 6304 2170**

Email: research.ethics@ecu.edu.au

This project has been approved by the ECU Human Research Ethics Committee and the Hollywood Private Hospital Research Ethics Committee.

You have been asked to participate in a research study.

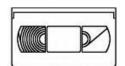






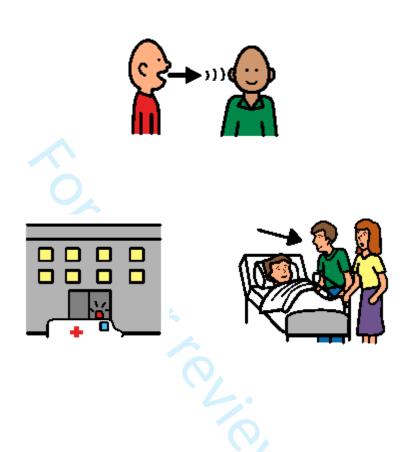
A researcher will record you with a tape recorder or a video camera, watch and write down what is happening in your environment including your activities.







A researcher will discuss with you your opinion regarding how your hospital surroundings affect your stay in hospital and your communication activity levels.



Your name and personal details will be kept private.







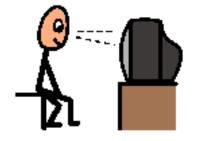




You can say no at any time.



We may use the **recordings** of **you** to make a **training package** (including a video).





You can have your face blurred out if you want.





If you **do not want** to be in the training package we will **not include you** in the training package or video.



I agree to take part in the above research project and give my consent freely.





I have been given a copy of the Information Statement and I understand that the project will be carried out as explained.



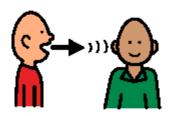


I understand and agree to:

 Complete three tests to assess how the stroke has affected me, my language, concentration and memory, at the beginning of the project.



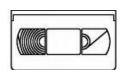
 A researcher spending approximately 1 hour discussing with me my opinion regarding how my hospital environment affects my stay in hospital and what I do.





 A researcher video recording, observing and writing down what is happening in my environment including my activities.





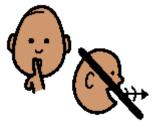


 A researcher looking at my hospital medical file to collect information for the study.



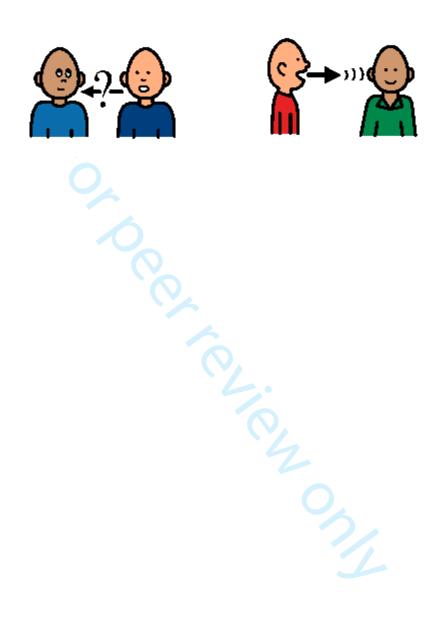


I understand that my identity, personal information and data will remain confidential.





I have had the **opportunity** to **ask questions** about the study and am **satisfied** with the **responses** that have been provided.



Witness

| Would you like | to be involved? | Yes | No |
|--|-------------------|-----|----|
| I agree to the reto make a train (including a vice | | Yes | No |
| I would like my | face blurred out. | Yes | No |
| Your Signature | | | |
| ; | Signature: | | |
| | Print name: | 2 | |
| | Date: | | |

Signature: _____

Print name: _____

Date: _____

Person responsible information sheet Stroke patients' communication activity in hospital

This research project is being undertaken as part of the requirements of a PhD at Edith Cowan University.

Researchers' contact details

| Edith Cowan University | | | |
|--|-----------------------------|------------------|--|
| Chief Investigator/ | Sarah D'Souza | Ph: 0439 982 451 | |
| PhD student | | | |
| Principal Supervisor | Professor Beth Armstrong | Ph: 08 6304 2769 | |
| Co-Supervisor | Associate Professor Natalie | Ph: 08 6304 2047 | |
| | Ciccone | | |
| Co-Supervisor | Associate Professor Erin | Ph: 08 6304 5901 | |
| | Godecke | | |
| Co-Supervisor | Associate Professor Deborah | Ph: 08 6304 2563 | |
| | Hersh | | |
| Hunter Stroke Service, University of Newcastle and Hunter Medical Research Institute | | | |
| Adjunct Supervisor | Dr Heidi Janssen | Ph: 02 40420417 | |

The participant is invited to take part in a research project. Sarah D'Souza, a Speech Pathologist and PhD student, is leading the study as Chief Investigator. This study has received ethical approval from ECU Human Research Ethics Committee and Hollywood Private Hospital Research Ethics Committee.

This project is investigating the hospital environment to see how this influences patient activity.

The participant has been selected to take part in this study as they have had a stroke and are receiving treatment at Hollywood Private Hospital. We are interested in

seeing how the hospital surroundings affect their communication activity throughout the day. Communication activity involves communication, such as talking with other patients, socialising, reading the paper, using the telephone, talking to staff, or engaging group activities including therapy.

This information sheet will explain the research project and will detail what is involved in the study. You will be given a copy of this information to keep for your reference.

Please read through all of the information carefully. You can ask the researcher questions about the study at any time.

Purpose of the research

Little is known about the impact of the hospital rehabilitation environment on patient communication activity levels during stroke recovery. This study will investigate how the hospital stroke ward environment influences patient communication activity levels. The information gathered from this study will assist in improving the Hollywood Private Hospital stroke ward environment to help the recovery of stroke survivors in the future.

What does the stroke patient have to do?

- Complete three tests and a recording of them talking to see how their stroke has affected their functioning including their language, concentration and memory. These tests will be conducted at the beginning of the project. The tests will take approximately 1 hour to complete with an option to complete the tests over two separate 30 minute sessions and with as many breaks as the participant needs.
- Spend approximately 1 hour discussing with the researcher their opinion regarding how their rehabilitation surroundings affect their stay in hospital and activity levels.
- Allow the researcher to video record, observe and write down what is happening in the
 participant's environment including their activities for a total of 12 hours over a 3 day
 period. Video recording is a useful way of capturing the details of everyday activities on

the ward. Often, people forget that the camera is there. Obviously, personal or private activity such as toileting would not be filmed. The participant may not want to be video recorded. If they request, they will not be video recorded. In this case the researcher will only observe, audio record and write down what is happening in their environment including their activities.

- A researcher will look at the participant's hospital medical file to collect information regarding:
 - The participant's details (such as their age, living arrangements, occupation and level of functioning before stroke)
 - Any relevant conditions or diseases the participant may have
 - Information about the participant's stroke (for example when it happened, the area of the brain affected, how it has affected their functioning and abilities)
 - Details about how long the participant has been in hospital since their stroke

The participant will not miss out on any treatment. Participation will not cost anything. After completing the tests and the interview the participant will be asked to continue their normal activities.

The participant's hospital discharge will not be affected because they are in this study. The participant will be discharged from hospital when the hospital medical team decides that they are ready.

There are no known risks of participating in this study. If the participant feels uncomfortable at any time, you or the participant are free to tell the researcher and observations within their room will stop immediately. The participant may become upset during the tests or the interview. If this happens you or the participant can ask to take a break or stop the interview.

There will be no immediate benefit to you or the participant from taking part in this research; however their participation will allow the collection of information that may help improve stroke hospital wards which may benefit future stroke survivors.

Participating in this study is completely voluntary. The participant can withdraw from taking part in the study at any time without giving a reason for withdrawing.

The participant can request access to their research data at any time. They can request any of the information collected to be amended or removed if it is incorrect or they disagree with it. Please contact Sarah D'Souza (phone: 0439 982 451) if you would like to discuss accessing the participant's information.

The video, audio and written data will be identified by code. The information you provide will remain completely confidential. There will be no identifying information attached to the data and any information that may reveal the participant's identity will be removed. A list of participant names and codes will be kept in a locked filing cabinet at Hollywood Private Hospital and will only be accessible by the research team. All personal health information will be accessed, used and stored in accordance with Commonwealth Privacy Laws. The data will be stored on a password controlled computer or in a locked cabinet at Edith Cowan University. Electronic data will be backed-up on a password controlled hard drive only accessible by the Chief Investigator. Data will be stored for a maximum of 15 years after completion of the study. Video and audio recordings will then be permanently deleted and hard copy data will be shredded.

Non-identifiable data will be accessible by researchers through data sharing archives. This data will be governed by an overarching body to ensure data is only used for approved research purposes. Researchers who access this data from the data bank will not have access to participant information therefore data will not be re-identifiable.

The results of this study may be published in research journals or presented at conferences. The results will not include any information that may identify participants. Data may be used in higher degree by research studies in the future. In this circumstance, confidentiality will be maintained and no identifying information will be used.

Data collected from this study (including videos) may be used to develop training packages to improve future stroke survivors' communication activity levels in the future. We can blur out

the participant's face if they want. If they do not want to be in the training package we will not include them in the training package.

At the end of the research project a summary of the results will be provided to you and the participant.

If you have any questions or require any further information about the research project, please contact: Sarah D'Souza [Ph: 0439 982 451].

Yours sincerely,

Sarah D'Souza

If you have any concerns or complaints about the research project and wish to talk to an independent person, you may contact:

Kim Gifkins

Senior Research Ethics Advisor

Edith Cowan University

270 Joondalup Drive

JOONDALUP WA 6027

Phone: (08) 6304 2170

Email: research.ethics@ecu.edu.au

This project has been approved by the ECU Human Research Ethics Committee and the Hollywood Private Hospital Research Ethics Committee.

Visitors and communication partners information and consent form Investigating Enhanced Environments after stroke

This research project is being undertaken as part of the requirements of a PhD at Edith Cowan University.

Researchers' contact details

| Edith Cowan University | | | | |
|--|-------------------------------------|------------------|--|--|
| Chief Investigator/ | Sarah D'Souza | Ph: 0439 982 451 | | |
| PhD student | | | | |
| Principal Supervisor | Professor Beth Armstrong | Ph: 08 6304 2769 | | |
| Co-Supervisor | Associate Professor Natalie Ciccone | Ph: 08 6304 2047 | | |
| Co-Supervisor | Associate Professor Erin Godecke | Ph: 08 6304 5901 | | |
| Co-Supervisor | Associate Professor Deborah Hersh | Ph: 08 6304 2563 | | |
| Hunter Stroke Service, University of Newcastle and Hunter Medical Research Institute | | | | |
| Adjunct Supervisor | Dr Heidi Janssen | Ph: 02 40420417 | | |

Description of the research project

This study is exploring stroke patient's experiences in regards to the environment of an in-patient stroke rehabilitation unit. We want to explore stroke patient communication activity, which includes activities such as talking with other patients and visitors, socialising, reading the paper, using the telephone, talking to staff, or engaging group activities including therapy.

The participant has agreed to take part in this study. They have agreed to be video recorded for a total of 12 hours over a three day period.

Your interactions with the patient will be video recorded and manually recorded by the chief investigator to explore patient communication activity levels. You can choose to be observed by the researcher only if you do not want to be video recorded. You do not need to do anything other than complete your usual tasks and activities. We will not record if you are having sensitive conversations with the participant, if they are behind closed curtains or completing sensitive tasks such as toileting or showering.

We may use the recordings of you to make a training package (including a video). You can have your face blurred if you want. If you do not want to be in the training package we will not include you in the training package.

There will be no cost to you associated with the investigation. Participation is completely voluntary. You do not have to participate if you don't want to. If you decide to participate you may withdraw at any time without giving a reason and withdrawing will not disadvantage you or the participant in any way.

You may also benefit from the knowledge that you are helping future stroke survivors. It is possible that you may not benefit from participating in this study. There are no known risks associated with participating in this study.

Confidentiality of information

The video, audio and written data will be identified by code. There will be no identifying information attached to the data and any information that may reveal your identity will be removed. A list of participant names and codes will be kept in a locked filing cabinet at Hollywood Private Hospital and will only be accessible by the research team. All data will be accessed, used and stored in accordance with Commonwealth Privacy Laws. The data will be stored on a password controlled computer or in a locked cabinet at Edith Cowan University. Electronic data will be backed-up on password controlled hard drive only accessible by the Chief Investigator. Data will be stored for a maximum of 15 years after completion of the study. Video and audio recordings will then be permanently deleted and hard copy data will be shredded.

Non-identifiable data will be accessible by researchers through data sharing archives. This data will be governed by an overarching body to ensure data is only used for approved research purposes. Researchers who access this data from the data bank will not have access to participant information therefore data will not be re-identifiable.

The results of this study may be published in research journals or presented at conferences. The results will not include any information that may identify participants. Data may be used in higher degree by research studies in the future. In this circumstance, confidentiality will be maintained and no identifying information will be used.

Please read this Information Statement and be sure you understand its content before you consent to take part.

If you would like to take part, please complete the consent form and return it to Sarah D'Souza or a member of the research team.

Questions or further information?

If you have any questions or require any further information about the research project, please contact: Sarah D'Souza [Ph: 0439 982 451]

Thank you for considering the invitation to take part in this research project.

Yours sincerely,

Sarah D'Souza

If you have any concerns or complaints about the research project and wish to talk to an independent person, you may contact: Kim Gifkins

Research Ethics Officer

Edith Cowan University

270 Joondalup Drive

JOONDALUP WA 6027

Phone: (08) 6304 2170

Email: research.ethics@ecu.edu.au

This project has been approved by the ECU Human Research Ethics Committee and the Hollywood Private Hospital Research Ethics Committee.

| | | 22 0.00 |
|----------------|-------------|---|
| I | | (print name), give my consent freely and |
| agree to | o participa | te in observations of my interactions with the participant. |
| Yes | No | (please circle) |
| I agree | to the rese | earcher video recording my interactions with the participant |
| Yes | No | (please circle) |
| I agree | to be inclu | ided in a training package (including a video). |
| Yes | No | (please circle) |
| If I am i | ncluded in | the video training package I would like my face blurred out. |
| Yes | No | (please circle) |
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| I unders | stand I car | n withdraw from the project at any time and do not have to give a reason for withdrawing. |
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Staff information and consent form Investigating Enriched Environments after stroke

This research project is being undertaken as part of the requirements of a PhD at Edith Cowan University.

Researchers' contact details

| Edith Cowan University | | | |
|--|-------------------------------------|------------------|--|
| Chief Investigator/ | Sarah D'Souza | Ph: 0439 982 451 | |
| PhD student | | | |
| Principal Supervisor | Professor Beth Armstrong | Ph: 08 6304 2769 | |
| Co-Supervisor | Associate Professor Natalie Ciccone | Ph: 08 6304 2047 | |
| Co-Supervisor | Associate Professor Erin Godecke | Ph: 08 6304 5901 | |
| Co-Supervisor | Associate Professor Deborah Hersh | Ph: 08 6304 2563 | |
| Hunter Stroke Service, University of Newcastle and Hunter Medical Research Institute | | | |
| Adjunct Supervisor | Dr Heidi Janssen | Ph: 02 40420417 | |

Description of the research project

This study is exploring staff and stroke patient's experiences in regards to the environment of the Edwards and Woods wards at Hollywood Private Hospital. We want to explore stroke patient communication activity, which includes activities such as talking with other patients, socialising, reading the paper, using the telephone, talking to staff, or engaging group activities including therapy. We would like to explore staffs' perceptions of barriers and facilitators to communication activity on the wards and address these in order to enhance the ward environment.

Staff have been selected to participate in order to gain a range of perspectives in regards to the day to day operations, procedures, policies and interactions that influence the environment of the Edwards and Woods wards. A training program for staff will be designed to address barriers and facilitators identified on the wards.

There are two components of this research study that involve staff. You may wish to consent to participate in one or both parts of this study.

<u>Part 1:</u> Stroke in-patients will be video recorded for a total of 12 hours over a three day period. Your interactions with the patient will be video recorded and manually recorded by a member of the research team to explore patient communication activity levels. You can choose to be observed by the researcher only if you do not want to be video recorded. You do not need to do anything other than complete your usual daily tasks and activities. We will not record if you are behind closed curtains or completing sensitive tasks such as toileting or showering the patient.

We may want use the recordings of you to make a training package (including a video). We will show you the video we want to use and explain exactly how this will be used before we do anything. You can have your face blurred out if you want. If you don't want to be included in the training package we will not include any videos of you in the training package.

<u>Part 2:</u> You will be asked to take part in the following:

edited or have your comments erased.

- A focus group with the researcher and your co-workers for approximately 1 hour to explore your perceptions of environmental barriers and facilitators to activity.
- Attend a training program for approximately 1.5 hours. This will focus on training staff to promote
 patient communication on the ward. This session will be located at Hollywood Private Hospital and
 will be offered over several dates to facilitate your ability to attend. If you are unable to attend the
 training program we may provide training and video resources to facilitate your participation in
 training.
- Complete an anonymous short questionnaire before and after attending the training program to gain feedback on training and explore your perception of changes in your knowledge, skills and attitudes towards communication and aphasia.
- A final focus group with the researcher for approximately 1 hour to again explore your perceptions
 of environmental barriers and facilitators to activity.
 The focus groups will be tape recorded however at any stage you may ask for the tape to stopped,

There will be no cost to you associated with the investigation. Participation is completely voluntary. You do not have to participate if you don't want to. If you decide to participate you may withdraw at any time without giving a reason and withdrawing will not disadvantage you in any way.

You may benefit from gaining knowledge and skills regarding communication from attending the training program. Additionally, you may also benefit from the knowledge that you are helping future stroke

survivors. It is possible that you may not benefit from participating in this study. There are no known risks associated with participating in this study.

Confidentiality of information

The information you provide during the interviews will be audio recorded by the Chief Investigator. Your perspectives and opinions will be analysed and grouped into common 'themes' and 'stories'. This will be used to inform the development and review of the training program.

The video, audio and written data will be identified by code. The information you provide will remain completely confidential. There will be no identifying information attached to the data and any information that may reveal your identity will be removed. A list of participant names and codes will be kept in a locked filing cabinet at Hollywood Private Hospital and will only be accessible by the research team. All data will be accessed, used and stored in accordance with Commonwealth Privacy Laws. The data will be stored on a password controlled computer or in a locked cabinet at Edith Cowan University. Electronic data will be backed-up on a password controlled hard drive only accessible by the Chief Investigator. Data will be stored for a maximum of 15 years after completion of the study. Video and audio recordings will then be permanently deleted and hard copy data will be shredded.

Non-identifiable data will be accessible by researchers through data sharing archives. This data will be governed by an overarching body to ensure data is only used for approved research purposes. Researchers who access this data from the data bank will not have access to participant information therefore data will not be re-identifiable.

The results of this study may be published in research journals or presented at conferences. The results will not include any information that may identify participants. Data may be used in higher degree by research studies in the future. In this circumstance, confidentiality will be maintained and no identifying information will be used.

A summary of the results will be provided through Hollywood Private Hospital 18 months after the completion of the study.

Please read this Information Statement and be sure you understand its content before you consent to take part.

If you would like to take part, please complete the consent form and return it to Sarah D'Souza, Claire Tucak or a member of the research team.

Questions or further information?

You may wish to consult with your manager before agreeing to take part in this study.

If you have any questions or require any further information about the research project, please contact:

Sarah D'Souza [Ph: 0439 982 451]

Thank you for considering the invitation to take part in this research project.

Yours sincerely,

Sarah D'Souza

If you have any concerns or complaints about the research project and wish to talk to an independent person, you may contact: Kim Gifkins

Research Ethics Officer

Edith Cowan University

270 Joondalup Drive

JOONDALUP WA 6027

Phone: (08) 6304 2170

Email: research.ethics@ecu.edu.au

This project has been approved by the ECU Human Research Ethics Committee and the Hollywood Private Hospital Research Ethics Committee.

| I | | (print name), give my consent freely and |
|---------------------------|-------------------|---|
| agree to partici | pate in (please | |
| Part 1: | | |
| Yes | No | Observations of your |
| | | interactions with stroke patients. |
| Yes | No | Video recording of your |
| | | interactions with stroke patients. |
| <u>Part 2:</u> | | |
| Yes | No | Complete two focus groups with the researcher, complete two short questionnaires and attend a training program. |
| I understand th retained. | e project will be | conducted as stated in the information letter, a copy of which I have |
| I understand I | can withdraw fro | om the project at any time and do not have to give a reason for withdrawing. |
| I understand pe | ersonal informat | ion will remain confidential to the researchers. |
| I have been giv | en the opportur | nity to raise any questions or concerns I have and am satisfied with the |
| responses I wa | | 7 |
| <u>Participant</u> | | |
| Print name: | | |
| Signature: | | |
| Phone numbe | r: | |
| Email address | 3: | |
| Date: | | |
| <u>Witness</u> | | |
| Print name: | | |
| Signature: | | |
| Date: | | |

Volunteer information and consent form Investigating Enriched Environments after stroke

This research project is being undertaken as part of the requirements of a PhD at Edith Cowan University.

Researchers' contact details

| Edith Cowan University | | | |
|------------------------|---|--------------------------|--|
| Chief Investigator/ | Sarah D'Souza | Ph: 0439 982 451 | |
| PhD student | | | |
| Principal Supervisor | Professor Beth Armstrong | Ph: 08 6304 2769 | |
| Co-Supervisor | Associate Professor Natalie Ciccone | Ph: 08 6304 2047 | |
| Co-Supervisor | Associate Professor Erin Godecke | Ph: 08 6304 5901 | |
| Co-Supervisor | Associate Professor Deborah Hersh | Ph: 08 6304 2563 | |
| Hunter Stroke Servic | e, University of Newcastle and Hunter Med | dical Research Institute | |
| Adjunct Supervisor | Dr Heidi Janssen | Ph: 02 40420417 | |

Description of the research project

This study is a Communication Enhanced Environment (CEE) at Hollywood Private Hospital. A CEE involves several initiatives that aim to provide more opportunities for communication for stroke survivors on the ward. One of these initiatives involves the participation of volunteers.

As a volunteer participant, you will be asked to take part in the following:

- Attend a training program for approximately 1.5 hours. This will focus on training volunteers in
 communicating with stroke patients with communication difficulties. This session will be located at
 Hollywood Private Hospital and will be offered over several dates to facilitate your ability to attend. If
 you are unable to attend the training program we may provide training and video resources to
 facilitate your participation in training.
- Complete an anonymous short questionnaire before and after attending the training program to obtain your feedback on the training session.

- A focus group with the researcher and other volunteers for approximately 1 hour to explore your
 perceptions of communicating with stroke patients. The focus group will be tape recorded however
 at any stage you may ask for the tape to stopped, edited or have your comments erased.
- Host a communal dining and lounge area once a week to offer tea and coffee and provide social companionship for stroke patients.
- Your interactions with the patient may be video recorded and manually recorded by a member of
 the research team to explore patient communication activity levels. You can choose to be observed
 by the researcher only if you do not want to be video recorded. We will not record if you are having
 sensitive conversations with the stroke patient/s.

There will be no cost to you associated with participating in this study. Participation is completely voluntary. You do not have to participate if you don't want to. If you decide to participate you may withdraw at any time without giving a reason and withdrawing will not disadvantage you in any way.

You may benefit from gaining knowledge and skills regarding communication from attending the training program. Additionally, you may also benefit from the knowledge that you are helping future stroke survivors. It is possible that you may not benefit from participating in this study. There are no known risks associated with participating in this study.

Confidentiality of information

The information you provide during the interviews will be audio recorded by the Chief Investigator. Your perspectives and opinions will be analysed and grouped into common 'themes' and 'stories'.

The video, audio and written data will be identified by code. The information you provide will remain completely confidential. There will be no identifying information attached to the data and any information that may reveal your identity will be removed. A list of participant names and codes will be kept in a locked filing cabinet at Hollywood Private Hospital and will only be accessible by the research team. All data will be accessed, used and stored in accordance with Commonwealth Privacy Laws. The data will be stored on a password controlled computer or in a locked cabinet at Edith Cowan University. Electronic data will be backed-up on a password controlled hard drive only accessible by the Chief Investigator. Data will be stored for a maximum of 15 years after completion of the study. Video and audio recordings will then be permanently deleted and hard copy data will be shredded.

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The results of this study may be published in research journals or presented at conferences. The results will not include any information that may identify participants. Data may be used in higher degree by research studies in the future. In this circumstance, confidentiality will be maintained and no identifying information will be used.

A summary of the results will be provided through Hollywood Private Hospital 18 months after the completion of the study.

Please read this Information Statement and be sure you understand its content before you consent to take part.

If you would like to take part, please complete the consent form and return it to Sarah D'Souza, Claire Tucak or a member of the research team.

Questions or further information?

If you have any questions or require any further information about the research project, please contact: Sarah D'Souza [Ph: 0439 982 451]

Thank you for considering the invitation to take part in this research project.

Yours sincerely,

Sarah D'Souza

If you have any concerns or complaints about the research project and wish to talk to an independent person, you may contact: Kim Gifkins

Research Ethics Officer

Edith Cowan University

270 Joondalup Drive

JOONDALUP WA 6027

Phone: (08) 6304 2170

Email: research.ethics@ecu.edu.au

ad by the ECC immittee. This project has been approved by the ECU Human Research Ethics Committee and the Hollywood Private Hospital Research Ethics Committee.

| I (print name), give my consent freely and |
|--|
| agree to participate in (please circle) this study as described in this information and consent form. |
| I understand the project will be conducted as stated in the information letter, a copy of which I have retained. |
| I understand I can withdraw from the project at any time and do not have to give a reason for withdrawin |
| I understand personal information will remain confidential to the researchers. |
| I have been given the opportunity to raise any questions or concerns I have and am satisfied with the |
| responses I was given. |
| Participant |
| Print name: |
| Signature: |
| Phone number: |
| Email address: |
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| <u>Witness</u> |
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BMJ Open

Hospital staff's, volunteers', and patients' perceptions of barriers and facilitators to communication following stroke in an acute and rehabilitation private hospital ward: A qualitative description study.

| Journal: | BMJ Open |
|----------------------------------|--|
| Manuscript ID | bmjopen-2020-043897.R2 |
| Article Type: | Original research |
| Date Submitted by the Author: | 02-Mar-2021 |
| Complete List of Authors: | D'Souza, Sarah; Edith Cowan University, School of Medical and Health Sciences; La Trobe University, Centre for Aphasia Recovery and Rehabilitation Research Godecke, Erin; Edith Cowan University, School of Medical and Health Sciences; La Trobe University, Centre for Aphasia Recovery and Rehabilitation Research Ciccone, Natalie; Edith Cowan University, School of Medical and Health Sciences Hersh, Deborah; Edith Cowan University, School of Medical and Health Sciences Janssen, Heidi; The University of Newcastle Hunter Medical Research Institute Armstrong, Elizabeth; Edith Cowan University, School of Medical and Health Sciences |
| Primary Subject Heading : | Neurology |
| Secondary Subject Heading: | Qualitative research, Rehabilitation medicine |
| Keywords: | Stroke < NEUROLOGY, Adult neurology < NEUROLOGY, QUALITATIVE RESEARCH |
| | |

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Title page

Title

Hospital staff's, volunteers', and patients' perceptions of barriers and facilitators to communication following stroke in an acute and rehabilitation private hospital ward: A qualitative description study.

Authors

Sarah D'Souza^{1,2}, Erin Godecke^{1,2}, Natalie Ciccone¹, Deborah Hersh¹, Heidi Janssen³, Elizabeth Armstrong¹

Affiliations

- 1. Edith Cowan University, Perth, Western Australia, Australia
- La Trobe University, Centre for Aphasia Recovery and Rehabilitation Research
 Melbourne, Victoria, Australia
- 3. Hunter New England Local Health District, NSW Health, New South Wales, Australia

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b.armstrong@ecu.edu.au

Key words: stroke, adult neurology, qualitative research

Reporting guidelines checklist: The consolidated criteria for reporting qualitative studies (COREQ)⁹ was used to guide reporting this study.

Corresponding author: Sarah D'Souza is the corresponding author, s.dsouza@ecu.edu.au

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All authors have completed the <u>Unified Competing Interest form</u>) and declare: This research was funded by The Hollywood Private Hospital Research Grant (RF087). SD received an Australian Post Graduate Award Scholarship for the first year of this study and received an ECU Research Travel Grant. No other support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years, no other relationships or activities that could appear to have influenced the submitted work.

The lead author (the manuscript's guarantor) affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned have been explained.

This study has Ethics approval from the Edith Cowan University Human Research Ethics Committee (ECU HREC 12149) and The Hollywood Private Hospital Research Ethics Committee (HPH431).

Abstract

Objectives: To explore barriers and facilitators to patient communication in an acute and rehabilitation ward setting from the perspectives of hospital staff, volunteers and patients following stroke.

Design: A qualitative descriptive study as part of a larger study which aimed to develop and test a Communication Enhanced Environment in an acute and a rehabilitation ward.

Setting: A metropolitan Australian private hospital.

Participants: Focus groups with acute and rehabilitation doctors, nurses, allied health staff and volunteers (n=51) and interviews with patients following stroke (n=7), including three with aphasia, were conducted

Results: The key themes related to barriers and facilitators to communication, contained sub-categories related to hospital, staff and patient factors. Hospital related barriers to communication were private rooms, mixed wards, the physical hospital environment, hospital policies, the power imbalance between staff and patients, and task specific communication. Staff related barriers to communication were staff's perception of time pressures, underutilisation of available resources, staff individual factors such as personality, role perception and lack of knowledge and skills regarding communication strategies. The patient related barrier to communication involved patients' functional and medical status. Hospital related facilitators to communication were shared rooms/colocation of patients, visitors and volunteers. Staff related facilitators to communication were utilisation of resources, speech pathology support, staff knowledge and utilisation of communication strategies and individual staff factors such as personality. No patient related facilitators to communication were reported by staff, volunteers or patients.

Conclusions: Barriers and facilitators to communication appeared to be interconnected and likely to influence one another suggests communication access may vary between patients within the same setting. Practical changes may promote communication opportunities for patients in hospital early after stroke such as access to areas for patient co-location as well as areas for privacy, encouraging visitors, enhancing patient autonomy, and providing communication trained health staff and volunteers.

Study strengths

- This study involved a large number of staff in comparison to previous studies and included volunteers as well patients after stroke with and without aphasia.
- Data saturation was reached within the staff focus groups.

Study limitations

- The results in this study reflect the perceptions of a small number of medical (n=2) and nursing staff (n= 11) compared to allied health staff (N= 32).
- This study involved exploring the perceptions a small number of patients; a broader range of perspectives may have been expressed with a larger number of participants.
- This study was conducted at a private hospital involving a mixed acute and a mixed rehabilitation ward therefore these results reflect this context.

Background

Aphasia research supports the theory that commencing aphasia rehabilitation in the early phase post-stroke (<1-month post-stroke) results in better outcomes than therapy commenced in the chronic phase (>6-months post stroke).^{1,2} However, patients in hospital following stroke spend on average 50-94% of their day inactive.^{3,4} Despite improvements in functional independence during their hospital admission following stroke, patients' engagement in cognitive and social activity remains largely unchanged.⁵ Patients with aphasia spend two thirds less time engaged in social interactions with family and friends compared to those without aphasia.⁶ A lack of social and cognitive activity early after stroke for patients with aphasia has the potential to contribute to: i) the development of maladaptive compensatory communication behaviours, and ii) the learned non-use of language, which may ultimately impact on their quality of life and overall language recovery.⁶

Patients following stroke with and without aphasia have described time outside therapy as "dead" and "wasted", reporting a lack of stimulation and inactivity in hospital impacting their ability to self-direct their rehabilitation outside of therapy. They report the experience of boredom is worse in the evenings and weekends when there are less structured activities. They also perceive that boredom negatively influences their mood, motivation, and contributes to their experience of post-stroke fatigue. Boredom is associated with a loss of autonomy and sense of control and contributes to patients becoming passive recipients of care, which may have negative implications for stroke recovery.

This study aimed to explore hospital staff and volunteer, and patient perceptions of barriers and facilitators to patient communication in an acute and a rehabilitation hospital ward. Identifying barriers and facilitators to patients' communication will inform the development of a Communication Enhanced Environment (CEE) for the purposes of increasing their engagement in language activity within a hospital ward to maximise post-stroke aphasia language recovery.

Methods

Design

This was a sub-study of a larger study which aimed to develop and test a CEE model within an acute and a rehabilitation ward (see supplementary file for study protocol and

procedure). This sub-study contributed to the baseline phase of the larger study outlined below:

- i) Baseline phase: observe and quantify levels of engagement in language activity in the acute and rehabilitation ward environment for patients following stroke, and explore hospital staff, volunteers, and patients' perceptions of barriers and facilitators to communication in hospital;
- ii) Implementation phase: develop and implement the CEE model on the acute and rehabilitation wards;
- *Post-implementation phase:* assess the impact of the CEE model on patient engagement in language activity, and hospital staff, volunteers and patients' perceptions of barriers to communication in hospital.

This study has Ethics approval from the Edith Cowan University Human Research Ethics Committee (ECU HREC 12149) and The Hollywood Private Hospital Research Ethics Committee (HPH431).

Reporting guidelines

The consolidated criteria for reporting qualitative studies (COREQ)⁹ was used to guide reporting this study (Appendix A.).

Research authors' relationship with participants

The first author who was external to the hospital conducted focus groups and interviews. The first author engaged key hospital team members for the duration of the study to inform the study design to ensure it aligned with the hospital policies and priorities.

Patient and public involvement

Patients and the public were not involved in the design of this study however this data informed the development of the CEE model in the larger study. A working group consisting of key members of the stroke multidisciplinary team provided feedback on this study's findings and were involved in the development of the CEE model and embedding approach, which was based on the outcomes of this sub-study.

Setting

This study was conducted on an acute and a rehabilitation ward at a private hospital in Perth, Western Australia. The acute ward was a 26- bed unit with patients following acute stroke as well as other medical conditions. The acute ward had four individual rooms and

nine shared rooms, two rooms with four beds per room, and seven rooms with two beds per room. Patients ate meals in their rooms and had access to an outdoor balcony area. The rehabilitation ward was a 44-bed mixed rehabilitation unit for patients following stroke and other medical, orthopaedic and post-surgical conditions. There were thirty-six individual rooms, and four shared rooms with two beds in each room. Patients had breakfast in their rooms but were encouraged to eat lunch and dinner in one of two communal dining areas.

Participants

Hospital staff participants: Purposeful sampling of acute and rehabilitation hospital staff was conducted to include at least one representative from each acute and rehabilitation staff group including medical, nursing, volunteers, and allied health staff members who were over 18 years of age. Formal consent to participate in the study was completed by the first author (see supplementary file for consent forms and procedures). A total of 51 staff and volunteers were recruited (Table 1.) by contacting staff department managers who identified staff currently working or had previously worked with patients following stroke on the acute or rehabilitation wards.

Table 1. Staff participants

| Staff/volunteer groups | | | |
|------------------------------|---|---------------------------------------|--------------------|
| Medical & Nursing | N | Allied Health | N Volunteer N |
| Acute nurses (AN) | 2 | Dietitian (DT) | 1 Volunteers (V) 6 |
| Clinical nurse manager (CNM) | 1 | Occupational therapy manager (OTM) | 1 |
| Medical consultants (MC) | 2 | Occupational therapists (OT) | 5 |
| Rehabilitation nurses | 8 | Occupational therapy assistants (OTA) | 3 |
| | | Physiotherapists (PT) | 8 |

| Volunteer manager (VM) | 1 |
|----------------------------------|---|
| Speech pathology assistant (SPA) | 1 |
| Speech pathologists (SP) | 4 |
| Speech pathology manager (SPM) | 1 |
| Social workers (SW) | 5 |
| Physiotherapy assistants (PTA) | 2 |
| Dhysiotherany | 2 |

Patient participants: All patients consecutively admitted following stroke from January to February 2016, and June 2016 to July 2017 were screened for eligibility by the hospital site champions to participate in the study. Inclusion criteria: i) admitted to the acute or rehabilitation ward with an acute stroke, ii) less than 21 days post-stroke during data collection, iii) able to provide informed consent based on the judgement of the medical team responsible for the medical management of the patient, iv) Glasgow Coma Scale¹⁰ greater than 10, v) estimated total length of hospital stay greater than 14 days, vi) adequate English proficiency to participate in interviews as determined by managing speech pathologist or medical team. Exclusion criteria: i) uncorrected hearing or vision (for example hearing impairment without the use of hearing aids or vision impairment without the use of glasses), ii) medically unstable, iii) documented diagnosis of current untreated depression, documented diagnosis of dementia, previous aphasia or traumatic brain injury. The diagnosis of aphasia was confirmed for those who achieved a Western Aphasia Battery-Revised¹¹ Aphasia Quotient score less than 93.7. Eligible patients were approached by the site investigators for consent to be approached by the research team. The first author completed formal consent with all patient participants (see supplementary file for consent forms and procedures). A total of 9 patients were recruited, however 2 patients were withdrawn as they became medically unwell. Data collection was completed for 4 patients without aphasia and 3 patients with aphasia. See Figure 1. for the summary of patient screening and recruitment. Patient details and demographics are detailed in Table 2.

No staff or patients withdrew from participating in this study.

Data collection

The first author, a female speech pathologist (Bachelor of Speech Pathology, Honours) and PhD student with seven years clinical experience working in the hospital setting and five years research experience, including conducting interviews and focus groups, completed all semi-structured interviews and focus groups. Staff were informed that the researchers wanted to investigate their perceptions of the hospital ward environment in regards to communication opportunities to inform the development of a Communication Enhanced Environment (see supplementary file for staff and volunteer information and consent forms). Patients were informed that the researchers wanted to explore how the hospital environment influenced patient activity (see supplementary file for patient information and consent forms).

All interviews and focus groups were conducted using interview and focus group guides (staff focus groups and interview guide Appendix B., patient interview guide Appendix C.) and were audio recorded. Field notes were completed by the first author during data collection. Seven staff focus groups were conducted with two to eight participants in each focus group. One-on-one interviews were conducted with two staff members. All staff focus groups were completed on the hospital site in various locations that were private and quiet. Six out of seven patient interviews were conducted in person during their inpatient admission in their hospital room, and one was completed over the phone (patient without aphasia) one day following discharge from hospital. All patient interviews were conducted within fifteen days post-stroke. Interview and focus groups were 20-60 minutes long, often varying based on the number of participants. Supported conversation strategies¹² were used during interviews with patients with aphasia to facilitate their participation in the interview. One patient with aphasia had two family members present during the interview. During the interviews and focus groups, clarifying questions and paraphrasing participant comments were used to confirm and clarify their perspectives and insights.

[Figure 1. inserted here]



Table 2. Patient characteristics

| | Group | PWA | PWOA |
|---|-----------|-----------|------------|
| | (n=7) | (n = 3) | (n = 4) |
| Participants | | | |
| Age (yr), mean (SD) | 83 (7) | 81 (5) | 84 (8.10) |
| Sex, n females | 4 | 1 | 3 |
| Pre-morbid mobility, n needing aids | 1 | 1 | 0 |
| Pre-morbid living arrangement, n alone | 3 | 1 | 2 |
| Time since stroke (d), mean (SD) | 14 (5) | 13 (7) | 15 (5) |
| Stroke severity (NIHSS ¹³ 0-42), mean (SD) | 4 (3) | 5 (4) | 5 (3) |
| Mild, n score < 8 | 5 | 2 | 3 |
| Moderate, n score 8-15 | 2 | 1 | 1 |
| Severe, n score > 15 | 0 | 0 | 0 |
| Mobility status at time of data collection | | | |
| Independent +/- walking aid | 1 | 0 | 1 |
| Stand-by assistance | 3 | 1 | 2 |
| 1-2 person assistance | 2 | 1 | 1 |
| Hoist/wheelchair | 1 | 1 | 0 |
| Cognition (MOCA ¹⁴), median (range) | 18 (9-22) | 16 (9-18) | 20 (17-22) |
| Aphasia severity, WAB-R ¹¹ AQ mean, (SD) | | 77 (6.50) | |
| Ward (d) | | | |
| Acute (%) | 4 (17) | 4 (40) | 0 (0) |
| Rehabilitation (%) | 19 (83) | 6 (60) | 13 (100) |
| Average number of days in single room per participant (%) | 3.1 (96) | 3 (90) | 3.3 (100) |

Notes: PWA= patient with aphasia; PWOA= patient without aphasia; NIHSS=National Institute of Health Stroke Scale¹³; MoCA= Montreal Cognitive Assessment¹⁴; WABAQ=Western Aphasia Battery-Revised¹¹ Aphasia Quotient score.

Data analysis

Focus groups and interviews were transcribed verbatim. Responses to any leading questions were removed from the data set.¹⁵

The theoretical framework for this research was a qualitative description approach. ¹⁶ This approach involves describing patient experiences, with minimal interpretation of the data to minimise potential bias of the researchers. ¹⁶ Participant experiences were analysed using NVivo¹⁷ computer software to manage the data. Data were grouped into themes according to content. ¹⁶ The first level of coding identified the broad content of the data then sub-categories were identified. ¹⁶ Single lines of data were not removed from their 'story' during data analysis to maintain the context and help ensure meaning was not lost or misinterpreted. ¹⁶ Ongoing critical review of the categories were conducted and themes were reviewed by a second researcher. ¹⁶ Staff were provided feedback on the findings.

Results

The key themes from the focus group and interviews related to barriers and facilitators to communication, with sub-categories identified which related to hospital, staff and patient factors (Figure 2.).

[Figure 2. inserted here]



Barriers to Communication

Hospital related factors

Private rooms reduce opportunities for social interaction

Staff and patients described the impact of single rooms which limited incidental socialisation with other patients and their visitors.

We used to co-locate our stroke patients [sic] and often using our shared rooms. That's when people had more opportunities for interacting with one another. (MedC1)

Mixed wards affect staff acquisition of specialist skills

Staff described their perception of the negative effect a mixed hospital ward had on the acquisition of stroke specific specialist skills.

Having a stroke specific ward... everybody on the ward would be trained...and that's the only thing they'd have to focus on rather than having lots of other patients with lots of medical conditions. (OT4)

Hospital environment does not encourage socialising

Staff talked about the physical hospital ward environment affecting social interaction as it contributed to a sterile atmosphere rather than one that promoted social activity. Staff also talked about the consequence of background noise and environmental distractors in large shared rooms on the acute ward which reduced their ability to communicate with patients with communication impairments.

My general feeling of rehab [rehabilitation] is that they come to their sessions and then they go back to their lonely dark room... I don't really see the rooms as a particularly happy, busy place where they are getting a lot out of being in there... the dining rooms... they're not a particularly pleasant place to be either. (PT2)

They [patients] can hear other people talking... there is [sic] a lot of voices going on which is going to impact on their understanding as well. (PT3)

Hospital policies restrict the development of communication-promoting ideas and initiatives

Hospital policies were perceived by staff as a barrier to communication, negatively influencing their ability to develop ideas and initiatives to increase patients' opportunities for social interaction. This included policies regarding leaving patients unattended in dining

areas without patient care assistants supervising them and requiring nurses to supervise patients if they are eating; and reported limitations around food related activities as a result of food hygiene policies and occupational health and safety.

It's just every time you try and do something you hit a barrier... you do try and think outside the box what more can you do for this patient and you get another hospital rule. (PT2)

Power imbalance of staff and patients in hospital controls patients' ability to access communication opportunities

Staff and patients discussed the influence of the power imbalance for patients in hospital, and patient perceptions that they have to do what is expected in the hospital environment. This appeared to limit the patients' ability to freely engage and explore the environment resulting in patients retreating to their rooms and limiting their opportunities to engage in activities.

I think most males like to account for their time um and I felt like I haven't been able to do that and that's, that's the bit that I'm really, really lacking. (PWA2)

I was in the hospital so I think I had to stick into the room, to the rules. (PWOA2)

Very often when you're in a hospital you do what you think you're expected to do. (SP4)

Task specific communication reduces patients' communication opportunities

Staff talked about the nature of interactions with patients as often being driven by the patient's care, restricting opportunities for communication beyond this context.

I know we aim to be very holistic... but very often care is very[sic] directed from a medical health care perspective (SP4)

Staff related factors

Staff's perception of time pressures limiting opportunities for communication

Both patients and staff perceived staff time pressures as a barrier negatively effecting communication on the wards. This may be the reflection of actual time pressures, or staff perceptions of their available time. Some staff reported that they felt interactions with patients with communication impairments required extra time which was challenging in a time pressured hospital environment. Time pressures were also perceived to restrict the staff's ability to facilitate opportunities for patients to socialise with other patients. For

example, nurses appeared to deprioritise transferring patients to the communal area for lunch in busier times.

If they're hoist patients it might not be as easy for staff to get them to the dining room, that wouldn't totally prevent someone from going, it would just depend on the time that people had on the day. (SW3)

Staff and patient's underutilisation of available resources

Staff described the lack of accessible resources as a factor negatively affecting staff-patient communication. They described the need for resources when communicating with patients with aphasia and other communication impairments but felt unsure about what these were or how to access them. They also described a number of resources that they felt patients were not aware of and therefore did not utilise such as volunteer services that promote communication opportunities and facilitate patient access to outdoor areas.

I feel like I don't know where else to go. I don't know if other things that [sic] could help us, maybe there's things out there that I don't know about that would help us communicate with these patients. (PT2)

There are all of these opportunities but I don't think a lot of the patients access them so it sounds like great communicative opportunities for them but the reality is that a lot of them are sitting in their rooms most of the times by themselves watching television and most of the interactions they have is with the nurses or just whoever comes in to see them. (SP4)

Individual staff factors leading to restricted opportunities for communication

Staff described individual staff factors such as personality, values and attitudes influencing communication opportunities for patients, such as staff providing patients with opportunities for incidental social interaction during routine tasks.

Often if people need to go in and see the patient let's just say to take obs [observations] or to do a wash... they don't always use that opportunity as an opportunity to chat... there could be more opportunity to chat at those times whilst they are doing what they need to get done and you know that varies from person to person, personality as well and how busy people are, what else is going on. (SP3)

Staff's perception their role does not include communication tasks

Some staff perceived communication as a task separate from the responsibility of their role therefore limiting their facilitation of communication opportunities for patients.

They [speech pathologists] do their bit and we do ours... we don't have time to practice speech with them because we really do have to get all of our jobs filled in the time and it's specifically rostered for us to do our work, not to help with someone else's. (RehabN1)

Lack of staff knowledge and skills resulting in unsuccessful communication interactions or avoiding communication interactions

Staff described a lack of knowledge and skills in communicating with patients with communication impairments. Some staff reported feeling anxious about encouraging patients to communicate as communication breakdowns may cause stress and anxiety for the patient, and the staff member. Staff reported a lack of confidence in their ability to repair communication breakdowns which resulted in increased time pressures in their sessions, often leading them to avoid encouraging communication interactions within their treatment sessions.

I find it challenging... knowing how the best way to communicate with that person [with aphasia]... then [they] become very frustrated and not have the tools themselves to communicate back to me and you would never want to leave someone in that space. So that's something that I struggle with. (SW2)

Patient related factors

Patient related factors reflected their functional and medical status, personality, mood and motivation, which were perceived by staff and patients to often act as a barrier to engaging in communication interactions during their hospital admission early after stroke.

Patients' functional and medical status limiting their ability to seek out and engage in activities

Staff and patients perceived patients' medical status as a barrier to communication by limiting their ability to engage with their environment including independently seeking out activities and being able to utilise communal areas.

If someone is bed bound, you know the interaction is very minimal... you often walk past and you see them alone in their room... you wonder what happens during those periods of time where they're just in their room and they don't have family. (OT2) Well, I can't do anything cos I can't go off by myself and do anything. (PWOA2)

Individual patient factors limiting opportunities for communication

Staff described individual patient factors such as personality, mood and motivation communication opportunities for patients such as independent practice of communication therapy tasks, and social opportunities with patients and hospital staff.

We have to recognise some patients who have had strokes... they're fed up with having people poking and prodding them then have a volunteer and go "do you want to do your exercises for speech?" (VM)

They need a break after OT [the occupational therapist] has done a shower. If they don't get that break then the physio isn't going the be as good for them because they're so tired, so we also have to look at break times in between each sessions... (OTA1)

Facilitators to Communication

Hospital related factors

Shared rooms/co-location encourages incidental social interactions

Staff talked about use of communal areas at other hospitals which facilitated socialisation and communication during non-therapy times and during group therapy. Staff described the importance of the use of communal areas given the large number of private rooms on the ward. Patients also described the need to be co-located to promote social interaction.

I think that, put the [sic] whole lot of people together and ah and they [sic] something collective, that's what human beings are put together for ... sitting around talking... over the proverbial cuppa. (PWA2)

Visitors provide patients opportunities for socialisation

Staff identified visitors as a facilitator to communication interaction for patients outside of therapy times during their inpatient admission.

Interaction with the family... it's not therapy based but it's their [patients'] opportunity to practice. (PT1)

Volunteers facilitate opportunities for patients to engage in social activities

Staff discussed the benefit of volunteers in facilitating opportunities for patients to engage in social interactions including programs involving therapy dogs, book loaning, hand massages, and taking patients off the ward.

If we see people that are lonely, are not getting visitors, there's many volunteers... to go and visit them and if they're well enough they can take them out... the volunteers, we do rely on them. (OTA1)

Staff related factors

Staff utilisation of resources promote communication exchange

Staff identified access to resources such as chat books and alternative and augmentative communication boards often facilitated communication interactions with patients with communication impairments on the ward.

Sometimes with the ... signs... "do you want to drink? some water?" or something, so they can just point because ... they want to say something and maybe the right words are not coming out... that also helps. (RehabN3)

Speech pathology support and education facilitates staff's use of communication promoting strategies

Staff reported support and education from speech pathology staff facilitated their ability to interact successfully with patients with aphasia.

I had a patient who had word finding difficulties... I just was observing the speechie [speech pathologist], she would just be like "no, what do you mean?" and he'll be like [pointing] and she'll be like "tell me what's the word"... it's something I could have just added to my session. (PT4)

Staff knowledge and utilisation of communication strategies promotes communication activities

Staff and volunteers discussed the use of communication strategies and resources to facilitate communication on the ward for patients with a variety of communication impairments.

We use communication boards, pictures, writing things down, talking slowly. (MedC2)

If they are having trouble, I will say to them "it's okay you don't need to hurry, that's fine". (V1)

Individual staff factors promote communication opportunities for patients

Staff and patients talked about how individual characteristics of staff, including rapport building and being friendly, facilitated communication for patients with communication difficulties.

Sometimes they [patients] look for that specific person... the more they get confident, the more they get relaxed, the more their speech enhances as well. (RehabN3)

Discussion

This study aimed to explore hospital staff, volunteers and patients' perceptions of barriers and facilitators to communication on an acute and a rehabilitation ward. A wide range of factors were perceived to act as potential barriers or facilitators to communication. Additionally, a number of factors influencing patient access to communication opportunities appeared to influence one another.

The co-location of patients in therapy spaces, dining areas or in shared rooms were perceived as facilitators to communication for patients, providing opportunities for incidental social interactions with other patients and their visitors. However, background noise in these shared spaces was also perceived to act as a barrier to their ability to engage in communication. Patient access to communal spaces was influenced by a number of factors including patients' sense of autonomy to freely explore the hospital ward environment, and their medical and mobility status, and staff's perception of their available time, which influenced staff's perception of whether they transferred patients to these spaces. Rosbergen et al¹⁸ reported that in an acute stroke ward enriched environment communal mealtimes and group activities were perceived to facilitate social activity. The study by Rosbergen et al¹⁸ found that staff reported perceptions that shared rooms limited staff and patients' ability to engage in private conversations, consistent with O'Halloran et al's¹⁹ findings. It may be that access to both private and communal spaces available within the hospital environment play critical roles in regards to providing opportunities for social interactions with other patients and their visitors and opportunities for privacy when required.

The acute and rehabilitation wards had a large proportion of single rooms, which could have been considered the result of this study being conducted at a private hospital.

However, there has been a perceived trend towards increased proportions of single rooms

in newly built public hospitals to promote infection control and patient privacy which may have a detrimental effect on communication.^{20,21} The predominance of single rooms and limited opportunities to access shared spaces may have increased the effect of other barriers on communication opportunities for patients. For example, a patient with poor autonomy may be more likely to remain alone in their single room when they are not attending therapy, as they perceive they are not 'allowed' to freely explore the hospital environment. This may reduce the likelihood of the individual independently seeking out social interactions beyond their room. If they also have reduced mobility, they may be more reliant on staff to facilitate transfers to communal spaces which may be impacted by staff time constraints. The patient's functional status and levels of fatigue may also limit their ability to initiate and engage in activities while they are in their room. Therefore, the combined effect of these barriers may significantly limit this patient's communication opportunities.

These communication barriers may be mitigated by having scheduled rest periods, and periods allocated to encouraging visitors to provide opportunities for communication and socialisation within their room, and facilitate patient access to shared spaces, such as helping mobilise wheelchair users into communal dining areas or education to patients that they are allowed to explore the hospital ward environment. Rosbergen et al¹⁸ identified patient and family autonomy to initiate and direct activity as a factor enriching the acute ward environment. Therefore, increasing patient autonomy within this setting may facilitate their ability to seek out interactions within the environment and increase engagement in communication activity, which may then reduce the effect of being in a single room with reduced mobility and time poor staff.

A potential lack of opportunities to access social interactions with other patients means staff, including volunteers, and visitors may become the main communication partner for patients. Godecke et al's⁶ observation study found that nurses are the most frequent communication partner for patients following stroke with aphasia, after their family members, therefore patient-staff interactions may play a significant role for those patients with minimal or no visitors. It is interesting to note that this study recruited a limited number of acute nurses in comparison to rehabilitation nurses. This could be interpreted as a reflection of differences in nurses' capacity for additional activities within the demands and time restrictions of the acute ward context in comparison to the

rehabilitation ward context. Within the current study, communication between staff and patients appeared to be dependent on a number of factors including staff perception of their role, their knowledge and skills in facilitating communication, their values and attitudes towards communication and whether supporting language and communication for patients with aphasia is part of their 'role', their willingness to be flexible with their time, and their knowledge of and access to resources which may be used to facilitate communication. This also highlights the potential impact of the perceived power imbalance between staff and patients and the significance of interactions that are task directed. Hersh et al²¹ reported patients with aphasia felt disempowered in communicative interactions with nurses. Nurses often talked to the task and controlled interactions with patients.^{22,23}This highlights the need for communication partner training which may provide staff with the knowledge and skills required to support effective communication with patients with aphasia.²⁴ Implementation strategies will need to be considered to promote behaviour change as well as the uptake and maintenance of training including involvement of management and ward champions, and ensuring trained communication strategies are easy to learn, apply and audit in order to be applicable in this busy context.²⁵

Time pressure was perceived as a major barrier to communication impacting on staff's ability to support successful communication within their interactions with patients and facilitate patients' opportunities to engage in interactions in social or communal areas. Time constraints have been reported to limit communicative opportunities between patients following stroke and nurses. ²⁶ Ball et al²⁶ found that 86% of surveyed nurses reported one or more activities had been "left undone" in their last shift as a result of lack of time. The study found that activities most likely to be missed by nurses as a result of time constraints were comforting and talking to patients (66%) and patient education (52%). ²⁶ This has also been identified by patients who "did not like to bother the busy nurse". ²⁷ Time limitations and pressures on the wards may be facilitated by developing staff knowledge of and skills in using communication promoting strategies. Effective and efficient nurse patient communication as a result of nurse training has been found to save time, reduce frustration and reduce the burden associated with caring for patients following stroke with aphasia. ²⁸ Additionally, time limitations reported by staff may lend to an argument for additional nursing allocation for patients with communication impairments.

This study included a small number of medical and nursing staff in comparison to compared to allied health staff which may be reflected in the reported results. This study also involved a small number of patients and a broader range of perspectives may have been expressed with a larger number of participants. This study was conducted at a private hospital involving a mixed acute and a mixed rehabilitation ward, and a relatively homogenous groups of participants linguistically and ethnically, therefore these results reflect this context and may not be directly generalisable to hospitals in the public sector, nor did they explore cultural factors contributing to communication.

Conclusions

The barriers and facilitators to communication appear to be interconnected and likely to influence one another, suggesting that the level of communication access may vary from patient to patient within the same setting. Results of this study highlight a number of practical changes that could be implemented to promote communication opportunities for patients admitted to hospital early after stroke. However, implementation of behaviour and cultural change strategies may be pertinent to promote meaningful and sustainable change within the hospital setting. Consideration of areas for co-location for patients such as therapy spaces, dining areas or shared rooms as well as access to private spaces may potentially address the need for social opportunities with other patients as well as access to privacy when required. The promotion of visitors attending the wards may facilitate communication opportunities for patients between therapy times by providing socialisation in patients' rooms as well as facilitating and advocating for patient access to communal areas. This has the potential to mitigate the effect of social isolation in single rooms, staff time restraints and limitations as a result of patients' medical status. Strategies to promote patient autonomy in hospital may promote their ability to freely explore the environment beyond their room may help address the power imbalance that can occur between patients and hospital staff. Additionally, health staff and volunteer education in using communication promoting strategies may increase opportunities for interactions between patients, and staff or volunteers and promote communication exchange within those interactions. These factors will be explored in a Communication Enhanced Environment, which aims to increase patients' opportunities to engage in language activities during early stroke recovery in hospital.

Acknowledgements

The authors would like to thank the hospital and staff for supporting this study and assisting in participant recruitment. We would also like to thank all the participants in this study for sharing their experiences and insights.

Author contributions

SD, EG, NC, DH, HJ and EA designed the study and the protocol. EG reviewed the final copies of the protocol documents. SD conducted the semi-structured interviews and focus groups. SD performed data analysis. DH conducted the critical review of the categories and review of themes. SD, EG, NC, DH, HJ and EA contributed to the manuscript and approved the manuscript.

Competing interests statement

This research was funded by The Hollywood Private Hospital Research Grant (RF087). SD received an Australian Post Graduate Award Scholarship for the first year of this study and received an ECU Research Travel Grant. The authors have no other competing interests to declare.

Funding statement

This work was supported by the Hollywood Private Hospital Research Foundation grant number RF087. SD received an Australian Post Graduate Award Scholarship for the first year of this study and received an ECU Research Travel Grant.

Data sharing statement

Patient interview and staff focus group data are stored in the Edith Cowan University data storage repository. This data will be available in a de-identified format by request through the first author ORCiD https://orcid.org/0000-0001-6221-3229. The availability and use of the data are governed by Edith Cowan University Research Ethics.

Figures

Figure 1. Summary of patient screening and recruitment.

Figure 2. Summary of themes and subthemes of staff and patient perceptions to barriers and facilitators to patient following stroke.

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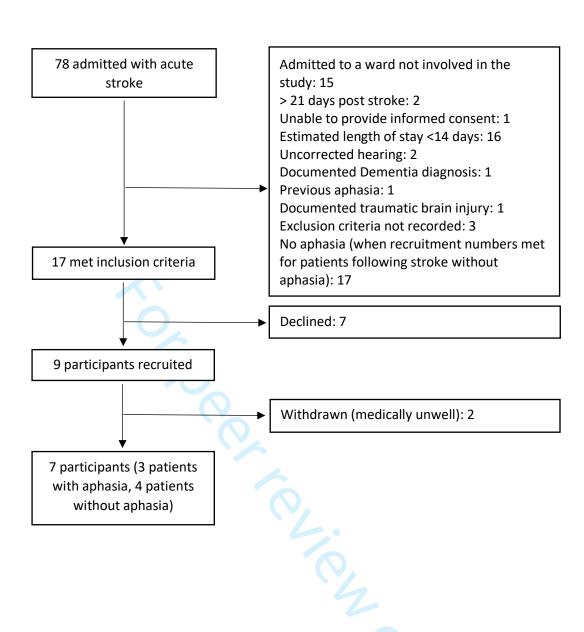


Figure 1. Summary of patient screening and recruitment

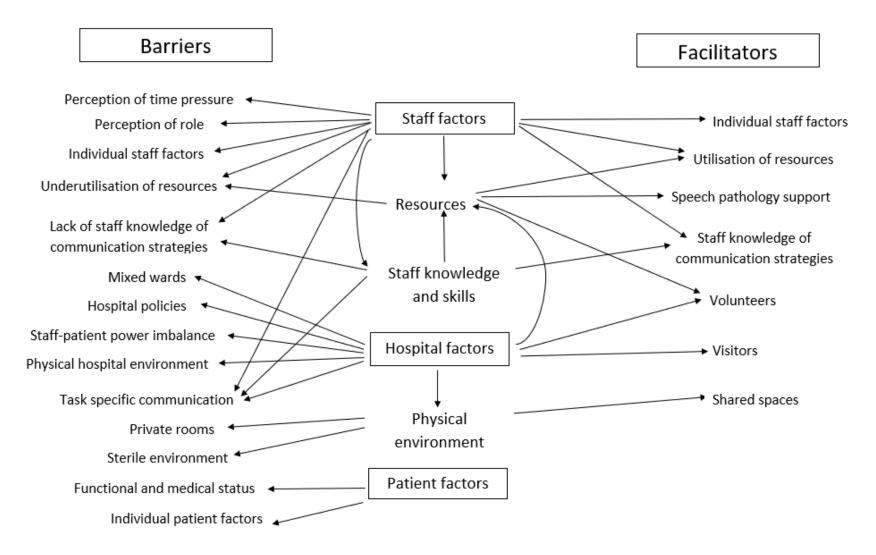


Figure 2. Summary of themes and subthemes of staff and patient perceptions to barriers and facilitators to patient communication in hospital.

Appendix A.

Consolidated criteria for reporting qualitative studies (COREQ)9: 32-item checklist

| No Item | Guide questions/description | Location within paper | |
|---|---|--|--|
| Domain 1: Research team and reflexivity | | | |
| Personal Characteristics | | | |
| 1. Interviewer/facilitator | Which author/s conducted the interview or focus group? | Page 10 | |
| 2. Credentials | What were the researcher's credentials? E.g. PhD, MD | Page 10 | |
| 3. Occupation | What was their occupation at the time of the study? | Page 10 | |
| 4. Gender | Was the researcher male or female? | Page 10 | |
| 5. Experience and training | What experience or training did the researcher have? | Page 10 | |
| Relationship with participants | (Ch. | Page 7 | |
| 6. Relationship established | Was a relationship established prior to study commencement? | Page 7 | |
| 7. Participant knowledge of the | What did the participants know about the | Supplementary files, participant information | |
| interviewer | researcher? e.g. personal goals, reasons for doing the research | and consent forms, page 10 | |
| 8. Interviewer characteristics | What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic | Page 10 | |
| Domain 2: study design | · | | |
| Theoretical framework | | | |

| 9. Methodological orientation and Theory | What methodological orientation was stated | Page 13 |
|--|---|------------------------|
| | to underpin the study? e.g. grounded theory, | |
| | discourse analysis, ethnography, | |
| | phenomenology, content analysis | |
| Participant selection | | |
| 10. Sampling | How were participants selected? e.g. | Page 8, 10 |
| | purposive, convenience, consecutive, | |
| | snowball | |
| 11. Method of approach | How were participants approached? e.g. | Page 8, 10 |
| | face-to-face, telephone, mail, email | |
| 12. Sample size | How many participants were in the study? | Page 8, 10 |
| 13. Non-participation | How many people refused to participate or | Figure 1, page 8 |
| | dropped out? Reasons? | |
| 14. Setting | Setting of data collection Where was the | Page 7-8 |
| | data collected? e.g. home, clinic, workplace | |
| 15. Presence of non-participants | Was anyone else present besides the | Page 11 |
| | participants and researchers? | |
| 16. Description of sample | What are the important characteristics of the | Table 2, page 12 |
| | sample? e.g. demographic data, date | |
| Data collection | | 6 |
| 17. Interview guide | Were questions, prompts, guides provided | Appendix B, Appendix C |
| | by the authors? Was it pilot tested? | |
| 18. Repeat interviews | Were repeat interviews carried out? If yes, | NA |
| | how many? | |
| 19. Audio/visual recording | Did the research use audio or visual | Page 10 |
| | recording to collect the data? | |
| 20. Field notes | Were field notes made during and/or after | Page 10 |
| | the interview or focus group? | |
| 21. Duration | What was the duration of the interviews or | Page 11 |
| | focus group? | |

| 22. Data saturation | Was data saturation discussed? | Page 5 |
|------------------------------------|---|------------|
| 23. Transcripts returned | Were transcripts returned to participants for | No |
| | comment and/or correction? | |
| Domain 3: analysis and findings | | |
| Data analysis | | |
| 24. Number of data coders | How many data coders coded the data? | Page 13 |
| 25. Description of the coding tree | Did authors provide a description of the | Figure 2 |
| | coding tree? | |
| 26. Derivation of themes | Were themes identified in advance or | Page 13 |
| | derived from the data? | |
| 27. Software | What software, if applicable, was used to | Page 13 |
| | manage the data? | |
| 28. Participant checking | Did participants provide feedback on the | Page 13 |
| | findings? | |
| Reporting | 10 | |
| 29. Quotations presented | Were participant quotations presented to | Page 14-20 |
| | illustrate the themes / findings? Was each | |
| | quotation identified? e.g. participant number | |
| 30. Data and findings consistent | Was there consistency between the data | Page 14-20 |
| | presented and the findings? | 6 |
| 31. Clarity of major themes | Were major themes clearly presented in the | Figure 2 |
| | findings? | 1/1/ |
| 32. Clarity of minor themes | Is there a description of diverse cases or | Page 14-20 |
| | discussion of minor themes? | |

Appendix B.

Investigating Communication Enhanced Environments after stroke: Staff focus group guide

What kind of language activities or language tasks do patients following stroke currently participate in on the ward?

What kind of language activities or language tasks would you like see patients following stroke have access to on the wards?

Describe your experience of communicating with patients following stroke at the moment.

Can you tell me about anything that facilitates your ability to communicate with patients following stroke on the ward?

Can you tell me about any barriers you experience that impact your ability to communicate with patients following stroke on the ward?

What changes would you like to see to enhance communication between staff and patients following stroke on the ward?

What changes would you like to see to enhance communication between visitors and patients following stroke on the ward?

How could we enhance or optimise communication and language tasks and activities for patients following stroke on the ward?

What do you think a communication and language enhanced stroke ward environment might look like?

Appendix C.

Investigating Communication Enhanced Environments after stroke: Patient interview guide

Tell me about what kind of activities you do while you are here (in hospital).

Describe your experience of communicating with people on the ward.

What makes it easier to communicate with people on the ward?

What makes it hard to communicate with people on the ward?

What can we do to make communicating with people easier?

Investigating a Communication Enhanced Environment (CEE) model early after stroke: A before-after non-

randomised controlled pilot study.

Study protocol version 1 19.05.20

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| | |

1 Abbreviations and Definitions of Terms

CEE model: Communication Enhanced Environment model, an adapted model of an Enriched Environment, an environment that provides stroke patients opportunities to engage in language activities during inpatient rehabilitation.

PWA: Patients following stroke with aphasia.

PWOA: Patients following stroke without aphasia.

Language activities: Language tasks that consist of solitary or interactive language activities.

Solitary language activities: Activities that may promote aphasia recovery such as reading, writing, listening to the radio, and the use of iPad applications.

Interactive language activities: activities which are based in communicative interactions that involve an exchange of information with a communication partner involving talking, gesture and/or facial expression, reading, writing or drawing to communicate.

EE: Enriched Environment, an environment that promotes physical, cognitive and social activity.

2. Protocol Synopsis

| Study Title: | Investigating a Communication Enhanced Environment model on acute and rehabilitation wards early after stroke: A before-after non-randomised controlled pilot study | | | |
|---------------------|--|--|--|--|
| Study type: | Interventional | | | |
| Study Intervention: | A Communication Enhanced Environment (CEE) model will be developed from pre-intervention observations of inpatient language activities and investigations of barriers and facilitators to communication together through focus groups with hospital staff and interviews with patients on the acute and rehabilitation wards. | | | |
| | Sixteen patients following stroke will be recruited in this prospective before-after non-randomised controlled pilot study set in an acute and a rehabilitation ward of a metropolitan private hospital. The study includes: i) The baseline phase which involves observation of patients following stoke (n=8, 4 patients with aphasia (PWA) and 4 patients without aphasia (PWOA)); the collection of qualitative data through focus groups and semi-structured interviews to determine patient and staff perceived barriers and facilitators to communication; ii) the implementation phase where a CEE model will be developed and embedded in usual care; iii) the post-implementation phase which will involve repeated baseline data collection on a different cohort of patients (n=8, 4 PWA and 4 PWOA) to determine i) how solitary and interactive language activity levels changed following implementation of the CEE model, ii) the differences post CEE implementation in hospital staff's use of communication promoting strategies when interacting with patients, iii) the differences post CEE implementation in staff and patient perceptions of the barriers and facilitators to inpatient language activities. | | | |
| | The CEE model will include the provision of: i) CEE model equipment, for example reading materials such as books and magazines, and access and encouragement to reside in a communal dining area; ii) CEE model education, support and training for staff with the aim to develop the ability to facilitate language activities for patients after stroke. The training program will be guided by research evidence, expert opinion and baseline data. Staff will complete a questionnaire pre and post training to determine changes in their knowledge, skills and attitudes regarding communication and aphasia. | | | |
| | Control treatment: Patients following stroke with and without aphasia will be observed and video recorded over two week days and one weekend day pre (n=8) and post (n=8) implementation of a CEE model. Behavioural mapping will record patient interactive and solitary language activity observed within the first minute of 5-minute intervals in 4-hour time periods between 7am and 7pm. Solitary language activities are activities that may promote aphasia recovery such as reading, writing, listening to the radio, and the use of iPad applications. Interactive language activities are activities which are based in communicative interactions that involve an exchange of information with a communication partner involving talking, gesture and/or facial expression, reading, writing or drawing to communicate. | | | |

| Objectives of the | This study aims to investigate a CEE model on an acute and rehabilitation | | | |
|---------------------------|--|--|--|--|
| Study: | ward and if stakeholders perceive a CEE model as valuable by addressing | | | |
| Study. | the following research questions: | | | |
| | - Does a CEE model increase the amount of time PWA and PWOA spend | | | |
| | in participating in solitary and interactive language activities on acute | | | |
| | | | | |
| | and rehabilitation wards during the early post-stroke period? | | | |
| | - What are the differences in patients' experience of communication in a | | | |
| | CEE model compared to patients' experience of communication in a | | | |
| | standard environment on in-patient acute and rehabilitation wards? | | | |
| | - What is the experience of implementing a CEE model for staff working | | | |
| | with PWA and PWOA within in-patient acute and rehabilitation wards? | | | |
| | - Do staffs' perceptions of their knowledge of, skills with, and attitude | | | |
| | towards communication and aphasia change following implementation | | | |
| | of a CEE model? | | | |
| Number of Centres: | 1 | | | |
| Study duration: | 5 years | | | |
| Study Hypothesis: | A CEE model will increase patient engagement in solitary and interactive | | | |
| ' '' | language activities and improve staff and patient experiences of | | | |
| | communication compared to a standard ward environment. | | | |
| Primary outcomes: | The primary outcome is the change in the proportion of solitary and | | | |
| , | interactive language activities as a percentage of total observed activity | | | |
| | after the implementation of the CEE model. | | | |
| | | | | |
| | Timepoint: Patient observations completed within 21 days post stroke. | | | |
| Secondary outcomes: | The differences post CEE model implementation in staff and patient | | | |
| Secondary outcomes. | perceptions of the barriers and facilitators to inpatient language | | | |
| | activities. | | | |
| | Timepoint: Within 18 months of embedding the CEE model. | | | |
| Study docions | | | | |
| | | | | |
| Study design: | Before-after non-randomised pilot study | | | |
| Key inclusion criteria: | Patients will be eligible for inclusion if they have/are: admitted to the | | | |
| | Patients will be eligible for inclusion if they have/are: admitted to the acute or rehabilitation ward for a stroke, less than 21 days post stroke | | | |
| | Patients will be eligible for inclusion if they have/are: admitted to the acute or rehabilitation ward for a stroke, less than 21 days post stroke during baseline phase or post-implementation phase, the ability to | | | |
| | Patients will be eligible for inclusion if they have/are: admitted to the acute or rehabilitation ward for a stroke, less than 21 days post stroke during baseline phase or post-implementation phase, the ability to provide informed consent as determined by the medical team, a | | | |
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| | Patients will be eligible for inclusion if they have/are: admitted to the acute or rehabilitation ward for a stroke, less than 21 days post stroke during baseline phase or post-implementation phase, the ability to provide informed consent as determined by the medical team, a Glasgow Coma Scale¹ score greater than 10 at the time of screening, an estimated length of hospital stay greater than 14 days, adequate English proficiency to participate in semi-structured interviews and are above 18 | | | |
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| _ | , |
|---------------------|--|
| | Staff will participate in a one-hour focus group to explore their |
| | perceptions of barriers and facilitators to inpatient language activities. A |
| | focus group interview schedule will be used across all focus groups. |
| | Implementation phase: The CEE model will be implemented within the |
| | acute and rehabilitation wards. |
| | Post-implementation phase: Intervention group patient observations |
| | and interviews, and staff focus groups will replicate baseline data |
| | collection. |
| Safety parameters | Patients and/or their significant others may experience increased levels |
| | of distress during recruitment and/or data collection. This may be the |
| | result of adjustment following stroke and/or diagnosis of aphasia and |
| | increased awareness of impairment. No other risks known regarding |
| | participation in this project. The baseline assessments and interview will |
| | be conducted by the Chief Investigator who has experience in supporting |
| | patients during this early stage of stroke recovery. If a patient or any |
| | significant others becomes upset or distressed, the assessment or |
| | interview will be paused with the option to |
| | discontinue and counselling strategies will be provided. |
| Statistical methods | Patient demographic and stroke characteristics will be presented using |
| /analysis | descriptive statistics. One-way ANOVA or the Kruskal-Wallis and chi- |
| • | square tests will examine differences in characteristics between groups. |
| | Time spent observed in interactive and solitary language activities will be |
| | expressed as a percentage of total observations. A mixed design ANOVA |
| | will be used to calculate the within-subjects variable of presence of |
| | aphasia and the between-subjects variable of a CEE on language activity |
| | levels of patients by comparing baseline to intervention phase |
| | observations. A qualitative description research approach will be used |
| | for the qualitative component of this research. The mixed methods |
| | design will enable the triangulation of the qualitative and quantitative |
| | data. |
| Sample size | The patient sample size was selected for this pilot study to collect data |
| determination: | across each observation period for each patient group in the baseline |
| | and intervention phases (see document: |
| | Observation_protocol_SD_version 3_23-02-16). The sample size for staff |
| | participants was selected to capture a sufficient breadth of professional |
| | perspectives. |

3. Introduction

Aphasia is an acquired communication disorder that affects approximately 30% of first ever ischaemic stroke survivors³ and persists in up to 61% of survivors one-year post stroke.⁴ Aphasia impacts all communication modalities with significant negative consequences for social participation, interpersonal relationships, autonomy, capacity to work and quality of life.⁵

Patients following stroke with aphasia (PWA) have been observed to spend less than 28% of their day communicating and 44% of their day alone during their first weeks of inpatient rehabilitation.⁶ Inadequate opportunities for communication places PWA at risk of developing maladaptive behaviours such as learned non-use of language.⁷

Environmental Enrichment (EE) refers to conditions which promote physical, cognitive and social activity and has been shown in animal models of stroke to enhance neuroplasticity⁸, promote better learning and memory and contribute to significant improvements in motor function.⁹ The human equivalent model¹⁰ in a rehabilitation unit results in patients spending more time engaged in activity and less time sleeping and alone.¹¹

4. Objectives

Aphasia is a complex language impairment and PWA may need additional support within an Enriched Environment. This pilot study seeks to develop and test an adapted model of an Enriched Environment, a Communication Enhanced Environment (CEE), as a strategy to provide PWA and patients following stroke without aphasia (PWOA) more opportunities to engage in language activities during inpatient rehabilitation. Within this study language activities include both *solitary activities* that may promote aphasia recovery such as reading, writing, listening to the radio, and the use of iPad applications, and *interactive activities* which are based in communicative interactions that involve an exchange of information with a communication partner involving talking, gesture and/or facial expression, reading, writing or drawing to communicate.

4.1 Hypotheses

A CEE will increase patient solitary and interactive language activities and improve staff and patient experiences of communication compared to a standard ward environment.

5. Study design

This mixed methods pilot study is a prospective before-after non-randomised controlled design in an acute and a rehabilitation ward of a metropolitan private hospital. The study involves three phases:

- i) Baseline: observe and quantify the current ward environment;
- ii) Implementation of the CEE model;
- iii) Post-implementation: assess the impact of the CEE model.

6. Study Population

i) Patients: The baseline group (n=8, 4 PWA, 4 PWOA) recruited within the baseline phase, and the intervention group (n=8, 4 PWA, 4 PWOA) recruited during the post-implementation phase.

ii) Staff participants: One representative from each acute and rehabilitation staff group including medical, nursing, volunteers, and allied health staff members (n=17), who are over 18 years old.

6.1 inclusion and exclusion criteria

Patients will be eligible for inclusion if they have/are: admitted to the acute or rehabilitation ward for a stroke, less than 21 days post stroke during baseline phase or intervention phase, the ability to provide informed consent as determined by the medical team, a Glasgow Coma Scale¹ score greater than 10 at the time of screening, an estimated length of hospital stay greater than 14 days, adequate English proficiency to participate in semi-structured interviews and are above 18 years of age. Patients with aphasia will also have an Aphasia Quotient below 93.7 on the Western Aphasia Battery-Revised.²

Patients will be excluded if they have/are: uncorrected hearing or vision, not medically stable, a documented diagnosis of dementia, traumatic brain injury or previous aphasia, a documented current untreated depression at the time of acute admission or are a participant in another research trial which may affect any of this study's outcome measures.

Staff and volunteers who are over 18 years old will be eligible to participate in this study.

7. Study Assessments and Procedures

Baseline

All recruited patients will complete the Montreal Cognitive Assessment, ¹¹ and The NIH Stroke Scale. ¹² PWA will also complete the Western Aphasia Battery-Revised. ² Patients' behaviour will be observed and video recorded for four hours per day on a Sunday, Monday and Tuesday between 7am to 7pm. A behaviour mapping tool (Appendix A) developed for this study will record patient engagement in language activities in the first minute of each five-minute interval across each four-hour observation period. Semi-structured interviews will explore patients' perceptions of barriers and facilitators to inpatient language activities. An interview schedule will be used across all interviews (Appendix B.). Supportive communication strategies will be used to facilitate PWA participation in interviews with transcriptions annotated to capture any non-verbal responses.

Staff will participate in a one-hour focus group to explore their perceptions of barriers and facilitators to inpatient language activities. A focus group/interview schedule (Appendix C.) will be used across all focus groups.

Implementation

The CEE model will be implemented within the acute and rehabilitation wards.

Post implementation

Intervention group patient observations and interviews, and staff focus groups will replicate baseline data collection.

8. Study Treatment

The CEE model incorporates the following strategies to encourage engagement in language activities:

- Staff training to facilitate patients' communication and provide opportunities to engage in language activities;
- ii) Patient access to:

- a) Communication enhancement resources such as iPads and audiobooks;
- b) Communal areas to facilitate engagement amongst patients.

9. Participant Completion and Discontinuation

9.1 Participant Completion

Participants will have completed the study when they have completed the semi-structured interview.

9.2 Participant withdrawal

Participation in this study is voluntary. The participant can withdraw from taking part in the study at any time without giving a reason for withdrawing.

10. Data analysis

10.1 Primary Analysis

The proportion of observed episodes where PWA and PWOA are engaged in language activities at baseline and post implementation will be analysed using a mixed design ANOVA.

10.2 Secondary Analysis

The differences in staff and patient perceptions of the barriers and facilitators to inpatient language activities and communication post CEE implementation will be analysed through a qualitative description approach. Triangulation of the qualitative and quantitative data will be conducted.

11. Data management

The data collected will be confidential. No identifying information will be attached to the data and any information that may reveal participant's identity will be removed. The master list of participant names and codes will be kept in a locked filing cabinet at the hospital site which will only be accessible by the research team. All data will be accessed, used and stored in accordance with Commonwealth Privacy Laws. The de-identified data will be stored on a password-controlled computer and/or in a locked cabinet at Edith Cowan University. Electronic data will be backed up on a password controlled hard drive only accessible by the Chief Investigator.

The data collected from this study will have a significant contribution to the aphasia research area and therefore will be stored for 15 years following the completion of this study. Data may be accessed for future studies by the study investigators or higher degrees by research (HDR). In the case of HDR use of the data, the use of the data will be bound by a two-way confidentiality agreement. The data may be used for teaching purposes only with the additional written permission from participants. The data may be made accessible to consumer groups (for example the Australian Aphasia Association) and information may be made available through the National Stroke Foundation and scientific journals. Confidentiality will be maintained in all circumstances. Non-identifiable data will be accessible by researchers through data sharing archives. This data will be governed by an overarching body to ensure data are only used for approved purposes. Researchers who access this data from the data bank will not have access to the participant keys that attach participants to codes therefore data will only be re-identifiable by the Chief Investigator. Data will be deleted from electronic storage and hard copy data will be shredded by the chief

investigator after 15 years completion of the research study (with Ethics Committee approval, Ethics approval numbers: HPH431 and ECU HREC 12149). Non-identifiable data will be added to data archives for data sharing. Researchers who access data archives will not have access to information attaching participants to coded data.

12. Study Report

This study will be published in a PhD thesis as part of the Chief Investigator's Higher Research Degree. Outcomes from this study will be published in peer review journals and at conferences.

13. Administration Procedures

13.1 Ethical Considerations

This research is likely to have a significant impact on aphasia recovery following stroke and will form the basis for future study designs. This study will develop a teaching and learning package that can be used in the future to facilitate and promote increased levels of communication activity during early stroke recovery. The implementation of a CEE may address missed opportunities for language stimulation, harness increased levels of neuroplasticity and optimise aphasia language recovery after stroke. The benefit of a CEE may extend beyond patients with aphasia and may improve health care experience and communication access for all patients following stroke. Additionally, these benefits may extend beyond patients involved in the study as trained staff may use skills and knowledge obtained in the training program to enhance the communication environment of all patients they care for.

13.2 Ethical Review Committee

All processes and documentation used within this study will be reviewed and approved by the Edith Cowan University Research Ethics Committee and the site Ethics Committee. The Chief Investigator will complete the annual ethics reports and will be responsible for reporting any adverse events to the Ethics Committees.

13.3 Informed Consent

Participants will be excluded if they do not have adequate English proficiency to participate in semi-structured interviews and focus groups. Any participants that require an interpreter will be excluded from inclusion in this study as determined by the medical team.

Patients with aphasia will be provided with aphasia friendly information sheets and consent forms with simple language, bold key words and pictorial support. This will be read and explained by the researcher. Supported conversation strategies will be used to support and facilitate patients with aphasia's involvement and understanding of the research process, informed consent and their rights to withdraw at any time. This will be provided by the Chief Investigator who is a qualified speech pathologist with experience in communicating with patients with aphasia using supported conversation techniques to facilitate and support communication. A detailed information will also be provided to the 'person responsible' for all patients.

13.4 Protocol Amendments

All protocol amendments will be reviewed and accepted by the Edith Cowan University Research Ethics Committee and the site research Ethics Committee.

14. References

- 1. Teasdale G, Jennett B. Assessment of coma and impaired consciousness. A practical scale. Lancet. 1974;2(7872): 81–4.
- 2. Kertesz A. Western Aphasia Battery- Revised. San Antonio, TX, Harcourt Assessment; 2006.
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- 5. Kruithof WJ, van Mierlo ML, Visser-Meily JM, van Heugten CM, Post MW. Associations between social support and stroke survivors' health-related quality of life a systematic review. Patient Educ Couns. 2013;93(2): 169–76.
- 6. Godecke E, Armstrong E, Hersh D, Bernhardt J. Missed Opportunities: Communicative interactions in early stroke recovery. Stroke Society of Australasia Annual Scientific Meeting. Hamilton Island, Queensland. 2014.
- 7. Nithianantharajah J, Hannan AJ. Enriched environments, experience dependent plasticity and disorders of the nervous system. Nat Rev Neuroscience. 2006;7(9): 697-709.
- 8. Janssen H, Bernhardt J, Collier JM, et al. An enriched environment improves sensorimotor function post–ischemic stroke. Neurorehab Neural Re, 2010;24(9), 802–813.
- 9. Janssen H, Ada L, Karayanidis F, et al. Translating the use of an enriched environment poststroke from bench to bedside: study design and protocol used to test the feasibility of environmental enrichment on stroke patients in rehabilitation. Int J Stroke. 2012;7: 521–526.
- 10. Janssen H, Ada L, Bernhardt J, et al. An enriched environment increases activity in stroke patients undergoing rehabilitation in a mixed rehabilitation unit: A pilot non-randomized controlled trial. Disabil Rehabil. 2014;36(3), 255–262.
- 11. Nasreddine ZS, Phillips NA, Bédirian, V, et al. The Montreal Cognitive Assessment, MoCA: A brief screening tool for mild cognitive impairment. J Am Geriatr Soc. 2005;53(4); 695-9.
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| Гіте (5 min): | NO LANGUAGE ACTIVIT | COMMENTS | | |
|--|--|--|---|----------|
| Location (select one) | People present INTERACTIVE LANGUAGE ACTIVITIES | | 'OTHER' FUNCTIONAL LANGUAGE ACTIVITIES | |
| Amenities | Nurse | In person | Typing/writing | |
| sedroom | Personal care assistant | Telephone | Reading (describe) | |
| Hall | Doctor | Therapy session/ward round | , , , , , , , , , , , , , , , , , , , | |
| herapy area | Physio | Other (describe) | Texting (mobile phone) | |
| amily Mtg Room | OT | Carlot (addende) | Listening to radio/music | |
| Activity room | SP | Patient | Watching TV | |
| totivity room | DT | Verbal communication | Internet use (describe) | |
| ON WARD | Social worker | Non-verbal gesture/facial expression (describe) | internet use (describe) | |
| Doctor's room | Family/Friend | Non-verbai gestare/raciai expression (describe) | Word games with a partner | |
| Dining room | Other patient | Written aids (writing or reading (circle)) | Other (describe) | |
| o . | • | | Other (describe) | |
| Communal area (describe) | Alone | Pictorial aids (describe) | | |
| OFF WARD | Other (describe) | Other communication aid (describe) | NON FUNCTIONAL / NON PROPOSITIONAL | |
| OFF WARD Outside | | Communication partner/s | NON-FUNCTIONAL/ NON-PROPOSITIONAL LANGUAGE ACTIVITIES | |
| Off-unit <i>(describe)</i> | | Verbal communication | | |
| on-unit (describe) | | Non-verbal gesture/facial expression (describe) | Singing Word games (alone) | |
| Other (december) | | Non-verbai gesture/raciai expression(describe) | , | |
| Other (describe) | | Main an aide | Language apps (alone) | |
| | | Written aids | Copying written letters, words, sentences (alone). | |
| | | Pictorial aids | OTHER | |
| | | Other communication aid (describe) | Talking to observer | |
| | | | Talking to self: appropriate/inappropriate (describe) | |
| | | | | |
| Гіте (5 min): | NO LANGUAGE ACTIVIT | TIES OBSERVED (describe) | 10. | COMMENTS |
| Location (select one) | People present | INTERACTIVE LANGUAGE ACTIVITIES | 'OTHER' FUNCTIONAL LANGUAGE ACTIVITIES | |
| Amenities | Nurse | In person | Typing/writing | |
| Bedroom | Personal care assistant | Telephone | Reading (describe) | |
| Hall | Doctor | Therapy session/ward round | | |
| herapy area | Physio | Other (describe) | Texting (mobile phone) | |
| amily Mtg Room | OT | . | Listening to radio/music | |
| Activity room | SP | Patient | Watching TV | |
| NI WADD | DT Conint worker | Verbal communication | Internet use (describe) | |
| ON WARD Ooctor's room | Social worker | Non-verbal gesture/facial expression (describe) | Word games with a partner | |
| Doctor's room Dining room | Family/Friend Other patient | Writton aids (writing or reading (sirele)) | Word games with a partner Other (describe) | |
| Dining room Communal area <i>(describe)</i> | Alone | Written aids (writing or reading (circle)) Pictorial aids (describe) | Other (describe) | |
| ommunai area (uescribe) | Other (describe) | Other communication aid (describe) | NON-FUNCTIONAL/ NON-PROPOSITIONAL | |
| OFF WARD | Cities (describe) | Other communication aid (describe) | LANGUAGE ACTIVITIES | |
| Outside | | Communication partner/s | Singing | |
| Off-unit <i>(describe)</i> | | Verbal communication | Word games (alone) | |
| u.m (4000/100) | | Non-verbal gesture/facial expression(describe) | Language apps (alone) | |
| Other (describe) | | (orbai gootaro/radiai expression(accombe) | Copying written letters, words, sentences (alone). | |
| (10000) | | Written aids | OTHER | |
| | | Pictorial aids | | |
| | | Other communication aid (describe) | Talking to observer | |
| | 1 | - 1 | Talking to self: appropriate/inappropriate (describe) | 1 |

Appendix B. Patient interview guide

Investigating Communication Enhanced Environments after stroke Patient Interview guide, version 1_11-8-15

Tell me about what kind of activities you do while you are here (in hospital).

Describe your experience of communicating with people on the ward.

What makes it easier to communicate with people on the ward?

What makes it hard to communicate with people on the ward?

What can we do to make communicating with people easier?



Appendix C. Staff focus group guide.

Investigating Communication Enhanced Environments after stroke Staff focus group guide, version 1_27-7-15

STAFF FOCUS GROUP GUIDE BASELINE PHASE

What kind of language activities or language tasks do stroke patients currently participate in on the ward?

What kind of language activities or language tasks would you like see stroke patients have access to on the wards?

Describe your experience of communicating with stroke patients at the moment.

Can you tell me about anything that facilitates your ability to communicate with stroke patients on the ward?

Can you tell me about any barriers you experience that impact your ability to communicate with stroke patients on

the ward?

What changes would you like to see to enhance communication between staff and stroke patients on the ward?

What changes would you like to see to enhance communication between visitors and stroke patients on the ward?

How could we enhance or optimise communication and language tasks and activities for stroke patients on the

ward?

What do you think a communication and language enhanced stroke ward environment might look like?

STAFF FOCUS GROUP GUIDE POST-IMPLEMENTATION PHASE

Describe your experience of communicating with stroke patients at the moment.

Can you tell me about any barriers you experience that impact your ability to communicate with stroke patients on

the ward?

Describe the differences in the communication environment since implementing the model.

What changes did you see to enhance communication between staff and stroke patients on the ward?

What changes did you see to enhance communication between visitors and stroke patients on the ward?

What was it like to use the model?

How do you feel about the model?

Can you tell me about anything that helped you use the model with stroke patients on the ward?

Can you tell me about any barriers you experienced while implementing the model?

How can we improve the model?

Communication Enhanced Environments after Stroke

Study procedure version 2_23-02-16

BASELINE:

Staff recruitment: The Chief Investigator will recruit staff participants through a verbal explanation of the study and the provision of the information sheets and written consent forms. Staff will be provided 48 hours to discuss the study and ask questions before consenting to participate. Staff interviews and focus groups will commence as staff participants are recruited. Staff will participate in a one-hour focus group or a one-hour semi-structured interview (in person or via telephone) to explore staff perceptions of environmental barriers and facilitators to language activity and communication on in-patient acute and rehabilitation wards.

Patient recruitment: All consecutively admitted patients following stroke during the baseline period will be screened for eligibility to participate in the study. The hospital site investigators will identify potential stroke participants that meet the inclusion and exclusion criteria. Stroke participants with aphasia will be identified by the hospital speech pathology or medical team as having a diagnosis of aphasia (aphasia diagnosis will be confirmed via Western Aphasia Battery-Revised (WAB-R)¹ Aphasia Quotient score <93.7 during data collection). The site investigators will approach potential participants and gain verbal consent from the patient to be approached by a member of the research team and have their 3-point identification released to the research team. This will be documented in the patient's integrated medical progress notes. Once verbal consent has been gained and documented, the site investigators will email the Chief Investigator the patient alert proforma identifying the patient as meeting the inclusion/exclusion criteria. The research team will liaise with the medical team to confirm the potential stroke participant meets the inclusion criteria: (i) admitted to the in-patient rehabilitation stroke unit for recent stroke, (ii) are less than 21 days post stroke and during baseline phase or intervention phase, (iii) have the ability to provide informed consent as determined by the medical team iv) Glasgow Coma Scale² greater than 10 at the time of screening, (v) have an estimated length of stay greater than 14 days and (vi) have adequate English proficiency to participate in semi-structured interviews. Patients will be excluded if they (i) have uncorrected hearing or vision (for example hearing impairment without hearing aids, vision impairment without glasses), (ii) are not medically stable, (iii) have a documented diagnosis of major depression or (iv) have a documented history of dementia or significant cognitive decline, traumatic brain injury or previous aphasia at the time of admission for the acute event, (v) or are a participant in a research study that will influence this study's outcomes. Stroke participant recruitment will follow the stroke participant consent procedure (see document: SD_Communication Enhanced Environments after Stroke consent procedure version 1_3-2-15). A record of identifying participant details attached to patient codes will be kept at the hospital site in a locked filing cabinet. An email summary of the baseline assessment results will be sent to the hospital speech pathology generic email address. The patient will be identified by patient code and ward/room number. The hospital speech pathology team will write a summary of the assessment results in the patient's integrated medical progress notes.

Patient data collection: All recruited stroke participants will complete the NIH Stroke Scale³ (by someone trained in using this tool) and the Montreal Cognitive Assessment (MoCA).⁴ Participants with aphasia will also complete an assessment of aphasia, the WAB-R¹ and provide a personal narrative language sample on their reason for admission to confirm a diagnosis of aphasia. After patient recruitment has been completed, the Chief Investigator and/or trained medical team members will recruit the patient's family, friends and significant others to consent to video recording and observations of their interactions with stroke participants.

Observations of stroke participants will commence 1-3 days after obtaining written consent. Patients' behaviour will be observed by the Chief Investigator or a Research Assistant, and video recorded for a total of 12 hours to enable behaviour mapping of video data (see document: Observation_protocol_SD_version 3_23-02-16). Patients will be observed and video recorded for 4 hours per day on weekend day and two consecutive weekdays between 7am to 7pm. The observation periods will be grouped into 4-hour observation intervals (e.g. 7am-11am, 11am-3pm and 3pm-7pm). Each day the patient will be observed and video recorded for one observation interval. The participant will be observed and video recorded during a different observation interval each day to gain a general insight into the patients' activities (see Figure 1. below). Patients who do not consent to video recording will be provided with the option of audio recording and manual observation conducted by the researcher to enable the collection of case notes regarding patient behaviour. An observational protocol developed for this study will be used to measure the frequency stroke participants engage in language activities. These will be categorised into solitary language activities for example reading, writing, listening to the radio, use of iPad applications, and interactive language activities defined as i) an interaction involving an exchange of information, ii) with a communication partner including gesture and/or facial expression, reading, writing or drawing for the purpose of communication and use of technology including talking on the telephone. The observational protocol will be based on the behavioural mapping techniques of Janssen et al.⁵ Patients' solitary and interactive language activities will be recorded in 5-minute intervals and activity observed within the first minute of the observation interval will be recorded on a checklist of the predetermined behaviours. Semi-structured supported conversation interviews for stroke participants will be conducted within 5 days of the last observation. The interviews will explore patients' perceptions of environmental barriers and facilitators to language activities and communication and their experience of communication on the acute and rehabilitation wards.

IMPLEMENTATION:

A model of a CEE will be implemented within the acute and rehabilitation wards. The model will be developed as part of the research project. We hypothesise that our model of CEE will include the provision of:

- i) CEE equipment, for example reading materials such as books and magazines, access to a computer with internet and access to a communal dining area,
- ii) CEE education, support and training for staff, patients and their family, friends and significant others with the aim to develop the ability to support and facilitate 'language activity' and 'communication activity' for patients after stroke. This will be accessible via multiple modalities including one-on-one training and group training sessions, as

well as through the provision of video and written resources. A questionnaire will be administered pre and post training in order to determine staffs' perceptions of changes in their knowledge, skills and attitude towards communication and aphasia. Additionally, feedback regarding the content and format of the training program will be obtained through questionnaires administered after the completion of the training program. Training and support provided in the implementation phase will be continued until the end of the intervention phase.

POST-IMPLEMENTATION:

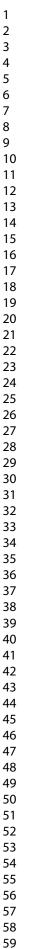
Staff participant semi-structured interviews and focus groups will be conducted. Staff will participate in a one-hour semi-structured interview or a one-hour focus group to explore staff perceptions of environmental barriers and facilitators to language activities and communication.

The procedures for participant recruitment and data collection during the post-implementation phase will replicate those used in the baseline phase.

There is no travel commitment for all participants as all data collection and training will be conducted at the hospital.

| Observation | Observation | Day 1: | Day 2: | Day 3: |
|-----------------------------------|-------------|--------|--------|---------|
| interval | time | Sunday | Monday | Tuesday |
| | | | | |
| 1 | 7am-8am | PWA1 | PWA3 | PWA2 |
| | 8am-9am | PWOA1 | PWOA3 | PWOA2 |
| | 9am-10am | | | |
| | 10am-11am | | | |
| 2 | 11am-12pm | PWA2 | PWA1 | PWOA |
| | 12pm-1pm | PWOA2 | PWOA1 | PWOA3 |
| | 1pm-2pm | | | |
| | 2pm-3pm | | | |
| 3 | 3pm-4pm | PWA3 | PWA2 | PWA1 |
| | 4pm-5pm | PWOA3 | PWOA2 | PWOA1 |
| | 5pm-6pm | | | |
| | 6pm-7pm | | | |
| igure 1. CEE Observation schedule | | | | |
| | | | | |
| | | | | |
| | | | | |

Figure 1. CEE Observation schedule



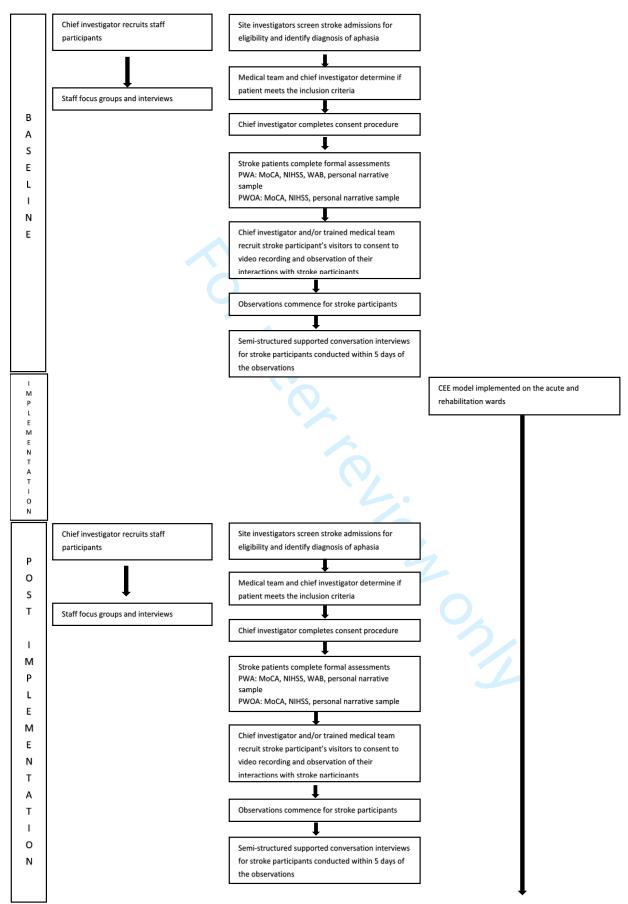


Figure 2. Study flow diagram

References

- 1. Kertesz A. Western Aphasia Battery-Revised. San Antonio, TX, Harcourt Assessment; 2006.
- 2. Teasdale G, Jennett B. Assessment of coma and impaired consciousness. A practical scale. Lancet. 1974;2(7872): 81–4.
- 3. NIH stroke scale [Internet]. Bethesda, Md, National Institute of Neurological Disorders and Stroke (U.S.). 2011 [cited 2016 Feb 10]. Available from https://www.ninds.nih.gov/sites/default/files/NIH_Stroke_Scale.pdf
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- 5. Janssen H, Ada L, Bernhardt J, et al. An enriched environment increases activity in stroke patients undergoing rehabilitation in a mixed rehabilitation unit: A pilot non-randomized controlled trial. Disabil Rehab, 2014; 36(3), 255–262. doi: 10.3109/09638288.2013.788218

Communication Enhanced Environments after Stroke consent procedure

Version 1_3-2-15

Stroke participants

The following consenting procedure will be used for all participants who are identified as potential research participants. Recruitment will only be completed by the Chief Investigator.

- 1. Check the stroke participant meets the inclusion criteria and exclusion criteria.
- 2. Read the participant information sheet to the participant. Use the pictures on the participant consent form to support the patient's comprehension of verbal information. Use gesture, written and pictorial support to facilitate verbal communication as required.
- 3. Provide the person responsible with the person responsible information sheet and consent form.
- 4. Provide time for the stroke patient and the person responsible to discuss the study and ask questions to their satisfaction.
- 5. Ask the stroke participant if they consent to the study using simple closed questions (e.g. "Do you understand what the study is about?", "Do you have any questions about the study?", "Do you want to be in the study?", "Will you sign the form?". Use multi-modal communication strategies and repeat information/questions as required. Use the pictures on the participant consent form to support patient comprehension of verbal information.
- 6. If the stroke patient agrees to participate in the study, ensure they sign the consent form witnessed by someone independent of the study.
- 7. Provide the stroke participant with a copy of the information sheet and consent form for their own records.
- 8. Add the participant study number to the consent form
- 9. Store the signed consent forms in a locked cabinet at the hospital site. This cabinet will only be accessible by the research investigators.

Investigating Communication Enhanced Environments after stroke Observation Protocol version 3_ 23-2-16

During the baseline and intervention period, patients' behaviour will be observed and video recorded for a total of 12 hours. Patients who do not consent to video recording will be provided with the option of audio recording and manual observation. This will enable the collection of relevant notes about factors that might influence the interactions that may not be captured in the video or behavioural mapping, for example the context of the interactions or details about the environment.

Patients will be manually observed <u>and</u> video recorded for four hours per day on two weekdays and one weekend day between 7am to 7pm. The observations will be grouped into three x 4-hour observation intervals (e.g. 7am-11am, 11am-3pm, 3pm-7pm). Each day the patient will be observed and video recorded for one of the 4-hour observation intervals. The 4- hour observation period will be split into 5-minute intervals. All language and communication activity observed within the first minute of the 5-minute interval will be recorded on the behavioural mapping sheet with predetermined behaviours (Appendix 1). The free smart phone app 'Impetus' can be used to time 1-minute observations. You can set the timer to vibrate briefly when the 1-minute observation interval begins and ends.

Observation times (see Figure 1.) will be randomly selected by drawing out of an envelope. This will be conducted by the primary investigator prior to commencing patient observations. It may not be possible to observe the patient during the planned observation time, for example as a result of scheduled testing or home visits. If this occurs, patients can be observed during the next available observation interval. Changing or modifying the observation schedule should be avoided where possible.

| Observation | Observation | Day 1: | Day 2: | Day 3: |
|-------------|-------------|---------|--------|---------|
| interval | time | Sunday | Monday | Tuesday |
| | | | | |
| 1 | 7am-8am | *PWA1 | PWA3 | PWA2 |
| | 8am-9am | **PWOA1 | PWOA3 | PWOA2 |
| | 9am-10am | | | |
| | 10am-11am | | | |
| 2 | 11am-12pm | PWA2 | PWA1 | PWA3 |
| | 12pm-1pm | PWOA2 | PWOA1 | PWOA3 |
| | 1pm-2pm | | | |
| | 2pm-3pm | | | |
| 3 | 3pm-4pm | PWA3 | PWA2 | PWA1 |
| | 4pm-5pm | PWOA3 | PWOA2 | PWOA1 |
| | 5pm-6pm | | | |
| | 6pm-7pm | | | |

Figure 1. Observation schedule *PWA: patient with aphasia

^{**}PWOA: patient without aphasia

DISCOURSE SAMPLE

You must collect a personal narrative discourse sample for each participant at the beginning of the first observation. Once you have set up the video camera and have started recording, ask the patient "what has brought you into hospital?". Once the patient has finished telling you their personal narrative, tell the patient you will now start the observations.

VIDEO RECORDING SET-UP

Place the video camera facing the patient approximately 1-2 metres away from them. Ensure the camera is placed in an area where it is unlikely to be moved for the duration of the observation time (for example at the end of the patient's bed). Ensure the camera frame is capturing the patient as well as their surroundings (e.g. potential communication partners, visitors, etc). If the patient relocates, reposition the camera to ensure the patient and their surroundings remain in frame. Observe and manually record the patient's behaviour and their environment according to the procedure for behavioural mapping.

Do not record the patient in the bathroom or shower or during any other inappropriate circumstances (this may include sensitive conversations, culturally sensitive situations or if the patient requests). If the patient indicates that they don't want to be recorded or becomes agitated, upset or distressed, use the 'withdrawal from observations visual resource' (if appropriate) and ask the patient:

- 1. Do they want you to stop video recording?
- Do they want to be manually observed and audio recorded instead?If the patient responds 'no', ask the patient-
- 3. Can you come back another time to observe them?

If the patient asks you to stop recording you must cease recording immediately. The patient may allow you to continue with manual observations or come back another time to complete the observations. If the patient allows you to complete manual observations and audio recording, follow the audio-recording set-up and protocol below.

AUDIO RECORDING SET-UP AND PROTOCOL

This protocol is to be followed if the patient or their family indicate they do not want to be video recorded however agree to audio recording and manual observations. Place the cap on the video camera and continue recording in order to capture audio. If using a battery-operated audio recorder, place it on a table close to the patient (within 1 metre). Ensure the audio recorder is placed in a location where it will not be touched or moved throughout the

observation time. Observe and manually record the patient's behaviour and their environment according to the procedure for behavioural mapping. Ensure spare batteries for the audio recorder are available if required.

COMMUNICATION PARTNERS AND VISITORS

Take note of all communication partners and visitors who have provided consent to video recording and/or observations of their patient interactions. If someone enters the room during recording politely interrupt the interaction, introduce yourself and inform the person that the patient is being video recorder recorded as a part of the study the patient has agreed to participate in. Ask the visitor if they would like to go out of the room with the researcher to find out about the study and the video recording. Provide a verbal explanation of the study and provide the 'Visitors/communication partners' information and consent form'. Offer the visitor the option of no video or manual recoding during their interaction with the patient. If the person chooses not to participate in manual or video observations inform the person that any incidental recordings of them will be deleted and will not be included in the study. The researcher will step out of the room for the duration of their visit.

PROCEDURE FOR BEHAVIOURAL MAPPING

- Position self where the patient can be clearly observed
- Remain inconspicuous as possible
- Circle ALL appropriate components on the observation schedule in regards to location, activity, people
 present and details of language and communication observed within the first minute of each five-minute
 interval.
- You can circle more than one key per section if required (except for location).
- If you require a toilet break, leave the camera recording while you take a break. If you miss a 1-minute
 observation, place a line through the observation interval on the behavioural mapping sheet and write
 'unobserved-toilet break'.

TIME

Write the time at the beginning of the 1-minute observation interval

LOCATION

- Circle only one location
- If the patient is moving between two locations, circle the location the patient is moving towards

AMENITIES: Toilet, shower.

BEDROOM: Around the patient's room or bed. If the patient is outside of their doorway this is considered 'hall'.

HALL: Any hallway within the hospital ward.

THERAPY AREA: In an allied health therapy session, including occupational therapy, physiotherapy, speech pathology, nursing.

FAMILY MEETING ROOM: Family meeting room.

DOCTOR'S ROOM: Doctor's office.

DINING ROOM: Dining room during meal times or any other time.

COMMUNAL AREA: Communal dining area.

OUTSIDE: Outside areas including the garden, car park.

OFF UNIT: Off-site locations, home visits, testing off site.

OTHER: Anything that doesn't fit into the above categories-provide description of location.

PEOPLE PRESENT

People present include any person that is near the patient and is able to have an interaction with the patient. If you do not know how to classify the person make a note to check with staff at a later time and complete the observation schedule.

Exceptions: People who are near the patient but are unable to interact with the patient, e.g. cognitive or behavioural issues, barriers between person and the patient preventing them from interacting- e.g. curtain drawn, people in the way. If an interaction is occurring despite objects in the way, the communication partner is considered as a 'person present'.

PEOPLE PRESENT: Nurse, nurse assistant, doctor, physio (physiotherapist), OT (occupational therapist), SP (speech pathologist), DT (dietician), SW (social worker), family/friend, other patient, alone (no-one present that is conducive to interactions), other (describe).

ACTIVITIES

UNOBSERVED: If you are unable to observe the patient. Place a line through the observation

interval and write unobserved.

NO LANGUAGE ACTIVITY: If the patient is observed not engaged in any communication activity.

- Circle 'no activity' on the checklist
- Write what the patient is doing, e.g. 'sleeping'

INTERACTIVE LANGUAGE ACTIVITIES: Defined as an interaction involving an immediate communicative exchange with a communication partner. Interactive language activities may include talking, gesture and/or facial expression, reading, writing or drawing for the purpose of communication, use of communication aids or AAC devices and use of technology including talking on the telephone. Non-verbal gesture or facial expression includes eye contact to

initiate interactions, hand gestures (e.g. waving, thumbs up), body movements for the purpose of conveying a communicative message (e.g. shrugging) and/or facial expressions for the purpose of communication.

Communication aids or AAC devices includes any use of alternative and augmentative devices for the purpose of communication, e.g. high-tech or low-tech AAC devices such as letter boards, pictures/photos, whiteboard, writing or drawing, smart phones, iPad. Please describe communication aids observed.

OTHER FUNCTIONAL COMMUNICATION ACTIVITIES: All other communication activities that do not involve a direct immediate communicative exchange with a communication partner. Functional communication activity may include reading, typing/writing, emailing, internet use, watching TV, listening to talking on the radio. Note the patient must be looking directly at the TV to be considered 'watching TV'. If the TV is on in the background, do not include this as 'watching TV'.

NON-FUNCTIONAL/NON-PROPOSITIONAL LANGUAGE ACTIVITIES: Singing, word games (carried out alone), language apps (used alone), copying written letters, words or sentences (carried out alone).

OTHER: Communication or language activities that do not fit the criteria of interactive language activity, 'other' functional communication activities, non-functional/non-propositional language activities or may be a confounding variable (for example, talking to self and talking to the observer). If a patient is talking to themself, note if this is appropriate (for example, saying 'excuse me' after burping) or inappropriate (for example, an extensive monologue) and describe the context. If the patient's verbal output is inaudible, write this is in the space underneath 'talking to self'.

Note: If the patient is using a computer, phone, smart device, or iPad where the activity they are engaged in (e.g. texting, emailing, playing a game, etc) cannot be accurately determined, note this in the comments section. After the 1-minute observation interval has been completed ask the patient if they mind sharing if what activity they were completing on their device and record this in the relevant section. If the patient does not wish to share this information with you, record this in the 'other' section.

COMMENTS

Describe the context of the interactions or details about the environment in the comments section. This will provide information regarding factors that may influence the interactions, for example 'background noise'. Additionally, write down any information that may be missed in the video data, for example, people out of the camera frame, interactions that may be overheard in the room that might impact on the current interactions.

Draw a line under the final comment after the one-minute observation had been completed. Write any additional observations within the final 4 minutes below this line (see example).

If you have any queries or questions regarding this observation protocol or the observation protocol please contact chief investigator Sarah D'Souza.

Stroke participant information and consent form Communication activity in hospital

This research project is being undertaken as **part of** the **requirements** of a **PhD at Edith Cowan University**.

Researchers' contact details

| Edith Cowan University | | | |
|---|---------------------|------------------|--|
| Chief Investigator/ | Sarah D'Souza | Ph: 0439 982 451 | |
| PhD student | | | |
| Principal Supervisor | Professor Beth | Ph: 08 6304 2769 | |
| | Armstrong | | |
| Co-Supervisor | Associate Professor | Ph: 08 6304 2047 | |
| | Natalie Ciccone | | |
| Co-Supervisor | Associate Professor | Ph: 08 6304 5901 | |
| | Erin Godecke | | |
| Co-Supervisor | Associate Professor | Ph: 08 6304 2563 | |
| | Deborah Hersh | | |
| Hunter Stroke Service, University of Newcastle and Hunter | | | |
| Medical Research Institute | | | |
| Adjunct Supervisor | Dr Heidi Janssen | Ph: 02 40420417 | |

You are **invited** to participate in a research project. Sarah D'Souza, a speech pathologist and PhD student is leading the study as Chief Investigator. This study has received ethical **approval** from **ECU** Human Research **Ethics Committee** and the Hollywood Private Hospital Research Ethics Committee.

This project is investigating the **hospital environment** to see how this **influences** patient **communication activity**. Communication activity involves communication, such as **talking** with other patients, **socialising**, **reading** the paper, using the **telephone**, talking to staff, or engaging in group activities including **therapy**.

You have been selected to participate as you have had a stroke and are receiving treatment at Hollywood Private Hospital. We are interested in seeing how the hospital surroundings affect what you do throughout the day.

What would you have to do?

You will be **asked** to provide **consent** to **agree to participate** in the study.

You will be **asked to consent** to:

Complete three tests to see how your stroke has affected you
including your language, concentration and memory. These tests
will be conducted at the beginning of the project. The tests will take
approximately 1 hour to complete with an option to complete the tests

over **two separate 30 minute sessions** and with as many **breaks** as you may need.

- A researcher spending approximately 1 hour discussing with you
 your opinion regarding how your rehabilitation surroundings affect
 your stay in hospital and your communication activity levels.
- A researcher video recording, observing and writing down what is happening in your environment including your activities. You will be observed and recorded for a total of 12 hours over 3 days.

You may **not want** to be **video recorded**. If you **request**, you will **not** be **video recorded**. You can ask not to be video recorded at **any time**. In this case the researcher will **only observe**, **audio record** and **write down** what is **happening in your** environment **including** your activities.

- A researcher looking at your hospital medical file to collect information regarding:
 - Your details (such as your age, your living arrangements, your occupation and your level of functioning before your stroke)
 - Any conditions or diseases you may have
 - Information about your stroke (for example when it happened, the area of the brain affected, how it has affected your functioning and abilities)
 - Details about how long you have been in hospital since your stroke

If you decide to participate in this study, you will not miss out on any treatment. Participation will not cost you anything and after completing the tests and the interview you will be asked to continue participating in your normal activities.

We will **not record** if you are **behind closed curtains** or completing sensitive tasks such as when you are in the **toilet** or **shower**.

We may use the **recordings** of **you** to make a **training package** (including a video). You can have **your face blurred out** if you want. If you **do not want** to be in the training package we will **not include you** in the training package or video.

Your hospital **discharge** will **not be affected** because you are in this study. **You** will be **discharged** from hospital when the hospital **medical team decides** that you are **ready**.

There are **no known risks** of participating in this study. If you feel uncomfortable at any time, you are free to **tell the researcher** and **observations** within your room will **stop immediately**. You may become **upset** during the **tests** or the **interview**. If this happens you can **ask** to take a **break or stop** the interview.

There will be **no immediate benefit** to you from participating in this research; however your participation will allow the collection of

information that may **help improve** stroke **hospital wards** which may **benefit** future stroke survivors.

Participating in this study is completely voluntary. You do not have to participate if you don't want to. If you decide to participate you may withdraw at any time without giving a reason and withdrawing will not disadvantage you in any way and will not affect your hospital treatment. If you decide that you do not want to participate in the study, you can ask to remove all of your information from the study.

All the **information** you give will be **confidential**. You will **not be identified** by name. You will be **assigned** a unique **code** and any information that may reveal your **identity** will be **removed**.

All personal health information will be accessed, used and stored in accordance with Commonwealth Privacy Laws. **Information** from all the people in the study is **combined** and **summarised**.

We will store all your electronic information on a password locked computer and password locked hard drive only accessible by the Chief Investigator. Your hard copy information will be kept in a locked cabinet at Edith Cowan University. You information will only be accessible to researchers named on this study.

The **results** of this study may be **published** in research **journals** or presented at **conferences**. Your **name** will **not** be **used**.

Data may be **used** in higher degree by **research studies** in the **future**. **Confidentiality** will be **maintained** and no identifying information will be used.

Data will be **accessible by researchers** through data sharing archives. This data will be governed by an overarching body to ensure data is **only used for approved research** purposes. Researchers who access this data from the data bank will not have access to participant information and therefore **will not know your identity**.

Read this information and be sure you **understand** its content **before** you **agree** to participate in this study.

If you would like to participate in this study, please sign the form below and return it to a staff member or a member of the research team.

Questions or further information?

You may wish to discuss this information with your doctor, a relative or friend before agreeing to take part in this study.

If you are interested in participating, please tell the researchers. If you have any questions or require any further information about the research project, please contact: Sarah D'Souza [Ph: 0439 982 451].

Thank you for considering the invitation to take part in this research project.

Yours sincerely,

Sarah D'Souza

If you have any **concerns or complaints** about the research project and wish to **talk to an independent person**, you may contact:

Kim Gifkins

Senior Research Ethics Advisor

Edith Cowan University

270 Joondalup Drive

JOONDALUP WA 6027

Phone: **(08) 6304 2170**

Email: research.ethics@ecu.edu.au

This project has been approved by the ECU Human Research Ethics Committee and the Hollywood Private Hospital Research Ethics Committee.

You have been asked to participate in a research study.

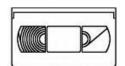






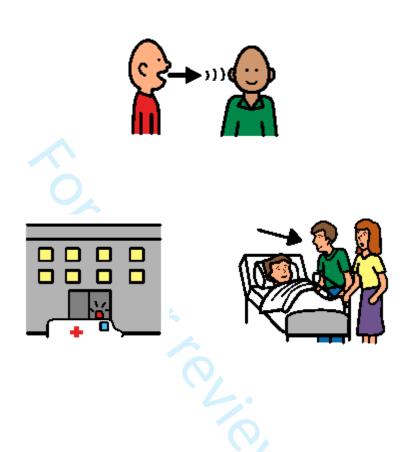
A researcher will record you with a tape recorder or a video camera, watch and write down what is happening in your environment including your activities.







A researcher will discuss with you your opinion regarding how your hospital surroundings affect your stay in hospital and your communication activity levels.



Your name and personal details will be kept private.







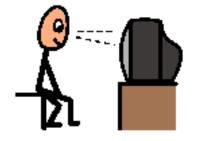




You can say no at any time.



We may use the **recordings** of **you** to make a **training package** (including a video).





You can have your face blurred out if you want.





If you **do not want** to be in the training package we will **not include you** in the training package or video.



I agree to take part in the above research project and give my consent freely.





I have been given a copy of the Information Statement and I understand that the project will be carried out as explained.



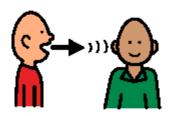


I understand and agree to:

 Complete three tests to assess how the stroke has affected me, my language, concentration and memory, at the beginning of the project.



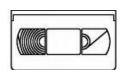
 A researcher spending approximately 1 hour discussing with me my opinion regarding how my hospital environment affects my stay in hospital and what I do.





 A researcher video recording, observing and writing down what is happening in my environment including my activities.





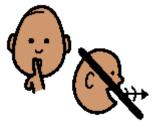


 A researcher looking at my hospital medical file to collect information for the study.



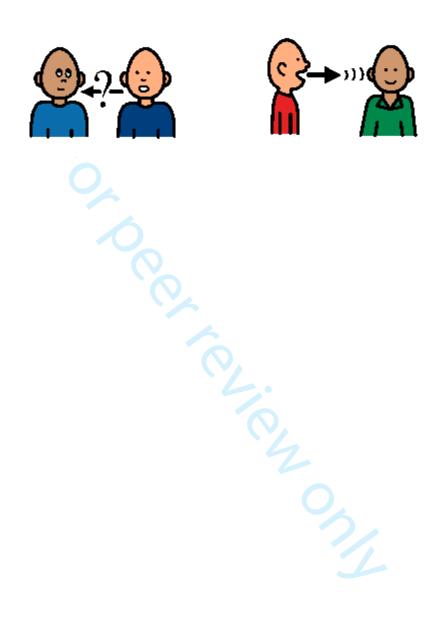


I understand that my identity, personal information and data will remain confidential.





I have had the **opportunity** to **ask questions** about the study and am **satisfied** with the **responses** that have been provided.



Witness

| Would you like | to be involved? | Yes | No |
|--|-------------------|-----|----|
| I agree to the reto make a train (including a vice | | Yes | No |
| I would like my | face blurred out. | Yes | No |
| Your Signature | | | |
| ; | Signature: | | |
| | Print name: | 2 | |
| | Date: | | |

Signature: _____

Print name: _____

Date: _____

Person responsible information sheet Stroke patients' communication activity in hospital

This research project is being undertaken as part of the requirements of a PhD at Edith Cowan University.

Researchers' contact details

| Edith Cowan University | | |
|--|-----------------------------|------------------|
| Chief Investigator/ | Sarah D'Souza | Ph: 0439 982 451 |
| PhD student | | |
| Principal Supervisor | Professor Beth Armstrong | Ph: 08 6304 2769 |
| Co-Supervisor | Associate Professor Natalie | Ph: 08 6304 2047 |
| | Ciccone | |
| Co-Supervisor | Associate Professor Erin | Ph: 08 6304 5901 |
| | Godecke | |
| Co-Supervisor | Associate Professor Deborah | Ph: 08 6304 2563 |
| | Hersh | |
| Hunter Stroke Service, University of Newcastle and Hunter Medical Research Institute | | |
| Adjunct Supervisor | Dr Heidi Janssen | Ph: 02 40420417 |

The participant is invited to take part in a research project. Sarah D'Souza, a Speech Pathologist and PhD student, is leading the study as Chief Investigator. This study has received ethical approval from ECU Human Research Ethics Committee and Hollywood Private Hospital Research Ethics Committee.

This project is investigating the hospital environment to see how this influences patient activity.

The participant has been selected to take part in this study as they have had a stroke and are receiving treatment at Hollywood Private Hospital. We are interested in

seeing how the hospital surroundings affect their communication activity throughout the day. Communication activity involves communication, such as talking with other patients, socialising, reading the paper, using the telephone, talking to staff, or engaging group activities including therapy.

This information sheet will explain the research project and will detail what is involved in the study. You will be given a copy of this information to keep for your reference.

Please read through all of the information carefully. You can ask the researcher questions about the study at any time.

Purpose of the research

Little is known about the impact of the hospital rehabilitation environment on patient communication activity levels during stroke recovery. This study will investigate how the hospital stroke ward environment influences patient communication activity levels. The information gathered from this study will assist in improving the Hollywood Private Hospital stroke ward environment to help the recovery of stroke survivors in the future.

What does the stroke patient have to do?

- Complete three tests and a recording of them talking to see how their stroke has affected their functioning including their language, concentration and memory. These tests will be conducted at the beginning of the project. The tests will take approximately 1 hour to complete with an option to complete the tests over two separate 30 minute sessions and with as many breaks as the participant needs.
- Spend approximately 1 hour discussing with the researcher their opinion regarding how their rehabilitation surroundings affect their stay in hospital and activity levels.
- Allow the researcher to video record, observe and write down what is happening in the
 participant's environment including their activities for a total of 12 hours over a 3 day
 period. Video recording is a useful way of capturing the details of everyday activities on

the ward. Often, people forget that the camera is there. Obviously, personal or private activity such as toileting would not be filmed. The participant may not want to be video recorded. If they request, they will not be video recorded. In this case the researcher will only observe, audio record and write down what is happening in their environment including their activities.

- A researcher will look at the participant's hospital medical file to collect information regarding:
 - The participant's details (such as their age, living arrangements, occupation and level of functioning before stroke)
 - Any relevant conditions or diseases the participant may have
 - Information about the participant's stroke (for example when it happened, the area of the brain affected, how it has affected their functioning and abilities)
 - Details about how long the participant has been in hospital since their stroke

The participant will not miss out on any treatment. Participation will not cost anything. After completing the tests and the interview the participant will be asked to continue their normal activities.

The participant's hospital discharge will not be affected because they are in this study. The participant will be discharged from hospital when the hospital medical team decides that they are ready.

There are no known risks of participating in this study. If the participant feels uncomfortable at any time, you or the participant are free to tell the researcher and observations within their room will stop immediately. The participant may become upset during the tests or the interview. If this happens you or the participant can ask to take a break or stop the interview.

There will be no immediate benefit to you or the participant from taking part in this research; however their participation will allow the collection of information that may help improve stroke hospital wards which may benefit future stroke survivors.

Participating in this study is completely voluntary. The participant can withdraw from taking part in the study at any time without giving a reason for withdrawing.

The participant can request access to their research data at any time. They can request any of the information collected to be amended or removed if it is incorrect or they disagree with it. Please contact Sarah D'Souza (phone: 0439 982 451) if you would like to discuss accessing the participant's information.

The video, audio and written data will be identified by code. The information you provide will remain completely confidential. There will be no identifying information attached to the data and any information that may reveal the participant's identity will be removed. A list of participant names and codes will be kept in a locked filing cabinet at Hollywood Private Hospital and will only be accessible by the research team. All personal health information will be accessed, used and stored in accordance with Commonwealth Privacy Laws. The data will be stored on a password controlled computer or in a locked cabinet at Edith Cowan University. Electronic data will be backed-up on a password controlled hard drive only accessible by the Chief Investigator. Data will be stored for a maximum of 15 years after completion of the study. Video and audio recordings will then be permanently deleted and hard copy data will be shredded.

Non-identifiable data will be accessible by researchers through data sharing archives. This data will be governed by an overarching body to ensure data is only used for approved research purposes. Researchers who access this data from the data bank will not have access to participant information therefore data will not be re-identifiable.

The results of this study may be published in research journals or presented at conferences. The results will not include any information that may identify participants. Data may be used in higher degree by research studies in the future. In this circumstance, confidentiality will be maintained and no identifying information will be used.

Data collected from this study (including videos) may be used to develop training packages to improve future stroke survivors' communication activity levels in the future. We can blur out

the participant's face if they want. If they do not want to be in the training package we will not include them in the training package.

At the end of the research project a summary of the results will be provided to you and the participant.

If you have any questions or require any further information about the research project, please contact: Sarah D'Souza [Ph: 0439 982 451].

Yours sincerely,

Sarah D'Souza

If you have any concerns or complaints about the research project and wish to talk to an independent person, you may contact:

Kim Gifkins

Senior Research Ethics Advisor

Edith Cowan University

270 Joondalup Drive

JOONDALUP WA 6027

Phone: (08) 6304 2170

Email: research.ethics@ecu.edu.au

This project has been approved by the ECU Human Research Ethics Committee and the Hollywood Private Hospital Research Ethics Committee.

Visitors and communication partners information and consent form Investigating Enhanced Environments after stroke

This research project is being undertaken as part of the requirements of a PhD at Edith Cowan University.

Researchers' contact details

| Edith Cowan University | | | |
|--|-------------------------------------|------------------|--|
| Chief Investigator/ | Sarah D'Souza | Ph: 0439 982 451 | |
| PhD student | | | |
| Principal Supervisor | Professor Beth Armstrong | Ph: 08 6304 2769 | |
| Co-Supervisor | Associate Professor Natalie Ciccone | Ph: 08 6304 2047 | |
| Co-Supervisor | Associate Professor Erin Godecke | Ph: 08 6304 5901 | |
| Co-Supervisor | Associate Professor Deborah Hersh | Ph: 08 6304 2563 | |
| Hunter Stroke Service, University of Newcastle and Hunter Medical Research Institute | | | |
| Adjunct Supervisor | Dr Heidi Janssen | Ph: 02 40420417 | |

Description of the research project

This study is exploring stroke patient's experiences in regards to the environment of an in-patient stroke rehabilitation unit. We want to explore stroke patient communication activity, which includes activities such as talking with other patients and visitors, socialising, reading the paper, using the telephone, talking to staff, or engaging group activities including therapy.

The participant has agreed to take part in this study. They have agreed to be video recorded for a total of 12 hours over a three day period.

Your interactions with the patient will be video recorded and manually recorded by the chief investigator to explore patient communication activity levels. You can choose to be observed by the researcher only if you do not want to be video recorded. You do not need to do anything other than complete your usual tasks and activities. We will not record if you are having sensitive conversations with the participant, if they are behind closed curtains or completing sensitive tasks such as toileting or showering.

We may use the recordings of you to make a training package (including a video). You can have your face blurred if you want. If you do not want to be in the training package we will not include you in the training package.

There will be no cost to you associated with the investigation. Participation is completely voluntary. You do not have to participate if you don't want to. If you decide to participate you may withdraw at any time without giving a reason and withdrawing will not disadvantage you or the participant in any way.

You may also benefit from the knowledge that you are helping future stroke survivors. It is possible that you may not benefit from participating in this study. There are no known risks associated with participating in this study.

Confidentiality of information

The video, audio and written data will be identified by code. There will be no identifying information attached to the data and any information that may reveal your identity will be removed. A list of participant names and codes will be kept in a locked filing cabinet at Hollywood Private Hospital and will only be accessible by the research team. All data will be accessed, used and stored in accordance with Commonwealth Privacy Laws. The data will be stored on a password controlled computer or in a locked cabinet at Edith Cowan University. Electronic data will be backed-up on password controlled hard drive only accessible by the Chief Investigator. Data will be stored for a maximum of 15 years after completion of the study. Video and audio recordings will then be permanently deleted and hard copy data will be shredded.

Non-identifiable data will be accessible by researchers through data sharing archives. This data will be governed by an overarching body to ensure data is only used for approved research purposes. Researchers who access this data from the data bank will not have access to participant information therefore data will not be re-identifiable.

The results of this study may be published in research journals or presented at conferences. The results will not include any information that may identify participants. Data may be used in higher degree by research studies in the future. In this circumstance, confidentiality will be maintained and no identifying information will be used.

Please read this Information Statement and be sure you understand its content before you consent to take part.

If you would like to take part, please complete the consent form and return it to Sarah D'Souza or a member of the research team.

Questions or further information?

If you have any questions or require any further information about the research project, please contact: Sarah D'Souza [Ph: 0439 982 451]

Thank you for considering the invitation to take part in this research project.

Yours sincerely,

Sarah D'Souza

If you have any concerns or complaints about the research project and wish to talk to an independent person, you may contact: Kim Gifkins

Research Ethics Officer

Edith Cowan University

270 Joondalup Drive

JOONDALUP WA 6027

Phone: (08) 6304 2170

Email: research.ethics@ecu.edu.au

This project has been approved by the ECU Human Research Ethics Committee and the Hollywood Private Hospital Research Ethics Committee.

| | | 22 0.00 |
|----------------|-------------|---|
| I | | (print name), give my consent freely and |
| agree to | o participa | te in observations of my interactions with the participant. |
| Yes | No | (please circle) |
| I agree | to the rese | earcher video recording my interactions with the participant |
| Yes | No | (please circle) |
| I agree | to be inclu | ided in a training package (including a video). |
| Yes | No | (please circle) |
| If I am i | ncluded in | the video training package I would like my face blurred out. |
| Yes | No | (please circle) |
| I unders | · | project will be conducted as stated in the information letter, a copy of which I have |
| I unders | stand I car | n withdraw from the project at any time and do not have to give a reason for withdrawing. |
| I unders | stand pers | onal information will remain confidential to the researchers. |
| I have b | een given | the opportunity to raise any questions or concerns I have and am satisfied with the |
| | ses I was (| |
| <u>Partici</u> | <u>oant</u> | |
| Print na | ame: | |
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| Date: | | |

Staff information and consent form Investigating Enriched Environments after stroke

This research project is being undertaken as part of the requirements of a PhD at Edith Cowan University.

Researchers' contact details

| Edith Cowan University | | | |
|--|-------------------------------------|------------------|--|
| Chief Investigator/ | Sarah D'Souza | Ph: 0439 982 451 | |
| PhD student | | | |
| Principal Supervisor | Professor Beth Armstrong | Ph: 08 6304 2769 | |
| Co-Supervisor | Associate Professor Natalie Ciccone | Ph: 08 6304 2047 | |
| Co-Supervisor | Associate Professor Erin Godecke | Ph: 08 6304 5901 | |
| Co-Supervisor | Associate Professor Deborah Hersh | Ph: 08 6304 2563 | |
| Hunter Stroke Service, University of Newcastle and Hunter Medical Research Institute | | | |
| Adjunct Supervisor | Dr Heidi Janssen | Ph: 02 40420417 | |

Description of the research project

This study is exploring staff and stroke patient's experiences in regards to the environment of the Edwards and Woods wards at Hollywood Private Hospital. We want to explore stroke patient communication activity, which includes activities such as talking with other patients, socialising, reading the paper, using the telephone, talking to staff, or engaging group activities including therapy. We would like to explore staffs' perceptions of barriers and facilitators to communication activity on the wards and address these in order to enhance the ward environment.

Staff have been selected to participate in order to gain a range of perspectives in regards to the day to day operations, procedures, policies and interactions that influence the environment of the Edwards and Woods wards. A training program for staff will be designed to address barriers and facilitators identified on the wards.

There are two components of this research study that involve staff. You may wish to consent to participate in one or both parts of this study.

<u>Part 1:</u> Stroke in-patients will be video recorded for a total of 12 hours over a three day period. Your interactions with the patient will be video recorded and manually recorded by a member of the research team to explore patient communication activity levels. You can choose to be observed by the researcher only if you do not want to be video recorded. You do not need to do anything other than complete your usual daily tasks and activities. We will not record if you are behind closed curtains or completing sensitive tasks such as toileting or showering the patient.

We may want use the recordings of you to make a training package (including a video). We will show you the video we want to use and explain exactly how this will be used before we do anything. You can have your face blurred out if you want. If you don't want to be included in the training package we will not include any videos of you in the training package.

<u>Part 2:</u> You will be asked to take part in the following:

edited or have your comments erased.

- A focus group with the researcher and your co-workers for approximately 1 hour to explore your perceptions of environmental barriers and facilitators to activity.
- Attend a training program for approximately 1.5 hours. This will focus on training staff to promote
 patient communication on the ward. This session will be located at Hollywood Private Hospital and
 will be offered over several dates to facilitate your ability to attend. If you are unable to attend the
 training program we may provide training and video resources to facilitate your participation in
 training.
- Complete an anonymous short questionnaire before and after attending the training program to gain feedback on training and explore your perception of changes in your knowledge, skills and attitudes towards communication and aphasia.
- A final focus group with the researcher for approximately 1 hour to again explore your perceptions
 of environmental barriers and facilitators to activity.
 The focus groups will be tape recorded however at any stage you may ask for the tape to stopped,

There will be no cost to you associated with the investigation. Participation is completely voluntary. You do not have to participate if you don't want to. If you decide to participate you may withdraw at any time without giving a reason and withdrawing will not disadvantage you in any way.

You may benefit from gaining knowledge and skills regarding communication from attending the training program. Additionally, you may also benefit from the knowledge that you are helping future stroke

survivors. It is possible that you may not benefit from participating in this study. There are no known risks associated with participating in this study.

Confidentiality of information

The information you provide during the interviews will be audio recorded by the Chief Investigator. Your perspectives and opinions will be analysed and grouped into common 'themes' and 'stories'. This will be used to inform the development and review of the training program.

The video, audio and written data will be identified by code. The information you provide will remain completely confidential. There will be no identifying information attached to the data and any information that may reveal your identity will be removed. A list of participant names and codes will be kept in a locked filing cabinet at Hollywood Private Hospital and will only be accessible by the research team. All data will be accessed, used and stored in accordance with Commonwealth Privacy Laws. The data will be stored on a password controlled computer or in a locked cabinet at Edith Cowan University. Electronic data will be backed-up on a password controlled hard drive only accessible by the Chief Investigator. Data will be stored for a maximum of 15 years after completion of the study. Video and audio recordings will then be permanently deleted and hard copy data will be shredded.

Non-identifiable data will be accessible by researchers through data sharing archives. This data will be governed by an overarching body to ensure data is only used for approved research purposes. Researchers who access this data from the data bank will not have access to participant information therefore data will not be re-identifiable.

The results of this study may be published in research journals or presented at conferences. The results will not include any information that may identify participants. Data may be used in higher degree by research studies in the future. In this circumstance, confidentiality will be maintained and no identifying information will be used.

A summary of the results will be provided through Hollywood Private Hospital 18 months after the completion of the study.

Please read this Information Statement and be sure you understand its content before you consent to take part.

If you would like to take part, please complete the consent form and return it to Sarah D'Souza, Claire Tucak or a member of the research team.

Questions or further information?

You may wish to consult with your manager before agreeing to take part in this study.

If you have any questions or require any further information about the research project, please contact:

Sarah D'Souza [Ph: 0439 982 451]

Thank you for considering the invitation to take part in this research project.

Yours sincerely,

Sarah D'Souza

If you have any concerns or complaints about the research project and wish to talk to an independent person, you may contact: Kim Gifkins

Research Ethics Officer

Edith Cowan University

270 Joondalup Drive

JOONDALUP WA 6027

Phone: (08) 6304 2170

Email: research.ethics@ecu.edu.au

This project has been approved by the ECU Human Research Ethics Committee and the Hollywood Private Hospital Research Ethics Committee.

| I | | (print name), give my consent freely and |
|---------------------------|-------------------|---|
| agree to partici | pate in (please | |
| Part 1: | | |
| Yes | No | Observations of your |
| | | interactions with stroke patients. |
| Yes | No | Video recording of your |
| | | interactions with stroke patients. |
| <u>Part 2:</u> | | |
| Yes | No | Complete two focus groups with the researcher, complete two short questionnaires and attend a training program. |
| I understand th retained. | e project will be | conducted as stated in the information letter, a copy of which I have |
| I understand I | can withdraw fro | om the project at any time and do not have to give a reason for withdrawing. |
| I understand pe | ersonal informat | ion will remain confidential to the researchers. |
| I have been giv | en the opportur | nity to raise any questions or concerns I have and am satisfied with the |
| responses I wa | | 7 |
| <u>Participant</u> | | |
| Print name: | | |
| Signature: | | |
| Phone numbe | r: | |
| Email address | 3: | |
| Date: | | |
| <u>Witness</u> | | |
| Print name: | | |
| Signature: | | |
| Date: | | |

Volunteer information and consent form Investigating Enriched Environments after stroke

This research project is being undertaken as part of the requirements of a PhD at Edith Cowan University.

Researchers' contact details

| Edith Cowan University | | | |
|--|-------------------------------------|------------------|--|
| Chief Investigator/ | Sarah D'Souza | Ph: 0439 982 451 | |
| PhD student | | | |
| Principal Supervisor | Professor Beth Armstrong | Ph: 08 6304 2769 | |
| Co-Supervisor | Associate Professor Natalie Ciccone | Ph: 08 6304 2047 | |
| Co-Supervisor | Associate Professor Erin Godecke | Ph: 08 6304 5901 | |
| Co-Supervisor | Associate Professor Deborah Hersh | Ph: 08 6304 2563 | |
| Hunter Stroke Service, University of Newcastle and Hunter Medical Research Institute | | | |
| Adjunct Supervisor | Dr Heidi Janssen | Ph: 02 40420417 | |

Description of the research project

This study is a Communication Enhanced Environment (CEE) at Hollywood Private Hospital. A CEE involves several initiatives that aim to provide more opportunities for communication for stroke survivors on the ward. One of these initiatives involves the participation of volunteers.

As a volunteer participant, you will be asked to take part in the following:

- Attend a training program for approximately 1.5 hours. This will focus on training volunteers in
 communicating with stroke patients with communication difficulties. This session will be located at
 Hollywood Private Hospital and will be offered over several dates to facilitate your ability to attend. If
 you are unable to attend the training program we may provide training and video resources to
 facilitate your participation in training.
- Complete an anonymous short questionnaire before and after attending the training program to obtain your feedback on the training session.

- A focus group with the researcher and other volunteers for approximately 1 hour to explore your
 perceptions of communicating with stroke patients. The focus group will be tape recorded however
 at any stage you may ask for the tape to stopped, edited or have your comments erased.
- Host a communal dining and lounge area once a week to offer tea and coffee and provide social companionship for stroke patients.
- Your interactions with the patient may be video recorded and manually recorded by a member of
 the research team to explore patient communication activity levels. You can choose to be observed
 by the researcher only if you do not want to be video recorded. We will not record if you are having
 sensitive conversations with the stroke patient/s.

There will be no cost to you associated with participating in this study. Participation is completely voluntary. You do not have to participate if you don't want to. If you decide to participate you may withdraw at any time without giving a reason and withdrawing will not disadvantage you in any way.

You may benefit from gaining knowledge and skills regarding communication from attending the training program. Additionally, you may also benefit from the knowledge that you are helping future stroke survivors. It is possible that you may not benefit from participating in this study. There are no known risks associated with participating in this study.

Confidentiality of information

The information you provide during the interviews will be audio recorded by the Chief Investigator. Your perspectives and opinions will be analysed and grouped into common 'themes' and 'stories'.

The video, audio and written data will be identified by code. The information you provide will remain completely confidential. There will be no identifying information attached to the data and any information that may reveal your identity will be removed. A list of participant names and codes will be kept in a locked filing cabinet at Hollywood Private Hospital and will only be accessible by the research team. All data will be accessed, used and stored in accordance with Commonwealth Privacy Laws. The data will be stored on a password controlled computer or in a locked cabinet at Edith Cowan University. Electronic data will be backed-up on a password controlled hard drive only accessible by the Chief Investigator. Data will be stored for a maximum of 15 years after completion of the study. Video and audio recordings will then be permanently deleted and hard copy data will be shredded.

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Researchers who access this data from the data bank will not have access to participant information therefore data will not be re-identifiable.

The results of this study may be published in research journals or presented at conferences. The results will not include any information that may identify participants. Data may be used in higher degree by research studies in the future. In this circumstance, confidentiality will be maintained and no identifying information will be used.

A summary of the results will be provided through Hollywood Private Hospital 18 months after the completion of the study.

Please read this Information Statement and be sure you understand its content before you consent to take part.

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Questions or further information?

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Thank you for considering the invitation to take part in this research project.

Yours sincerely,

Sarah D'Souza

If you have any concerns or complaints about the research project and wish to talk to an independent person, you may contact: Kim Gifkins

Research Ethics Officer

Edith Cowan University

270 Joondalup Drive

JOONDALUP WA 6027

Phone: (08) 6304 2170

Email: research.ethics@ecu.edu.au

ad by the ECC immittee. This project has been approved by the ECU Human Research Ethics Committee and the Hollywood Private Hospital Research Ethics Committee.

| I (print name), give my consent freely and |
|--|
| agree to participate in (please circle) this study as described in this information and consent form. |
| I understand the project will be conducted as stated in the information letter, a copy of which I have retained. |
| I understand I can withdraw from the project at any time and do not have to give a reason for withdrawin |
| I understand personal information will remain confidential to the researchers. |
| I have been given the opportunity to raise any questions or concerns I have and am satisfied with the |
| responses I was given. |
| Participant |
| Print name: |
| Signature: |
| Phone number: |
| Email address: |
| Date: |
| <u>Witness</u> |
| Print name: |
| Signature: |
| Date: |
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BMJ Open

Hospital staff's, volunteers', and patients' perceptions of barriers and facilitators to communication following stroke in an acute and rehabilitation private hospital ward: A qualitative description study.

| Journal: | BMJ Open |
|--------------------------------------|--|
| Manuscript ID | bmjopen-2020-043897.R3 |
| Article Type: | Original research |
| Date Submitted by the Author: | 16-Mar-2021 |
| Complete List of Authors: | D'Souza, Sarah; Edith Cowan University, School of Medical and Health Sciences; La Trobe University, Centre for Aphasia Recovery and Rehabilitation Research Godecke, Erin; Edith Cowan University, School of Medical and Health Sciences; La Trobe University, Centre for Aphasia Recovery and Rehabilitation Research Ciccone, Natalie; Edith Cowan University, School of Medical and Health Sciences Hersh, Deborah; Edith Cowan University, School of Medical and Health Sciences Janssen, Heidi; The University of Newcastle Hunter Medical Research Institute Armstrong, Elizabeth; Edith Cowan University, School of Medical and Health Sciences |
| Primary Subject Heading : | Neurology |
| Secondary Subject Heading: | Qualitative research, Rehabilitation medicine |
| Keywords: | Stroke < NEUROLOGY, Adult neurology < NEUROLOGY, QUALITATIVE RESEARCH |
| | |

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Title page

Title

Hospital staff's, volunteers', and patients' perceptions of barriers and facilitators to communication following stroke in an acute and rehabilitation private hospital ward: A qualitative description study.

Authors

Sarah D'Souza^{1,2}, Erin Godecke^{1,2}, Natalie Ciccone¹, Deborah Hersh¹, Heidi Janssen³, Elizabeth Armstrong¹

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Key words: stroke, adult neurology, qualitative research

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All authors have completed the <u>Unified Competing Interest form</u>) and declare: This research was funded by The Hollywood Private Hospital Research Grant (RF087). SD received an Australian Post Graduate Award Scholarship for the first year of this study and received an ECU Research Travel Grant. No other support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years, no other relationships or activities that could appear to have influenced the submitted work.

The lead author (the manuscript's guarantor) affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned have been explained.

Abstract

Objectives: To explore barriers and facilitators to patient communication in an acute and rehabilitation ward setting from the perspectives of hospital staff, volunteers and patients following stroke.

Design: A qualitative descriptive study as part of a larger study which aimed to develop and test a Communication Enhanced Environment in an acute and a rehabilitation ward.

Setting: A metropolitan Australian private hospital.

Participants: Focus groups with acute and rehabilitation doctors, nurses, allied health staff and volunteers (n=51) and interviews with patients following stroke (n=7), including three with aphasia, were conducted

Results: The key themes related to barriers and facilitators to communication, contained sub-categories related to hospital, staff and patient factors. Hospital related barriers to communication were private rooms, mixed wards, the physical hospital environment, hospital policies, the power imbalance between staff and patients, and task specific communication. Staff related barriers to communication were staff's perception of time pressures, underutilisation of available resources, staff individual factors such as personality, role perception and lack of knowledge and skills regarding communication strategies. The patient related barrier to communication involved patients' functional and medical status. Hospital related facilitators to communication were shared rooms/colocation of patients, visitors and volunteers. Staff related facilitators to communication were utilisation of resources, speech pathology support, staff knowledge and utilisation of communication strategies and individual staff factors such as personality. No patient related facilitators to communication were reported by staff, volunteers or patients.

Conclusions: Barriers and facilitators to communication appeared to be interconnected and likely to influence one another suggests communication access may vary between patients within the same setting. Practical changes may promote communication opportunities for patients in hospital early after stroke such as access to areas for patient co-location as well as areas for privacy, encouraging visitors, enhancing patient autonomy, and providing communication trained health staff and volunteers.

Study strengths

- This study involved a large number of staff in comparison to previous studies and included volunteers as well patients after stroke with and without aphasia.
- Data saturation was reached within the staff focus groups.

Study limitations

- The results in this study reflect the perceptions of a small number of medical (n=2) and nursing staff (n= 11) compared to allied health staff (N= 32).
- This study involved exploring the perceptions a small number of patients; a broader range of perspectives may have been expressed with a larger number of participants.
- This study was conducted at a private hospital involving a mixed acute and a mixed rehabilitation ward therefore these results reflect this context.

Background

Aphasia research supports the theory that commencing aphasia rehabilitation in the early phase post-stroke (<1-month post-stroke) results in better outcomes than therapy commenced in the chronic phase (>6-months post stroke).^{1,2} However, patients in hospital following stroke spend on average 50-94% of their day inactive.^{3,4} Despite improvements in functional independence during their hospital admission following stroke, patients' engagement in cognitive and social activity remains largely unchanged.⁵ Patients with aphasia spend two thirds less time engaged in social interactions with family and friends compared to those without aphasia.⁶ A lack of social and cognitive activity early after stroke for patients with aphasia has the potential to contribute to: i) the development of maladaptive compensatory communication behaviours, and ii) the learned non-use of language, which may ultimately impact on their quality of life and overall language recovery.⁶

Patients following stroke with and without aphasia have described time outside therapy as "dead" and "wasted", reporting a lack of stimulation and inactivity in hospital impacting their ability to self-direct their rehabilitation outside of therapy. They report the experience of boredom is worse in the evenings and weekends when there are less structured activities. They also perceive that boredom negatively influences their mood, motivation, and contributes to their experience of post-stroke fatigue. Boredom is associated with a loss of autonomy and sense of control and contributes to patients becoming passive recipients of care, which may have negative implications for stroke recovery.

This study aimed to explore hospital staff and volunteer, and patient perceptions of barriers and facilitators to patient communication in an acute and a rehabilitation hospital ward. Identifying barriers and facilitators to patients' communication will inform the development of a Communication Enhanced Environment (CEE) model for the purposes of increasing their engagement in language activity within a hospital ward to maximise post-stroke aphasia language recovery.

Methods

Design

This study was part of a larger study which aimed to develop and test a CEE model within an acute and a rehabilitation ward (see supplementary file for study protocol and procedure). This study contributed to the baseline phase of the larger study outlined below:

- i) Baseline phase: observe and quantify levels of engagement in language activity in the acute and rehabilitation ward environment for patients following stroke, and explore hospital staff, volunteers, and patients' perceptions of barriers and facilitators to communication in hospital;
- ii) Implementation phase: develop and implement the CEE model on the acute and rehabilitation wards;
- *Post-implementation phase:* assess the impact of the CEE model on patient engagement in language activity, and hospital staff, volunteers and patients' perceptions of barriers to communication in hospital.

Ethical approval

This study has Ethics approval from the Edith Cowan University Human Research Ethics Committee (ECU HREC 12149) and The Hollywood Private Hospital Research Ethics Committee (HPH431).

Reporting guidelines

The consolidated criteria for reporting qualitative studies (COREQ)⁹ was used to guide reporting this study (Appendix A.).

Research authors' relationship with participants

The first author who was external to the hospital conducted focus groups and interviews. The first author engaged key hospital team members for the duration of the study to inform the study design to ensure it aligned with the hospital policies and priorities.

Patient and public involvement

Patients and the public were not involved in the design of this study however this data informed the development of the CEE model in the larger study. A working group consisting of key members of the stroke multidisciplinary team provided feedback on this study's findings and were involved in the development of the CEE model and embedding approach, which was based on the outcomes of this study.

Setting

This study was conducted on an acute and a rehabilitation ward at a private hospital in Perth, Western Australia. The acute ward was a 26- bed unit with patients following acute stroke as well as other medical conditions. The acute ward had four individual rooms and nine shared rooms, two rooms with four beds per room, and seven rooms with two beds per room. Patients ate meals in their rooms and had access to an outdoor balcony area. The rehabilitation ward was a 44-bed mixed rehabilitation unit for patients following stroke and other medical, orthopaedic and post-surgical conditions. There were thirty-six individual rooms, and four shared rooms with two beds in each room. Patients had breakfast in their rooms but were encouraged to eat lunch and dinner in one of two communal dining areas.

Participants

Hospital staff participants: Purposeful sampling of acute and rehabilitation hospital staff was conducted to include at least one representative from each acute and rehabilitation staff group including medical, nursing, volunteers, and allied health staff members who were over 18 years of age. The first author obtained formal consent from all participants in the study (see supplementary file for consent forms and procedures). A total of 51 staff and volunteers were recruited (Table 1.) by contacting staff department managers who identified staff currently working or had previously worked with patients following stroke on the acute or rehabilitation wards.

Table 1. Staff participants

| Staff/volunteer groups | | | | | |
|------------------------------|---|------------------------------------|---|----------------|---|
| Medical & Nursing | N | Allied Health | N | Volunteer | N |
| Acute nurses (AN) | 2 | Dietitian (DT) | 1 | Volunteers (V) | 6 |
| Clinical nurse manager (CNM) | 1 | Occupational therapy manager (OTM) | 1 | | |
| Medical consultants (MC) | 2 | Occupational therapists (OT) | 5 | | |

| Rehabilitation nurses | 8 | Occupational therapy | 3 |
|-----------------------|---|-----------------------|---|
| (RN) | | assistants (OTA) | |
| | | Physiotherapists (PT) | 8 |
| | | Physiotherapy | 2 |
| | | assistants (PTA) | |
| | | Social workers (SW) | 5 |
| | | Speech pathology | 1 |
| | | manager (SPM) | |
| | | Speech pathologists | 4 |
| | | (SP) | |
| | | Speech pathology | 1 |
| | | assistant (SPA) | |
| | | Volunteer manager | 1 |
| | | (VM) | |
| | | | 7 |
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Patient participants: All patients consecutively admitted following stroke from January to February 2016, and June 2016 to July 2017 were screened for eligibility by the hospital site champions to participate in the study. Inclusion criteria: i) admitted to the acute or rehabilitation ward with an acute stroke, ii) less than 21 days post-stroke during data collection, iii) able to provide informed consent based on the judgement of the medical team responsible for the medical management of the patient, iv) Glasgow Coma Scale¹⁰ greater than 10, v) estimated total length of hospital stay greater than 14 days, vi) adequate English proficiency to participate in interviews as determined by managing speech pathologist or medical team. Exclusion criteria: i) uncorrected hearing or vision (for example hearing impairment without the use of hearing aids or vision impairment without the use of glasses), ii) medically unstable, iii) documented diagnosis of current untreated depression, documented diagnosis of dementia, previous aphasia or traumatic brain injury. The diagnosis of aphasia was confirmed for those who achieved a Western Aphasia Battery-Revised¹¹ Aphasia Quotient score less than 93.7. Eligible patients were approached by the site investigators for consent to be approached by the research team. The first author completed formal consent with all patient participants (see supplementary file for consent forms and procedures). A total of 9 patients were recruited, however 2 patients were withdrawn as they became medically unwell. Data collection was completed for 4 patients without aphasia and 3 patients with aphasia. See Figure 1. for the summary of patient screening and recruitment. Patient details and demographics are detailed in Table 2.

No staff or patients withdrew from participating in this study.

Data collection

The first author, a female speech pathologist (Bachelor of Speech Pathology, Honours) and PhD student with seven years clinical experience working in the hospital setting and five years research experience, including conducting interviews and focus groups, completed all semi-structured interviews and focus groups. Staff were informed that the researchers wanted to investigate their perceptions of the hospital ward environment in regards to communication opportunities to inform the development of a Communication Enhanced Environment (see supplementary file for staff and volunteer information and consent forms). Patients were informed that the researchers wanted to explore how the hospital environment influenced patient activity (see supplementary file for patient information and consent forms).

All interviews and focus groups were conducted using interview and focus group guides (staff focus groups and interview guide Appendix B., patient interview guide Appendix C.) and were audio recorded. Field notes were completed by the first author during data collection. Seven staff focus groups were conducted with two to eight participants in each focus group. One-on-one interviews were conducted with two staff members. All staff focus groups were completed on the hospital site in various locations that were private and quiet. Six out of seven patient interviews were conducted in person during their inpatient admission in their hospital room, and one was completed over the phone (patient without aphasia) one day following discharge from hospital. All patient interviews were conducted within fifteen days post-stroke. Interview and focus groups were 20-60 minutes long, often varying based on the number of participants. Supported conversation strategies¹² were used during interviews with patients with aphasia to facilitate their participation in the interview. One patient with aphasia had two family members present during the interview. During the interviews and focus groups, clarifying questions and paraphrasing participant comments were used to confirm and clarify their perspectives and insights.

[Figure 1. inserted here]



Table 2. Patient characteristics

| | Group | PWA | PWOA |
|---|-----------|-----------|------------|
| | (n=7) | (n = 3) | (n = 4) |
| Participants | | | |
| Age (yr), mean (SD) | 83 (7) | 81 (5) | 84 (8.10) |
| Sex, n females | 4 | 1 | 3 |
| Pre-morbid mobility, n needing aids | 1 | 1 | 0 |
| Pre-morbid living arrangement, n alone | 3 | 1 | 2 |
| Time since stroke (d), mean (SD) | 14 (5) | 13 (7) | 15 (5) |
| Stroke severity (NIHSS ¹³ 0-42), mean (SD) | 4 (3) | 5 (4) | 5 (3) |
| Mild, n score < 8 | 5 | 2 | 3 |
| Moderate, n score 8-15 | 2 | 1 | 1 |
| Severe, n score > 15 | 0 | 0 | 0 |
| Mobility status at time of data collection | | | |
| Independent +/- walking aid | 1 | 0 | 1 |
| Stand-by assistance | 3 | 1 | 2 |
| 1-2 person assistance | 2 | 1 | 1 |
| Hoist/wheelchair | 1 | 1 | 0 |
| Cognition (MOCA ¹⁴), median (range) | 18 (9-22) | 16 (9-18) | 20 (17-22) |
| Aphasia severity, WAB-R ¹¹ AQ mean, (SD) | | 77 (6.50) | |
| Ward (d) | | | |
| Acute (%) | 4 (17) | 4 (40) | 0 (0) |
| Rehabilitation (%) | 19 (83) | 6 (60) | 13 (100) |
| Average number of days in single room per participant (%) | 3.1 (96) | 3 (90) | 3.3 (100) |

Notes: PWA= patient with aphasia; PWOA= patient without aphasia; NIHSS=National Institute of Health Stroke Scale¹³; MoCA= Montreal Cognitive Assessment¹⁴; WABAQ=Western Aphasia Battery-Revised¹¹ Aphasia Quotient score.

Data analysis

Focus groups and interviews were transcribed verbatim. Responses to any leading questions were removed from the data set.¹⁵

The theoretical framework for this research was a qualitative description approach. ¹⁶ This approach involves describing patient experiences, with minimal interpretation of the data to minimise potential bias of the researchers. ¹⁶ Participant experiences were analysed using NVivo¹⁷ computer software to manage the data. Data were grouped into themes according to content. ¹⁶ The first level of coding identified the broad content of the data then sub-categories were identified. ¹⁶ Single lines of data were not removed from their 'story' during data analysis to maintain the context and help ensure meaning was not lost or misinterpreted. ¹⁶ Ongoing critical review of the categories were conducted and themes were reviewed by a second researcher. ¹⁶ Staff were provided feedback on the findings.

Results

The key themes from the focus group and interviews related to barriers and facilitators to communication, with sub-categories identified which related to hospital, staff and patient factors (Figure 2.).

[Figure 2. inserted here]



Barriers to Communication

Hospital related factors

Private rooms reduce opportunities for social interaction

Staff and patients described the impact of single rooms which limited incidental socialisation with other patients and their visitors.

We used to co-locate our stroke patients [sic] and often using our shared rooms. That's when people had more opportunities for interacting with one another. (MedC1)

Mixed wards affect staff acquisition of specialist skills

Staff described their perception of the negative effect a mixed hospital ward had on the acquisition of stroke specific specialist skills.

Having a stroke specific ward... everybody on the ward would be trained...and that's the only thing they'd have to focus on rather than having lots of other patients with lots of medical conditions. (OT4)

Hospital environment does not encourage socialising

Staff talked about the physical hospital ward environment affecting social interaction as it contributed to a sterile atmosphere rather than one that promoted social activity. Staff also talked about the consequence of background noise and environmental distractors in large shared rooms on the acute ward which reduced their ability to communicate with patients with communication impairments.

My general feeling of rehab [rehabilitation] is that they come to their sessions and then they go back to their lonely dark room... I don't really see the rooms as a particularly happy, busy place where they are getting a lot out of being in there... the dining rooms... they're not a particularly pleasant place to be either. (PT2)

They [patients] can hear other people talking... there is [sic] a lot of voices going on which is going to impact on their understanding as well. (PT3)

Hospital policies restrict the development of communication-promoting ideas and initiatives

Hospital policies were perceived by staff as a barrier to communication, negatively influencing their ability to develop ideas and initiatives to increase patients' opportunities for social interaction. This included policies regarding leaving patients unattended in dining

areas without patient care assistants supervising them and requiring nurses to supervise patients if they are eating; and reported limitations around food related activities as a result of food hygiene policies and occupational health and safety.

It's just every time you try and do something you hit a barrier... you do try and think outside the box what more can you do for this patient and you get another hospital rule. (PT2)

Power imbalance of staff and patients in hospital controls patients' ability to access communication opportunities

Staff and patients discussed the influence of the power imbalance for patients in hospital, and patient perceptions that they have to do what is expected in the hospital environment. This appeared to limit the patients' ability to freely engage and explore the environment resulting in patients retreating to their rooms and limiting their opportunities to engage in activities.

I think most males like to account for their time um and I felt like I haven't been able to do that and that's, that's the bit that I'm really, really lacking. (PWA2)

I was in the hospital so I think I had to stick into the room, to the rules. (PWOA2)

Very often when you're in a hospital you do what you think you're expected to do. (SP4)

Task specific communication reduces patients' communication opportunities

Staff talked about the nature of interactions with patients as often being driven by the patient's care, restricting opportunities for communication beyond this context.

I know we aim to be very holistic... but very often care is very[sic] directed from a medical health care perspective (SP4)

Staff related factors

Staff's perception of time pressures limiting opportunities for communication

Both patients and staff perceived staff time pressures as a barrier negatively effecting communication on the wards. This may be the reflection of actual time pressures, or staff perceptions of their available time. Some staff reported that they felt interactions with patients with communication impairments required extra time which was challenging in a time pressured hospital environment. Time pressures were also perceived to restrict the staff's ability to facilitate opportunities for patients to socialise with other patients. For

example, nurses appeared to deprioritise transferring patients to the communal area for lunch in busier times.

If they're hoist patients it might not be as easy for staff to get them to the dining room, that wouldn't totally prevent someone from going, it would just depend on the time that people had on the day. (SW3)

Staff and patient's underutilisation of available resources

Staff described the lack of accessible resources as a factor negatively affecting staff-patient communication. They described the need for resources when communicating with patients with aphasia and other communication impairments but felt unsure about what these were or how to access them. They also described a number of resources that they felt patients were not aware of and therefore did not utilise such as volunteer services that promote communication opportunities and facilitate patient access to outdoor areas.

I feel like I don't know where else to go. I don't know if other things that [sic] could help us, maybe there's things out there that I don't know about that would help us communicate with these patients. (PT2)

There are all of these opportunities but I don't think a lot of the patients access them so it sounds like great communicative opportunities for them but the reality is that a lot of them are sitting in their rooms most of the times by themselves watching television and most of the interactions they have is with the nurses or just whoever comes in to see them. (SP4)

Individual staff factors leading to restricted opportunities for communication

Staff described individual staff factors such as personality, values and attitudes influencing communication opportunities for patients, such as staff providing patients with opportunities for incidental social interaction during routine tasks.

Often if people need to go in and see the patient let's just say to take obs [observations] or to do a wash... they don't always use that opportunity as an opportunity to chat... there could be more opportunity to chat at those times whilst they are doing what they need to get done and you know that varies from person to person, personality as well and how busy people are, what else is going on. (SP3)

Staff's perception their role does not include communication tasks

Some staff perceived communication as a task separate from the responsibility of their role therefore limiting their facilitation of communication opportunities for patients.

They [speech pathologists] do their bit and we do ours... we don't have time to practice speech with them because we really do have to get all of our jobs filled in the time and it's specifically rostered for us to do our work, not to help with someone else's. (RehabN1)

Lack of staff knowledge and skills resulting in unsuccessful communication interactions or avoiding communication interactions

Staff described a lack of knowledge and skills in communicating with patients with communication impairments. Some staff reported feeling anxious about encouraging patients to communicate as communication breakdowns may cause stress and anxiety for the patient, and the staff member. Staff reported a lack of confidence in their ability to repair communication breakdowns which resulted in increased time pressures in their sessions, often leading them to avoid encouraging communication interactions within their treatment sessions.

I find it challenging... knowing how the best way to communicate with that person [with aphasia]... then [they] become very frustrated and not have the tools themselves to communicate back to me and you would never want to leave someone in that space. So that's something that I struggle with. (SW2)

Patient related factors

Patient related factors reflected their functional and medical status, personality, mood and motivation, which were perceived by staff and patients to often act as a barrier to engaging in communication interactions during their hospital admission early after stroke.

Patients' functional and medical status limiting their ability to seek out and engage in activities

Staff and patients perceived patients' medical status as a barrier to communication by limiting their ability to engage with their environment including independently seeking out activities and being able to utilise communal areas.

If someone is bed bound, you know the interaction is very minimal... you often walk past and you see them alone in their room... you wonder what happens during those periods of time where they're just in their room and they don't have family. (OT2) Well, I can't do anything cos I can't go off by myself and do anything. (PWOA2)

Individual patient factors limiting opportunities for communication

Staff described individual patient factors such as personality, mood and motivation communication opportunities for patients such as independent practice of communication therapy tasks, and social opportunities with patients and hospital staff.

We have to recognise some patients who have had strokes... they're fed up with having people poking and prodding them then have a volunteer and go "do you want to do your exercises for speech?" (VM)

They need a break after OT [the occupational therapist] has done a shower. If they don't get that break then the physio isn't going the be as good for them because they're so tired, so we also have to look at break times in between each sessions... (OTA1)

Facilitators to Communication

Hospital related factors

Shared rooms/co-location encourages incidental social interactions

Staff talked about use of communal areas at other hospitals which facilitated socialisation and communication during non-therapy times and during group therapy. Staff described the importance of the use of communal areas given the large number of private rooms on the ward. Patients also described the need to be co-located to promote social interaction.

I think that, put the [sic] whole lot of people together and ah and they [sic] something collective, that's what human beings are put together for ... sitting around talking... over the proverbial cuppa. (PWA2)

Visitors provide patients opportunities for socialisation

Staff identified visitors as a facilitator to communication interaction for patients outside of therapy times during their inpatient admission.

Interaction with the family... it's not therapy based but it's their [patients'] opportunity to practice. (PT1)

Volunteers facilitate opportunities for patients to engage in social activities

Staff discussed the benefit of volunteers in facilitating opportunities for patients to engage in social interactions including programs involving therapy dogs, book loaning, hand massages, and taking patients off the ward.

If we see people that are lonely, are not getting visitors, there's many volunteers... to go and visit them and if they're well enough they can take them out... the volunteers, we do rely on them. (OTA1)

Staff related factors

Staff utilisation of resources promote communication exchange

Staff identified access to resources such as chat books and alternative and augmentative communication boards often facilitated communication interactions with patients with communication impairments on the ward.

Sometimes with the ... signs... "do you want to drink? some water?" or something, so they can just point because ... they want to say something and maybe the right words are not coming out... that also helps. (RehabN3)

Speech pathology support and education facilitates staff's use of communication promoting strategies

Staff reported support and education from speech pathology staff facilitated their ability to interact successfully with patients with aphasia.

I had a patient who had word finding difficulties... I just was observing the speechie [speech pathologist], she would just be like "no, what do you mean?" and he'll be like [pointing] and she'll be like "tell me what's the word"... it's something I could have just added to my session. (PT4)

Staff knowledge and utilisation of communication strategies promotes communication activities

Staff and volunteers discussed the use of communication strategies and resources to facilitate communication on the ward for patients with a variety of communication impairments.

We use communication boards, pictures, writing things down, talking slowly. (MedC2)

If they are having trouble, I will say to them "it's okay you don't need to hurry, that's fine". (V1)

Individual staff factors promote communication opportunities for patients

Staff and patients talked about how individual characteristics of staff, including rapport building and being friendly, facilitated communication for patients with communication difficulties.

Sometimes they [patients] look for that specific person... the more they get confident, the more they get relaxed, the more their speech enhances as well. (RehabN3)

Discussion

This study aimed to explore hospital staff, volunteers and patients' perceptions of barriers and facilitators to communication on an acute and a rehabilitation ward. A wide range of factors were perceived to act as potential barriers or facilitators to communication. Additionally, a number of factors influencing patient access to communication opportunities appeared to influence one another.

The co-location of patients in therapy spaces, dining areas or in shared rooms were perceived as facilitators to communication for patients, providing opportunities for incidental social interactions with other patients and their visitors. However, background noise in these shared spaces was also perceived to act as a barrier to their ability to engage in communication. Patient access to communal spaces was influenced by a number of factors including patients' sense of autonomy to freely explore the hospital ward environment, and their medical and mobility status, and staff's perception of their available time, which influenced staff's perception of whether they transferred patients to these spaces. Rosbergen et al¹⁸ reported that in an acute stroke ward enriched environment communal mealtimes and group activities were perceived to facilitate social activity. The study by Rosbergen et al¹⁸ found that staff reported perceptions that shared rooms limited staff and patients' ability to engage in private conversations, consistent with O'Halloran et al's¹⁹ findings. It may be that access to both private and communal spaces available within the hospital environment play critical roles in regards to providing opportunities for social interactions with other patients and their visitors and opportunities for privacy when required.

The acute and rehabilitation wards had a large proportion of single rooms, which could have been considered the result of this study being conducted at a private hospital.

However, there has been a perceived trend towards increased proportions of single rooms

in newly built public hospitals to promote infection control and patient privacy which may have a detrimental effect on communication.^{20,21} The predominance of single rooms and limited opportunities to access shared spaces may have increased the effect of other barriers on communication opportunities for patients. For example, a patient with poor autonomy may be more likely to remain alone in their single room when they are not attending therapy, as they perceive they are not 'allowed' to freely explore the hospital environment. This may reduce the likelihood of the individual independently seeking out social interactions beyond their room. If they also have reduced mobility, they may be more reliant on staff to facilitate transfers to communal spaces which may be impacted by staff time constraints. The patient's functional status and levels of fatigue may also limit their ability to initiate and engage in activities while they are in their room. Therefore, the combined effect of these barriers may significantly limit this patient's communication opportunities.

These communication barriers may be mitigated by having scheduled rest periods, and periods allocated to encouraging visitors to provide opportunities for communication and socialisation within their room, and facilitate patient access to shared spaces, such as helping mobilise wheelchair users into communal dining areas or education to patients that they are allowed to explore the hospital ward environment. Rosbergen et al¹⁸ identified patient and family autonomy to initiate and direct activity as a factor enriching the acute ward environment. Therefore, increasing patient autonomy within this setting may facilitate their ability to seek out interactions within the environment and increase engagement in communication activity, which may then reduce the effect of being in a single room with reduced mobility and time poor staff.

A potential lack of opportunities to access social interactions with other patients means staff, including volunteers, and visitors may become the main communication partner for patients. Godecke et al's⁶ observation study found that nurses are the most frequent communication partner for patients following stroke with aphasia, after their family members, therefore patient-staff interactions may play a significant role for those patients with minimal or no visitors. It is interesting to note that this study recruited a limited number of acute nurses in comparison to rehabilitation nurses. This could be interpreted as a reflection of differences in nurses' capacity for additional activities within the demands and time restrictions of the acute ward context in comparison to the

rehabilitation ward context. Within the current study, communication between staff and patients appeared to be dependent on a number of factors including staff perception of their role, their knowledge and skills in facilitating communication, their values and attitudes towards communication and whether supporting language and communication for patients with aphasia is part of their 'role', their willingness to be flexible with their time, and their knowledge of and access to resources which may be used to facilitate communication. This also highlights the potential impact of the perceived power imbalance between staff and patients and the significance of interactions that are task directed. Hersh et al²¹ reported patients with aphasia felt disempowered in communicative interactions with nurses. Nurses often talked to the task and controlled interactions with patients.^{22,23}This highlights the need for communication partner training which may provide staff with the knowledge and skills required to support effective communication with patients with aphasia.²⁴ Implementation strategies will need to be considered to promote behaviour change as well as the uptake and maintenance of training including involvement of management and ward champions, and ensuring trained communication strategies are easy to learn, apply and audit in order to be applicable in this busy context.²⁵

Time pressure was perceived as a major barrier to communication impacting on staff's ability to support successful communication within their interactions with patients and facilitate patients' opportunities to engage in interactions in social or communal areas. Time constraints have been reported to limit communicative opportunities between patients following stroke and nurses. ²⁶ Ball et al²⁶ found that 86% of surveyed nurses reported one or more activities had been "left undone" in their last shift as a result of lack of time. The study found that activities most likely to be missed by nurses as a result of time constraints were comforting and talking to patients (66%) and patient education (52%). ²⁶ This has also been identified by patients who "did not like to bother the busy nurse". ²⁷ Time limitations and pressures on the wards may be facilitated by developing staff knowledge of and skills in using communication promoting strategies. Effective and efficient nurse patient communication as a result of nurse training has been found to save time, reduce frustration and reduce the burden associated with caring for patients following stroke with aphasia. ²⁸ Additionally, time limitations reported by staff may lend to an argument for additional nursing allocation for patients with communication impairments.

This study included a small number of medical and nursing staff in comparison to compared to allied health staff which may be reflected in the reported results. This study also involved a small number of patients and a broader range of perspectives may have been expressed with a larger number of participants. This study was conducted at a private hospital involving a mixed acute and a mixed rehabilitation ward, and a relatively homogenous groups of participants linguistically and ethnically, therefore these results reflect this context and may not be directly generalisable to hospitals in the public sector, nor did they explore cultural factors contributing to communication.

Conclusions

The barriers and facilitators to communication appear to be interconnected and likely to influence one another, suggesting that the level of communication access may vary from patient to patient within the same setting. Results of this study highlight a number of practical changes that could be implemented to promote communication opportunities for patients admitted to hospital early after stroke. However, implementation of behaviour and cultural change strategies may be pertinent to promote meaningful and sustainable change within the hospital setting. Consideration of areas for co-location for patients such as therapy spaces, dining areas or shared rooms as well as access to private spaces may potentially address the need for social opportunities with other patients as well as access to privacy when required. The promotion of visitors attending the wards may facilitate communication opportunities for patients between therapy times by providing socialisation in patients' rooms as well as facilitating and advocating for patient access to communal areas. This has the potential to mitigate the effect of social isolation in single rooms, staff time restraints and limitations as a result of patients' medical status. Strategies to promote patient autonomy in hospital may promote their ability to freely explore the environment beyond their room may help address the power imbalance that can occur between patients and hospital staff. Additionally, health staff and volunteer education in using communication promoting strategies may increase opportunities for interactions between patients, and staff or volunteers and promote communication exchange within those interactions. These factors will be explored in a Communication Enhanced Environment, which aims to increase patients' opportunities to engage in language activities during early stroke recovery in hospital.

Acknowledgements

The authors would like to thank the hospital and staff for supporting this study and assisting in participant recruitment. We would also like to thank all the participants in this study for sharing their experiences and insights.

Author contributions

SD, EG, NC, DH, HJ and EA designed the study and the protocol. EG reviewed the final copies of the protocol documents. SD conducted the semi-structured interviews and focus groups. SD performed data analysis. DH conducted the critical review of the categories and review of themes. SD, EG, NC, DH, HJ and EA contributed to the manuscript and approved the manuscript.

Competing interests statement

This research was funded by The Hollywood Private Hospital Research Grant (RF087). SD received an Australian Post Graduate Award Scholarship for the first year of this study and received an ECU Research Travel Grant. The authors have no other competing interests to declare.

Funding statement

This work was supported by the Hollywood Private Hospital Research Foundation grant number RF087. SD received an Australian Post Graduate Award Scholarship for the first year of this study and received an ECU Research Travel Grant.

Data sharing statement

Patient interview and staff focus group data are stored in the Edith Cowan University data storage repository. This data will be available in a de-identified format by request through the first author ORCiD https://orcid.org/0000-0001-6221-3229. The availability and use of the data are governed by Edith Cowan University Research Ethics.

Figures

Figure 1. Summary of patient screening and recruitment.

Figure 2. Summary of themes and subthemes of staff and patient perceptions to barriers and facilitators to patient communication in hospital.

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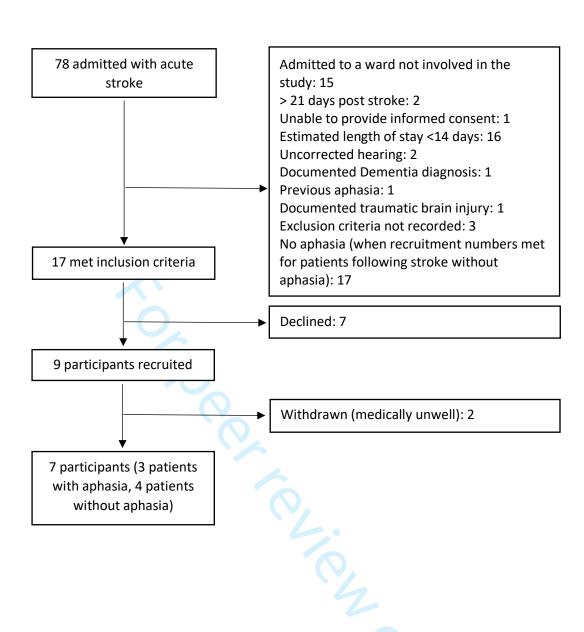


Figure 1. Summary of patient screening and recruitment

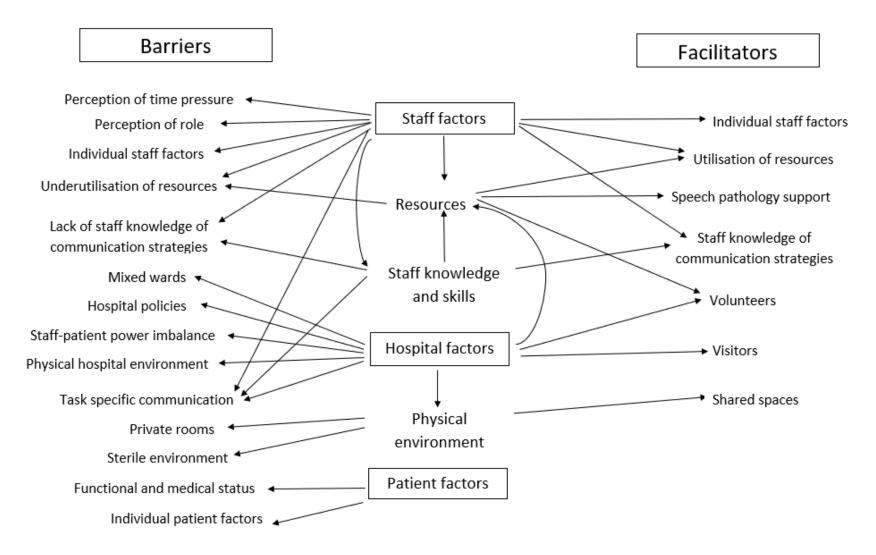


Figure 2. Summary of themes and subthemes of staff and patient perceptions to barriers and facilitators to patient communication in hospital.

Appendix A.

Consolidated criteria for reporting qualitative studies (COREQ)9: 32-item checklist

| No Item | Guide questions/description | Location within paper |
|---|---|--|
| Domain 1: Research team and reflexivity | | |
| Personal Characteristics | | |
| 1. Interviewer/facilitator | Which author/s conducted the interview or focus group? | Page 10 |
| 2. Credentials | What were the researcher's credentials? E.g. PhD, MD | Page 10 |
| 3. Occupation | What was their occupation at the time of the study? | Page 10 |
| 4. Gender | Was the researcher male or female? | Page 10 |
| 5. Experience and training | What experience or training did the researcher have? | Page 10 |
| Relationship with participants | 10h. | Page 7 |
| 6. Relationship established | Was a relationship established prior to study commencement? | Page 7 |
| 7. Participant knowledge of the | What did the participants know about the | Supplementary files, participant information |
| interviewer | researcher? e.g. personal goals, reasons for doing the research | and consent forms, page 10 |
| 8. Interviewer characteristics | What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic | Page 10 |
| Domain 2: study design | | |
| Theoretical framework | | |

| 9. Methodological orientation and Theory | What methodological orientation was stated | Page 13 |
|--|---|------------------------|
| | to underpin the study? e.g. grounded theory, | |
| | discourse analysis, ethnography, | |
| | phenomenology, content analysis | |
| Participant selection | | |
| 10. Sampling | How were participants selected? e.g. | Page 8, 10 |
| | purposive, convenience, consecutive, | |
| | snowball | |
| 11. Method of approach | How were participants approached? e.g. | Page 8, 10 |
| | face-to-face, telephone, mail, email | |
| 12. Sample size | How many participants were in the study? | Page 8, 10 |
| 13. Non-participation | How many people refused to participate or | Figure 1, page 8 |
| | dropped out? Reasons? | |
| 14. Setting | Setting of data collection Where was the | Page 7-8 |
| | data collected? e.g. home, clinic, workplace | |
| 15. Presence of non-participants | Was anyone else present besides the | Page 11 |
| | participants and researchers? | |
| 16. Description of sample | What are the important characteristics of the | Table 2, page 12 |
| | sample? e.g. demographic data, date | |
| Data collection | | 4- |
| 17. Interview guide | Were questions, prompts, guides provided | Appendix B, Appendix C |
| | by the authors? Was it pilot tested? | 1/1/ |
| 18. Repeat interviews | Were repeat interviews carried out? If yes, | NA |
| | how many? | |
| 19. Audio/visual recording | Did the research use audio or visual | Page 10 |
| - | recording to collect the data? | |
| 20. Field notes | Were field notes made during and/or after | Page 10 |
| | the interview or focus group? | |
| 21. Duration | What was the duration of the interviews or | Page 11 |
| | focus group? | |

| 22. Data saturation | Was data saturation discussed? | Page 5 | |
|------------------------------------|---|------------|--|
| 23. Transcripts returned | Were transcripts returned to participants for | No | |
| | comment and/or correction? | | |
| Domain 3: analysis and findings | | | |
| Data analysis | | | |
| 24. Number of data coders | How many data coders coded the data? | Page 13 | |
| 25. Description of the coding tree | Did authors provide a description of the | Figure 2 | |
| | coding tree? | | |
| 26. Derivation of themes | Were themes identified in advance or | Page 13 | |
| | derived from the data? | | |
| 27. Software | What software, if applicable, was used to | Page 13 | |
| | manage the data? | | |
| 28. Participant checking | Did participants provide feedback on the | Page 13 | |
| | findings? | | |
| Reporting | 10 | | |
| 29. Quotations presented | Were participant quotations presented to | Page 14-20 | |
| | illustrate the themes / findings? Was each | | |
| | quotation identified? e.g. participant number | | |
| 30. Data and findings consistent | Was there consistency between the data | Page 14-20 | |
| | presented and the findings? | 6 | |
| 31. Clarity of major themes | Were major themes clearly presented in the | Figure 2 | |
| | findings? | 1/1/ | |
| 32. Clarity of minor themes | Is there a description of diverse cases or | Page 14-20 | |
| | discussion of minor themes? | | |

Appendix B.

Investigating Communication Enhanced Environments after stroke: Staff focus group guide

What kind of language activities or language tasks do patients following stroke currently participate in on the ward?

What kind of language activities or language tasks would you like see patients following stroke have access to on the wards?

Describe your experience of communicating with patients following stroke at the moment.

Can you tell me about anything that facilitates your ability to communicate with patients following stroke on the ward?

Can you tell me about any barriers you experience that impact your ability to communicate with patients following stroke on the ward?

What changes would you like to see to enhance communication between staff and patients following stroke on the ward?

What changes would you like to see to enhance communication between visitors and patients following stroke on the ward?

How could we enhance or optimise communication and language tasks and activities for patients following stroke on the ward?

What do you think a communication and language enhanced stroke ward environment might look like?

Appendix C.

Investigating Communication Enhanced Environments after stroke: Patient interview guide

Tell me about what kind of activities you do while you are here (in hospital).

Describe your experience of communicating with people on the ward.

What makes it easier to communicate with people on the ward?

What makes it hard to communicate with people on the ward?

What can we do to make communicating with people easier?

Investigating a Communication Enhanced Environment (CEE) model early after stroke: A before-after non-

randomised controlled pilot study.

Study protocol version 1 19.05.20

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1 Abbreviations and Definitions of Terms

CEE model: Communication Enhanced Environment model, an adapted model of an Enriched Environment, an environment that provides patients following stroke opportunities to engage in language activities during inpatient rehabilitation.

PWA: Patients following stroke with aphasia.

PWOA: Patients following stroke without aphasia.

Language activities: Language tasks that consist of solitary or interactive language activities.

Solitary language activities: Activities that may promote aphasia recovery such as reading, writing, listening to the radio, and the use of iPad applications.

Interactive language activities: activities which are based in communicative interactions that involve an exchange of information with a communication partner involving talking, gesture and/or facial expression, reading, writing or drawing to communicate.

EE: Enriched Environment, an environment that promotes physical, cognitive and social activity.

2. Protocol Synopsis

| Study Title: | Investigating a Communication Enhanced Environment model on acute and rehabilitation wards early after stroke: A before-after non-randomised controlled pilot study |
|---------------------|--|
| Study type: | Interventional |
| Study Intervention: | A Communication Enhanced Environment (CEE) model will be developed from pre-intervention observations of inpatient language activities and investigations of barriers and facilitators to communication together through focus groups with hospital staff and interviews with patients on the acute and rehabilitation wards. |
| | Sixteen patients following stroke will be recruited in this prospective before-after non-randomised controlled pilot study set in an acute and a rehabilitation ward of a metropolitan private hospital. The study includes: i) The baseline phase which involves observation of patients following stoke (n=8, 4 patients with aphasia (PWA) and 4 patients without aphasia (PWOA)); the collection of qualitative data through focus groups and semi-structured interviews to determine patient and staff perceived barriers and facilitators to communication; ii) the implementation phase where a CEE model will be developed and embedded in usual care; iii) the post-implementation phase which will involve repeated baseline data collection on a different cohort of patients (n=8, 4 PWA and 4 PWOA) to determine i) how solitary and interactive language activity levels changed following implementation of the CEE model, ii) the differences post CEE implementation in hospital staff's use of communication promoting strategies when interacting with patients, iii) the differences post CEE implementation in staff and patient perceptions of the barriers and facilitators to inpatient language activities. |
| | The CEE model will include the provision of: i) CEE model equipment, for example reading materials such as books and magazines, and access and encouragement to reside in a communal dining area; ii) CEE model education, support and training for staff with the aim to develop the ability to facilitate language activities for patients after stroke. The training program will be guided by research evidence, expert opinion and baseline data. Staff will complete a questionnaire pre and post training to determine changes in their knowledge, skills and attitudes regarding communication and aphasia. |
| | Control treatment: Patients following stroke with and without aphasia will be observed and video recorded over two weekdays and one weekend day pre (n=8) and post (n=8) implementation of a CEE model. Behavioural mapping will record patient interactive and solitary language activity observed within the first minute of 5-minute intervals in 4-hour time periods between 7am and 7pm. Solitary language activities are activities that may promote aphasia recovery such as reading, writing, listening to the radio, and the use of iPad applications. Interactive language activities are activities which are based in communicative interactions that involve an exchange of information with a communication partner involving talking, gesture and/or facial expression, reading, writing or drawing to communicate. |

| Objectives of the | This study aims to investigate a CEE model on an acute and rehabilitation | | |
|--|---|--|--|
| Study: | ward and if stakeholders perceive a CEE model as valuable by addressing | | |
| Study. | the following research questions: | | |
| | - Does a CEE model increase the amount of time PWA and PWOA spend | | |
| | in participating in solitary and interactive language activities on acute | | |
| | | | |
| | and rehabilitation wards during the early post-stroke period? | | |
| | - What are the differences in patients' experience of communication in a | | |
| | CEE model compared to patients' experience of communication in a | | |
| | standard environment on in-patient acute and rehabilitation wards? | | |
| | - What is the experience of implementing a CEE model for staff working | | |
| | with PWA and PWOA within in-patient acute and rehabilitation wards? | | |
| | - Do staffs' perceptions of their knowledge of, skills with, and attitude | | |
| | towards communication and aphasia change following implementation | | |
| | of a CEE model? | | |
| Number of Centres: | 1 | | |
| Study duration: | 5 years | | |
| Study Hypothesis: | A CEE model will increase patient engagement in solitary and interactive | | |
| | language activities and improve staff and patient experiences of | | |
| | communication compared to a standard ward environment. | | |
| Primary outcomes: | The primary outcome is the change in the proportion of solitary and | | |
| , | interactive language activities as a percentage of total observed activity | | |
| | after the implementation of the CEE model. | | |
| | | | |
| | Timepoint: Patient observations completed within 21 days post stroke. | | |
| Secondary outcomes: | The differences post CEE model implementation in staff and patient | | |
| Secondary outcomes. | perceptions of the barriers and facilitators to inpatient language | | |
| | activities. | | |
| | | | |
| Ctudy docions | Timepoint: Within 18 months of embedding the CEE model. | | |
| Study design: | Before-after non-randomised pilot study | | |
| Key inclusion criteria: | Patients will be eligible for inclusion if they have/are: admitted to the | | |
| | acute or rehabilitation ward for a stroke, less than 21 days post stroke | | |
| | during baseline phase or post-implementation phase, the ability to | | |
| | provide informed consent as determined by the medical team, a | | |
| | Classess Cause Carle accuse annotate the a 10 at the time of annousing and | | |
| | Glasgow Coma Scale ¹ score greater than 10 at the time of screening, an | | |
| | estimated length of hospital stay greater than 14 days, adequate English | | |
| | estimated length of hospital stay greater than 14 days, adequate English proficiency to participate in semi-structured interviews and are above 18 | | |
| | estimated length of hospital stay greater than 14 days, adequate English proficiency to participate in semi-structured interviews and are above 18 years of age. Patients with aphasia will also have an Aphasia Quotient | | |
| | estimated length of hospital stay greater than 14 days, adequate English proficiency to participate in semi-structured interviews and are above 18 years of age. Patients with aphasia will also have an Aphasia Quotient below 93.7 on the Western Aphasia Battery-Revised. ² | | |
| | estimated length of hospital stay greater than 14 days, adequate English proficiency to participate in semi-structured interviews and are above 18 years of age. Patients with aphasia will also have an Aphasia Quotient below 93.7 on the Western Aphasia Battery-Revised. ² Staff participants: One representative from each acute and rehabilitation | | |
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| Key exclusion criteria: | estimated length of hospital stay greater than 14 days, adequate English proficiency to participate in semi-structured interviews and are above 18 years of age. Patients with aphasia will also have an Aphasia Quotient below 93.7 on the Western Aphasia Battery-Revised. ² Staff participants: One representative from each acute and rehabilitation staff group including medical, nursing, volunteers, and allied health staff members (n=17), who are over 18 years old. Patients will be excluded if they have/are: uncorrected hearing or vision, | | |
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| Key exclusion criteria: | estimated length of hospital stay greater than 14 days, adequate English proficiency to participate in semi-structured interviews and are above 18 years of age. Patients with aphasia will also have an Aphasia Quotient below 93.7 on the Western Aphasia Battery-Revised. ² Staff participants: One representative from each acute and rehabilitation staff group including medical, nursing, volunteers, and allied health staff members (n=17), who are over 18 years old. Patients will be excluded if they have/are: uncorrected hearing or vision, not medically stable, a documented diagnosis of dementia, traumatic brain injury or previous aphasia, a documented current untreated | | |
| Key exclusion criteria: | estimated length of hospital stay greater than 14 days, adequate English proficiency to participate in semi-structured interviews and are above 18 years of age. Patients with aphasia will also have an Aphasia Quotient below 93.7 on the Western Aphasia Battery-Revised. ² Staff participants: One representative from each acute and rehabilitation staff group including medical, nursing, volunteers, and allied health staff members (n=17), who are over 18 years old. Patients will be excluded if they have/are: uncorrected hearing or vision, not medically stable, a documented diagnosis of dementia, traumatic brain injury or previous aphasia, a documented current untreated depression at the time of acute admission or are a participant in another | | |
| Key exclusion criteria: | estimated length of hospital stay greater than 14 days, adequate English proficiency to participate in semi-structured interviews and are above 18 years of age. Patients with aphasia will also have an Aphasia Quotient below 93.7 on the Western Aphasia Battery-Revised. ² Staff participants: One representative from each acute and rehabilitation staff group including medical, nursing, volunteers, and allied health staff members (n=17), who are over 18 years old. Patients will be excluded if they have/are: uncorrected hearing or vision, not medically stable, a documented diagnosis of dementia, traumatic brain injury or previous aphasia, a documented current untreated | | |
| | estimated length of hospital stay greater than 14 days, adequate English proficiency to participate in semi-structured interviews and are above 18 years of age. Patients with aphasia will also have an Aphasia Quotient below 93.7 on the Western Aphasia Battery-Revised. ² Staff participants: One representative from each acute and rehabilitation staff group including medical, nursing, volunteers, and allied health staff members (n=17), who are over 18 years old. Patients will be excluded if they have/are: uncorrected hearing or vision, not medically stable, a documented diagnosis of dementia, traumatic brain injury or previous aphasia, a documented current untreated depression at the time of acute admission or are a participant in another research trial which may affect this study's outcome measures. | | |
| Key exclusion criteria: Study Procedures: | estimated length of hospital stay greater than 14 days, adequate English proficiency to participate in semi-structured interviews and are above 18 years of age. Patients with aphasia will also have an Aphasia Quotient below 93.7 on the Western Aphasia Battery-Revised. ² Staff participants: One representative from each acute and rehabilitation staff group including medical, nursing, volunteers, and allied health staff members (n=17), who are over 18 years old. Patients will be excluded if they have/are: uncorrected hearing or vision, not medically stable, a documented diagnosis of dementia, traumatic brain injury or previous aphasia, a documented current untreated depression at the time of acute admission or are a participant in another research trial which may affect this study's outcome measures. Baseline phase: Eligible patients during the baseline phase will be | | |
| | estimated length of hospital stay greater than 14 days, adequate English proficiency to participate in semi-structured interviews and are above 18 years of age. Patients with aphasia will also have an Aphasia Quotient below 93.7 on the Western Aphasia Battery-Revised. ² Staff participants: One representative from each acute and rehabilitation staff group including medical, nursing, volunteers, and allied health staff members (n=17), who are over 18 years old. Patients will be excluded if they have/are: uncorrected hearing or vision, not medically stable, a documented diagnosis of dementia, traumatic brain injury or previous aphasia, a documented current untreated depression at the time of acute admission or are a participant in another research trial which may affect this study's outcome measures. Baseline phase: Eligible patients during the baseline phase will be observed and video recorded for 4 hours on 3 consecutive days (one | | |
| | estimated length of hospital stay greater than 14 days, adequate English proficiency to participate in semi-structured interviews and are above 18 years of age. Patients with aphasia will also have an Aphasia Quotient below 93.7 on the Western Aphasia Battery-Revised. ² Staff participants: One representative from each acute and rehabilitation staff group including medical, nursing, volunteers, and allied health staff members (n=17), who are over 18 years old. Patients will be excluded if they have/are: uncorrected hearing or vision, not medically stable, a documented diagnosis of dementia, traumatic brain injury or previous aphasia, a documented current untreated depression at the time of acute admission or are a participant in another research trial which may affect this study's outcome measures. Baseline phase: Eligible patients during the baseline phase will be observed and video recorded for 4 hours on 3 consecutive days (one weekend and two weekdays) and will complete a semi-structured | | |
| | estimated length of hospital stay greater than 14 days, adequate English proficiency to participate in semi-structured interviews and are above 18 years of age. Patients with aphasia will also have an Aphasia Quotient below 93.7 on the Western Aphasia Battery-Revised. ² Staff participants: One representative from each acute and rehabilitation staff group including medical, nursing, volunteers, and allied health staff members (n=17), who are over 18 years old. Patients will be excluded if they have/are: uncorrected hearing or vision, not medically stable, a documented diagnosis of dementia, traumatic brain injury or previous aphasia, a documented current untreated depression at the time of acute admission or are a participant in another research trial which may affect this study's outcome measures. Baseline phase: Eligible patients during the baseline phase will be observed and video recorded for 4 hours on 3 consecutive days (one weekend and two weekdays) and will complete a semi-structured interview to explore their experiences of communication, and their | | |
| | estimated length of hospital stay greater than 14 days, adequate English proficiency to participate in semi-structured interviews and are above 18 years of age. Patients with aphasia will also have an Aphasia Quotient below 93.7 on the Western Aphasia Battery-Revised. ² Staff participants: One representative from each acute and rehabilitation staff group including medical, nursing, volunteers, and allied health staff members (n=17), who are over 18 years old. Patients will be excluded if they have/are: uncorrected hearing or vision, not medically stable, a documented diagnosis of dementia, traumatic brain injury or previous aphasia, a documented current untreated depression at the time of acute admission or are a participant in another research trial which may affect this study's outcome measures. Baseline phase: Eligible patients during the baseline phase will be observed and video recorded for 4 hours on 3 consecutive days (one weekend and two weekdays) and will complete a semi-structured | | |

| | Staff will participate in a one-hour focus group to explore their perceptions of barriers and facilitators to inpatient language activities. A focus group interview schedule will be used across all focus groups. Implementation phase: The CEE model will be implemented within the acute and rehabilitation wards. Post-implementation phase: Intervention group patient observations and interviews, and staff focus groups will replicate baseline data collection. |
|----------------------------------|---|
| Safety parameters | Patients and/or their significant others may experience increased levels of distress during recruitment and/or data collection. This may be the result of adjustment following stroke and/or diagnosis of aphasia and increased awareness of impairment. No other risks known regarding participation in this project. The baseline assessments and interview will be conducted by the Chief Investigator who has experience in supporting patients during this early stage of stroke recovery. If a patient or any significant others becomes upset or distressed, the assessment or interview will be paused with the option to discontinue and counselling strategies will be provided. |
| Statistical methods /analysis | Patient demographic and stroke characteristics will be presented using descriptive statistics. One-way ANOVA or the Kruskal-Wallis and chisquare tests will examine differences in characteristics between groups. Time spent observed in interactive and solitary language activities will be expressed as a percentage of total observations. A mixed design ANOVA will be used to calculate the within-subjects variable of presence of aphasia and the between-subjects variable of a CEE on language activity levels of patients by comparing baseline to intervention phase observations. A qualitative description research approach will be used for the qualitative component of this research. The mixed methods design will enable the triangulation of the qualitative and quantitative data. |
| Sample size determination: | The patient sample size was selected for this pilot study to collect data across each observation period for each patient group in the baseline and intervention phases (see document: Observation_protocol_SD_version 3_23-02-16). The sample size for staff participants was selected to capture a sufficient breadth of professional perspectives. |

3. Introduction

Aphasia is an acquired communication disorder that affects approximately 30% of first ever ischaemic stroke survivors³ and persists in up to 61% of survivors one-year post stroke.⁴ Aphasia impacts all communication modalities with significant negative consequences for social participation, interpersonal relationships, autonomy, capacity to work and quality of life.⁵

Patients following stroke with aphasia (PWA) have been observed to spend less than 28% of their day communicating and 44% of their day alone during their first weeks of inpatient rehabilitation. Inadequate opportunities for communication places PWA at risk of developing maladaptive behaviours such as learned non-use of language.

Environmental Enrichment (EE) refers to conditions which promote physical, cognitive and social activity and has been shown in animal models of stroke to enhance neuroplasticity⁸, promote better learning and memory and contribute to significant improvements in motor function.⁹ The human equivalent model¹⁰ in a rehabilitation unit results in patients spending more time engaged in activity and less time sleeping and alone.¹¹

4. Objectives

Aphasia is a complex language impairment and PWA may need additional support within an Enriched Environment. This pilot study seeks to develop and test an adapted model of an Enriched Environment, a Communication Enhanced Environment (CEE), as a strategy to provide PWA and patients following stroke without aphasia (PWOA) more opportunities to engage in language activities during inpatient rehabilitation. Within this study language activities include both *solitary activities* that may promote aphasia recovery such as reading, writing, listening to the radio, and the use of iPad applications, and *interactive activities* which are based in communicative interactions that involve an exchange of information with a communication partner involving talking, gesture and/or facial expression, reading, writing or drawing to communicate.

4.1 Hypotheses

A CEE will increase patient solitary and interactive language activities and improve staff and patient experiences of communication compared to a standard ward environment.

5. Study design

This mixed methods pilot study is a prospective before-after non-randomised controlled design in an acute and a rehabilitation ward of a metropolitan private hospital. The study involves three phases:

- i) Baseline: observe and quantify the current ward environment;
- ii) Implementation of the CEE model;
- iii) Post-implementation: assess the impact of the CEE model.

6. Study Population

i) Patients: The baseline group (n=8, 4 PWA, 4 PWOA) recruited within the baseline phase, and the intervention group (n=8, 4 PWA, 4 PWOA) recruited during the post-implementation phase.

ii) Staff participants: One representative from each acute and rehabilitation staff group including medical, nursing, volunteers, and allied health staff members (n=17), who are over 18 years old.

6.1 inclusion and exclusion criteria

Patients will be eligible for inclusion if they have/are: admitted to the acute or rehabilitation ward for a stroke, less than 21 days post stroke during baseline phase or intervention phase, the ability to provide informed consent as determined by the medical team, a Glasgow Coma Scale¹ score greater than 10 at the time of screening, an estimated length of hospital stay greater than 14 days, adequate English proficiency to participate in semi-structured interviews and are above 18 years of age. Patients with aphasia will also have an Aphasia Quotient below 93.7 on the Western Aphasia Battery-Revised.²

Patients will be excluded if they have/are: uncorrected hearing or vision, not medically stable, a documented diagnosis of dementia, traumatic brain injury or previous aphasia, a documented current untreated depression at the time of acute admission or are a participant in another research trial which may affect any of this study's outcome measures.

Staff and volunteers who are over 18 years old will be eligible to participate in this study.

7. Study Assessments and Procedures

Baseline

All recruited patients will complete the Montreal Cognitive Assessment, ¹¹ and The NIH Stroke Scale. ¹² PWA will also complete the Western Aphasia Battery-Revised. ² Patients' behaviour will be observed and video recorded for four hours per day on a Sunday, Monday and Tuesday between 7am to 7pm. A behaviour mapping tool (Appendix A) developed for this study will record patient engagement in language activities in the first minute of each five-minute interval across each four-hour observation period. Semi-structured interviews will explore patients' perceptions of barriers and facilitators to inpatient language activities. An interview schedule will be used across all interviews (Appendix B.). Supportive communication strategies will be used to facilitate PWA participation in interviews with transcriptions annotated to capture any non-verbal responses.

Staff will participate in a one-hour focus group to explore their perceptions of barriers and facilitators to inpatient language activities. A focus group/interview schedule (Appendix C.) will be used across all focus groups.

Implementation

The CEE model will be implemented within the acute and rehabilitation wards.

Post implementation

Intervention group patient observations and interviews, and staff focus groups will replicate baseline data collection.

8. Study Treatment

The CEE model incorporates the following strategies to encourage engagement in language activities:

- Staff training to facilitate patients' communication and provide opportunities to engage in language activities;
- ii) Patient access to:

- a) Communication enhancement resources such as iPads and audiobooks;
- b) Communal areas to facilitate engagement amongst patients.

9. Participant Completion and Discontinuation

9.1 Participant Completion

Participants will have completed the study when they have completed the semi-structured interview.

9.2 Participant withdrawal

Participation in this study is voluntary. The participant can withdraw from taking part in the study at any time without giving a reason for withdrawing.

10. Data analysis

10.1 Primary Analysis

The proportion of observed episodes where PWA and PWOA are engaged in language activities at baseline and post implementation will be analysed using a mixed design ANOVA.

10.2 Secondary Analysis

The differences in staff and patient perceptions of the barriers and facilitators to inpatient language activities and communication post CEE implementation will be analysed through a qualitative description approach. Triangulation of the qualitative and quantitative data will be conducted.

11. Data management

The data collected will be confidential. No identifying information will be attached to the data and any information that may reveal participant's identity will be removed. The master list of participant names and codes will be kept in a locked filing cabinet at the hospital site which will only be accessible by the research team. All data will be accessed, used and stored in accordance with Commonwealth Privacy Laws. The de-identified data will be stored on a password-controlled computer and/or in a locked cabinet at Edith Cowan University. Electronic data will be backed up on a password controlled hard drive only accessible by the Chief Investigator.

The data collected from this study will have a significant contribution to the aphasia research area and therefore will be stored for 15 years following the completion of this study. Data may be accessed for future studies by the study investigators or higher degrees by research (HDR). In the case of HDR use of the data, the use of the data will be bound by a two-way confidentiality agreement. The data may be used for teaching purposes only with the additional written permission from participants. The data may be made accessible to consumer groups (for example the Australian Aphasia Association) and information may be made available through the National Stroke Foundation and scientific journals. Confidentiality will be maintained in all circumstances. Non-identifiable data will be accessible by researchers through data sharing archives. This data will be governed by an overarching body to ensure data are only used for approved purposes. Researchers who access this data from the data bank will not have access to the participant keys that attach participants to codes therefore data will only be re-identifiable by the Chief Investigator. Data will be deleted from electronic storage and hard copy data will be shredded by the chief

investigator after 15 years completion of the research study (with Ethics Committee approval, Ethics approval numbers: HPH431 and ECU HREC 12149). Non-identifiable data will be added to data archives for data sharing. Researchers who access data archives will not have access to information attaching participants to coded data.

12. Study Report

This study will be published in a PhD thesis as part of the Chief Investigator's Higher Research Degree. Outcomes from this study will be published in peer review journals and at conferences.

13. Administration Procedures

13.1 Ethical Considerations

This research is likely to have a significant impact on aphasia recovery following stroke and will form the basis for future study designs. This study will develop a teaching and learning package that can be used in the future to facilitate and promote increased levels of communication activity during early stroke recovery. The implementation of a CEE may address missed opportunities for language stimulation, harness increased levels of neuroplasticity and optimise aphasia language recovery after stroke. The benefit of a CEE may extend beyond patients with aphasia and may improve health care experience and communication access for all patients following stroke. Additionally, these benefits may extend beyond patients involved in the study as trained staff may use skills and knowledge obtained in the training program to enhance the communication environment of all patients they care for.

13.2 Ethical Review Committee

All processes and documentation used within this study will be reviewed and approved by the Edith Cowan University Research Ethics Committee and the site Ethics Committee. The Chief Investigator will complete the annual ethics reports and will be responsible for reporting any adverse events to the Ethics Committees.

13.3 Informed Consent

Participants will be excluded if they do not have adequate English proficiency to participate in semi-structured interviews and focus groups. Any participants that require an interpreter will be excluded from inclusion in this study as determined by the medical team.

Patients with aphasia will be provided with aphasia friendly information sheets and consent forms with simple language, bold key words and pictorial support. This will be read and explained by the researcher. Supported conversation strategies will be used to support and facilitate patients with aphasia's involvement and understanding of the research process, informed consent and their rights to withdraw at any time. This will be provided by the Chief Investigator who is a qualified speech pathologist with experience in communicating with patients with aphasia using supported conversation techniques to facilitate and support communication. A detailed information will also be provided to the 'person responsible' for all patients.

13.4 Protocol Amendments

All protocol amendments will be reviewed and accepted by the Edith Cowan University Research Ethics Committee and the site research Ethics Committee.

14. References

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Appendix A. Behavioural mapping tool

| Time (5 min): | NO LANGUAGE ACTIVIT | IES OBSERVED (describe) | | COMMENTS |
|---|--|---|--|----------|
| Location (select one) | People present | INTERACTIVE LANGUAGE ACTIVITIES | 'OTHER' FUNCTIONAL LANGUAGE ACTIVITIES | |
| Amenities Bedroom Hall | Nurse Personal care assistant Doctor | In person Telephone Therapy session/ward round | Typing/writing Reading (describe) | |
| Therapy area Family Mtg Room Activity room | Physio OT SP | Other (describe) Patient | Texting (mobile phone) Listening to radio/music Watching TV | |
| ON WARD | DT Social worker | Verbal communication Non-verbal gesture/facial expression (describe) | Internet use (describe) | |
| Doctor's room Dining room Communal area (describe) | Family/Friend Other patient Alone Other (describe) | Written aids (writing or reading (circle)) Pictorial aids (describe) Other communication aid (describe) | Word games with a partner Other (describe) | |
| OFF WARD Outside Off-unit (describe) | | Communication partner/s Verbal communication | NON-FUNCTIONAL/ NON-PROPOSITIONAL LANGUAGE ACTIVITIES | |
| Other (describe) | | Non-verbal gesture/facial expression (describe) | Singing Word games (alone) Language apps (alone) | |
| | | Written aids Pictorial aids Other communication aid (describe) | Copying written letters, words, sentences (alone). OTHER Talking to observer | |
| | | () | Talking to self: appropriate/inappropriate (describe) | |
| Time (5 min): | NO LANGUAGE ACTIVITIES OBSERVED (describe) | | | COMMENTS |
| Location (select one) | People present | INTERACTIVE LANGUAGE ACTIVITIES | 'OTHER' FUNCTIONAL LANGUAGE ACTIVITIES | |
| Amenities Bedroom Hall Therapy area Family Mtg Room Activity room | Nurse Personal care assistant Doctor Physio OT SP | In person Telephone Therapy session/ward round Other (describe) Patient | Typing/writing Reading (describe) Texting (mobile phone) Listening to radio/music Watching TV | |
| ON WARD Doctor's room | DT Social worker Family/Friend | Verbal communication Non-verbal gesture/facial expression (describe) | Internet use (describe) Word games with a partner | |
| Dining room Communal area (describe) | Other patient Alone Other (describe) | Written aids (writing or reading (circle)) Pictorial aids (describe) Other communication aid (describe) | Other (describe) NON-FUNCTIONAL/ NON-PROPOSITIONAL | |
| OFF WARD Outside Off-unit (describe) | | Communication partner/s Verbal communication | LANGUAGE ACTIVITIES Singing Word games (alone) | |
| Other (describe) | | Non-verbal gesture/facial expression(describe) Written aids | Language apps (alone) Copying written letters, words, sentences (alone). OTHER | |
| | | Pictorial aids Other communication aid (describe) | Talking to observer Talking to self: appropriate/inappropriate (describe) | |

Appendix B. Patient interview guide

Investigating Communication Enhanced Environments after stroke Patient Interview guide, version 1_11-8-15

Tell me about what kind of activities you do while you are here (in hospital).

Describe your experience of communicating with people on the ward.

What makes it easier to communicate with people on the ward?

What makes it hard to communicate with people on the ward?

What can we do to make communicating with people easier?



Appendix C. Staff focus group guide.

Investigating Communication Enhanced Environments after stroke Staff focus group guide, version 1_27-7-15

STAFF FOCUS GROUP GUIDE BASELINE PHASE

What kind of language activities or language tasks do patients following stroke currently participate in on the ward?

What kind of language activities or language tasks would you like see patients following stroke have access to on the

wards?

Describe your experience of communicating with patients following stroke at the moment.

Can you tell me about anything that facilitates your ability to communicate with patients following stroke on the

ward?

Can you tell me about any barriers you experience that impact your ability to communicate with patients following

stroke on the ward?

What changes would you like to see to enhance communication between staff and patients following stroke on the

ward?

What changes would you like to see to enhance communication between visitors and patients following stroke on

the ward?

How could we enhance or optimise communication and language tasks and activities for patients following stroke on

the ward?

What do you think a communication and language enhanced stroke ward environment might look like?

STAFF FOCUS GROUP GUIDE POST-IMPLEMENTATION PHASE

Describe your experience of communicating with patients following stroke at the moment.

Can you tell me about any barriers you experience that impact your ability to communicate with patients following

stroke on the ward?

Describe the differences in the communication environment since implementing the model.

What changes did you see to enhance communication between staff and patients following stroke on the ward?

What changes did you see to enhance communication between visitors and patients following stroke on the ward?

What was it like to use the model?

How do you feel about the model?

Can you tell me about anything that helped you use the model with patients following stroke on the ward?

Can you tell me about any barriers you experienced while implementing the model?

How can we improve the model?

Communication Enhanced Environments after Stroke

Study procedure version 2_23-02-16

BASELINE:

Staff recruitment: The Chief Investigator will recruit staff participants through a verbal explanation of the study and the provision of the information sheets and written consent forms. Staff will be provided 48 hours to discuss the study and ask questions before consenting to participate. Staff interviews and focus groups will commence as staff participants are recruited. Staff will participate in a one-hour focus group or a one-hour semi-structured interview (in person or via telephone) to explore staff perceptions of environmental barriers and facilitators to language activity and communication on in-patient acute and rehabilitation wards.

Patient recruitment: All consecutively admitted patients following stroke during the baseline period will be screened for eligibility to participate in the study. The hospital site investigators will identify potential patient participants that meet the inclusion and exclusion criteria. Patients following stroke with aphasia will be identified by the hospital speech pathology or medical team as having a diagnosis of aphasia (aphasia diagnosis will be confirmed via Western Aphasia Battery-Revised (WAB-R)¹ Aphasia Quotient score <93.7 during data collection). The site investigators will approach potential participants and gain verbal consent from the patient to be approached by a member of the research team and have their 3-point identification released to the research team. This will be documented in the patient's integrated medical progress notes. Once verbal consent has been gained and documented, the site investigators will email the Chief Investigator the patient alert proforma identifying the patient as meeting the inclusion/exclusion criteria. The research team will liaise with the medical team to confirm the potential participant meets the inclusion criteria: (i) admitted to the in-patient unit for recent stroke, (ii) are less than 21 days post stroke and during baseline phase or intervention phase, (iii) have the ability to provide informed consent as determined by the medical team iv) Glasgow Coma Scale² greater than 10 at the time of screening, (v) have an estimated length of stay greater than 14 days and (vi) have adequate English proficiency to participate in semi-structured interviews. Patients will be excluded if they (i) have uncorrected hearing or vision (for example hearing impairment without hearing aids, vision impairment without glasses), (ii) are not medically stable, (iii) have a documented diagnosis of major depression or (iv) have a documented history of dementia or significant cognitive decline, traumatic brain injury or previous aphasia at the time of admission for the acute event, (v) or are a participant in a research study that will influence this study's outcomes. Patient participant recruitment will follow the patient participant consent procedure (see document: SD_Communication Enhanced Environments after Stroke consent procedure version 1_3-2-15). A record of identifying participant details attached to patient codes will be kept at the hospital site in a locked filing cabinet. An email summary of the baseline assessment results will be sent to the hospital speech pathology generic email address. The patient will be identified by patient code and ward/room number. The hospital speech pathology team will write a summary of the assessment results in the patient's integrated medical progress notes.

Patient data collection: All recruited patient participants will complete the NIH Stroke Scale³ (by someone trained in using this tool) and the Montreal Cognitive Assessment (MoCA).⁴ Participants with aphasia will also complete an

assessment of aphasia, the WAB-R¹ and provide a personal narrative language sample on their reason for admission to confirm a diagnosis of aphasia. After patient recruitment has been completed, the Chief Investigator and/or trained medical team members will recruit the patient's family, friends and significant others to consent to video recording and observations of their interactions with patient participants.

Observations of patient participants will commence 1-3 days after obtaining written consent. Patients' behaviour will be observed by the Chief Investigator or a Research Assistant, and video recorded for a total of 12 hours to enable behaviour mapping of video data (see document: Observation_protocol_SD_version 3_23-02-16). Patients will be observed and video recorded for 4 hours per day on weekend day and two consecutive weekdays between 7am to 7pm. The observation periods will be grouped into 4-hour observation intervals (e.g. 7am-11am, 11am-3pm and 3pm-7pm). Each day the patient will be observed and video recorded for one observation interval. The participant will be observed and video recorded during a different observation interval each day to gain a general insight into the patients' activities (see Figure 1. below). Patients who do not consent to video recording will be provided with the option of audio recording and manual observation conducted by the researcher to enable the collection of case notes regarding patient behaviour. An observational protocol developed for this study will be used to measure the frequency patient participants engage in language activities. These will be categorised into solitary language activities for example reading, writing, listening to the radio, use of iPad applications, and interactive language activities defined as i) an interaction involving an exchange of information, ii) with a communication partner including gesture and/or facial expression, reading, writing or drawing for the purpose of communication and use of technology including talking on the telephone. The observational protocol will be based on the behavioural mapping techniques of Janssen et al.⁵ Patients' solitary and interactive language activities will be recorded in 5-minute intervals and activity observed within the first minute of the observation interval will be recorded on a checklist of the predetermined behaviours. Semi-structured supported conversation interviews for patient participants will be conducted within 5 days of the last observation. The interviews will explore patients' perceptions of environmental barriers and facilitators to language activities and communication and their experience of communication on the acute and rehabilitation wards.

IMPLEMENTATION:

A model of a CEE will be implemented within the acute and rehabilitation wards. The model will be developed as part of the research project. We hypothesise that our model of CEE will include the provision of:

- i) CEE equipment, for example reading materials such as books and magazines, access to a computer with internet and access to a communal dining area,
- ii) CEE education, support and training for staff, patients and their family, friends and significant others with the aim to develop the ability to support and facilitate 'language activity' and 'communication activity' for patients after stroke. This will be accessible via multiple modalities including one-on-one training and group training sessions, as well as through the provision of video and written resources. A questionnaire will be administered pre and post training in order to determine staffs' perceptions of changes in their knowledge, skills and attitude towards

communication and aphasia. Additionally, feedback regarding the content and format of the training program will be obtained through questionnaires administered after the completion of the training program. Training and support provided in the implementation phase will be continued until the end of the intervention phase.

POST-IMPLEMENTATION:

Staff participant semi-structured interviews and focus groups will be conducted. Staff will participate in a one-hour semi-structured interview or a one-hour focus group to explore staff perceptions of environmental barriers and facilitators to language activities and communication.

The procedures for participant recruitment and data collection during the post-implementation phase will replicate those used in the baseline phase.

There is no travel commitment for all participants as all data collection and training will be conducted at the hospital.

| Observation | Observation | Day 1: | Day 2: | Day 3: |
|-------------|-------------|--------|--------|---------|
| interval | time | Sunday | Monday | Tuesday |
| | | | | |
| 1 | 7am-8am | PWA1 | PWA3 | PWA2 |
| | 8am-9am | PWOA1 | PWOA3 | PWOA2 |
| | 9am-10am | | | |
| | 10am-11am | | | |
| 2 | 11am-12pm | PWA2 | PWA1 | PWOA |
| | 12pm-1pm | PWOA2 | PWOA1 | PWOA3 |
| | 1pm-2pm | | | |
| | 2pm-3pm | | | |
| 3 | 3pm-4pm | PWA3 | PWA2 | PWA1 |
| | 4pm-5pm | PWOA3 | PWOA2 | PWOA1 |
| | 5pm-6pm | | | |
| | 6pm-7pm | | | |

Figure 1. CEE Observation schedule

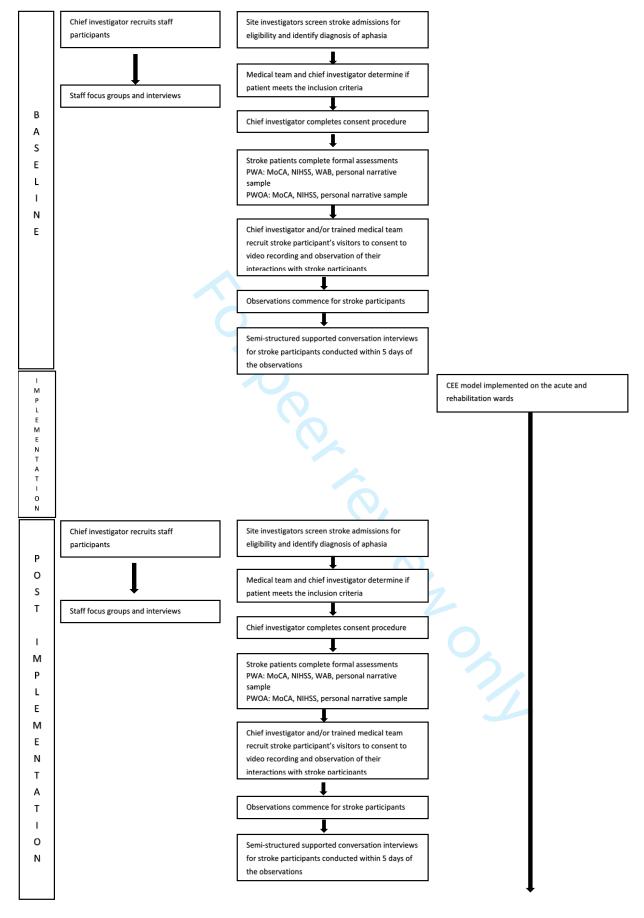


Figure 2. Study flow diagram

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- 2. Teasdale G, Jennett B. Assessment of coma and impaired consciousness. A practical scale. Lancet. 1974;2(7872): 81–4.
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- 5. Janssen H, Ada L, Bernhardt J, et al. An enriched environment increases activity in stroke patients undergoing rehabilitation in a mixed rehabilitation unit: A pilot non-randomized controlled trial. Disabil Rehab, 2014; 36(3), 255–262. doi: 10.3109/09638288.2013.788218

Communication Enhanced Environments after Stroke consent procedure

Version 1_3-2-15

Patient participants

The following consenting procedure will be used for all participants who are identified as potential research participants. Recruitment will only be completed by the Chief Investigator.

- 1. Check the patient meets the inclusion criteria and exclusion criteria.
- 2. Read the participant information sheet to the patient. Use the pictures on the participant consent form to support their comprehension of verbal information. Use gesture, written and pictorial support to facilitate verbal communication as required.
- 3. Provide the person responsible with the person responsible information sheet and consent form.
- 4. Provide time for the patient and the person responsible to discuss the study and ask questions to their satisfaction.
- 5. Ask the patient if they consent to the study using simple closed questions (e.g. "Do you understand what the study is about?", "Do you have any questions about the study?", "Do you want to be in the study?", "Will you sign the form?". Use multi-modal communication strategies and repeat information/questions as required. Use the pictures on the participant consent form to support patient comprehension of verbal information.
- 6. If the patient agrees to participate in the study, ensure they sign the consent form witnessed by someone independent of the study.
- 7. Provide the patient with a copy of the information sheet and consent form for their own records.
- 8. Add the participant study number to the consent form
- 9. Store the signed consent forms in a locked cabinet at the hospital site. This cabinet will only be accessible by the research investigators.

Investigating Communication Enhanced Environments after stroke Observation Protocol version 3_ 23-2-16

During the baseline and intervention period, patients' behaviour will be observed and video recorded for a total of 12 hours. Patients who do not consent to video recording will be provided with the option of audio recording and manual observation. This will enable the collection of relevant notes about factors that might influence the interactions that may not be captured in the video or behavioural mapping, for example the context of the interactions or details about the environment.

Patients will be manually observed <u>and</u> video recorded for four hours per day on two weekdays and one weekend day between 7am to 7pm. The observations will be grouped into three x 4-hour observation intervals (e.g. 7am-11am, 11am-3pm, 3pm-7pm). Each day the patient will be observed and video recorded for one of the 4-hour observation intervals. The 4- hour observation period will be split into 5-minute intervals. All language and communication activity observed within the first minute of the 5-minute interval will be recorded on the behavioural mapping sheet with predetermined behaviours (Appendix 1). The free smart phone app 'Impetus' can be used to time 1-minute observations. You can set the timer to vibrate briefly when the 1-minute observation interval begins and ends.

Observation times (see Figure 1.) will be randomly selected by drawing out of an envelope. This will be conducted by the primary investigator prior to commencing patient observations. It may not be possible to observe the patient during the planned observation time, for example as a result of scheduled testing or home visits. If this occurs, patients can be observed during the next available observation interval. Changing or modifying the observation schedule should be avoided where possible.

| Observation | Observation | Day 1: | Day 2: | Day 3: |
|-------------|-------------|---------|----------|---------|
| interval | time | Sunday | Monday | Tuesday |
| interval | time | Juliuay | Widilday | Tuesday |
| | - 0 | ****** | 211112 | 21114 |
| 1 | 7am-8am | *PWA1 | PWA3 | PWA2 |
| | 8am-9am | **PWOA1 | PWOA3 | PWOA2 |
| | 9am-10am | | | |
| | 10am-11am | | | |
| 2 | 11am-12pm | PWA2 | PWA1 | PWA3 |
| | 12pm-1pm | PWOA2 | PWOA1 | PWOA3 |
| | 1pm-2pm | | | |
| | 2pm-3pm | | | |
| 3 | 3pm-4pm | PWA3 | PWA2 | PWA1 |
| | 4pm-5pm | PWOA3 | PWOA2 | PWOA1 |
| | 5pm-6pm | | | |
| | 6pm-7pm | | | |

Figure 1. Observation schedule

^{*}PWA: patient with aphasia

^{**}PWOA: patient without aphasia

DISCOURSE SAMPLE

You must collect a personal narrative discourse sample for each participant at the beginning of the first observation. Once you have set up the video camera and have started recording, ask the patient "what has brought you into hospital?". Once the patient has finished telling you their personal narrative, tell the patient you will now start the observations.

VIDEO RECORDING SET-UP

Place the video camera facing the patient approximately 1-2 metres away from them. Ensure the camera is placed in an area where it is unlikely to be moved for the duration of the observation time (for example at the end of the patient's bed). Ensure the camera frame is capturing the patient as well as their surroundings (e.g. potential communication partners, visitors, etc). If the patient relocates, reposition the camera to ensure the patient and their surroundings remain in frame. Observe and manually record the patient's behaviour and their environment according to the procedure for behavioural mapping.

Do not record the patient in the bathroom or shower or during any other inappropriate circumstances (this may include sensitive conversations, culturally sensitive situations or if the patient requests). If the patient indicates that they don't want to be recorded or becomes agitated, upset or distressed, use the 'withdrawal from observations visual resource' (if appropriate) and ask the patient:

- 1. Do they want you to stop video recording?
- Do they want to be manually observed and audio recorded instead?If the patient responds 'no', ask the patient-
- 3. Can you come back another time to observe them?

If the patient asks you to stop recording you must cease recording immediately. The patient may allow you to continue with manual observations or come back another time to complete the observations. If the patient allows you to complete manual observations and audio recording, follow the audio-recording set-up and protocol below.

AUDIO RECORDING SET-UP AND PROTOCOL

This protocol is to be followed if the patient or their family indicate they do not want to be video recorded however agree to audio recording and manual observations. Place the cap on the video camera and continue recording in order to capture audio. If using a battery-operated audio recorder, place it on a table close to the patient (within 1 metre). Ensure the audio recorder is placed in a location where it will not be touched or moved throughout the

observation time. Observe and manually record the patient's behaviour and their environment according to the procedure for behavioural mapping. Ensure spare batteries for the audio recorder are available if required.

COMMUNICATION PARTNERS AND VISITORS

Take note of all communication partners and visitors who have provided consent to video recording and/or observations of their patient interactions. If someone enters the room during recording politely interrupt the interaction, introduce yourself and inform the person that the patient is being video recorder recorded as a part of the study the patient has agreed to participate in. Ask the visitor if they would like to go out of the room with the researcher to find out about the study and the video recording. Provide a verbal explanation of the study and provide the 'Visitors/communication partners' information and consent form'. Offer the visitor the option of no video or manual recoding during their interaction with the patient. If the person chooses not to participate in manual or video observations inform the person that any incidental recordings of them will be deleted and will not be included in the study. The researcher will step out of the room for the duration of their visit.

PROCEDURE FOR BEHAVIOURAL MAPPING

- Position self where the patient can be clearly observed
- Remain inconspicuous as possible
- Circle ALL appropriate components on the observation schedule in regards to location, activity, people
 present and details of language and communication observed within the first minute of each five-minute
 interval.
- You can circle more than one key per section if required (except for location).
- If you require a toilet break, leave the camera recording while you take a break. If you miss a 1-minute
 observation, place a line through the observation interval on the behavioural mapping sheet and write
 'unobserved-toilet break'.

TIME

• Write the time at the beginning of the 1-minute observation interval

LOCATION

- Circle only one location
- If the patient is moving between two locations, circle the location the patient is moving towards

AMENITIES: Toilet, shower.

BEDROOM: Around the patient's room or bed. If the patient is outside of their doorway this is considered 'hall'.

HALL: Any hallway within the hospital ward.

THERAPY AREA: In an allied health therapy session, including occupational therapy, physiotherapy, speech pathology, nursing.

FAMILY MEETING ROOM: Family meeting room.

DOCTOR'S ROOM: Doctor's office.

DINING ROOM: Dining room during meal times or any other time.

COMMUNAL AREA: Communal dining area.

OUTSIDE: Outside areas including the garden, car park.

OFF UNIT: Off-site locations, home visits, testing off site.

OTHER: Anything that doesn't fit into the above categories-provide description of location.

PEOPLE PRESENT

People present include any person that is near the patient and is able to have an interaction with the patient. If you do not know how to classify the person make a note to check with staff at a later time and complete the observation schedule.

Exceptions: People who are near the patient but are unable to interact with the patient, e.g. cognitive or behavioural issues, barriers between person and the patient preventing them from interacting- e.g. curtain drawn, people in the way. If an interaction is occurring despite objects in the way, the communication partner is considered as a 'person present'.

PEOPLE PRESENT: Nurse, nurse assistant, doctor, physio (physiotherapist), OT (occupational therapist), SP (speech pathologist), DT (dietician), SW (social worker), family/friend, other patient, alone (no-one present that is conducive to interactions), other (describe).

ACTIVITIES

UNOBSERVED: If you are unable to observe the patient. Place a line through the observation

interval and write unobserved.

NO LANGUAGE ACTIVITY: If the patient is observed not engaged in any communication activity.

- Circle 'no activity' on the checklist
- Write what the patient is doing, e.g. 'sleeping'

INTERACTIVE LANGUAGE ACTIVITIES: Defined as an interaction involving an immediate communicative exchange with a communication partner. Interactive language activities may include talking, gesture and/or facial expression, reading, writing or drawing for the purpose of communication, use of communication aids or AAC devices and use of technology including talking on the telephone. Non-verbal gesture or facial expression includes eye contact to

initiate interactions, hand gestures (e.g. waving, thumbs up), body movements for the purpose of conveying a communicative message (e.g. shrugging) and/or facial expressions for the purpose of communication.

Communication aids or AAC devices includes any use of alternative and augmentative devices for the purpose of communication, e.g. high-tech or low-tech AAC devices such as letter boards, pictures/photos, whiteboard, writing or drawing, smart phones, iPad. Please describe communication aids observed.

OTHER FUNCTIONAL COMMUNICATION ACTIVITIES: All other communication activities that do not involve a direct immediate communicative exchange with a communication partner. Functional communication activity may include reading, typing/writing, emailing, internet use, watching TV, listening to talking on the radio. Note the patient must be looking directly at the TV to be considered 'watching TV'. If the TV is on in the background, do not include this as 'watching TV'.

NON-FUNCTIONAL/NON-PROPOSITIONAL LANGUAGE ACTIVITIES: Singing, word games (carried out alone), language apps (used alone), copying written letters, words or sentences (carried out alone).

OTHER: Communication or language activities that do not fit the criteria of interactive language activity, 'other' functional communication activities, non-functional/non-propositional language activities or may be a confounding variable (for example, talking to self and talking to the observer). If a patient is talking to themself, note if this is appropriate (for example, saying 'excuse me' after burping) or inappropriate (for example, an extensive monologue) and describe the context. If the patient's verbal output is inaudible, write this is in the space underneath 'talking to self'.

Note: If the patient is using a computer, phone, smart device, or iPad where the activity they are engaged in (e.g. texting, emailing, playing a game, etc) cannot be accurately determined, note this in the comments section. After the 1-minute observation interval has been completed ask the patient if they mind sharing if what activity they were completing on their device and record this in the relevant section. If the patient does not wish to share this information with you, record this in the 'other' section.

COMMENTS

Describe the context of the interactions or details about the environment in the comments section. This will provide information regarding factors that may influence the interactions, for example 'background noise'. Additionally, write down any information that may be missed in the video data, for example, people out of the camera frame, interactions that may be overheard in the room that might impact on the current interactions.

Draw a line under the final comment after the one-minute observation had been completed. Write any additional observations within the final 4 minutes below this line (see example).

If you have any queries or questions regarding this observation protocol or the observation protocol please contact chief investigator Sarah D'Souza.

Patient participant information and consent form Communication activity in hospital

This research project is being undertaken as **part of** the **requirements** of a **PhD at Edith Cowan University**.

Researchers' contact details

| Edith Cowan University | | | | |
|---|---------------------|------------------|--|--|
| Chief Investigator/ | Sarah D'Souza | Ph: 0439 982 451 | | |
| PhD student | | | | |
| Principal Supervisor | Professor Beth | Ph: 08 6304 2769 | | |
| | Armstrong | | | |
| Co-Supervisor | Associate Professor | Ph: 08 6304 2047 | | |
| | Natalie Ciccone | | | |
| Co-Supervisor | Associate Professor | Ph: 08 6304 5901 | | |
| | Erin Godecke | | | |
| Co-Supervisor | Associate Professor | Ph: 08 6304 2563 | | |
| | Deborah Hersh | | | |
| Hunter Stroke Service, University of Newcastle and Hunter | | | | |
| Medical Research Institute | | | | |
| Adjunct Supervisor | Dr Heidi Janssen | Ph: 02 40420417 | | |

You are **invited** to participate in a research project. Sarah D'Souza, a speech pathologist and PhD student is leading the study as Chief Investigator. This study has received ethical **approval** from **ECU** Human Research **Ethics Committee** and the Hollywood Private Hospital Research Ethics Committee.

This project is investigating the **hospital environment** to see how this **influences** patient **communication activity**. Communication activity involves communication, such as **talking** with other patients, **socialising**, **reading** the paper, using the **telephone**, talking to staff, or engaging in group activities including **therapy**.

You have been selected to participate as you have had a stroke and are receiving treatment at Hollywood Private Hospital. We are interested in seeing how the hospital surroundings affect what you do throughout the day.

What would you have to do?

You will be **asked** to provide **consent** to **agree to participate** in the study.

You will be **asked to consent** to:

Complete three tests to see how your stroke has affected you
including your language, concentration and memory. These tests
will be conducted at the beginning of the project. The tests will take
approximately 1 hour to complete with an option to complete the tests

over **two separate 30 minute sessions** and with as many **breaks** as you may need.

- A researcher spending approximately 1 hour discussing with you
 your opinion regarding how your rehabilitation surroundings affect
 your stay in hospital and your communication activity levels.
- A researcher video recording, observing and writing down what is happening in your environment including your activities. You will be observed and recorded for a total of 12 hours over 3 days.

You may **not want** to be **video recorded**. If you **request**, you will **not** be **video recorded**. You can ask not to be video recorded at **any time**. In this case the researcher will **only observe**, **audio record** and **write down** what is **happening in your** environment **including** your activities.

- A researcher looking at your hospital medical file to collect information regarding:
 - Your details (such as your age, your living arrangements, your occupation and your level of functioning before your stroke)
 - Any conditions or diseases you may have
 - Information about your stroke (for example when it happened, the area of the brain affected, how it has affected your functioning and abilities)
 - Details about how long you have been in hospital since your stroke

If you decide to participate in this study, you will not miss out on any treatment. Participation will not cost you anything and after completing the tests and the interview you will be asked to continue participating in your normal activities.

We will **not record** if you are **behind closed curtains** or completing sensitive tasks such as when you are in the **toilet** or **shower**.

We may use the **recordings** of **you** to make a **training package** (including a video). You can have **your face blurred out** if you want. If you **do not want** to be in the training package we will **not include you** in the training package or video.

Your hospital **discharge** will **not be affected** because you are in this study. **You** will be **discharged** from hospital when the hospital **medical team decides** that you are **ready**.

There are **no known risks** of participating in this study. If you feel uncomfortable at any time, you are free to **tell the researcher** and **observations** within your room will **stop immediately**. You may become **upset** during the **tests** or the **interview**. If this happens you can **ask** to take a **break or stop** the interview.

There will be **no immediate benefit** to you from participating in this research; however your participation will allow the collection of

information that may **help improve** stroke **hospital wards** which may **benefit** future stroke survivors.

Participating in this study is completely voluntary. You do not have to participate if you don't want to. If you decide to participate you may withdraw at any time without giving a reason and withdrawing will not disadvantage you in any way and will not affect your hospital treatment. If you decide that you do not want to participate in the study, you can ask to remove all of your information from the study.

All the **information** you give will be **confidential**. You will **not be identified** by name. You will be **assigned** a unique **code** and any information that may reveal your **identity** will be **removed**.

All personal health information will be accessed, used and stored in accordance with Commonwealth Privacy Laws. **Information** from all the people in the study is **combined** and **summarised.**

We will store all your electronic information on a password locked computer and password locked hard drive only accessible by the Chief Investigator. Your hard copy information will be kept in a locked cabinet at Edith Cowan University. You information will only be accessible to researchers named on this study.

The **results** of this study may be **published** in research **journals** or presented at **conferences**. Your **name** will **not** be **used**.

Data may be **used** in higher degree by **research studies** in the **future**. **Confidentiality** will be **maintained** and no identifying information will be used.

Data will be **accessible by researchers** through data sharing archives. This data will be governed by an overarching body to ensure data is **only used for approved research** purposes. Researchers who access this data from the data bank will not have access to participant information and therefore **will not know your identity**.

Read this information and be sure you **understand** its content **before** you **agree** to participate in this study.

If **you** would **like** to **participate** in this study, please **sign the form** below and **return** it to a **staff** member or a member of the **research team**.

Questions or further information?

You may wish to discuss this information with your doctor, a relative or friend before agreeing to take part in this study.

If you are interested in participating, please tell the researchers. If you have any questions or require any further information about the research project, please contact: Sarah D'Souza [Ph: 0439 982 451].

Thank you for considering the invitation to take part in this research project.

Yours sincerely,

Sarah D'Souza

If you have any **concerns or complaints** about the research project and wish to **talk to an independent person**, you may contact:

Kim Gifkins

Senior Research Ethics Advisor

Edith Cowan University

270 Joondalup Drive

JOONDALUP WA 6027

Phone: **(08) 6304 2170**

Email: research.ethics@ecu.edu.au

This project has been approved by the ECU Human Research Ethics Committee and the Hollywood Private Hospital Research Ethics Committee.

You have been asked to participate in a research study.

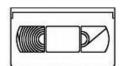






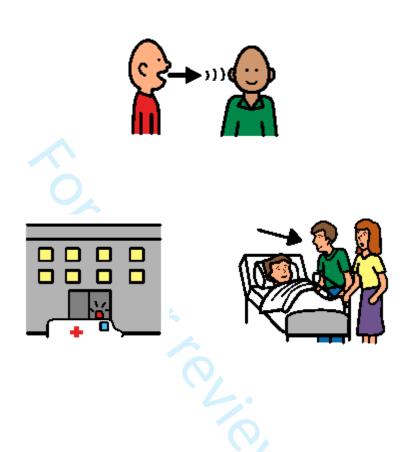
A researcher will record you with a tape recorder or a video camera, watch and write down what is happening in your environment including your activities.







A researcher will discuss with you your opinion regarding how your hospital surroundings affect your stay in hospital and your communication activity levels.



Your name and personal details will be kept private.



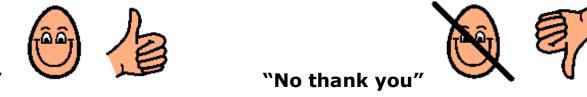




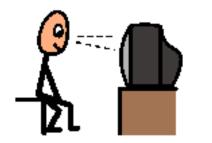




You can say no at any time.



We may use the **recordings** of **you** to make a **training package** (including a video).





You can have your face blurred out if you want.





If you **do not want** to be in the training package we will **not include you** in the training package or video.



I agree to take part in the above research project and give my consent freely.





I have been **given a copy** of the **Information Statement** and I understand that the **project** will be **carried out** as **explained**.



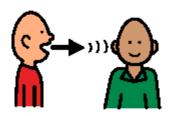


I understand and agree to:

 Complete three tests to assess how the stroke has affected me, my language, concentration and memory, at the beginning of the project.



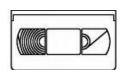
 A researcher spending approximately 1 hour discussing with me my opinion regarding how my hospital environment affects my stay in hospital and what I do.





 A researcher video recording, observing and writing down what is happening in my environment including my activities.





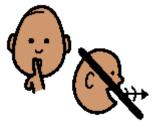


 A researcher looking at my hospital medical file to collect information for the study.



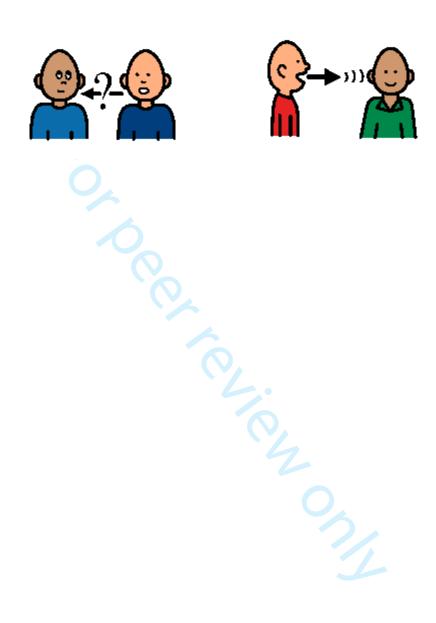


I understand that my identity, personal information and data will remain confidential.





I have had the **opportunity** to **ask questions** about the study and am **satisfied** with the **responses** that have been provided.



| Would you lik | e to be involved? | Yes | No |
|---|-------------------|-----|----|
| I agree to the to make a train (including a v | | Yes | No |
| I would like m y | face blurred out. | Yes | No |
| Your Signatur | ė | | |
| | Signature: | 7 | |
| | Print name: | 2 | |
| | Date: | | |
| Witness | Signature: | | |
| | Print name: | | |
| | Date: | | |

Person responsible information sheet Patient communication activity in hospital after stroke

This research project is being undertaken as part of the requirements of a PhD at Edith Cowan University.

Researchers' contact details

| Edith Cowan University | | |
|--|-----------------------------|------------------|
| Chief Investigator/ | Sarah D'Souza | Ph: 0439 982 451 |
| PhD student | | |
| Principal Supervisor | Professor Beth Armstrong | Ph: 08 6304 2769 |
| Co-Supervisor | Associate Professor Natalie | Ph: 08 6304 2047 |
| | Ciccone | |
| Co-Supervisor | Associate Professor Erin | Ph: 08 6304 5901 |
| | Godecke | |
| Co-Supervisor | Associate Professor Deborah | Ph: 08 6304 2563 |
| | Hersh | |
| Hunter Stroke Service, University of Newcastle and Hunter Medical Research Institute | | |
| Adjunct Supervisor | Dr Heidi Janssen | Ph: 02 40420417 |

The participant is invited to take part in a research project. Sarah D'Souza, a Speech Pathologist and PhD student, is leading the study as Chief Investigator. This study has received ethical approval from ECU Human Research Ethics Committee and Hollywood Private Hospital Research Ethics Committee.

This project is investigating the hospital environment to see how this influences patient activity.

The participant has been selected to take part in this study as they have had a stroke and are receiving treatment at Hollywood Private Hospital. We are interested in

seeing how the hospital surroundings affect their communication activity throughout the day. Communication activity involves communication, such as talking with other patients, socialising, reading the paper, using the telephone, talking to staff, or engaging group activities including therapy.

This information sheet will explain the research project and will detail what is involved in the study. You will be given a copy of this information to keep for your reference.

Please read through all of the information carefully. You can ask the researcher questions about the study at any time.

Purpose of the research

Little is known about the impact of the hospital rehabilitation environment on patient communication activity levels during stroke recovery. This study will investigate how the hospital stroke ward environment influences patient communication activity levels. The information gathered from this study will assist in improving the Hollywood Private Hospital stroke ward environment to help the recovery of stroke survivors in the future.

What does the patient have to do?

- Complete three tests and a recording of them talking to see how their stroke has
 affected their functioning including their language, concentration and memory. These
 tests will be conducted at the beginning of the project. The tests will take
 approximately 1 hour to complete with an option to complete the tests over two
 separate 30 minute sessions and with as many breaks as the participant needs.
- Spend approximately 1 hour discussing with the researcher their opinion regarding how their rehabilitation surroundings affect their stay in hospital and activity levels.
- Allow the researcher to video record, observe and write down what is happening in the
 participant's environment including their activities for a total of 12 hours over a 3 day
 period. Video recording is a useful way of capturing the details of everyday activities on

the ward. Often, people forget that the camera is there. Obviously, personal or private activity such as toileting would not be filmed. The participant may not want to be video recorded. If they request, they will not be video recorded. In this case the researcher will only observe, audio record and write down what is happening in their environment including their activities.

- A researcher will look at the participant's hospital medical file to collect information regarding:
 - The participant's details (such as their age, living arrangements, occupation and level of functioning before stroke)
 - Any relevant conditions or diseases the participant may have
 - Information about the participant's stroke (for example when it happened, the area of the brain affected, how it has affected their functioning and abilities)
 - Details about how long the participant has been in hospital since their stroke

The participant will not miss out on any treatment. Participation will not cost anything. After completing the tests and the interview the participant will be asked to continue their normal activities.

The participant's hospital discharge will not be affected because they are in this study. The participant will be discharged from hospital when the hospital medical team decides that they are ready.

There are no known risks of participating in this study. If the participant feels uncomfortable at any time, you or the participant are free to tell the researcher and observations within their room will stop immediately. The participant may become upset during the tests or the interview. If this happens you or the participant can ask to take a break or stop the interview.

There will be no immediate benefit to you or the participant from taking part in this research; however their participation will allow the collection of information that may help improve stroke hospital wards which may benefit future stroke survivors.

Participating in this study is completely voluntary. The participant can withdraw from taking part in the study at any time without giving a reason for withdrawing.

The participant can request access to their research data at any time. They can request any of the information collected to be amended or removed if it is incorrect or they disagree with it. Please contact Sarah D'Souza (phone: 0439 982 451) if you would like to discuss accessing the participant's information.

The video, audio and written data will be identified by code. The information you provide will remain completely confidential. There will be no identifying information attached to the data and any information that may reveal the participant's identity will be removed. A list of participant names and codes will be kept in a locked filing cabinet at Hollywood Private Hospital and will only be accessible by the research team. All personal health information will be accessed, used and stored in accordance with Commonwealth Privacy Laws. The data will be stored on a password controlled computer or in a locked cabinet at Edith Cowan University. Electronic data will be backed-up on a password controlled hard drive only accessible by the Chief Investigator. Data will be stored for a maximum of 15 years after completion of the study. Video and audio recordings will then be permanently deleted and hard copy data will be shredded.

Non-identifiable data will be accessible by researchers through data sharing archives. This data will be governed by an overarching body to ensure data is only used for approved research purposes. Researchers who access this data from the data bank will not have access to participant information therefore data will not be re-identifiable.

The results of this study may be published in research journals or presented at conferences. The results will not include any information that may identify participants. Data may be used in higher degree by research studies in the future. In this circumstance, confidentiality will be maintained and no identifying information will be used.

Data collected from this study (including videos) may be used to develop training packages to improve future stroke survivors' communication activity levels in the future. We can blur out

the participant's face if they want. If they do not want to be in the training package we will not include them in the training package.

At the end of the research project a summary of the results will be provided to you and the participant.

If you have any questions or require any further information about the research project, please contact: Sarah D'Souza [Ph: 0439 982 451].

Yours sincerely,

Sarah D'Souza

If you have any concerns or complaints about the research project and wish to talk to an independent person, you may contact:

Kim Gifkins

Senior Research Ethics Advisor

Edith Cowan University

270 Joondalup Drive

JOONDALUP WA 6027

Phone: (08) 6304 2170

Email: research.ethics@ecu.edu.au

This project has been approved by the ECU Human Research Ethics Committee and the Hollywood Private Hospital Research Ethics Committee.

Visitors and communication partners information and consent form Investigating Enhanced Environments after stroke

This research project is being undertaken as part of the requirements of a PhD at Edith Cowan University.

Researchers' contact details

| | Edith Cowan University | |
|--|-------------------------------------|------------------|
| Chief Investigator/ | Sarah D'Souza | Ph: 0439 982 451 |
| PhD student | | |
| Principal Supervisor | Professor Beth Armstrong | Ph: 08 6304 2769 |
| Co-Supervisor | Associate Professor Natalie Ciccone | Ph: 08 6304 2047 |
| Co-Supervisor | Associate Professor Erin Godecke | Ph: 08 6304 5901 |
| Co-Supervisor | Associate Professor Deborah Hersh | Ph: 08 6304 2563 |
| Hunter Stroke Service, University of Newcastle and Hunter Medical Research Institute | | |
| Adjunct Supervisor | Dr Heidi Janssen | Ph: 02 40420417 |

Description of the research project

This study is exploring patient's experiences following stroke in regards to the environment of an in-patient stroke rehabilitation unit. We want to explore patients' communication activity, which includes activities such as talking with other patients and visitors, socialising, reading the paper, using the telephone, talking to staff, or engaging group activities including therapy.

The participant has agreed to take part in this study. They have agreed to be video recorded for a total of 12 hours over a three day period.

Your interactions with the patient will be video recorded and manually recorded by the chief investigator to explore patient communication activity levels. You can choose to be observed by the researcher only if you do not want to be video recorded. You do not need to do anything other than complete your usual tasks and activities. We will not record if you are having sensitive conversations with the participant, if they are behind closed curtains or completing sensitive tasks such as toileting or showering.

We may use the recordings of you to make a training package (including a video). You can have your face blurred if you want. If you do not want to be in the training package we will not include you in the training package.

There will be no cost to you associated with the investigation. Participation is completely voluntary. You do not have to participate if you don't want to. If you decide to participate you may withdraw at any time without giving a reason and withdrawing will not disadvantage you or the participant in any way.

You may also benefit from the knowledge that you are helping future stroke survivors. It is possible that you may not benefit from participating in this study. There are no known risks associated with participating in this study.

Confidentiality of information

The video, audio and written data will be identified by code. There will be no identifying information attached to the data and any information that may reveal your identity will be removed. A list of participant names and codes will be kept in a locked filing cabinet at Hollywood Private Hospital and will only be accessible by the research team. All data will be accessed, used and stored in accordance with Commonwealth Privacy Laws. The data will be stored on a password controlled computer or in a locked cabinet at Edith Cowan University. Electronic data will be backed-up on password controlled hard drive only accessible by the Chief Investigator. Data will be stored for a maximum of 15 years after completion of the study. Video and audio recordings will then be permanently deleted and hard copy data will be shredded.

Non-identifiable data will be accessible by researchers through data sharing archives. This data will be governed by an overarching body to ensure data is only used for approved research purposes. Researchers who access this data from the data bank will not have access to participant information therefore data will not be re-identifiable.

The results of this study may be published in research journals or presented at conferences. The results will not include any information that may identify participants. Data may be used in higher degree by research studies in the future. In this circumstance, confidentiality will be maintained and no identifying information will be used.

Please read this Information Statement and be sure you understand its content before you consent to take part.

If you would like to take part, please complete the consent form and return it to Sarah D'Souza or a member of the research team.

Questions or further information?

If you have any questions or require any further information about the research project, please contact: Sarah D'Souza [Ph: 0439 982 451]

Thank you for considering the invitation to take part in this research project.

Yours sincerely,

Sarah D'Souza

If you have any concerns or complaints about the research project and wish to talk to an independent person, you may contact: Kim Gifkins

Research Ethics Officer

Edith Cowan University

270 Joondalup Drive

JOONDALUP WA 6027

Phone: (08) 6304 2170

Email: research.ethics@ecu.edu.au

This project has been approved by the ECU Human Research Ethics Committee and the Hollywood Private Hospital Research Ethics Committee.

| ı | | (print name), give my consent freely and |
|-----------------|-------------|---|
| agree to | narticinat | te in observations of my interactions with the participant. |
| Yes | No No | (please circle) |
| 162 | NO | (please circle) |
| I agree | to the rese | earcher video recording my interactions with the participant |
| Yes | No | (please circle) |
| I agree | to be inclu | ded in a training package (including a video). |
| Yes | No | (please circle) |
| If I am i | ncluded in | the video training package I would like my face blurred out. |
| Yes | No | (please circle) |
| | | |
| I unders | stand the p | project will be conducted as stated in the information letter, a copy of which I have |
| retained | d. | |
| I unders | stand I can | withdraw from the project at any time and do not have to give a reason for withdrawing. |
| | | |
| I unders | stand pers | onal information will remain confidential to the researchers. |
| | | |
| | | the opportunity to raise any questions or concerns I have and am satisfied with the |
| respons | ses I was g | jiven. |
| | | |
| <u>Particip</u> | | |
| Print na | ame: | |
| Signatu | ıre: | |
| Phone | number: _ | |
| Email a | ddress:_ | |
| Date: _ | | |
| Witnes | <u>s</u> | |
| Print na | ame: | |
| | | |
| Doto | | |

Staff information and consent form Investigating Enriched Environments after stroke

This research project is being undertaken as part of the requirements of a PhD at Edith Cowan University.

Researchers' contact details

| | Edith Cowan University | |
|--|-------------------------------------|------------------|
| Chief Investigator/ | Sarah D'Souza | Ph: 0439 982 451 |
| PhD student | | |
| Principal Supervisor | Professor Beth Armstrong | Ph: 08 6304 2769 |
| Co-Supervisor | Associate Professor Natalie Ciccone | Ph: 08 6304 2047 |
| Co-Supervisor | Associate Professor Erin Godecke | Ph: 08 6304 5901 |
| Co-Supervisor | Associate Professor Deborah Hersh | Ph: 08 6304 2563 |
| Hunter Stroke Service, University of Newcastle and Hunter Medical Research Institute | | |
| Adjunct Supervisor | Dr Heidi Janssen | Ph: 02 40420417 |

Description of the research project

This study is exploring staff and patient's experiences in regards to the environment of the Edwards and Woods wards at Hollywood Private Hospital. We want to explore patient communication activity, which includes activities such as talking with other patients, socialising, reading the paper, using the telephone, talking to staff, or engaging group activities including therapy. We would like to explore staffs' perceptions of barriers and facilitators to communication activity on the wards and address these in order to enhance the ward environment.

Staff have been selected to participate in order to gain a range of perspectives in regards to the day to day operations, procedures, policies and interactions that influence the environment of the Edwards and Woods wards. A training program for staff will be designed to address barriers and facilitators identified on the wards.

There are two components of this research study that involve staff. You may wish to consent to participate in one or both parts of this study.

<u>Part 1:</u> Patients will be video recorded for a total of 12 hours over a three day period. Your interactions with the patient will be video recorded and manually recorded by a member of the research team to explore patient communication activity levels. You can choose to be observed by the researcher only if you do not want to be video recorded. You do not need to do anything other than complete your usual daily tasks and activities. We will not record if you are behind closed curtains or completing sensitive tasks such as toileting or showering the patient.

We may want use the recordings of you to make a training package (including a video). We will show you the video we want to use and explain exactly how this will be used before we do anything. You can have your face blurred out if you want. If you don't want to be included in the training package we will not include any videos of you in the training package.

<u>Part 2:</u> You will be asked to take part in the following:

- A focus group with the researcher and your co-workers for approximately 1 hour to explore your perceptions of environmental barriers and facilitators to activity.
- Attend a training program for approximately 1.5 hours. This will focus on training staff to promote
 patient communication on the ward. This session will be located at Hollywood Private Hospital and
 will be offered over several dates to facilitate your ability to attend. If you are unable to attend the
 training program we may provide training and video resources to facilitate your participation in
 training.
- Complete an anonymous short questionnaire before and after attending the training program to gain feedback on training and explore your perception of changes in your knowledge, skills and attitudes towards communication and aphasia.
- A final focus group with the researcher for approximately 1 hour to again explore your perceptions
 of environmental barriers and facilitators to activity.
 The focus groups will be tape recorded however at any stage you may ask for the tape to stopped,
 edited or have your comments erased.

There will be no cost to you associated with the investigation. Participation is completely voluntary. You do not have to participate if you don't want to. If you decide to participate you may withdraw at any time without giving a reason and withdrawing will not disadvantage you in any way.

You may benefit from gaining knowledge and skills regarding communication from attending the training program. Additionally, you may also benefit from the knowledge that you are helping future stroke

survivors. It is possible that you may not benefit from participating in this study. There are no known risks associated with participating in this study.

Confidentiality of information

The information you provide during the interviews will be audio recorded by the Chief Investigator. Your perspectives and opinions will be analysed and grouped into common 'themes' and 'stories'. This will be used to inform the development and review of the training program.

The video, audio and written data will be identified by code. The information you provide will remain completely confidential. There will be no identifying information attached to the data and any information that may reveal your identity will be removed. A list of participant names and codes will be kept in a locked filing cabinet at Hollywood Private Hospital and will only be accessible by the research team. All data will be accessed, used and stored in accordance with Commonwealth Privacy Laws. The data will be stored on a password controlled computer or in a locked cabinet at Edith Cowan University. Electronic data will be backed-up on a password controlled hard drive only accessible by the Chief Investigator. Data will be stored for a maximum of 15 years after completion of the study. Video and audio recordings will then be permanently deleted and hard copy data will be shredded.

Non-identifiable data will be accessible by researchers through data sharing archives. This data will be governed by an overarching body to ensure data is only used for approved research purposes. Researchers who access this data from the data bank will not have access to participant information therefore data will not be re-identifiable.

The results of this study may be published in research journals or presented at conferences. The results will not include any information that may identify participants. Data may be used in higher degree by research studies in the future. In this circumstance, confidentiality will be maintained and no identifying information will be used.

A summary of the results will be provided through Hollywood Private Hospital 18 months after the completion of the study.

Please read this Information Statement and be sure you understand its content before you consent to take part.

If you would like to take part, please complete the consent form and return it to Sarah D'Souza, Claire Tucak or a member of the research team.

Questions or further information?

You may wish to consult with your manager before agreeing to take part in this study.

If you have any questions or require any further information about the research project, please contact:

Sarah D'Souza [Ph: 0439 982 451]

Thank you for considering the invitation to take part in this research project.

Yours sincerely,

Sarah D'Souza

If you have any concerns or complaints about the research project and wish to talk to an independent person, you may contact: Kim Gifkins

Research Ethics Officer

Edith Cowan University

270 Joondalup Drive

JOONDALUP WA 6027

Phone: (08) 6304 2170

Email: research.ethics@ecu.edu.au

This project has been approved by the ECU Human Research Ethics Committee and the Hollywood Private Hospital Research Ethics Committee.

| I | | (print name), give my consent fr | eely and |
|--------------------|----------------------|---|--------------|
| agree to partio | cipate in (please c | ircle): | · |
| <u> Part 1:</u> | | | |
| Yes | No | Observations of your | |
| | | interactions with patients following stroke. | |
| Yes | No | Video recording of your | |
| | | interactions with patients following stroke. | |
| <u> Part 2:</u> | | | |
| Yes | No | Complete two focus groups with the researcher, complete two short questionnaires and attend a training program. | |
| I understand t | he project will be | conducted as stated in the information letter, a copy of which I l | have |
| I understand I | can withdraw from | m the project at any time and do not have to give a reason for w | vithdrawing. |
| I understand բ | personal information | on will remain confidential to the researchers. | |
| I have been g | iven the opportuni | ity to raise any questions or concerns I have and am satisfied w | vith the |
| responses I w | as given. | | |
| <u>Participant</u> | | | |
| Print name: _ | | | |
| Signature: _ | | | |
| Phone numb | er: | | |
| Email addres | ss: | | |
| | | | |
| <u>Witness</u> | | | |
| Print name: _ | | | |
| | | | |
| Date: | | | |

Volunteer information and consent form Investigating Enriched Environments after stroke

This research project is being undertaken as part of the requirements of a PhD at Edith Cowan University.

Researchers' contact details

| | Edith Cowan University | |
|--|-------------------------------------|------------------|
| Chief Investigator/ | Sarah D'Souza | Ph: 0439 982 451 |
| PhD student | | |
| Principal Supervisor | Professor Beth Armstrong | Ph: 08 6304 2769 |
| Co-Supervisor | Associate Professor Natalie Ciccone | Ph: 08 6304 2047 |
| Co-Supervisor | Associate Professor Erin Godecke | Ph: 08 6304 5901 |
| Co-Supervisor | Associate Professor Deborah Hersh | Ph: 08 6304 2563 |
| Hunter Stroke Service, University of Newcastle and Hunter Medical Research Institute | | |
| Adjunct Supervisor | Dr Heidi Janssen | Ph: 02 40420417 |

Description of the research project

This study is a Communication Enhanced Environment (CEE) at Hollywood Private Hospital. A CEE involves several initiatives that aim to provide more opportunities for communication for stroke survivors on the ward. One of these initiatives involves the participation of volunteers.

As a volunteer participant, you will be asked to take part in the following:

- Attend a training program for approximately 1.5 hours. This will focus on training volunteers in
 communicating with patients following stroke with communication difficulties. This session will be
 located at Hollywood Private Hospital and will be offered over several dates to facilitate your ability
 to attend. If you are unable to attend the training program we may provide training and video
 resources to facilitate your participation in training.
- Complete an anonymous short questionnaire before and after attending the training program to obtain your feedback on the training session.

- A focus group with the researcher and other volunteers for approximately 1 hour to explore your
 perceptions of communicating with patients following stroke. The focus group will be tape recorded
 however at any stage you may ask for the tape to stopped, edited or have your comments erased.
- Host a communal dining and lounge area once a week to offer tea and coffee and provide social companionship for patients following stroke.
- Your interactions with the patient may be video recorded and manually recorded by a member of
 the research team to explore patient communication activity levels. You can choose to be observed
 by the researcher only if you do not want to be video recorded. We will not record if you are having
 sensitive conversations with the patient/s.

There will be no cost to you associated with participating in this study. Participation is completely voluntary. You do not have to participate if you don't want to. If you decide to participate you may withdraw at any time without giving a reason and withdrawing will not disadvantage you in any way.

You may benefit from gaining knowledge and skills regarding communication from attending the training program. Additionally, you may also benefit from the knowledge that you are helping future stroke survivors. It is possible that you may not benefit from participating in this study. There are no known risks associated with participating in this study.

Confidentiality of information

The information you provide during the interviews will be audio recorded by the Chief Investigator. Your perspectives and opinions will be analysed and grouped into common 'themes' and 'stories'.

The video, audio and written data will be identified by code. The information you provide will remain completely confidential. There will be no identifying information attached to the data and any information that may reveal your identity will be removed. A list of participant names and codes will be kept in a locked filing cabinet at Hollywood Private Hospital and will only be accessible by the research team. All data will be accessed, used and stored in accordance with Commonwealth Privacy Laws. The data will be stored on a password controlled computer or in a locked cabinet at Edith Cowan University. Electronic data will be backed-up on a password controlled hard drive only accessible by the Chief Investigator. Data will be stored for a maximum of 15 years after completion of the study. Video and audio recordings will then be permanently deleted and hard copy data will be shredded.

Non-identifiable data will be accessible by researchers through data sharing archives. This data will be governed by an overarching body to ensure data is only used for approved research purposes.

Researchers who access this data from the data bank will not have access to participant information therefore data will not be re-identifiable.

The results of this study may be published in research journals or presented at conferences. The results will not include any information that may identify participants. Data may be used in higher degree by research studies in the future. In this circumstance, confidentiality will be maintained and no identifying information will be used.

A summary of the results will be provided through Hollywood Private Hospital 18 months after the completion of the study.

Please read this Information Statement and be sure you understand its content before you consent to take part.

If you would like to take part, please complete the consent form and return it to Sarah D'Souza, Claire Tucak or a member of the research team.

Questions or further information?

If you have any questions or require any further information about the research project, please contact: Sarah D'Souza [Ph: 0439 982 451]

Thank you for considering the invitation to take part in this research project.

Yours sincerely,

Sarah D'Souza

If you have any concerns or complaints about the research project and wish to talk to an independent person, you may contact: Kim Gifkins

Research Ethics Officer

Edith Cowan University

270 Joondalup Drive

JOONDALUP WA 6027

Phone: (08) 6304 2170

Email: research.ethics@ecu.edu.au

ad by the ECC immittee. This project has been approved by the ECU Human Research Ethics Committee and the Hollywood Private Hospital Research Ethics Committee.

| I (print name), give my consent freely and |
|---|
| agree to participate in (please circle) this study as described in this information and consent form. |
| I understand the project will be conducted as stated in the information letter, a copy of which I have |
| retained. |
| I understand I can withdraw from the project at any time and do not have to give a reason for withdrawing |
| I understand personal information will remain confidential to the researchers. |
| I have been given the opportunity to raise any questions or concerns I have and am satisfied with the |
| responses I was given. |
| <u>Participant</u> |
| Print name: |
| Signature: |
| Phone number: |
| Email address: |
| Date: |
| <u>Witness</u> |
| Print name: |
| Signature: |
| Date: |
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