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Interactions between a Speech Pathologist and people with aphasia in the first 6 weeks post stroke: A qualitative study of assessment experiences

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Abstract

This study examines clinician and client interactions in the context of an acute care unit in a small urban Western Australian Hospital. The study involved audiovisual recordings and observations of assessment sessions, and in-depth interviews with the assessing Speech Pathologist and her clients. Analysis used Discourse Analysis of assessment sessions and Thematic Analysis of interviews. There is growing evidence as to how less formal non-traditional assessment might be more supportive of people with aphasia—for instance, by using concepts and techniques drawn from Dynamic Assessment and principles of Adult Learning. Surveys of Australian and New Zealand Speech Pathologists reflect a move away from standardised tests in acute settings, finding Speech Pathologists are more likely to use informal and/or unstandardised assessment tools. However, little research has been conducted about the assessment experiences of people with aphasia, particularly in the early stages post- stroke. The purpose of this study is to describe and analyse typical contemporary speech pathology practices in assessment of people with aphasia in the early stages post-stroke, and explore how assessment is experienced by both the assessing clinician and the person assessed.

Keywords: aphasia, assessment, speech pathology, qualitative research, stimulated recall, thematic analysis, discourse analysis, Adult Learning Theory, dynamic assessment, therapeutic assessment

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Acknowledgements

Abbreviations

CA	Conversation Analysis
DAN	Discourse Analysis
DAX	Dynamic Assessment
PWA	People with Aphasia
SP	Speech Pathologist
TAN	Thematic Analysis

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Introduction

The audiologist Professor Emeritus David Luterman writes of clinicians who work with people with communication disorders as "grief workers". He explains that these clients are "people undergoing transitions in their lives because they have lost the life they thought they were going to have" (Luterman, 2001, p. 3). The early days with aphasia post-stroke are typically marked by confusion and fear as the individual discovers himself with an unforeseen communication disability in an acute medical situation (Boazman, 2003; Grohn, 2014; Parr, *et al.*, 1997; Tyson, Burton, McGovern, & Sharifi, 2014). Working in the presence of these emotions and this situation presents complexity for the Speech Pathologist (SP), the clinician whose role logically begins with the task of assessing her client to determine the extent of the stroke's impact on language (Galletta & Schaeffer, 2012).

How to reconcile objectivity with empathy in speech pathology assessment is an area of both speculative theoretical debate (e.g., Hersh, Worrall, O'Halloran, Brown, Grohn, & Rodriguez, 2013) and slowly emerging evidence (Hersh *et al.*, 2013; Parr, Byng, Gilpin, & Ireland, 1997). An aspect of the debate involves the possibility of assessment interactions being therapeutically beneficial for the individual with aphasia. Assessment which has value *as therapy* is significant in aphasia post-stroke given the potential for early intervention after stroke to be efficient and effective (Godecke *et al.*, 2014), alongside the reality that people with aphasia (PWA) post-stroke may be

receiving little more than two hours on average of direct therapy (Verna, Davidson, & Rose, 2009).

This study therefore strives to be part of an emerging evidence base for more effective yet empathetic skills around assessment of aphasia. To do this, the researcher examined four assessment sessions conducted by an experienced SP in the stroke unit of a small urban Western Australian hospital. Analysis of interactions within those sessions is supplemented with clinician and client reflections on their experiences of assessment.

Aphasia post-stroke

The term *aphasia* is used by SPs to describe a range of impairments to established language abilities. Impairment results from damage to parts of the brain governing language. Depending on the location of damage, aphasia may affect receptive and/or expressive language abilities across a range of modalities—speaking, understanding, reading, writing, communicating by gesture, and even aspects of thinking which relate to using internal language (Berens, 2011). Recovery of language function is dependent on location and severity of damage (Tyson, Burton, McGovern, & Sharifi, 2014). The most common cause of aphasia is stroke and about a third of people having a stroke will experience a period of aphasia (Berthier, 2005). Spontaneous recovery of language function often occurs, particularly within the first 5-6 months post-stroke (Saur *et al*, 2006).

Stages post-stroke vary within the literature with the timescale of acute stage given as 4-5 days (Saur *et al*, 2006) and 30 days (Vogel, Maruff, & Morgan, 2011). The most rapid rates of recovery from aphasia are seen in the period up to 4-5 months

(Ali, Lyden, Brady, & VISTA Collaboration, 2015; Plowman, Hentz, & Ellis, 2011;

Watila & Barabe, 2015).

Frustration, functional communication and identity in aphasia

PWA often report frustration with communication partners. The impacts of

aphasia are felt in reduced quality of communication interactions and these adversely

impact relationships (Worrall, Sherratt, Rogers, Howe, Hersh, & Ferguson, 2011).

PWA report difficulties integrating having aphasia with the person they feel they are,

and with showing others they are still the same person: "Even though I couldn't talk, I

still knew what I wanted, I was still a person" is how one person with aphasia

described their frustration (Jones, Mandy & Partridge, 2008, p. 512).

Clinical interactions with aphasia post-stroke

Even in the absence of aphasia, people who have had strokes report being

confused by clinical interactions (Rodgers, Bond, & Curless, 2001; Wachters-

Kaufmann, Schuling, The, & Meyboom-de Jong, 2005) and health professionals

(Tyson *et al*., 2014). PWA report finding clinical interactions difficult, including

finding assessment confusing and uninformative: "The speech therapist came once or

twice every week and gave me one of those tests, you know, with the spelling and

everything and I couldn't make head nor tail of it," said Betty, a woman with aphasia

in Parr, Byng, Gilpin and Ireland's (1997, p.77) study (cited in Hersh *et al*., 2013).

Betty's case suggests PWA can undergo assessment without understanding of either

the assessment itself or the rationale for administering it. Madonna, Armstrong, and

Togher (2002; cited in Ferguson & Armstrong, 2004) reported finding PWA have

limited understanding of processes of assessment, or of how they might take active

roles in assessment. Such findings point to experiences of assessment which make more sense to the assessor than the person being assessed (Hersh, *et al*., 2013).

Tyson, *et al*.'s (2014) study of client perspectives of assessment in stroke rehabilitation included PWA, and appears to be the first published paper specifically exploring their perspectives of assessment. These researchers found participants were frustrated by unexplained assessment procedures and unexplained repetitions of assessments.

Speculations on more supportive assessment practices

Discussion of more supportive practices with PWA is not new (e.g., Ferguson & Armstrong, 2004; Ferguson & Elliott, 2001). Various experts in the field of aphasiology have been questioning the value of formal assessment of aphasia, believing it does not support PWA. Saldert and colleagues for instance, concluded that less intrusive means of assessment such as Conversation Analysis (CA) of conversations with familiar conversation partners were more relevant for considering PWA (Saldert, Bergman, Hostensson, Jönsson, Nygren, Vennman, & Ferm, 2012). Given *functional* communication is not absolutely predicted by severity of impairment, their CA approach explored how assessment might demonstrate functional communication of PWA. Such an approach is at the most innovative edge of a general move within speech pathology assessment. This move is away from the use of standardised assessment protocols with PWA in the early stages post-stroke towards widespread use of unstandardized assessments, flexible use of standardised assessments, and informal tools such as conversation (Verna, *et al*., 2009; Vogel *et al*., 2010).

Hersh and colleagues (2013) describe conventional assessments of PWA as potentially formal occasions controlled by the objective and neutral clinician gathering the necessary information for decisions on therapy and measuring outcomes. They question whether this model can be in the best interests of clients with aphasia, suggesting the evidence is emerging that more supportive approaches are needed. They propose embedding dynamic assessment (DAX) and principles of adult learning within a holistic approach to assessment emphasising functional communication competences of PWA and their communication partners.

Applying Dynamic Assessment to assessment of adults with aphasia

Incorporating learning during assessment has been explored, particularly with children, as DAX (Peña, 1996). Principles informing DAX resonate with those of adult learning. For instance, the prevailing concern of a dynamic examiner is identifying how the client learns, and how learning strengths can be used to inform treatment options and goals. Muskett, Body and Perkins (2012) contrast DAX to *static assessment*: Static assessment renders an inventory of an individual's knowledge and abilities within the boundaries of the assessment tool used (Muskett *et al*, 2012). By contrast, DAX requires the clinician to evaluate, respond and even develop client performance, giving immediate feedback, and perhaps even adapting assessment as it unfolds.

DAX is specified for use with PWA in the Australian Aphasia Rehabilitation Pathway's (2014) website, reflecting increasing use of, and interest in, DAX amongst contemporary clinicians working with adults post-stroke in acute settings despite a lack of research evidence. Looking for spontaneous use of DAX in contemporary assessment practice is therefore timely.

Considering people with aphasia as Adult Learners

Research on adult learning has shown adults are motivated to participate in learning when they understand the relevance of what they are learning, how it will support them in real life, as well as when they choose their own goals (Kimbarow, 2007). The present study may provide insights into how adult learning principles currently apply in aphasia assessment. It is possible that if clinicians view PWA as adult learners, and embrace their own role as part of an adjustment process to the life-changing reality of aphasia, clinician- client interaction styles must surely change (Kimbarow, 2007).

Adult Learning principles acknowledge the competence of learners, and, in fact, PWA would *prefer* to be more active in decisions, for instance, concerning their treatment and goal setting (Worrall, Sherratt, Rogers, Howe, Hersh, & Ferguson, 2011). They wish to be better informed (Worrall, *et al.,* 2011). Meanwhile, contemporary holistic approaches emphasise the competence of PWA (rather than impairments), with the clinician's role being "insightful partner" promoting their client as a proactive, self-determining communicator (Lesser, 2000, p. 28).

Therapeutically beneficial assessment in aphasia

In early stages post-stroke, Hersh and colleagues (2013) advocate for the SP's specialist role in providing "the patient with an experience, very early on in his or her recovery from stroke, that demonstrates that there are professionals who are skilled in assisting with communication" (p. 154). They emphasise the significance of assessment practices which "enhance patients' ability to understand what has happened to them, to communicate their needs in the hospital, and to ask questions about and be involved in their health care to the extent that they would like to" and that this "may

also provide patients with a feeling of competence and hope, even when their aphasia is severe" (p. 154). In a context where a great deal of therapist time is spent in assessment, they propose making that time as productive as possible for both clinician and client. They argue for assessment sessions which do not leave PWA confused by the testing, emphasising assessments sessions can also be opportunities for clients to recognise their role as partners in therapy, better understand their impairment and their story relative to stroke and aphasia, start considering their goals, as well as have their questions and concerns addressed.

Through detailed consideration, observation and analysis of real sessions, complemented by the data on the perceptions of those involved, this study seeks to unpack those sorts of possibilities. Qualitative research supports the necessarily speculative status of the endeavour.

Role of qualitative research in studying aphasia

Qualitative researchers typically study naturalistic life encounters (for instance, by observation) and/or descriptions of real life experiences (for instance, by in-depth interviews). Their processes of analysis are intended to unpack participants' interpretations of those encounters and experiences in rich detail.

An underlying (covert or overt) interest underpinning qualitative research is finding out what people know and how people know what they know—that is, how they reach current interpretations via lived experiences. To give an example from another health discipline, a qualitative study of women who underwent treatments for breast cancer has revealed the women's *experiential knowledge*. In that study the researchers' conclusions emphasised understanding experiential knowledge is crucial to inform collaborative decision- making in healthcare (Sinding & Wierniowski, 2009).

People with communication disorders such as aphasia have often been excluded from decision-making and often been excluded from research, even from research investigating the experiences of people post-stroke (Tyson *et al*., 2014). This is a significant omission given the statistic mentioned above—that approximately one third of people who have strokes will experience aphasia immediately following stroke (Berthier, 2005).

Certainly the nature of the impairment in aphasia presents challenges to researchers relying exclusively on verbal interactions (Bronken & Kirkevold, 2013). However, a growing body of qualitative research involves PWA (Worrall, *et al*., 2011). Innovative methods have been tried, and evidence-based methods are therefore emerging as to conducting ethical and effective research with PWA (Luck & Rose, 2007). One method that is thought to be particularly effective for PWA, and used in this study, is facilitated recall (also called "stimulated recall"), where an audiovisual recording of the interactions under consideration is shown to the participant to assist their recall. For PWA, this might also assist their ability to explain the significance of what they are describing.

Also it is possible the qualitative researcher is well placed to facilitate research in aphasia. Facilitating communication acts which lead to transparency of data, and probing for elaboration of participants' experiences and insights, are commonplace in the qualitative researcher's toolbelt. Clinicians working with PWA typically use supported conversation techniques (explained below as part of the study's methodology), and these are appropriate to conducting qualitative research.

Also the researcher's own role in research activities is openly acknowledged: An underlying principle of all qualitative research is the explicit acknowledgement of the researcher's influence on collecting a participant's insider perspective (Barrow,

2001)—the fact of her presence, her role as incidental participant, and the subjective

yet shared nature of interpretations of experience. This reflexivity is appropriate to a

line of speculative enquiry where, due to the presence of communication disorder,

participants might require more communication support than is usual.

The study

Purpose of study and research questions

The purpose of this study is to examine client and clinician interactions during Speech Pathology assessments of PWA in the first 6 weeks post-stroke. To do this, the study analyses discourse collected from four assessment sessions conducted by a SP with four of her clients. Interviews with participants following their assessment sessions provide evidence of the insider perspectives of client and clinician experiences of those assessments.

The study seeks to address the following questions:

   1. What are the experiences of PWA and their SPs of assessment in the context of aphasia?

   2. What do assessment interactions actually look like in terms of clinician and client contributions?

   3. Do contemporary assessments incorporate aspects of adult learning, DAX, and functional communication building, and if so, how are these manifested within the client/clinician interaction?

Study design: An overview

This study employs qualitative research methodology and methods to explore client and clinician experiences of aphasia assessment. Epistemologically, the study is informed by Postmodernism's constructivist stance in privileging participants' own words and behaviours as truly representing their experiences of interactions (Liamputtong, 2013). In brief, Constructivism holds that meaning is the creation of individuals both internally and mutually within the external exchange—with meanings sometimes revised by collaboration within context (e.g., in negotiations around

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repairing a communication breakdown). Roles of client, clinician, and even researcher, create particular interactional contexts within this study's institutional context (i.e., acute unit of a small urban hospital), assigning roles to participants (i.e., client, clinician, researcher), and impacting individual and collective interpretations of interactions. The presence of a communication disorder such as aphasia is likely to lend unique nuances to how individuals experience their roles and create meanings within the specific clinical process of assessment.

In this study, qualitative research methods were used for analysis of assessment sessions and in-depth interviews with participants, enabling detailed scrutiny of real examples of client-clinician interactions from contemporary speech pathology practice.

Role of researcher and wider research team

The Honours student was also the main researcher responsible for data collection and bulk of analysis, in consultation with Supervisor and Associate Supervisor by email and face-to-face at regular intervals. Transcriptions were checked by three 4th year Speech Pathology students, and confirmed as fair representations of the data. The students also evaluated what they saw as crucial within the recordings they checked, supporting refinement of data analysis as well as confirming that what the researcher saw and interpreted was evident to other observers with less awareness of the aims of the study.

Setting and samples

Participants in this study were one SP (female) and four PWA (all male and aged between 48 and 88 years). Further details of participants are given in Tables 1 and 2. All names are pseudonyms.

The SP worked exclusively with acute patients in an acute care unit, fitting the study's inclusion criterion of being a SP whose usual caseload includes PWA after stroke. Recruiting more than one SP (as originally intended) was hampered by the hospital being in the process of closing. Changes to staff rosters and reduced staffing levels impacted involvement in the project.

Participants with aphasia post-stroke agreed to participate after being identified as fitting the study's inclusion criteria and invited by the participating SP. Inclusion criteria for clients were having aphasia post-stroke, being within 6 months of that stroke, without co- morbid diagnosis of dementia. They also need to be able to consistently indicate consent for participation. The focus of the study became narrower than predicted through participants with aphasia all being within 6 weeks (not just 6 months) of stroke.

All participants provided informed consent using materials designed for the study, which included aphasia-friendly consent forms (as attached in Appendix A).

Table 1. Details of SP

Pseudonym	Hannah
Gender (age)	Female (33)
Years working in present setting	7
Particular interest in clinical work	Neurology
SP qualification	Masters of Science (Speech Pathology) from an Australian university
Proportion of caseload comprising PWA	Up to 50% at times; typically 30-40%

Table 2. Details of PWA

Person with aphasia	Oliver	Stan	Michael	Donald
Gender (age)	Male (74)	Male (48)	Male (80)	Male (88)
Marital status/family	Married, grown up children and grand-children	De facto partner, ex-partner around, grown up children (late teens/early 20s)	Married, grown up children	Married, grown up daughters
Profession	Retired school principal	Recently unemployed, business manager	Retired gardening maintenance man	Retired psychologist
Languages at home	English	English	English	English, but also regularly speaks Cantonese
Time post-stroke	3 weeks	6 weeks	4 days	6 days
Type of stroke	Ischaemic left tempero-parietal-occipital infarct	Ischaemic left middle cerebral artery infarct	Ischaemic left subcortical	Haemorrahagic left middle cerebral artery infarct
Expressive aphasia	Moderate	Moderate + severe apraxia of speech	Moderate	Mild
Receptive aphasia	Mild	Moderate	Moderate	?Mild
Hearing	Some HI	None	Some HI	Some HI
Previous sessions with this SP	Yes, 3	Yes, regularly since admission	No	Yes, "several"
Other SPs	Yes, filling in for regular SP	Yes, filling in for regular SP	Yes, initial assessment and 1 therapy session	No

Key: HI = hearing impairment

Data collection

Data collection took place during May and June 2015. Assessment sessions for three of the four clinician-client dyads were audiovisually recorded. One assessment session was observed by the researcher without recording. Of these, one session (Stan's) also included a family member, Stan's daughter. In conducting these sessions, the SP was asked to follow her usual plan of assessment and care.

Assessment sessions and then interviews took place within the hospital, either in a lounge or dining area or at bedside. Similar interview questions (given in Appendix B) were used with the SP and person with aphasia to stimulate discussion of their assessment experience. Open-ended general questions were supplemented with the researcher's spontaneously generated questions and observations to prompt more specific reflection as subjects of interest arose. Both general and customised supported conversation materials were used with Stan, the participant with severe apraxia of speech. The customised "choice cards" used in Stan's interview are given in Appendix B. (For background to and details of the supported conversation approach to addressing the communication deficits of people with aphasia, please see Kagan, 1998.)

One participant with aphasia (Stan) requested that some of the audiovisual recording of his interview be deleted, although he was happy for the researcher to use observations/journal entries related to the entire interview. The researcher was unable to complete an interview with Michael due to his falling asleep whilst equipment was set up. Donald gave permission for his assessment to be observed, not audiovisually recorded.

Assessment session recordings lasted from 33 minutes to an hour (mean = 42 minutes; median = 33 minutes; N = 3). Interviews lasted from 12 to 55 minutes, mean

and median =22 minutes (N = 7). The extent of the data corpus is outlined in Appendix C.

Assessment session recordings were offered as stimulus to promote recall in separate interviews with both members of each dyad. The SP declined to use the recording in each case, whilst two participants watched parts of their recording.

During interviews it was apparent that interviews with PWA would benefit from more structure. A revised guided interview framework is given at Appendix D. However, as no fifth person with aphasia was interviewed, this was not used.

Data analysis

1. Transcription

This study involved two forms of transcription. Samples of assessment session recordings were transcribed using multiple layers (orthographic, non-verbal and discourse analysis). Interviews were transcribed verbatim orthographically with care to include details of nonverbal aspects of interactions (such as gestures and eye contact). Both sets of transcript followed guidelines from Müller (2006) with simplifications. See Appendix E for details.

2. Discourse Analysis of samples of assessment sessions

The samples from assessment sessions were analysed by following the Discourse Analysis (DAN) protocol devised by Pomerantz and Fehr (1997) as used in Hand's (2006) study of SPs' initial consultations with child clients and their caregivers. Hand's insightful work demonstrates the potential of this protocol for analysis within Speech Pathology research. Hand's (2006) summary of the procedure is given in

Appendix F. In the following description of how the procedure was used in this study, Pomerantz & Fehr's (1997) terms are given in *italics*.

Firstly audiovisual and transcribed records of assessment sessions were reviewed repeatedly, allowing the researcher to identify *sequences* of interactions with their own boundaries within the session as a whole—for instance, dialogue beginning with the clinician introducing what she intends for the session and closing at the point where she announces the first assessment task. Verbal and nonverbal *actions* within this sequence, which may cover more than one speaking turn or be accomplished with nothing more than a grunt, were considered, then *characterised* or described.

Because assessment involves some specifically stylised interaction, Ferguson and Elliott's (2001) terminology of *Dynamic Moves* was used to characterise some conversational acts. A list of Dynamic Moves is given at Appendix G.

Analysis continued by considering how the actions were *packaged* by the participants—that is, what informs the selection of a particular action, and alternatives they might have chosen but did not. In the present study, the actions of the participants were expected to be particularly constrained by the challenge-response pattern of assessment administration, meaning that modifications or breakdowns of these patterns were potentially of interest. Finally, analysis focused on the manner in which actions are used to construct participants' *roles* within the discourse, *identities*, and *relationships* between them.

3. Analysis of interviews with Thematic Analysis

Thematic Analysis (TAN) was used to summarise and expose significant aspects of the experiences of participants within assessment interactions. TAN facilitates minimal transformation of data during the process of analysis (Vaismoradi,

Turunen, and Bondas, 2013), preserving the character of that data. TAN involves use of the participants' own words with interpretations which are intuitive, simple and drawn directly from those words. For a small study like this, this rawness is important for allowing the process of interpretation to be obvious.

Interview transcripts were initially analysed by coding for themes using NVivo 10.0 software to create a framework of themes. The framework and the themes within it were analysed for patterns and exceptions, and revised repeatedly over the course of several months. Themes from any one individual's data were considered alone as well as part of the data as a whole (Braun & Clarke, 2013). Themes were eventually narrowed down to two sets (one set pertaining to the client and one to the clinician) to create what the researcher regards as a fair representation of interpretations of assessment made by participants. The final sets of themes reported in this paper were discussed and confirmed by the wider research team for their relevance to describing experiences of interaction in assessment.

Credibility

During data collection with PWA, supported conversation techniques and materials were used as required by the participant. Supported conversation enhances communication with people who might otherwise be seen as too difficult to interview. Supported conversation methods were particularly useful with Stan, whose severe apraxia in addition to aphasia made interpretations of his limited verbalisations difficult. Efforts were made to breach the gap and include Stan in this research. Stan was able to clearly indicate his feelings about his situation.

Member-checking is a means of ensuring that data given by research participants reflects their intended meanings (Carlson, 2010). The researcher gave a

brief verbal summary of how the SP's experiences had been interpreted, which the SP approved. The brevity of this member-checking was the SP's preference due to time considerations—viewing transcripts of her interviews, for instance, was also available. The study's design did not include opportunities to conduct member-checking with PWA (considered below as a limitation of the study).

At the data analysis stage, approximately 30% of assessment and interview transcripts were checked against recordings by three 4th year Speech Pathology students. The students also put forward their interpretations of key moments to the researcher, supporting deeper analysis in a process known as *peer-debriefing* (Houghton, Casey, Shaw & Murphy, 2013).

Other aspects of the study which enhance credibility are thick description of situation and context, gathering of multiple interpretations of the same event (clinician, client, researcher), and the reflective, reflexive journal-writing practices of the author (Houghton, *et al.*, 2013). At every stage, the study therefore involved prolonged engagement with the raw data in iterative processes of transcription and analysis.

An unexpected source of credibility revolves around power dynamics between researcher and participant can be relevant to the flow of authentic information: Kornbluh (2015) gives the example of how participants who regard the researcher as an expert may respond in ways which bias the data. In the case of this study, the researcher's student status and limited experience of aphasia and stroke contributed to her being unable to judge or pre- determine participant responses, inadvertently contributing to rigour, whilst checking with peers and experts during the analysis of data supported informed development of the study's findings.

Ethics approvals and ethical considerations

Ethics approvals for this research were given by Sir Charles Gairdner Hospital Human Research Ethics Committee and Edith Cowan University's Human Research Ethics Committee. Permission to work with speech pathology staff and patients at Swan Kalamunda District Hospital was given by the Executive Committee of Swan Kalamunda Health Service. See Appendix H. Names used are not real names. Data security measures are given in Appendix I.

Particular care was given to the consent processes used with PWA to ensure materials such as forms were "aphasia-friendly", and that opportunities were given to PWA to re-visit what they had agreed to do and re-confirm their decision to participate. Participant information and consent forms are given in Appendix A.

Findings

Findings are given in two sections, *Assessment sessions* and *Interviews*, and

cover:

1. DAN of the pattern characteristic of the assessment sessions;

2. Summaries of actual sessions;

3. DAN of sequences of interactions drawn from audiovisual recordings and their

   common 'threads'; and

4. TAN of interviews with participants following the sessions.

Findings part 1: Discourse analysis of assessments

The overview of these four assessment sessions demonstrates how in the

everyday practice of speech pathology, assessment is an event largely guided by, and

controlled by, the clinician (Ferguson & Armstrong, 2004). The clinician takes charge

of the location of the session, the time-keeping, and the flow of conversation. In this

study the SP guided a heterogeneous group of clients through similar sequences of

events as summarised in Table 3.

Table 3. Summary of typical sequence of events in assessment sessions

---

1. Greetings and transferring client via wheel chair from ward to quiet

      room, or greetings at bedside

2. Outline of session to come

3. General catch-up (e.g., breakfast, visits from family, a visit home)

4. Pre-amble to the assessment as a whole and/or the first assessment task

5. Administration of task 1

6. Feedback to the client

7. Administration of task 2

8. Feedback to the client

  (Repeats of task/feedback steps as necessary)

9. Feedback on performance on assessment

10. Thanks at bedside and farewell, or thanks, returning client to

      ward, and farewell.

Descriptions of assessment sessions

Descriptions of assessment sessions demonstrate how this sequence applied to specific clients:

1. Oliver

The SP pushed Oliver in a wheelchair to a vacant room at the hospital. Having conversed on the way to the room and whilst settling into place in the room, the SP began the session saying she would administer what is known as a "high level" language test (a test for people with milder aphasia; The Mount Wilga High Level Language Test or *Mt. Wilga*).

When interviewed, the SP reported choosing the Mt. Wilga to match the level of Oliver's pre-stroke language use as a retired headmaster, and what she understood of his family's perspective on how he should be treated, as well as her own previous observations. Administration of the Mt. Wilga took up most of the session, although its administration was peppered with more sociable chat. Then the SP briefly explored Oliver's functional communication in conversation concerning a family photo album before time ran out and Oliver needed to return to the ward for lunch.

This session was characterised by a high amount of rapport manifested in repeated and sustained eye contact, humour, mirrored gestures, and relevant yet personal comments from both clinician ("I've been as far as Kalbarri" in discussing Northern WA) and client ("Broome is what I consider mostly South").

2. Stan

The SP pushed Stan in a wheelchair to a vacant room at the hospital. Courtney, Stan's daughter, a student in her early 20s, participated sporadically in the session with questions and observations to the SP and attempts to support or clarify her father's (severely limited) verbalisations. Stan's assessment involved a series of reading comprehension tasks. The SP then revisited Stan's speech sounds (his preference was to work on sounds in isolation in addressing difficulties with severe apraxia of speech). At this point the SP transitioned to therapy. Over the session, Courtney and the SP repeated attempts to understand a problem Stan was unable to explain. The SP later discovered Stan's concern was whether the new tingling sensations he was experiencing in his paretic arm and leg, which were keeping him awake at night, were normal.

3. Michael

Michael's assessment was a bedside assessment, with the emphasis on receptive language and demands for expressive language reduced to a large extent. The SP combined tasks from a relatively formal assessment protocol based on the Western Aphasia Battery and informal picture-based tasks. Overall, the register of the session was set by the client's weakened, muted state just 4 days post-stroke.

4. Donald

Donald's assessment session (not recorded, but observed by the researcher and recorded by journal) was a bedside review of his reading and writing just a few hours before discharge. The SP had brought an informal test. However, Donald produced his own notebook and started to write in it. The SP dropped her more formal plan, instead reviewing what her client had written and asking him to read it aloud. She then initiated some discussion concerning Donald's expectations around returning to giving foreign language lessons (his most vital interest since retiring), reminding him of the hospital's outpatient services and informing him she would be following his progress with a phone call in a few days.

Samples from assessment sessions

After multiple viewings of audiovisual recordings, 5 interaction sequences were chosen for analysis. Selection sought to give instances illustrating the typical sequence of events outlined above in table 3 as well as demonstrate diverse aspects of the participants' behaviours during assessment. The resulting samples represented pproximately 15% of turns in the 3 assessment sessions recorded. The sequences were viewed many times by the researcher alone and with colleagues. The following

sequences were selected, an indication of length measured in discourse actions being given in brackets:

1. Hannah's pre-amble to Oliver's assessment (18 discourse actions)

2. Sequence of test items with Michael (19 discourse actions)

3. Handling Stan's daughter's request for information during assessment (28 discourse actions)

4. Between-task feedback to Michael (46 discourse actions)

5. Closing down Oliver's assessment session (13 discourse actions).

1. Hannah's pre-amble to assessment with Oliver

Sequence 1 was taken from the beginning of the assessment session with Oliver, immediately following settling in the room for the session and the recording. Hannah introduces her intended assessment. In a previous session, this client has told stories of his working life in rural remote Western Australia. Hannah later explains to the researcher how she found these stories fascinating.

Hannah responds to how important her client's life history is to him by embedding her explanation of the rationale in a narrative with episodes given in chronological order. The episodes are an assessment the previous week, improvements since then, and a family meeting. The clinician treats Oliver with respect and, in line with the principles of Adult Learning theory, explains her rationale for the choice of assessment tool, explicitly but delicately alluding to clinical reasoning in prefacing her pre-amble with "and I was thinking."

Oliver is markedly engaged, and clinician and client make frequent, sustained eye contact, smiling, and mirroring gestures. The SP creates a sense of adventure with several dramatically large arm gestures, vocal intonation and choice of words. She even

works up to a cliff-hanger: *Will Oliver be surprised by his performance on assessment today?* The impression that Oliver responds to her adventure metaphor is reinforced by his offering to tell more stories if she has a couple of years to spare.

The clinician attempts to engage with Oliver as a whole person, as an adult with a richly lived life, and with a continuing story which assessment will help to explore. She attempts to create a context for the assessment, which Oliver appears to appreciate, listening carefully and politely. Watching the recording, it is easier to see how the memory difficulties he is having since his stroke, on top of aphasia characterised by mild difficulties finding words, contributes to his interpreting this pre-amble as possibly an invitation to tell more stories, demonstrated by his asking, "you got a couple of years [to hear my stories]?", perhaps forgetting the assessment. What transpires from this lead-in is the administration of the non- standardised test (the Mount Wilga) in a conversational way with many interludes of conversation between test items.

2. Sequence of test items with Michael: "could you please raise your hand"

This sequence from Michael's bedside assessment starts with Hannah introducing the assessment task (inaccurately, as it happens). She states, "I'm going to ask you for some instructions" in a manner which is kind but firm, her speech rate slightly slower than usual and the words purposefully clear. The assessment runs smoothly for several test items (one- step instructions), meaning Michael has understood his role despite the potentially confusing instruction.

This is a formal sequence, reflects normal expectations of assessor-assessed roles, where each plays the role given by ritual of assessment for 3 pairs of challenge from the assessing clinician and response from the client. Michael plays the role of the

cooperative patient, and does not complain when a delayed but correct response is missed. Hannah misses his response because she is recording what she observed.

The SP's turns are much longer than Michael's and she controls the session with her turns, constraining Michaels' responses. The nature of this part of the test she is administering means Michael's required responses are non-verbal. Michael verbally asserts his need to hear or understand at one point, interrupting the assessment flow on the one hand, but also briefly redirecting the assessment process. They keep eye contact during this communication repair. The SP responds to by explaining the instruction both verbally and with gesture. The sequence ends with the SP moving on to the next set of tasks.

3. Handling family member's request for information during assessment: "would you have records of how he was (.) when he first read it?"

This sequence opens with the clinician asking Stan what he thinks of his progress with reading since she last assessed him. She explains that she thought Stan's reading was improving, "and then on Friday with Jon [Augmentative and Alternative Communications expert] he [Stan] was like "aw no" he didn't think so." The statement is addressed to Stan's daughter, Courtney. Addressing her directly appears to constitute an invitation for Courtney to discuss her concerns. Courtney asks whether the clinician has records of Stan's previous performance on the task, and the clinician appears to be taken by surprise.

Stan's demeanour appears grim and determined through much of the session. He rarely smiles. For the bulk of the session his eye-gaze rests downward, on the paper-based tasks in front of him rather than towards the SP or his daughter.

Stan carries forward his daughter's unanswered (spoken) question with (non-verbal) gestures towards the clinician's assessment score sheet, even jabbing it vigorously with one finger. Stan is evidently trying to pursue the subject. However, the severity of his aphasia and apraxia, and the lack of specificity in his gestures, mean that although the SP allows him time to take his turns, she does not understand what he is trying to convey.

Hannah acknowledges she has not been able to interpret Stan adequately. Interviewed afterwards, she says, "we got there in the end"—referring to the compromise she proposes, of trying to clarify Stan's concern "later". Meanwhile, Stan appears to be left frustrated and glum.

4. Between task feedback to Michael in presence of drowsiness in first few days post-stroke: "it's one day at a time, Mr Clyne"

This is a challenge/response test sequence framed by the clinician's checking, "Are you still going ok?" whilst she looks through her papers for the task and ending with feedback after three test items. Test items consist of Michael's naming each of a set of pictures, and identifying verbally or by gesture which is the odd one out. When Michael makes an error, the SP probes for why:

SP: why does the orange stand out to you?

Michael: *((quiet voice))* don't know.

SP: sorry?

Michael: *((louder))* I don't know.

SP: ok. it just does.

The SP goes on to give feedback in the form of how she would respond to the item: She would choose the broccoli because it is a vegetable in a set of fruit.

She records Michael's answers throughout the sequence, evidently writing comments as well as right/wrong answers. Feedback on the test items specifically relates to Michael's performance, broadening out to a brief summary of Michael's progress as she sees it, "I like seeing that progress because. 'cause I didn't see you over this weekend. so to come in and say you can do a lot more. you're talking to me. it's short little sentences now. it's one day at a time, Mr Clyne."

5. "we'll get there. we found other ways to get there": closing down Oliver's assessment session

In this sequence, the SP has wrapped up the formal part of the assessment. She is out of time for the session and Oliver is having difficulty naming the part of his boat: The SP proposed they look at a photo album Oliver's family have brought in, and, even during this, the SP was initially writing notes, probably on Oliver's performance in conversation.

When this sequence begins, the SP has put her pen down and her papers away. With mild aphasia, Oliver is able to acknowledge and verbalise his word-finding difficulty: "oh dear. I wish I could remember this. it's one of my th—that I'm supposed to be an expert on."

The SP is reassuring, "it's ok", and, more than this, she acknowledges his competence and expertise in suggesting Oliver can teach her about his area of expertise, even now. This sequence is interesting for the SP's specifically saying, "I can't always help you. we found other ways to get there (.) today." She then thanks him and he courteously replies, "it's a pleasure."

She performs four communication actions:

1. reassurance,

2. acknowledging prior knowledge and expertise,

3. specifying their interaction has been collaborative with "we got there"

4. indicating her own pleasure in the conversation, and

5. thanking him for *his* time.

The sincerity with which the SP does this is reflected in Oliver's next action, self- disclosure that he does not "see any point in hiding". He does not have the words to explain exactly from whom or what he is hiding, but the context suggests he means from his language impairment--from word-finding difficulties, from the effects of stroke. That this is a genuine moment of voluntary vulnerability is reflected in Oliver's raising his eyes from the wheelchair table to give the SP's face a prolonged gaze.

Characteristics of assessment of person with aphasia in first 6 weeks post-stroke drawn from Discourse Analysis

There were three threads running through all the samples of assessment sessions:

1. The clinician's sensitivity to the presence or likely imminent arrival of grief;

2. Sequences of clinician's challenges (test items) and client responses;

3. The clinician's recording (writing of scores and observations).

The clinician's words and actions clearly showed aspects of the psychological challenges of assessing an individual in the early days following stroke and the presence of or likely imminent arrival of grief. She was routinely gentle and reassuring. To assess intensively and comprehensively at this time would be to expose someone who has not yet understood the impact of what has happened to raw experiences of

impairment. This readily explains why, in this particular area of speech pathology, clinicians might prefer flexible and relatively informal assessment protocols.

The need for formal runs of challenges and responses remains, however. This SP tended to score and take notes intermittently throughout all sessions, including during more natural conversational elements of beginnings and endings of sessions. Her pen was often apparent in hand gestures still holding the pen. Her recording sheets or paper were more discretely tucked away on her lap at bedside, but they were always present. The notable exception to her mindfulness of note-taking was the very end of Oliver's session and, on Oliver's part, the conversation here contained observations which were private and personal. The depth of revelation is apparent in his checking of Hannah's reaction to his disclosure that he does not "see any point in hiding".

Findings part 2: Thematic Analysis of interviews

When interviewed, two participants watched their recorded assessment session with attention. However, despite the researcher's prompts and suggestions, they found it difficult, or declined, to comment directly on what they were watching. Without a doubt, explaining their experiences is challenging for PWA: Having volunteered to participate in the research, Oliver's response to the researcher's first question suggested how difficult the endeavour might seem to him: "oh boy. ah. this is going to be a problem. um."

The information given by participants is testimony to their willingness and desire to communicate, participate, and give to others the benefits of learning from their experiences. Full lists of the quotes representing each theme are given in Appendix J.

There was a single instance where client and clinician concerns were directly matched. Following a lengthy sequence of communication repairs across the assessment session, Oliver stated, "I'm a bushy", discussed below as part of client's assessment experiences as well as in a comparison between client and clinician experiences

Clients' assessment experiences

Analysis of interviews showed overlap of concerns between participants with aphasia. Five themes emerged as representative of concerns relevant particularly to assessment. These were *Disconnection*, *Not knowing*, *Having to trust the process and the professionals*, *Information-seeking*, and *Welcoming assessment as something to do.*

1. Disconnection: "not the sort of thing I'd go for normally"

PWA described experiences of disconnection with regard both to assessment in particular and experiences in hospital generally, giving a sense of their feeling out of place and stranded. Oliver, for instance, with a big sigh and unhappy expression, described assessment as "not the sort of thing I'd go for normally." Specifically mentioned disconnects included:

a. The novelty of being a patient within a hospital: The otherness of their involvement in Speech Pathology assessment was apparent in the descriptions of Oliver and Donald. Alienation related to disability was clear in the responses of Stan, who, when asked *What I want out of assessment,* pointed to the option of *Just for things to return to normal,* laughed, then burst into tears.

b. Lack of prior knowledge of Speech Pathology: Lack of experience with Speech Pathology services was common to all PWA participants: "I've never had

speech pathology, so I don't know um what that would entail. I'd have to wait and see" (Donald). None of the assessment sessions were initial assessments. Only Stan seemed (grimly) familiar with the speech pathology session routine. Oliver interpreted assessment as the SP "trying to find out a few things about my behaviour", whilst Donald said, "and then she's got to find out what she can do before she does it. um. I can't help her any way at all because um I don't know, I don't know what's the matter with me."

By contrast, long-stayer Stan demonstrated more certainty and was particularly emphatic about what was important to him in assessment—explanation of aphasia and apraxia, support to communicate better with family, and the SP's conveying the improvements she noticed (disregarding options such as *Don't care*, *Communicate with the hospital staff bette*r and *I just trust I will get what I need,* pointing to his responses without assistance).

c. Apparently random encounters with health professionals: Donald summarised with some irony in his voice, "there's an awful lot of assessing being done of me, but I don't know what it means. they generally say things look fairly good but um. I don't know what fairly good means." This appears to indicate confusion by a blurring of experiences of different health professionals.

d. Feeling misunderstood in the wider sense of who they are: "yes, 'cause I tend to be a bushy," said Oliver in his assessment, successfully reassuring the SP after a number of communication breakdowns concerning the importance to him of his life experiences living in remote Western Australia. In interview, he repeated his assertion of being a "bushy" (someone at home in remote places) explaining that, "the girls are good. but it's hard sometimes to talk about things with people who haven't been there, done that sort of thing. that's probably putting that wrong but."

2. Not knowing: "I don't know what's the matter with me"

There is a lot of evidence that PWA are rarely given enough information in ways they can absorb about stroke or associated impairments including aphasia. There is evidence too that PWA are likely to require repetition of any information given. For whichever reason, or through a combination of reasons, participants did not appear to have grasped their condition in ways which could be described as knowledge. For instance, Donald said "I don't know what's the matter with me. I don't know um how it can be put right. and I don't know whether it would be the right thing for me", and when the researcher suggested aphasia was the name for Oliver's word-finding difficulty, he said, "I know I have the difficulty. and I just try. and if I can't do it, I don't complicate it. I just let it go and take something I can do."

To the older participants, knowing and understanding was seen as less important than accepting and enduring, whereas Stan wanted to know.

3. Having to trust the process and the professionals: "hopefully there'll be more right decisions than wrong decisions"

Client attitudes to the medical processes and professionals with which they were dealing were characteristically passive, especially in the three older participants' words and behaviours. For example, Donald said, "Hopefully there'll be more right decisions than wrong decisions" and, like Oliver, "I just accept what happens to me." Lack of engagement in decision-making of contemporary older generations of clients in health care settings has been noted in previous studies (e.g., Schneider, Körner, Mehring, Wensing, Elwyn, & Szecsenyi, 2005), so this was not a surprise finding.

4. Information-seeking: "getting on the Google"

Donald emphasised his lack of resistance to what was happening to him in hospital. Consequently, he surprised the researcher by saying, "when I go home, the first thing I will do will be to get on the Google and find out as much as I can".

It seems likely that Stan would have wished to be more independent in information- seeking. He was specific about what information he wanted from the SP, choosing between options quickly, with certainty in his gestures.

Given only one participant mentioned wanting to take initiative in seeking information, let alone surfing the internet for it, this remark might have been dropped as a finding. However, Stan's daughter's showed evident disdain for there being no WiFi in the acute care unit (comment made within Stan's assessment session). This suggested that future generations of PWA may expect to access information via technology far earlier and will not sanction waiting upon discharge to independently seek information.

5. Welcoming assessment as something to do

Both Oliver and Donald welcomed assessment sessions (and participation in the research process) as distractions in long days of "nothing" in the hospital. As Oliver put it, "here I've been given more of nothing to do than something."

Clinician's assessment experiences

Analysis of interviews with the SP following assessment sessions rendered a picture of some complexity even within this small data corpus. The SP's concerns relevant to her clients' assessments were *Fitting assessment to the individual*,

Sensitivity to change, *Relevance of family to informed assessment*, *The time factor*, *Acknowledging patients' competences*, and *Possibility of assessment which is "not just one-sided"*. These are discussed more fully below.

1. Fitting assessment to the individual

The SP stated that her prevailing concern in assessing her clients was to investigate "how the flow of information works", meaning both functional communication and the client's individual ability to problem-solve in communication. Given different educational backgrounds, levels of severity of impairment, and individual preferences, styles, and motivations, she emphasised that the flow of information could not be the same in every case. Therefore, no assessment session could be "fairly typical". Congruent with this, none of the four assessment sessions observed for this study were identical in terms of materials or protocol, each being suited to the individual. In order to accommodate individuality, the SP stated a preference for informal assessment tools, including spontaneous conversation. She stated that, "[*a formal tool such as the Frenchay Aphasia Screening Test*] gives you a basic severity score, but a plan for starting therapy? [*no.*]"

2. Sensitivity to change

For this SP, an initial assessment created a baseline for the aphasia, "a starting point" to track any improvements to language abilities over the client's stay. The SP described how her early assessments "give you some place to go." The places to go were administering more detailed assessment using a more formal but focused tool, such as a subset of the PALPA, and/or starting therapy. Thereafter, assessment would be ongoing and "like a jigsaw puzzle, you keep adding little bits."

The SP saw the measurement of severity of aphasia (mild/moderate/severe) as useful only on handover of her client to other settings. Within the acute unit, she talked of assessment as inherently transitory. Through changes in physical wellness or presence of spontaneous recovery of function any particular state might be considered a momentary stop on the patient's journey. The SP had seen both types of recovery in all four clients in this study, even Stan who struggled to see improvements himself. The SP stated, "what language somebody gives you right at the start is a lot different to when you see them later during the week." She agreed it was important to bear possible changes in mind, that is:

> "[*do I*] go, "what's the trajectory and what's the pathway and where are
> we going to go next? or, what's going to happen in the future?" yeah."

3. Relevance of family to informed assessment

To this SP, a significant baseline for language was—in addition to their 'official' admission baseline immediately post-stroke—their pre-stroke functioning. This idea tallied clearly with the hopes of the clients to return to their pre-stroke language abilities. The family's understanding of pre-stroke language informed the assessment process on a number of levels, including the language the SP used and her choices of material. This meant she was able to conduct assessment which, through being informed about the individual, could their "passions or their interests", and feel appropriate to their "status". The SP used the word *status* to encompass her client's whole life experiences as well as the respect people might normally accord them in their interactions.

4. Acknowledging client competence

This SP demonstrated and spoke about her clients' competences in a number of ways:

- At the level of the task

- As an expert in their own state of mind and being

- In their ability to communicate despite deficits, that is, "gets his intended message across"; and

- As an adult with their own knowledge and expertise (and she acknowledges this to be probably very different from her own areas of knowledge and expertise).

The SP's words (corroborated by her actions within assessment sessions) demonstrated that she felt it was important to reflect these competences both to the client himself as well as to family members.

5. Possibility of assessment which is "not just one-sided"

The SP talked about counterweighting the deficits thrown up by assessment processes with less formal ways of informing herself about her clients. She felt that conversations, for instance, about subjects on which the client was knowledgeable, in which the client could engage with real passion, gave them a sense of control. For instance, of Oliver she had noted, "he was so fluent when he was talking about a passion that was so intrinsically motivating to his heart."

6. The time factor

The SP talked about the various constraints of the institutional setting, most of which impact on time available with her clients with aphasia. Researcher observations within the stroke unit reinforced the impression of 'time-sharing' of clients between

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medical and allied health professionals, with priority given to those professionals dealing with physical impairments.

Brevity of stay of patients exacerbated the problem of time. The three main impacts this had for the SP were 1. moving rapidly from assessment to therapy, 2. conservatively predicting how long she might have with clients with aphasia, especially those with fewer mobility concerns, and 3. early consideration of preparations for handover to the next service provider.

Where client and clinician experiences met in this study

There was one instance of crossover between client and clinician interviews. In his assessment session, Oliver made a memorable statement after lengthy attempts at communication repair— he and the SP were thinking of geographically distant parts of Western Australia which probably tested his patience. Oliver said, "I'm a bushy." To Oliver this seemed to summarise an unbreachable chasm between his experiences and those of the young woman assessing him. For the SP, this statement was an astounding example of someone with aphasia's functional communication and undaunted spirit.

Discussion

This study demonstrates the complexity of assessing aphasia in the first 6 weeks post- stroke. The findings display aspects of the dilemma facing the SP: To assess the individual with aphasia with clinical rigour at this time is to confront him to experiences of language deficits to which he has had little or no time to become accustomed. Long-term, life with aphasia requires resilience (Easton, 1999; Grohn, 2014). The clinician's inclination is to respond to the vulnerability of the PWA with reassurance rather than formality. The stoicism of her older clients lends pathos to the scenarios explored.

Analysis of assessment interactions showed the clinician customising her basic assessment session plan according to her predictions of how individuals might perform. This predicting was confirmed as her intention on interview. However, as seen, at least one of the four clients did not conform to her prediction (Donald), and she immediately adapted her assessment intention. She expected and prepared for spontaneous recovery of language abilities. Additionally, a flexible approach to assessment meant she could allow for heterogeneity of clients themselves, their aphasia and the presence of other impacts of stroke on communication. Clearly, given this number of variables, a clinician needs to be flexible, and assessment materials and procedures which are multi-purpose and multi-dimensional will be more generally useful. The study therefore provides insight as to why the preferences of SPs across similar settings when assessing clients rest with informal and unstandardised assessments which allow the clinician room to manoeuvre without invalidating results.

However, despite the clinician's adaptations of assessment materials and procedures, as in other arenas of communication, participants with aphasia reported some unsatisfactory experiences of assessment interactions. In this study, they reported

feeling confused and misunderstood. All clients demonstrated patience and/or frustration both in their assessment sessions and their interviews with the researcher. Difficulty due to aphasia itself was apparent. In addition, the SP's attempts to support people with aphasia sometimes missed the mark. Ferguson & Armstrong (2004) noted the imbalance of power between clients with aphasia and SPs during aphasia therapy sessions, particularly where there is communication breakdown between them. This study demonstrates how imbalance in power in response to communication breakdown was also true within these assessments. There were instances of clients with both mild and severe communication impairment, shrugging their shoulders more or less philosophically and relinquishing hope of the SP understanding them.

The SP's being required to record responses (which she did in hand-written notes during assessment) meant occasionally the person with aphasia's response was misinterpreted or went unnoticed. Analysis of Oliver's self-disclosure around his "not hiding"—stated when the clinician's testing and recording were over—revealed the possibly inhibitory nature of writing notes during client-clinician interactions. One party's taking notes is a behaviour which characterises assessment interactions as having a formal character. Note-taking is potentially a significant part of the power imbalance, tending to be performed by the more powerful participant in an exchange (cf. interviews of police officers with informants, or doctors with patients). Recording and scoring responses are expected during clinical assessment, meaning they might easily go unnoticed as a variable within the interaction. However, note-taking probably has a characteristic impact on interactions in aphasia which could be explored. The clinician's note-taking, when those notes are not openly shared with the client, might be at the heart of assessment processes which Hersh *et al*. (2013) describe as serving the clinician rather than the client.

Within the assessment interactions in this study, as is conventionally the case with assessment, the SP decided, not just what information to gather as part of her assessment, but also what information to share about that process and when. It was noticeable that more information was shared with the less severely impacted Oliver than aphasic and apraxic Stan. Given that this was an experienced SP, this suggests both how difficult making assessment more informative might be in the presence of severe communication disorders.

The participants with aphasia were largely not proactive in assessment interactions or in their attitudes to assessment. Between them, four people with aphasia asked a single question during assessment about their assessment. Unfortunately, Stan's requesting information by urgently gesturing to the results sheet the clinician had been working on was unable to be fulfilled due to the SP being unable to understand what he specifically wanted to know. However, passivity within the acute care unit was contrasted with Donald's intention to conduct active research on his condition once he was home and able to use the internet. This might have been something the SP could have done with him in the hospital environment. In a future era, the generation to which Stan's daughter belongs (now in her early 20s) may well routinely demand supported internet research as part of their early therapeutic intervention.

Easton (1999) theorised the typical progression of attitude and expectations in the longer term recovery from stroke as a journey from "agonising" (shock, fear, loss, loneliness and questioning) to "fantasizing" to "realizing" to "blending" to framing" and finally "owning" (control, acceptance, determination, and self-help; pp.72-73). This describes a progression from emotional turmoil to both acceptance and action. In the present study, Stan alone, at 6 weeks post-stroke the furthest along in his recovery

post-stroke, seemed to manifest agonising, fantasizing, and realizing in his responses. Otherwise, fatigue and resulting passivity of the very earliest days and weeks post-stroke appeared to militate against attempts to promote a more active role for the person with aphasia.

However, even despite the prevailing passivity, there were examples of interactions where the SP attempted to involve the client as an adult learner (i.e., potentially active learner) to which PWA responded positively. For example, she acknowledged prior knowledge and expertise, and this appeared to be appreciated during assessment, for example, shining through in Oliver's "pleasure" in his assessment session, even if not recalled by him when interviewed.

Processes of dynamic assessment inherently involve immediate and specific feedback to the client, and this was also observed. However, whilst the SP was conscious of the importance of assessment benefiting her clients, dynamic assessment was not reported as, or observed to be, consistently and consciously used as a strategy within assessment. This is perhaps a missed opportunity given, on the one hand, concerns regarding time constraints for seeing clients with aphasia in acute settings and, on the other, the benefits of early therapy for aphasia post-stroke.

The time available for assessment in this setting ran counter to making full functional communication assessments of people with aphasia, even where discharge was imminent (and mentioned as a concern by the SP). Under these circumstances, it might make sense to make better use of communication with family members to create functionally relevant assessment interactions. Saldert (2012) recommended the analysis of audiovisual recordings of interactions of PWA and family members as a way of assessing functional communication might prove to be far more relevant to clients. Whilst Saldert's CA proved to be time- consuming, other protocols for structured

observation have been devised within other fields of speech pathology which are time-efficient and clinically useful, for example, the Kagan Scales which can be used to measure communication skills and interactions of people with traumatic brain injury (Togher, Power, E., Tate, R., McDonald, S., & Rietdijk, 2010).

With traumatic brain injury, analysis of conversation is undertaken more for the purpose of coaching the communication partner. In aphasia, however, where people are typically cognitively intact despite their communication impairment, it would be possible to audiovisually record communications not just for the clinician to assess, or for coaching the PWA's communication partner, but for analysis and self-reflection by the client themselves. Certainly in this study, PWA were interested in seeing recordings of their assessments, watching long stretches with attention.

There are precedents for use of audiovisual 'reflective' materials within speech pathology's paediatric practices—predominantly in what is known as the Hanen Programme (Baxendale, Frankham and Hesketh, 2001). In the Hanen Programme, parents watch videos of their interactions with their children as a learning tool. Parents have found this "'real' and relevant" (Baxendale, *et al.*, 2001, p515), and this might prove to be the case with PWA also. The role of communication partners as crucial to the social engagement of people with aphasia in long-term outcomes has been discussed elsewhere (e.g., Dalemans *et al*, 2010). Finding ways to involve the regular communication partners of PWA—their family and even friends—might make assessment in these early stages more relevant in the long- term. Clinicians could be introducing problem-solving techniques and even attitudes towards communication required for living with aphasia (Grohn, 2014) more explicitly from an earlier stage. As the SP mentioned, standardised assessments produce scores and severity ratings which are useful 'shorthand' for handovers between professionals, but do not translate well

into useful information on functional communication or to the necessary long-term problem- solving in the presence of a communication disorder like aphasia.

In conclusion, it is not surprising that, in the type of setting where this study was conducted and under the circumstances in which their clients are experiencing speech pathology services for what is likely to be the first time, SPs prefer flexible assessments which respond to client heterogeneity. Meanwhile, PWA prefer immediate feedback as to how they are doing and how they are progressing, and immediate reassurance, even during assessment. Experiences of PWA in the early stages post-stroke are confusing and confronting as it is.

Limitations

Amongst the limitations of this study, the most significant were:

1. *Requiring more time with PWA to extract value from stimulated recall:* When interviewed after assessment sessions, participants were generally interested in watching their recording. However, in every case, they found it difficult, or declined to comment directly on what they were watching, despite the researcher's prompts and suggestions. Time pressures in this study were not helpful to interacting with PWA.

2. *Member-checking required with PWA*: Due to the permissions requested for this study, it was not possible to member check with participants with aphasia following their discharge from the setting. As assessment procedures may be repeated in new settings (e.g., community rehabilitation) this is a limitation it would be particularly informative to have address. Impacts of assessment might reverberate for clients long into the future, shaping subsequent experiences and perceptions of aphasia.

3. *Selection of assessment sequences for analysis:* Given only 15% of turns from the three (out of four possible) assessment recordings were analysed, a more

comprehensive, or a different selection, might have led to different findings.

Future research

This research raises more questions than it answers. One line of enquiry emerging from this study concerns how early do PWA want to, are able to, and benefit from researching their condition and situation via the internet, either independently or with support. Given this opportunity, what would be the research experiences that would augment experiences in acute medical care. That this will become more widely relevant as more technologically aware generations age—and, sadly, have strokes—is evident.

Whether informal assessments are effective clinically is not clear from the present study—it could be that their prime impact is on psychological well-being of not having to be formally assessed. One follow-up from what this study has found would be to ask those in chronic stage of aphasia past-stroke to recall more pointedly their early experiences of assessment. This does not seem to have been asked yet, but these people would be the experts.

Clinical implications of this research

Experiences of people with aphasia being assessed in the early stages post stroke are probably still not optimal, despite conscientious shifts of SPs towards more flexible assessment materials and procedures. Styles of interactions have impacts which are under- explored, and there are techniques still to be thoroughly explored. Until the research has been done regarding incorporating aspects of flexible and interactive assessment, such as dynamic assessment and principles of adult learning, the clinician who wishes to introduce these into her practice will find a general

evidence base only, with very little specific to speech pathology. However, instances

within this study where assessment comprised more truly interactive interactions was

shown to contribute to clients' positive experiences.

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Appendices

Appendix A: Information and consent forms

Appendix B: Interview questions and and Customised supported conversation tool:

Choice cards for Stan

Appendix C: Data corpus

Appendix D: Revised interview framework

Appendix E: Transcription guidelines

Appendix F: Discourse Analysis procedure

Appendix G: Dynamic Moves

Appendix H: Ethics approvals

Appendix I: Data security measures

Appendix J: Quotes from interviews with participants with aphasia

Participant Information & Consent Form

RESEARCH ABOUT **APHASIA & ASSESSMENT**	I have been invited to take part in a research project: '***Experiences of aphasia assessment in the first 6 months post stroke'.***
APHASIA IS A LANGUAGE PROBLEM	Aphasia is language difficulties after brain damage (stroke). It can affect **talking**, **understanding**, **reading** and **writing**. It does **not** affect intelligence.
RESEARCHER **STUDENT SPEECH PATHOLOGIST**	The researcher is a student speech pathologist at Edith Cowan University.

I UNDERSTAND

WHAT THE RESEARCH IS ABOUT

The researcher has explained what the research study is about.

TALK TO ME ABOUT

APHASIA

The researcher wants to talk to me about my experience of aphasia assessment with my speech pathologist.

THE RESEARCHER WILL **TALK TO**

MY SPEECH PATHOLOGIST

The researcher wants to talk to my speech pathologist about the assessment session we had.

VIDEO RECORDED

TRANSCRIPT MADE

MY REAL NAME WILL **NOT** BE INCLUDED

The researcher will videorecord my assessment session with my speech pathologist. I will watch the video with The researcher and I can tell her what I think.

The researcher will type up a transcript to discuss with her research supervisors. I can see the transcript if I want.

The transcript will not mention things that identify me.

FAMILY or FRIEND THERE TOO

I can have someone with me at the interview if I want.

If I want, they may contribute to the discussion too.

---

1 HOUR		Watching the video and giving an interview may take about one hour.
If I want to, I CAN: **REST** **ASK QUESTIONS** **STOP** **WITHDRAW CONSENT**		I can rest if I need to, or stop the interview if I want. I don't have to answer if I don't want to. I can ask questions. I can pull out of the study if I want to at any time without it influencing my future care.

CONFIDENTIAL

MY NAME AND DETAILS

WILL NOT BE USED

PRIVATE:

RECORDINGS KEPT **SECURE**

Everything I say will be kept confidential. The researcher will not reveal my name to anyone. She will not tell my speech pathologist what I have said.

All identifying information will be altered or removed in journal papers or reports about this research.

The recordings and transcripts will be kept secure at the university.

I CAN TALK ABOUT THIS RESEARCH
TO SOMEONE ELSE

SUPERVISOR: **DEBORAH HERSH**

OR

UNIVERSITY ETHICS COMMITTEE

OR

HOSPITAL ETHICS COMMITTEE

This study has been reviewed by Human Research Ethics Committees at Edith Cowan University and Sir Charles Gairdner Hospital.

I have the right to ask them questions or complain to them if I am concerned about anything.

The researcher is supervised by Dr Deborah Hersh, assisted by Professor Beth Armstrong.

Contact details for these people and the ethics committees are given below.

NOT THERAPY,

JUST RESEARCH

The researcher will *not* give me therapy.

The interview is just for research about the experience of aphasia assessment.

APHASIA & ASSESSMENT STUDY

MY **CONSENT**:

I _____ AM WILLING TO BE PART OF THIS RESEARCH.

SECTIONS OF AUDIOVISUAL RECORDINGS MAY BE USED FOR UNIVERSITY TEACHING AND TRAINING PURPOSES AND/OR CONFERENCES:

☐ (√ IF **YES**)   ☐ (√ IF **NO**)

WITH MY FACE   ☐ (√ IF YES)   FACE CONCEALED   ☐ (√ IF YES)

SIGNED: …………………………………………..   DATE: …………………………..

SIGNED (RESEARCHER): ………………………………   DATE: …………………………

CONTACTS:

Edith Cowan University Human Research Ethics Committee, Kim Gifkins   6304 2170
Edith Cowan University, Dr Deborah Hersh   6304 2563
Sir Charles Gairdner Human Research Ethics Committee   9346 2999
Student Researcher, Penny Wood   6304 2563   pwood4@our.ecu.edu.au

Adapted with permission from consent form in Braunack-Mayer & Hersh (2001), version 4, revised 4.3.2015

APHASIA & ASSESSMENT STUDY

FAMILY/FRIEND CONSENT:

I, _____ , BEING A FAMILY/FRIEND OF

_____ AM WILLING TO BE PART OF THIS RESEARCH.

SECTIONS OF AUDIOVISUAL RECORDINGS MAY BE USED FOR UNIVERSITY TEACHING AND TRAINING PURPOSES AND/OR CONFERENCES:

☐　(√ IF **YES**)　　　　　　　　　　　　　☐　(√ IF **NO**)

WITH MY FACE　　　　　　　☐　(√ IF YES)

WITH MY FACE CONCEALED　　☐　(√ IF YES)

SIGNED: ……………………………………….. 　　DATE: …………………………

SIGNED (RESEARCHER): ………………………… 　　DATE: …………………………

CONTACTS:

Edith Cowan University Human Research Ethics Committee, Kim Gifkins   6304 2170
Edith Cowan University, Dr Deborah Hersh   6304 2563
Sir Charles Gairdner Human Research Ethics Committee   9346 2999
Student Researcher, Penny Wood   6304 2563   pwood4@our.ecu.edu.au

Speech Pathology Honours Project 2015

Experiences of aphasia assessment in the first 6 months post stroke

Honours research project proposed by student speech pathologist, Penny Wood

Speech Pathologist information sheet

Research background

We know very little about how clients with aphasia experience being assessed or what they understand about the process. Very little has been published on this – and while there is a large literature on how and why speech pathologists should carry out assessments, we know less about how speech pathologists actually put this into practice and how clients make sense of it.

What does participation involve?

This study involves making a video-recording of assessment sessions with 3 clients from each of 2 speech pathologists (total 6). Student speech pathologist/researcher, Penny Wood, will set up the camera so clinician and client (and family member if present) are in the frame, and she will then leave. Alternatively, the clinician can set up a camera to film the session.

Following the filming (at some convenient time – but ideally within several days of this assessment session) Penny would like to interview both the speech pathologist and the client/family separately. Your interview will be conducted when and where convenient to you. We expect this to take a minimum of 15 minutes, but if you have time, you could also be involved in a stimulated recall interview where you and Penny both look through clips of the session to discuss and reflect on them. This interaction would also be recorded.

Penny will then transcribe interviews. Your transcription will be available to you to review and, if you desire, to adapt or add to, in order to reflect your thoughts.

Please note the following:

- We would access participants with aphasia through you. The inclusion criteria are very broad – the only stipulation is that the person has aphasia (following stroke), but without a diagnosis of dementia, and is within 6 months of their stroke. The client can have any level of severity of aphasia, but needs to be able to give consent (with relevant supports and an aphasia-friendly consent process).

Version 3, revised 4.3.2015

- The type of assessment is not important – we are interested in any kind of assessment whether a standardised test, informal screening, or any other assessment you would normally use in your setting. If you are also assessing for dysarthria or dyspraxia, that is also fine. We are interested in the process of assessment rather than the particular assessment chosen.
- We would like you both to be in the frame of the video.
- We will not share your comments on the video with your clients nor share their comments with you.
- We are interested in both professional and client perspectives of the process of assessment - particularly when that client has an aphasia.
- We would like to gather data from 2 clinicians if possible and therefore the experiences of 6 people with aphasia.
- Data collection would need to be complete by the end of August 2015 because the Honours project needs to be ready for submission by the end of October 2015.

Participation of both speech pathologist and clients will be entirely voluntary. You will be free to withdraw from the study without prejudice or negative consequences, and without having to explain why.

Confidentiality

Your involvement will be confidential, with only the researcher and her supervisors having access to any materials generated. Research documents will be securely kept at Edith Cowan University with identifying information removed or altered as necessary.

Computer data will be secured through the use of passwords in institutional information technology systems.

We would like to know if you are happy for clips of the session itself or of the stimulated recall session to be shown in educational settings or at conferences. We have a tick box option on the consent form for you to let us know if you are happy about this. We can obscure the faces through pixelation if you wish but still then have the option to show the interaction.

Publication of results

The results may be drawn upon for academic papers and conference presentations. In these, personal information of individuals will not be identifiable in any way and pseudonyms will be used. The researcher will provide access to you to any such papers generated.

The researcher will also be happy to customise a presentation for you and your colleagues at your setting to feed back results of the study if you wish.

Withdrawal from the study

Your participation in this study is entirely voluntary. You may withdraw from it at any time without prejudice or penalty, or any requirement to give your reason. In the event of withdrawal from the study, any data collected for you and your client(s) will be destroyed.

Your queries

The researcher, Penny Wood, will be supervised by Edith Cowan University staff working in Speech Pathology in the School of Psychology and Social Science. Queries about this study may therefore be directed to the study supervisor, Associate Professor Deborah Hersh. Her contact details are given below. Professor Beth Armstrong will also be supervising the study.

Ethics Committee Approval

The Edith Cowan University Human Research Ethics Committee and the Sir Charles Gairdner Human Research Ethics Committee have given approval for this study. Should you have any concerns about the research, their contact details are given on the consent form below.

Enquiries about the project

Contact	Telephone	Email
Penny Wood Speech Pathology Honours student	041 601 3065	pwood4@our.ecu.edu
Dr Deborah Hersh Study Supervisor	6304 2563	d.hersh@ecu.edu.au

Speech Pathology Honours Project 2015

Experiences of aphasia assessment in the first 6 months post stroke

Honours research project proposed by student speech pathologist, Penny Wood

Speech Pathologist consent form

I, _____ , am willing to be part of this research.

Sections of audiovisual recordings may be used for university teaching and training purposes and/or conferences. I am willing for clips of me to be used:

☐ (√ IF **YES**)   ☐ (√ IF **NO**)

WITH MY FACE   ☐   (√ IF YES)

WITH MY FACE CONCEALED ☐   (√ IF YES)

Signed: ……………………………………… Date: ………………

Signed (RESEARCHER): ……………………. Date: ..……………

CONTACTS:

Researchers:

Edith Cowan University Supervisor, Dr Deborah Hersh   6304 2563
Student Researcher, Penny Wood   6304 2563   041 601 3065
pwood4@our.ecu.edu.au

Ethics committees:

ECU Human Research Ethics Committee, Kim Gifkins   6304 2170
Sir Charles Gairdner Group Human Research Ethics Committee   9346 2999

Speech Pathology Honours Project 2015

Experiences of aphasia assessment
in the first 6 months post stroke

Topic guide for interviews with people with aphasia (and family members if present)

1. What was your overall impression of your session with your speech pathologist?

2. Tell me about your experience of having an assessment/being tested?

3. Do you feel you came out of the session with any or all of the information you wanted or needed?

4. Is there anything else about that session you would like to tell me?

As required, please note that the above questions will be offered through _supported conversation_ techniques (such as closed questions, rating scales, and gestural and pictorial options).

Interviewing while reviewing the video (_stimulated recall_) constitutes a supported conversation technique.

Speech Pathology Honours Project 2015

***Experiences of aphasia assessment
in the first 6 months post stroke***

Topic guide for interviews with speech pathologist

1. What was your overall impression of your session with your client?

2. What were your goals for this session and did you achieve them?

3. Can you tell me about any particular, key moments (that went well or not)?

4. If a family member or friend was there, was there anything notable for you about having them present?

5. Is there anything else about that session or the client's reaction to it that you would like to tell me?

Customised supported conversation tool: Choice cards for Stan

Choice card 1 (of 3):

How I think about the speech pathologist:

Helping me	Not helping me
Teaching me	Too much stuff I already know
Supporting me/my family	Stuff I don't need
Informing me	Confusing me
Someone I trust	Not sure about trusting
Good materials	Don't understand why we're doing this
Including my family and I like it	Including my family and I don't like it
Other things	

Choice card 2:

What I want out of assessment:

Don't care

Don't care—I am just doing it for something to do in hospital

Don't know

Increase my understanding

For speech pathologist to get best picture of where I'm at

Knowledge

Tools and techniques

Just get better

Just for things to return to normal

Experiences of getting over communication difficulty

Support for my family

Other things

Choice card 3:

What I want to understand when I come away from a session:

Don't know

Don't care

I just trust I will get what I need

What is wrong with me

What is improving

What I can expect in the future

What is going to help me

What I can do to amuse myself in hospital

How to communicate with hospital staff better

How to communicate with family better

What aphasia is

The labels for what my condition is

Other things

20 March 2015

Assoc Professor Deborah Hersh
Speech Pathology
School of Psychology and Social Sciences
Edith Cowan University
JOONDALUP   WA   6027

Dear Assoc Professor Hersh

HREC No: 2015-015
Project Title: Experiences of aphasia assessment in the first 6 months post stroke

The ethics application for the project referenced above was reviewed by the Sir Charles Gairdner Group (SCGG) Human Research Ethics Committee (HREC) at its meeting on 19 February 2015. It has been approved and the following documents have been approved for use in this project.

Documents
Protocol, version 2 dated 5 March 2015
Participant Information Sheet and Consent Form - Participant with Aphasia, version 4 dated 4 March 2015
Participant Information Sheet and Consent Form - Speech Pathologist, version 3 dated 4 March 2015
Invitation to Participate
Topic Guide, dated 26 January 2015
Participant Profile - Participant with Aphasia, dated 26 January 2015
Participant Profile - Speech Pathologist, dated 26 January 2015

Approval of this project from the Sir Charles Gairdner Group Human Research Ethics Committee EC00271 is valid to 20 March 2018 and on the basis of compliance with the 'Conditions of HREC Approval for a Research Project' (attached).

The nominated participating site/s in this project is/are:

Swan Districts Hospital

[Note: If additional sites are recruited prior to the commencement of, or during the research project, the Coordinating Principal Investigator is required to notify the HREC. Notification of withdrawn sites should also be provided to the HREC in a timely fashion.]

A copy of this ethical approval letter must be submitted by all site Principal Investigators to the Research Governance Office or equivalent body or individual at each participating institution in a timely manner to enable the institution to authorise the commencement of the project at its site/s.

This letter constitutes ethical approval only. This project cannot proceed at any site until separate site authorisation has been obtained from the CE, or delegate, of the site under whose auspices the research will be conducted at that site.

The SCGGHREC is registered with the Australian Health Ethics Committee and operates according to the NHMRC National Statement on Ethical Conduct in Human Research and International Conference on Harmonisation – Good Clinical Practice.

Should you have any queries about the HREC's consideration of your project, please contact me. The HREC's Terms of Reference, Standard Operating Procedures, membership and standard forms are available from http://www.scgh.health.wa.gov.au/Research/AboutUs.html or from the HREC Office.

Yours sincerely
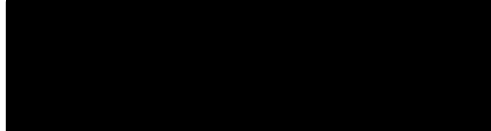
Sean Howarth
Delegate of the Chair
for
Hal Jackson
Chair
Sir Charles Gairdner Group
Human Research Ethics Committee

Associate Professor Deborah Hersh
Speech Pathology
Edith Cowan University
270 Joondalup Drive
Joondalup WA 6027

10 April 2015

Dear Deborah

RE: HREC Trial: 2015-015 Experiences of aphasia assessment in the first 6 months post stroke.

Thank you for your application to undertake research at Swan Kalamunda Health Service.
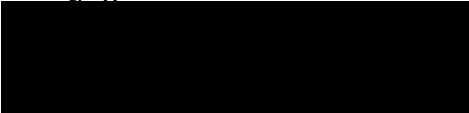
Your application has been presented to Executive for consideration and has been endorsed. Your Executive sponsor will be:

> Dr Peter Wynn Owen
> Executive Director
> PH: 9347 5502

You are required to provide to your sponsor a progress report annually and on completion of your activity (see attached Research/Project Annual/Final Report template). This annual/final report is tabled at SKHS Executive Committee to maintain communication of your progress.

Good luck in your research undertaking.

Regards

Dr Peter Wynn Owen
Executive Director
Swan Kalamunda Health Service

Swan Kalamunda Health Services

Swan Campus	Kalamunda Campus
Eveline Road, MIDDLE SWAN WA 6056	Elizabeth Street, KALAMUNDA WA 6076
PO BOX 195, MIDLAND WA 6936	PO BOX 243, KALAMUNDA WA 6926
Telephone: (08) 9347 5244 Facsimile (08) 9347 5255	Telephone: (08) 9257 8100 Facsimile: (08) 9293 2488
ABN: 13 993 250 709	ABN: 13 993 250 709

12846 WOOD ethics approval

Research Ethics <research.ethics@ecu.edu.au>

Fri 24/04/2015 11:27

Inbox

To:Penelope WOOD <pwood4@our.ecu.edu.au>;

Cc:'squidblossom@gmail.com' <squidblossom@gmail.com>; Deborah HERSH <d.hersh@ecu.edu.au>; Beth ARMSTRONG <b.armstrong@ecu.edu.au>; FHES Student Information Office <siofhes@ecu.edu.au>;

📎 1 attachment (54 KB)

Conditions of approval - multicentre.doc;

Dear Penny

Project Number: 12846 WOOD
Project Name: Experiences of aphasia assessment in the first 6 months post stroke

Student Number: 10269826

The ECU Human Research Ethics Committee (HREC) has reviewed your application and has granted ethics approval for your research project. The Committee noted that the project has previously been approved by the Sir Charles Gairdner Hospital Group Human Research Ethics Committee. In granting approval, the HREC has determined that the research project meets the requirements of the *National Statement on Ethical Conduct in Human Research*.

The approval period is from 24 April 2014 to 23 November 2015.

We will also inform the Faculty.

All research projects are approved subject to general conditions of approval. Please see the attached document for details of these conditions, which include monitoring requirements, changes to the project and extension of ethics approval.

Please feel free to contact me if you require any further information.

Regards
Kim

Kim Gifkins, Senior Research Ethics Advisor, Office of Research & Innovation, Edith Cowan University, 270 Joondalup Drive, Joondalup, WA 6027
Email: [research.ethics@ecu.edu.au]**research.ethics@ecu.edu.au** Tel: +61 08 6304 2170 | Fax: +61 08 6304 5044 | CRICOS IPC 00279B

Appendix C: Data corpus

Event	Participants	Duration
		hour:minute:second
Assessment sessions	SP and Oliver	00:33:18
	SP, Stan and Stan's daughter, Courtney	01:01:43
	SP and Michael	00:32:44
SP interviews	SP re Oliver	00:15:24
	SP re Stan and Courtney	00:22:18
	SP re Michael	00:12:41
	SP re Donald	00:13:44
Interviews with PWA	Oliver	00:55:18
	Stan*	00:12:43
	Donald	00:22:22
Total duration		06:42:15

* Stan preferred some of recording be deleted, with only researcher's notes accepted by him as data for that portion of his interview.

Appendix D: Revised interview framework for PWA

Guided conversation with people with aphasia (and family members if present)

You've just seen the Speech Pathologist, (SP's name).

She did (one of) her speech pathology assessments with you.

How about trying to tell me what you did with the speech pathologist. (You did X. How was that?)

Do you reckon she did a good job of it? (You're nodding/shaking your head. Try to explain.)

We have the video here, so let's watch a bit.

Then, I want to know what do **you** think about what happened.

What were you *understanding*?

How did the speech pathologist *help you understand*?

How did she make you *feel* when she was assessing you?

Did you feel better afterwards? Encouraged perhaps? Understanding more about what's going on? (You're nodding/shaking your head. Try to explain.)

You might have wanted to understand about what's wrong (aphasia)? (You're nodding/shaking your head. Try to explain.)

You might have wanted to understand what she wants to do to get better? (You're nodding/shaking your head. Try to explain.)

Do you know why she chose to do that test/asked you to do those things?

Why do you think that test might help her to help you?

You might have wanted to understand what's improving? (You're nodding/shaking your head. Try to explain.)

Did you have questions during the time with the Speech Pathologist? Were they answered?

What things are most worrying you at the moment about your ability to express yourself/talk/read/write?

Did the assessment help to answer your concerns?

Can you remember a time of being assessed before?

Did you know anything about speech pathology before your stroke?

What do you know about speech pathology now?

Some people say they feel confused by the number of health professionals they see in hospital. How are you coping with that?

Does your speech pathologist stand out in any way?

Is there anything else you would like to tell me?

Appendix E: Transcription conventions adapted from Müller (2006)

Basic layout of a multilayered transcript

	G	**Gaze and gesture**
	P	**P**rosody
line or turn #	Speaker ID	**O**rthographic transcription
	D	**D**iscourse: characteristics of spoken discourse, interaction
	C	**C**linically targeted or relevant behaviours

The orthographic layer

Intonation and emphasis

.	Falling intonation
,	Continuing intonation (maybe slight rise or fall)
?	Rising intonation
↑↓	Marked rise or fall on the syllable following the arrow
:	Lengthening of the preceding vowel or consonant sound
<u>Christ</u>mas	Underscore indicates marked emphasis
-	Indicates a cutoff of the syllable or sound preceding
NO	Capital letters indicate a syllable or word said with increased intensity compared to the speech around it

Pauses within speaker turns, and silences between turns

(.)	A pause of one beat
(2.5)	A timed pause, here 2.5 seconds

Overlaps, interruptions and latched talk

=	Latching (one utterance followed immediately by beginning of another, without overlap or pause)
[	Beginning of overlapping speech
*	End of overlapping speech

Markers for intelligibility

did you have a good time	Orthographic transcription without parentheses: no transcriber doubt; fully intelligible
(did you have a good time)	Transcriber's best guess at meaning
(did you have a XX)	X for each unidentified syllable
(3 seconds unintell.)	No identification possible beyond the fact that a speaker did speak.

Other verbal behaviours or sounds that may impact on interaction

For instance,

((coughs))

((sound of swallowing))

((3 seconds background noise))

Appendix F. Pomerantz & Fehr's (1997)Stages in Discourse Analysis adapted from Hand (2006)

The researcher/analyst:

1   Selects a sequence

2   Characterises the actions in the sequence

3   Considers how the speakers' packaging of actions, including their selections of reference terms, provides for certain understandings of the actions performed and the matters talked about. Consider the options for the recipient that are set up by that packaging.

4   Considers how the timing and taking of turns provide for certain understandings of the actions and the matters talked about, for example:

          Obtaining the turn

          Timing the start of the turn

          Terminating the turn

5   Considers how the ways the actions were accomplished implicate certain identities, roles and/or relationships for the interactants

Appendix G: Dynamic Moves from Ferguson & Elliot (2001)

"Move"	**Description of more specialised jargon**
backchannel	referring back to previous turn or action
forward channel	referring forward (usually to next turn)
confirmation	
response to confirmation	
confirmation request	
response to confirmation request	
check	blocking move (for example, a "No" response)
response to check	
clarification	
response to clarification	
clarification request	
response to clarification request	
challenge	
response to challenge	
replay	repeat of turn (may be same or similar)
replay request	
response to replay request	

Speech Pathology Honours Project 2015

Experiences of aphasia assessment in the first 6 months post stroke

Security and confidentiality protocol

Audiovisual recordings

Audiovisual recordings will only be viewed by the researcher and advisers, and the person with aphasia. If invited by the person, family members or friends of the person with aphasia may be involved in watching the recording.

The individual's speech pathologist will *not* have access to the recording or to the transcript of any discussion around that recording with the researcher.

De-identification of transcripts

Transcripts will be made of each interview with a speech pathologist or person with aphasia. Names will be changed to pseudonyms. Excerpts used in publication will conceal any personal details which could identify the speech pathologist or person with aphasia.

Permission to use sections of recordings

With the clinician and/or person with aphasia's permission, audiovisual recordings may be used at ECU for educational purposes or at conferences at a later date. The individual will have the option to allow their face to be visible or concealed by pixelation.

Security of electronic data

For the duration required by ethics approval, electronic data such as the audiovisual recordings will be kept locked at the Edith Cowan University. Computer data will be secured through the use of passwords in institutional information technology systems. As required, data will be destroyed at the end of that period.

Security of non-electronic data

For the duration required by ethics approval, all non-electronic data will be kept locked at Edith Cowan University. Data that has not been entirely de-identified in the research study process will be destroyed at the end of that period.

Theme	Oliver	Stan	Donald
Disconnection: From normal life From normal easy communication In communicating with speech pathologists Across assessment processes of different health professionals	*(sigh)* [Assessment is] not the sort of thing I'd go for normally. R: I noticed there were times when you were saying something and [the SP] got the wrong end of the stick. Oliver: That's nothing unusual at this stage of the game. R: Is it? Oliver: Because I often say the wrong word. The girls are very good… They. I I have a good opinion of them. Sometimes I don't understand. One of the things I've found hard is their understanding of what we're talking about often only gets about a thir- as far as the first town up. Asked opinion by the Speech Pathologist of the assessment he had just completed, Oliver said, "It's interesting. Sometimes I see the thing as slightly different. But. What the hell."	Researcher's journal: *Stan has watched the recording of the session almost in its entirety, sometimes looking out the window or distracted by the people but mainly seeming to be focused. He does not smile at the bits where everyone smiles and/or laughs. I keep wondering what is going through his head and wondering how on earth I am going to get it out of him. He looks grim, unhappy. He is not particularly interested in commenting. Agrees with everything I suggest. I have tried stopping the recording and asking about specific moments, but it is just not working and feels intrusive given he does not indicate any desire to comment. I have tried using emotion picture cards to ask how he felt about the session. He ignored those completely.* Stan's responses recorded in Researcher's Journal: *How I think about the speech pathologist is... All of them.**	There's an awful lot of assessing being done of me, but I don't know what it means.
Not knowing: What aphasia is That I have aphasia About speech pathology What the speech pathologist is	R: during that session with Hannah. She didn't say to you the word aphasia? Oliver: She could've. I can only remember things for about 3 or 3 minutes. R: Do you know that's to do with the aphasia? Oliver: Aphasia. Um.	Stan's responses recorded in Researcher's Journal: *How I think about the speech pathologist is... All of them.**	They generally say things look fairly good but um. I don't know what fairly good means. I assume I will just gradually regain my abilities to do what I've always done. Um. I've never had speech pathology so I don't

looking for What will happen next About recovery	R: That's the name of that language difficulty- Oliver: Ah yeah. R: -after stroke. Oliver: I know I have the difficulty. You know, I haven't seen a person for ages. *((laughs))* Until the last lot I was completely by myself for goodness knows how long.		know um what that would entail. I'd have to wait and see. It remains to be seen total recovery that I make. I can't help her [the speech pathologist] anyway at all because um I don't know, I don't know what's the matter with me. I don't know um how it can be put right. And I don't know whether it would be the right thing for me.
Having to trust the process and the professionals: No prior experience available No previous interest Acceptance of experts who know more about my difficulty than I do Waiting for the professionals to tell me what to do Assuming the professionals know what they're doing	I know I have the difficulty. And I just try. And if I can't do it, I don't complicate it. I just let it go and take something I can do. When there's a need you got to do it. Um. The. I suppose what would be more of interest is when you're talking about assessment as far as out there doing different things. It depends who's assessing you, whether they have the knowledge to do the assessment. Um. If they have the knowledge and the understanding, no problem. If they don't, no use. The point of view is that there are things that are more important. We had one day when I did nothing because there were emergencies on. That's life. Yeah. You can't help that.	Stan's responses recorded in Researcher's Journal: *How I think about the speech pathologist is... All of them.**	I've never had speech pathology, so I don't know um what that would entail. I'd have to wait and see. Um. Oh I don't know. I don't. Um. I just accept what happens to me. I wait until I get some instructions about what I should do to overcome whatever problems they may detect. Um. I don't really know at this stage what they're likely to do and um so I can't comment on that really, until something happens. Hopefully there'll be more right decisions than wrong decisions. I just assume it's relevant. Um. I assume that whatever she (X) with my speech. Somehow or other it'll be rectified. Um.

Appendix J: Quotes from interviews with participants with aphasia

Information-seeking: Specific and relevant information Getting "on the Google" Demands of future generations		Stan's responses recorded in Researcher's Journal: *What I want to understand when I come away from a session is... What is improving, How to communicate with my family better, and What aphasia is/what apraxia is.* Researcher's Journal: *Stan's daughter's surprise (maybe disgust even) that hospital has no Wi-Fi for patients is evident. I can't help wonder what behaviours will be seen in the people (future PWA) with remaining capacity to use technology so engrained in their lives.*	When I go home, the first thing I will do will be to get on the Google and find out as much as I can, that's for sure.
Welcoming assessment as something to do	I got nothing else to do really. I'm not a person who sits and does nothing and here I've been given more of nothing to do than something.		Comments to researcher recorded in journal

Key: R = researcher

*All of them = [The Speech Pathologist is] Helping me, Not helping me, teaching me, [providing] too much stuff I already know, supporting me/my family, [providing] stuff I don't need, informing me, confusing me, someone I trust, not sure I about trusting, [providing] good materials, [I] don't understand why we're doing this, including my family and I like it, including my family and I don't like it.