Interviewing people with aphasia: Insights into method adjustments from a pilot study

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Interviewing people with aphasia: Insights into method adjustments from a pilot study

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Background: An increasing number of researchers are using qualitative methods to study the impact of aphasia. However, there is a paucity of published research outlining if and how qualitative interview methods are altered with participants with aphasia, and how potential modifications impact on the rigour of such research.

Aims: In a qualitative, pilot study we investigated (1) What services do males in Victoria with mild chronic aphasia perceive could be provided by the Australian Aphasia Association? (2) How is qualitative in-depth interviewing method altered to accommodate the communicative difficulties experienced by people with aphasia?

This paper reports on the second aim.

Methods and Procedures: A qualitative phenomenological approach was adopted. Purposeful sampling was used to obtain four participants with mild chronic aphasia across the variables of geographical location and employment status at time of stroke. An interview guide was devised and refined with a fifth pilot participant. Interviews were videotaped to allow for transcription of total communication strategies and 20% of transcriptions were verified by an expert in aphasia.

Outcomes and Results: When using the traditional open-ended, non-directive approach to qualitative interviewing, very little information was obtained from the pilot participant. The results from four further participants revealed that with participants with aphasia, the researcher is required to step out of the traditional role of the qualitative interviewer by altering questioning style, offering ideas to participants, and using supportive conversation techniques. Strategies used by participants require that interviews be videotaped so that the meaning of the total communication strategies used can be verified.

Conclusions: Valuable data can be obtained from participants with aphasia when the interview method is altered appropriately to meet their communicative needs. The study highlights implications for enhancing rigour in qualitative interviews with people with aphasia.

The use of qualitative methods in aphasia research has been supported (Damico, Simmons-Mackie, & Schweitzer, 1995; Elman, 1995; Parr, 2001) and has been described as both a rigorous and powerful paradigm (Damico, Simmons-Mackie, 1995).

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Qualitative methods have been considered useful because they illustrate “insider perspectives” (Parr, 2001) and can provide some insight into the actual experience of aphasia. Interviews are most often used as the data collection method; however, interviewing participants with aphasia can become difficult when the nature of the condition itself impinges upon a person’s ability to communicate their perspective. Kagan (1995) argued that due to the deficits caused by aphasia, people with aphasia may need to rely on others to reveal their competence. Published information exists on supported conversation techniques (Kagan, 1995), good versus poor communication strategies of communication partners (Simmons-Mackie & Kagan, 1999), and general suggestions for promoting effective conversation with people with aphasia (Lyon et al., 1997; Simmons-Mackie, 2001). However, there is a paucity of information on how researchers may assist participants with aphasia to participate in qualitative interviews.

Consistent with a call for more qualitative research in aphasiology (Elman, 1995), an increasing number of studies have utilised interview approaches to explore aphasia. Several researchers have collected data from proxies, thus avoiding the inherent difficulties of interviewing people with severe aphasia (Herrmann & Wallesch, 1989; Michallet, Tretreault, & Le Dorze, 2003). Interviews with people with aphasia themselves have been used to explore factors around coping and functional reading and writing (Parr, 1994, 1995), the consequences of aphasia in relation to impairment, function, and participation restrictions (Le Dorze & Brassard, 1995), experiences of auditory comprehension problems (Le Dorze, Brassard, Larfeuil & Allaire, 1996), evaluation of counselling (Ireland & Wotton, 1996), social and psychological sequelae (Parr, Byng, Gilpin, & Ireland, 1997), psychosocial aspects of group communication therapy (Elman & Bernstein-Ellis, 1999), handicaps of aphasia (Zemva, 1999), experiences and perceptions of discharge (Hersh, 2001) and “speaking for” behaviour of spouses (Croteau, Vychtil, Larfeuil & Le Dorze, 2004). However, these studies provided limited information on the interview process itself and none overtly reported on issues arising from the data collection strategy of interviewing people with aphasia. This is surprising considering that interviews rely on conversation to elucidate answers to research questions, and that conversation is directly affected by aphasia. Both the interviewer and participant may need to use particular strategies for a successful communication exchange, and due to the heterogeneous nature of aphasia these strategies may well be unique to each individual.

People with aphasia may use a variety of communication strategies to augment their verbal skills including gesture, facial expression, drawing, writing, and use of environmental props such as common objects or a picture communication book/board. Such strategies are often termed “total communication strategies” to emphasise the importance of communication beyond the verbal modality (Jones, Turner, & Heard, 1992). People with aphasia may use gestures relating to Kendon’s (1988) predefined categories, including iconic (referring to a concrete action or object), metaphoric (depicting an abstract idea), and deictic gesticulations (pointing towards a present or absent referent). Language-like gestures may be used instead of speech to fill a grammatical place. Due to the diverse strategies that people with aphasia may utilise, studies that do not delineate how communication strategies were used or how inter-rater reliability was established in interpreting the meaning of non-verbal communications are compromised in credibility. Elman and
Bernstein-Ellis (1999) videotaped their interviews and stated that “participants with severe aphasia were encouraged to augment their answers with gestures, writing, drawings or other communicative resources when appropriate” (p. 66), but did not describe the process used to interpret the meaning of strategies used. The remaining studies used audio-tapes to record conversations, with the exception of Zemva (1999) who handwrote responses. None explicitly described if and how any total communication strategies were verified during transcription. Parr (2001) stated that “interviewers were free to rephrase queries, to describe and interpret non-verbal behaviour, to probe responses and to incorporate written and gestural responses into the data set” (p. 273), but did not discuss verification of these strategies.

Interviewers must make decisions on the best methods to ensure participant comprehension, how to support communication, and on the amount of interview structure required. Ensuring participant understanding is vital for data to be valid, yet none of the previous studies reported on how this was achieved. Le Dorze and Brassard (1995) simply stated that “questions were formulated to ensure comprehension by aphasic participants” (p. 243). Interviewers who do not use communication support strategies for people with aphasia may not be capturing the full extent of information available from these participants. Further, studies that employ such strategies should be required to explicitly report on them to satisfy rigour requirements and allow for a judgement on possible researcher bias. Only one of the previously mentioned studies briefly reported on this issue. Hersh (2001) stated that one participant’s interview “required some use of supported conversation techniques” (p. 82). Looking at a different population, a recent study reported on the influence of interview structure on the communicative performance of adolescents with pragmatic and paralinguistic deficits following frontal lobe impairment (Bernicot & Dardier, 2001). Structured, non-structured, and alternating interview methods were explored and results were measured in terms of speech quantity, amount of digression, and topic initiation demonstrated by participants. Results indicated that unstructured interviews elicited an increased amount of speech utterances and that alternating strategies were useful in developing a greater depth in the interview topics for their participants.

Credibility and dependability of data are compromised when researchers do not document the decision-making process, including decisions on supporting and interpreting conversations during the data collection stage. We argue that the transparency of methods used during this phase with participants with aphasia should be a critical component of rigorous research. In order to perform a detailed analysis of interview data, one must be sure that the transcription of the total communication strategies of the participants is complete and that the intended meanings of each communicative act are accurate. Traditionally, in qualitative research paradigms, in order to reduce interviewer bias, “the voices of the subjects are recorded with minimal influence from the researcher” (Fontana & Frey, 2000, p. 368). Interviewers are expected to use open-ended questions, which enable the participant to formulate a response from a full range of possibilities (Westby, 1990). Minichiello, Aroni, Timewell, and Alexander (1995) described a process by which the qualitative researcher introduces a topic and then “allows the conversation to meander according to the informant’s responses and the subsequent verbal interaction” (p. 83). This paper reports on how the traditional in-depth interview method was adapted to accommodate participants with aphasia and to explicitly report on the processes used to maintain rigour in a pilot study investigating the
perceptions of services that could be provided by the Australian Aphasia Association (AAA).

METHOD

There are several perspectives in qualitative research, including phenomenology, ethnography, and grounded theory (Portney & Watkins, 2000). The current study adopted a phenomenological approach. Phenomenology involves selecting a clinical phenomenon to be studied and then actively seeking to “draw meaning from complex realities through careful analysis of narrative subjective materials” (Portney & Watkins, 2000, p. 273). Heidegger’s Hermeneutical Phenomenological approach presupposes that the interviewer brings their own perceptions and biases to the research process, with rigour achieved by making these preconceptions explicit. This is essential for the researcher involved in supporting conversation with participants with aphasia.

Participants

Purposive sampling was used to select five participants (see Table 1). The pilot nature of the study, the time constraints involved, and indication of the time consuming nature of interviewing (Ireland & Wotton, 1996) dictated the small number of participants. This necessitated restrictions on possible variables. Selection was restricted to those with chronic aphasia. Chronic was defined as at least 1 year post stroke. As the current literature does not provide a consistent definition of chronic aphasia, a 12-month lapse post onset was selected, in line with a study by Hilari, Wiggins, Roy, Byng, and Smith (2003) which investigated health-related quality of life in people with chronic aphasia. As Australian males experience a higher risk of stroke across all age groups (Anderson et al., 1993), participants were male. The variables of employment status at time of stroke and geographical location (capital city versus regional centres) were selected as they were thought to be important factors impacting on perceived needs from a national association.

Participants were restricted to people with English as a first language and aphasia was confirmed using the Western Aphasia Battery (WAB, Kertesz, 1982). Limiting the study to mild cases of aphasia (that is, an Aphasia Quotient of 80+) allowed for capture of the heterogeneity of communicative performance of participants with sufficient deficits to illustrate methodological issues, but eliminated people with severe receptive and expressive disorders. Participants were not purposely excluded on the basis of concurrent apraxia of speech. People with perceptually severe

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Months post onset</th>
<th>Aphasia Quotient</th>
<th>Location</th>
<th>Employment status</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>74</td>
<td>28</td>
<td>95.2</td>
<td>City</td>
<td>Retired</td>
</tr>
<tr>
<td>2</td>
<td>66</td>
<td>13</td>
<td>97.3</td>
<td>Regional</td>
<td>Employed</td>
</tr>
<tr>
<td>3</td>
<td>89</td>
<td>42</td>
<td>96.4</td>
<td>Regional</td>
<td>Retired</td>
</tr>
<tr>
<td>4</td>
<td>56</td>
<td>27</td>
<td>91.9</td>
<td>City</td>
<td>Employed</td>
</tr>
<tr>
<td>Pilot</td>
<td>82</td>
<td>15</td>
<td>N/A</td>
<td>City</td>
<td>Retired</td>
</tr>
</tbody>
</table>
dysarthria were excluded. Self-report confirmed that the aphasia was due to a single stroke, that there were no other neurological conditions involved, and that hearing and vision status were sufficient for one-to-one conversation. Ethical approval was gained from La Trobe University Human Ethics Committee to recruit participants from the attendance list of the Australian Aphasia Association conference held in Melbourne Australia in November 2003.

Assessment and informed consent

Braunack-Mayer and Hersh (2001) provided an example of an *aphasia-friendly* consent form and strategies to assist in the comprehension of the informed consent process. Aphasia-friendly is described as verbal and written materials that are presented “clearly, simply and in Plain English” (Australian Aphasia Association, 2002, p. 3). All forms were modified appropriately in an aphasia-friendly manner. To counteract fatigue, the researcher visited participants on two separate occasions, first to explain the consent form and to conduct an oral peripheral examination and the WAB, and 2 days later to conduct the interview. To assist the informed consent process, the researcher explained the consent form during the initial visit and allowed time for questioning and clarification. None of the participants required further information. However, two people accepted the offer to keep the form to review alone or with a close other. Participants were informed that they could withdraw their consent at any time.

Interviews

Participants were interviewed in their homes. Previous researchers have interviewed people with aphasia with their partners present (Hersh, 2001; Parr, 1994). However, in the current study participants were interviewed alone to avoid the possibility of the “speaking-for” behaviours of spouses (Croteau et al., 2004). Interviews were videotaped to allow for accurate transcription of total communication and inter-rater reliability.

Interviews were semi-structured and used an approach similar to that adopted by Le Dorze and Brassard (1995) where “themes and some focused questions were formulated before subjects were interviewed in order to ensure that several areas of interest were covered” (p. 242). An initial interview guide was developed based on the aims of the Australian Aphasia Association (AAA), and results of the study by Parr et al. (1997) which demonstrated that people were concerned that voluntary organisations did not address day-to-day problems. The questions were: (1) What have you heard about the AAA? Why do you think membership numbers are low? (2) What could an association such as the AAA provide to help with the problems caused by aphasia? (3) Would you be interested in attending a local/state group? What would you like it to do? (4) How could the AAA support you with information services/day-to-day problems/social activities?

The guide was tested during a single pilot interview. The initial interview guide resulted in very little information being obtained from the pilot participant and was subsequently revised (see Appendix), following discussion between authors, to better suit the needs of participants with aphasia. The subsequent interviews began with the researcher giving the participant the opportunity to identify strategies that they found helpful during conversation. While participants did not offer specific
suggestions, it was considered important to acknowledge that communication breakdown was anticipated and to give the person permission to ask for assistance. The process of questioning during the interviews resembled the funnelling approach used in qualitative interviews as described by Minichiello et al. (1995), in effect introducing a broader topic and then narrowing it down towards specific areas of interest through further questions. For example, participants were asked about the day-to-day problems caused by their aphasia, and then invited to consider areas such as their social life and specific activities of daily living.

Transcription

Interviews were transcribed and double-checked by the researcher. Total communication strategies were transcribed into the data set. For example, the use of iconic gestures to replace words during word retrieval difficulty was indicated by transcribing the hand movements and enclosing in brackets, within the point of the sentence where the gestures occurred. Not unexpectedly (see Rose, 2006), one participant used so much natural gesture that in his case, only pertinent gestures were transcribed. The credibility of the interpreted meanings of non-verbal communication was addressed by the researcher identifying any ambiguities, to be verified by an expert (defined as a speech pathologist with a minimum of 10 years experience in aphasiology), and a further 20% of the videotaped data and transcriptions were randomly double-checked by the expert.

Data analysis

Analysis began in the early stages as the researcher made entries into three separate files, including a personal file to record reflections, impressions, and methodological issues from each contact with participants, an analytical file for emerging ideas and conceptual issues as the data collection progressed, and a transcript file for raw data (Minichiello et al., 1995). No a priori categories were utilised in the initial coding process. Emerging themes from the first transcript were noted, categorised, and then recorded in the analytical file. Data from the second transcript consistent with previously identified themes were noted and further emerging themes were added to the categories. Continuous coding of themes and categories occurred as familiarity with each transcript developed. Coding categories were reviewed and discussed by the co-authors and at that stage predefined categories to describe gesture, as described by Rose (2006), were introduced. The NUDIST-Vivo (Non-numerical, Unstructured Data – Identifying, Searching and Theorizing) computer program was then used to systematically code the data through repeated reading and scrutinising.

Rigour

The correlates of internal validity, external validity, reliability, and objectivity in qualitative research are credibility, transferability, dependability, and confirmability (Portney & Watkins, 2000). Credibility was achieved by recording the process in a research diary and maintaining personal, analytical, and transcript files. Transferability was addressed by reporting participant characteristics and keeping detailed notes and observations in the personal file. Dependability of transcription of total communication was assessed via the double-checking of ambiguities and a further 20% random
sample by an expert. There were six instances of ambiguities identified by the researcher and these were discussed with the expert until a consensus was agreed. In the checking of 20% of the transcripts by the expert, 100% agreement was achieved. Confirmability was ensured through transparent reporting of the analytical process in the analytical file. Coding of themes was confirmed by a qualitative researcher unrelated to the project. Complete agreement was found in the coding of themes. Some minor changes, in the form of added theme examples, were incorporated into the data set. No further relevant themes or categories were identified.

**RESULTS**

The emergent categories identified were: participant characteristics (used to provide the detailed description of participants), experience of stroke and rehabilitation, ideas relating to the AAA, and issues relating to interviewing people with aphasia. This paper only discusses those themes related to the category of interviewing people with aphasia. The following section presents the results under the headings of the three themes of interviewer strategies, participant strategies, and problems identified and specific sub-themes are discussed under each theme.

**Interviewer strategies**

The pilot, non-directive, minimally supportive interview resulted in very little generation of ideas by the participant:

A And the day-to-day problems that aphasia causes with your speaking, can you think of anything that the association might be able to do to help you with those?

P (wringing hands) nope (smile)  

(Paragraphs 228-229)

Interviewer strategies identified in the subsequent four interviews were coded into the four sub-themes of acknowledgement, interviewer clarification, supporting conversation, and interviewer-generated ideas. A summary of these is provided in Tables 2 and 3. The interviewer acknowledged at the start of interviews that communication problems may occur, and during interviews the researcher used strategies to ensure accurate interpretation of participant responses through clarification of words, meanings, and gestures wherever possible. However, it would be impossible and impractical to ask participants to clarify each subtle movement and facial expression, and therefore also impossible to infer accurate interpretation without visual evidence made available for scrutiny. This is particularly important as the study demonstrates that people with aphasia do sometimes use gestures to perform a demonstrative function as a supplement to speech, and at times in place of speech. In order to support conversation the interviewer made word offerings to participants, framed questions to continually probe for further information, and used strategies to maintain conversational flow. For example, words were offered when participants appeared to be having word-finding difficulties and probing was used to narrow questions down. To support the flow of conversation, participants were given plenty of time to complete their response, and acknowledgment that participant utterances had been understood was demonstrated through repetition of words and phrases used by participants. An abundance of encourager phrases such as “mmhmm” and “right” implied comprehension on the part of the researcher, and
<table>
<thead>
<tr>
<th>Interviewer strategies</th>
<th>Example from transcript</th>
</tr>
</thead>
</table>
| Acknowledgement of likely communication difficulties                                   | A. I’d just like to let you know that I’m expecting that there might be some communication difficulties that might come up with some of the questions, some might be easy to answer and some might not be as easy to answer.  
#3 (Repositioning self, nodding)  
A. If difficulties do arise during the conversation I’d like to be able to work through those with you, if I could.  
#3 (slight nodding)  
A. Is there anything you can think of that makes having a conversation easier?  
#3. No, ah, on a one-to-one situation except for slowness.  
A. Mmhm.  
#3. And difficulty in saying certain words  
A. Mmm.  
#3. Ah, I’m better at this (pointing gesture towards A) than in a group (points away)  
(Paragraphs 4–13)  

#2. (Pause). Yes um, well, I was given a- a tablet to affect which affected my ar, um …  
A. Can I offer you a word?  
#2. Yes  
(Paragraphs 543–545)  

Interviewer clarification  
– words  
#1. And that um … consoered me up and then  
A. That cheered you up?  
#1. Mmm.  
(Paragraphs 543–545)  

– meanings  
#3. Ah, they’re sympathetic but er, er (still waving hand back and forth) they are cruel.  
A. Cruel in their sympathy?  
#3. Cruel (slight shake of head) not deliberately but (raises right hand, palm facing outwards) quite unknowingly  
(Paragraphs 210–212)  

– gestures  
#4. Except I couldn’t work out (motions dialling numbers)  
A. The numbers  
#4. (opens mouth in an expression of disbelief, looking to where he had been pretending to dial)  
A. Yeah.  
(Paragraphs 139–142)
Interviewer strategies

Supporting conversation

– Word offerings (effective)

#4 Right now (hands paralleling each other, moving back and forth above table), an-an-and and con-begetive very very very on-on pet-com
A Competitive market
#4 (nod) Very very
(Paragraphs 764–766)

– Word offerings (ineffective)

P Yes at the we started a … (pointing with finger across himself to the right) golf … (eyes shut) choir … oh … tree … tree no not tree ka …
A Would it help to draw it for me? Can you draw?
P Yeah. (Pause, makes a small vertical mark on the page) Ah, I panic, that’s what I do when you speak to you or
A When you find it hard to get the words out?
P Yeah it just gets worse and worse
A Ok. Please don’t panic with me I’ve got all day (laugh)
P (Smile) tennis … er
A Was it a sport, P?
P No
A Singing?
P No um …
A Going somewhere?
P No no no (pause) Cards, cards!
(Paragraphs 233–245)

– Probing

A Can you tell me how having aphasia has affected day-to-day things for you? Like, shopping,
#4 no
A doing the banking
#4 nup (shaking head)
A It hasn’t affected those things?
#4 nup.
(Paragraphs 525–528)

– Maintaining conversational flow

#1 and I got it cut out and sewed out back up
A Mmmhmmm. So they took a chunk out?

• Giving time to respond

#1 Mmm.
A Ok
#1 Um ah (pause, looking up) and I think that’s ot. Um
A Mmmmm.
#1 Ah, that’s all
A Mmmmm.
(Paragraphs 27–33)

• Repetition

A Mmmmm. So how long ago did you have your stroke?
#3 Ah coming up four years
A Coming up four years.
agreement statements were used to confirm that the interviewer was “online” with what participants were saying. Interpretation and paraphrasing were also used to imply understanding.

During the coding process it became evident that while some of the ideas offered were independently generated by participants, others were generated by the interviewer or extrapolated from participant responses by the interviewer. These were coded as self-generated ideas and interviewer-generated ideas. Examples of interviewer-generated ideas are provided in Table 3. Self-generated ideas were initiated by participants themselves in response to broader questions or through the step-down approach to questioning. As previously discussed, there was a lack of self-generated ideas expressed by participants in response to broader questioning. The reporting of self- versus interviewer-generated ideas is essential in a qualitative paradigm that traditionally aims for limited researcher influence, and this obviously has implications for credibility of the data.

Participant strategies

Participants used gesture with related words and phrases that seemed to serve a demonstrative or emphatic function. Gesture was also used without related words or phrases, appearing to assist word finding. Gesture was used both to signal word-finding difficulty and to alert the researcher that the wrong word had been
said. Gestures in each of Kendon's predefined categories were evident. Those with implications for transcription purposes were iconic gesticulations, metaphoric gesticulations, and deictic gestures. Facial expression and language-like gesticulations were used instead of speech to fill a grammatical place. Participants also made explicit clarification requests. Examples of these are provided in Table 4.

Difficulties encountered

Participants demonstrated problems with formulating their responses, memory and fatigue as illustrated in Table 5.
<table>
<thead>
<tr>
<th>Participant strategies</th>
<th>Examples from transcript</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gesture</td>
<td>#3 I dialled the phone number (motions dialling, mimes bring a phone up to his ear) bler-bler-bler-bler. <em>(Paragraph 69)</em></td>
</tr>
<tr>
<td>– Demonstrative/emphatic (with related words)</td>
<td>*</td>
</tr>
<tr>
<td>– To assist word finding (without related words)</td>
<td>#1 um …. There’s a a (gestures around brain with left hand) there’s a comprehension in the bwain <em>(Paragraph 185)</em></td>
</tr>
<tr>
<td>– To signal word-finding difficulty</td>
<td>#1 Yeah um … the … aphasia association needs to get (fingers spread on right hand, fingertips contacting table in tapping and circular motion) six or something um … ah branches or … <em>(Paragraph 253)</em></td>
</tr>
<tr>
<td>– To indicate utterance error</td>
<td>#3 (pause) Well I’m, (points to finger on open left hand) I belong … I-I’m a (unintelligible) I belong to er, er, the-the group that Rotary sponsored for the elderly, er, er, I attended a meeting this morning (right hand extended towards A, palm upwards <em>(Paragraph 244)</em></td>
</tr>
<tr>
<td>– Iconic (Kendon, 1988)</td>
<td>#1 um … Bashically be self deficient</td>
</tr>
<tr>
<td></td>
<td>A Mmmmm.</td>
</tr>
<tr>
<td></td>
<td>#1 (Right hand positioned obliquely, moving back and forth) ah …aliases</td>
</tr>
<tr>
<td></td>
<td>A Self efficient?</td>
</tr>
<tr>
<td></td>
<td>#1 Yep</td>
</tr>
<tr>
<td></td>
<td><em>(Paragraphs 259–263)</em></td>
</tr>
<tr>
<td>– Metaphoric (Kendon, 1988)</td>
<td>#4 An-and in the where-wheelchair and he would have been I reckon he was probably three or four weeks from waips (motions lifting weights) and everything you know <em>(Paragraph 466)</em></td>
</tr>
<tr>
<td>– Deitic (Kendon, 1988)</td>
<td>#1 Um I think this one (left arm raised high) is … a top and then it’s (uses both index fingers to gesture from his ‘high’ point of reference downward in a triangular motion) um …</td>
</tr>
<tr>
<td></td>
<td>A You think it’s branching out from the top end</td>
</tr>
<tr>
<td></td>
<td>#1 Yeah</td>
</tr>
<tr>
<td></td>
<td><em>(Paragraphs 443–445)</em></td>
</tr>
<tr>
<td>– Facial expression/language-like (Kendon, 1988)</td>
<td>#1 And I (hand up to throat) I couldn’t sell … which was which … and I had their leg and arm and (gestures to left side of head) I couldn’t speak of course <em>(Paragraph 115)</em></td>
</tr>
<tr>
<td></td>
<td>#4 I’m going (opens mouth, bored expression)</td>
</tr>
<tr>
<td></td>
<td><em>(Paragraph 202)</em></td>
</tr>
<tr>
<td>Clarification requests</td>
<td>A How did you learn about it?</td>
</tr>
<tr>
<td></td>
<td>#3 How did you what?</td>
</tr>
<tr>
<td></td>
<td>A How did you learn about it?</td>
</tr>
<tr>
<td></td>
<td>#3 What?</td>
</tr>
<tr>
<td></td>
<td>A Aphasia</td>
</tr>
<tr>
<td></td>
<td><em>(Paragraphs 139–142)</em></td>
</tr>
</tbody>
</table>
As one participant stated, “The I-idea is to get cli-clarity, and that’s difficult f-with me these days, e-even my (pointing to head with right index finger) e-even inside my head” (Transcript 4, paragraphs 11–15). Aphasia is not simply an externally manifested disorder. Brumfitt (1993) discussed it as a deficit in the area of internal communication. Thus, if one has difficulty maintaining an internal dialogue, it follows that people with aphasia will find formulating and articulating complex ideas difficult. As one participant put it, “The … the very nature of the (raises right fist in front of self, moves it slightly) malady … makes it difficult to suggest … how to overcome problems. The very nature of … of the problem” (Transcript 3, Paragraph 347). It is therefore necessary to allow the person with aphasia time and opportunity to orientate themselves to a topic and their own perceptions of it.

The traditional qualitative research interviewing approach utilised with the pilot participant resulted in a short interview that yielded little relevant information in terms of understanding the perceptions of services which could be provided by the Australian Aphasia Association. In order to provide counselling to a man with severe aphasia, Cunningham (1998) needed to break certain counselling conventions by “making interpretations, which may not have been accurate … [and] directing the discussion in order to provide shape and meaning” (p. 352). To reveal the competence of people with aphasia during qualitative research, it is also necessary to adapt traditional conventions of the interviewing process. This means allowing the researcher to step in and support the conversation. In this study, gathering of information from participants was facilitated by the use of particular interviewer strategies such as acknowledgement of communication difficulties, narrowing of questions, requests for clarification of words, meanings, and gestures, the use of encouragers, and active extrapolation of ideas from participant responses. The interviewer used supporting conversation behaviours including offering words,
probing with yes/no questions, providing extended time to respond, using repetition to enhance comprehension, and paraphrasing participant responses. The use of such interviewer strategies comes relatively naturally to speech pathologists by nature of their occupation. Parr et al. (1997) stated that speech pathologists are often “appreciated … [due to] their skills in facilitating communication … [and] the fact that they seem to understand what aphasia is, and their acknowledgement of the aphasic person … [This is] met with relief, perhaps because these attributes seem rarely encountered elsewhere” (p. 80). To be able to reveal the competence of a participant with aphasia it is therefore necessary that the qualitative interviewer be experienced within the field of aphasiology or be trained as a skilled communication partner.

Participants were found to utilise significant amounts of participant strategies such as requests for clarification, and gestures and facial expressions to supplement speech and indeed at times to replace speech. Cunningham (1998) made suggestions that her participant could accept or reject. She stated that “this can be dangerous as too much can be assumed and consequently misinterpreted” (p. 347) and goes on to suggest that it highlights the importance of videotaping interactions. Videotaping the interviews in the current study was vital in terms of providing an avenue for establishing inter-rater reliability of non-verbal communication.

**CONCLUSION AND IMPLICATIONS**

This study demonstrated that there is a need for the interviewer to support the communication of participants with aphasia. The techniques used by the interviewer need to be made explicit in order for the research to maintain rigour. Accomplishing this in a rigorous fashion is no mean feat. Perhaps this is why in the past researchers have turned to proxies to gather information on the effects of aphasia. The use of proxies has been criticised, as it is difficult to separate a carer’s perceptions influencing the opinions given, as a result of their context, (Jordan & Kaiser, 1996), and turning to proxies serves to ensure that the competence of the person with aphasia remains concealed (Braunack-Mayer & Hersh, 2001). Parr and Byng (2000) suggested that excluding people with aphasia is actually a reflection of their exclusion from society. By excluding people with aphasia from research, we are reinforcing participation barriers. As participant #3 stated, “I cannot participate in the … the discussion. Because I take too long” (Paragraph 204). Other studies have confirmed that the process of simply being listened to has had a positive impact on participants (Cunningham, 1998; Ireland & Wotton, 1996). Indeed this was hinted at by participant #1: “… the sw-speechies, one of them er (two fingers of left hand on table)... encouraged me to speak like you are now” (Paragraph 155). By involving people with aphasia as informants in qualitative research, we are affirming that their opinions are valid and attainable.

The current study was limited by the small number of participants and sampling variables investigated. Further research is required to include females and to cater for the full range of aphasia severity and disorder types to investigate the effects of these variables on interviewing processes. It may also be useful to involve partners/carers during the verification of total communication strategies stage.

Strategies used when interviewing people with aphasia need to be made explicit so that studies maintain their credibility. When the researcher makes suggestions, to assist with word-finding difficulty or to extrapolate ideas from responses, explicit
reporting is the only way that a judgement can be made on potential interviewer bias. Videotaping interviews and detailed transcription was vital in this study in achieving the explicit reporting of such strategies.

REFERENCES


APPENDIX

Revised Interviewer Guide

Before we start I would like to let you know that I am expecting that some communication difficulties might come up in the interview, and I know that some of the questions might be hard to answer. If this happens, then I would like to be able to work through the difficulty with you if I could. Are there any things that I could do to help you as we go along?

Can you tell me about:

- Your health before your stroke
- Working life
- Your stroke
- Speech therapy
- Main problems after the stroke
- Do you know what aphasia is? (Explain)
- What do you know about the AAA? (Explain)
- Explain low membership numbers. Why do you think membership numbers are so low?
- What are the main problems/day-to-day problems that aphasia has caused for you?

Step – Can you tell me how having aphasia has affected your
Social life
Day-to-day activities

Step – Has aphasia caused you problems with:

- Shopping
- Driving
- Banking
- Telephone
- Reading newspaper/bills
- Talking to family and friends
- Going out
- Activities you were interested in before your stroke?

○ Probe how the AAA might be able to help with identified problems
○ If the AAA set up a local or state group for people with aphasia, what would you like it to do?

Step – would you be interested in going to a local or state group for people with aphasia? Why/why not?

○ Is there any information you would have liked about aphasia or stroke along the way?
Step – during hospital stay/now