Speech pathology services for primary progressive aphasia: Exploring an emerging area of practice

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Speech pathology services for primary progressive aphasia: Exploring an emerging area of practice

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Background: Primary progressive aphasia (PPA) is a clinical dementia syndrome characterised by the gradual dissolution of language without impairment of other cognitive domains for at least the first 2 years of illness (Mesulam, 2001). In recent years the authors had observed an increase in the number of referrals of individuals with a queried diagnosis of PPA to their speech pathology service. However, they perceived a lack of information on the best management path for these individuals.

Aims: The aim of this study was to collate information about current service provision for clients with PPA living in the Australian state of New South Wales (NSW) and their caregivers. This information would identify current referral rates and speech pathology management of this population. This information, when combined with a review of the literature and an examination of overseas service provision, would be used to develop a framework for future speech pathology service provision for progressive aphasia.

Method & Procedures: Data relating to individuals with queried or confirmed PPA was collected from speech pathologists via a survey. Speech pathology services with an adult neurological caseload were surveyed in rural and metropolitan regions across NSW. Questions asked for information relating to referral patterns, demographics, and interventions provided.

Outcomes & Results: Responses from the survey indicated that only a small number of clients with PPA are referred to speech pathologists state-wide. At facilities where individuals were referred with queried PPA, all respondent speech pathologists provided some form of intervention. All clients were assessed and various intervention types were delivered including individual therapy, group therapy, intermittent review, and client and carer education. Overwhelmingly respondents talked of an emerging field of practice, and the need for more accessible information for clinicians and people with PPA and their carers.

Conclusion: PPA appears to be an area of under-referral for speech pathologists in NSW. We would like to see increased referrals to speech pathology services and promotion of the role of the speech pathologist on dementia care teams. There is...
evidence that speech pathology intervention with this population can be effective. It is recommended that intervention targets both impairment and activity-participation levels but also we stress the importance of education and support that is specifically tailored to those with progressive language disorders.

**Keywords:** Primary progressive aphasia; Speech pathology; Language; Intervention.

The term primary progressive aphasia (PPA) was first used by Mesulam (1982). In an overview of progress in understanding PPA, Mesulam (2001, p. 425) defined this gradually worsening aphasia as a “focal dementia characterised by an isolated and gradual dissolution of language function.” Duffy (1987, modified in Chapey, 2001, p. 472) similarly defined PPA as:

… aphasia of insidious onset, gradual progression, and prolonged course, without evidence of non-language computational impairments that are shared by a common aetiology to the aphasia, and due to a degenerative condition that presumably and predominantly involves the left (language dominant) peri-sylvian region of the brain.

There is no published diagnostic test of PPA; rather, diagnosis generally follows criteria proposed by Mesulam and colleagues (Mesulam, 1982, 2001; Mesulam & Weintraub, 1992; Weintraub, Rubin & Mesulam, 1990). These criteria are (1) a minimum 2-year history of progressive language disturbance of insidious onset, (2) preservation of other mental functions (although acalculia or limb apraxia may be present), (3) independence in activities of daily living except those dependent on the person’s impaired language abilities, and (4) full neurological investigations excluding other causes of aphasia. A broad range of related disorders (including semantic dementia and primary progressive apraxia of speech) also show progressive language deterioration. There may be accompanying speech, motor, behavioural, personality, or other cognitive changes, sometimes emerging within 2 years of the initial language symptoms. Relationships between PPA and related disorders are discussed in Croot (2008, this issue).

PPA as defined by Mesulam and colleagues (see above) describes a clinical syndrome and not a disease process per se. Fluent and non-fluent varieties of PPA are observed, with the clinical picture varying depending on the distribution of the disease in brain tissue. However, despite different clinical presentations of aphasia, all individuals with PPA will have a distinct period of time, which may vary between 2 and 20 years, when they are living with an isolated aphasia and its concomitant effects on activity, participation, and well being (Duffy & Petersen, 1992; Rogers & Alarcon, 1999; Westbury & Bub, 1997). People with PPA “come to medical attention because of the onset of word finding difficulties, abnormal speech patterns and prominent spelling errors” (Mesulam, 2003, p. 1535)—a similar presentation to that of many people with acute onset aphasia who are referred for speech pathology services. There is substantial clinical similarity between individuals with acute onset aphasia and progressive aphasia, with the most important difference being the progressive nature of the latter. Further, because the criteria for a diagnosis of PPA call for relative preservation of non-language cognitive functions, learning might be well maintained by these clients. For these reasons, people with PPA would appear to be entirely appropriate candidates for intervention provided by Speech Pathologists (McNeil & Duffy, 2001).

The impetus for this research was a recent change in the referral pattern to speech pathology services in an aged care assessment and rehabilitation facility in Sydney, New South Wales, Australia. Over the previous 4 years, we had observed an increase
in the number of referrals to our service of individuals with a queried diagnosis of PPA (from less than one case per year in the first 3 of these 4 years to six cases (4.5% of caseload) in the fourth year). Although total referral numbers to the clinic were relatively small, the increase was significant—χ²1 sample (3 df) = 14.14, p = .003—and prompted several questions, including:

- Was this experience of a sharp increase in referral numbers typical?
- What was the current practice of speech pathologists with this client group?

In order to address these questions, we investigated current services to individuals with PPA by surveying speech pathologists across a range of adult healthcare settings throughout the Australian state of New South Wales. Healthcare services in Australia are administered primarily on a state-wide basis through a number of Area Health Services. New South Wales is Australia’s most populous state, with approximately 6.7 million people living in an area of around 800,000 km². The population is distributed across four geographical regions: major cities (71.4%), inner regional areas (20.6%), outer regional areas (7.3%), and remote or very remote areas (0.7%) (Australian Bureau of Statistics, 2005). A total of 13.5% of the state’s population are aged 65 years and over. We had two main reasons to expect that referrals for speech pathology services for people with PPA would be increasing in New South Wales. First, awareness of PPA as a disorder has been growing since Mesulam’s (1982) seminal report. In the 10 years before Mesulam’s 1982 paper, 2 cases were reported that fitted the criteria for PPA (Schwartz, Marin & Saffran, 1979; Warrington, 1975), whereas in the 10 years following, 57 new cases were reported (Mesulam & Weintraub, 1992). By 2001, Mesulam (2001) was able to propose that PPA may account for 20% of all dementia cases. Second, age is the most important risk factor for dementia (di Carlo, Baldereschi, Inzitari, & Amaducci, 1999), and the population of NSW is ageing as in the rest of the developed world. Henderson and Jorm (1998) reported that Australia-wide there were approximately 130,000 people with dementia in 1998, a number projected to rise to 183,000 in 2006 and 210,000 in 2011.

Our survey aimed to collect information about referral rates and current speech pathology service provision for clients with PPA and their carers living in New South Wales. Given that patients with diagnosed or queried PPA are suitable candidates for speech pathology intervention, we wanted to know whether speech pathology centres throughout New South Wales were being referred such cases, and if so, what services were being provided? We saw this as the first step towards providing improved services for these clients and their carers in the context of our state’s health services.

We will first provide details regarding the survey and its results. We will then discuss the implications for service delivery. We conclude the paper with discussion of the broader implications for clinical management of PPA.

METHOD AND PROCEDURES

We collected data regarding speech pathology and PPA using a postal survey. For the purpose of this research we used the definition of PPA first given by Mesulam (1982), and provided this in the preamble to the survey. Questions asked for information about referral patterns, demographics, and interventions provided to
patients referred with PPA or queried PPA across the specified 12-month period. All responses were anonymous. The survey questions are provided in the Appendix.

We attempted to ensure that all speech pathologists in New South Wales who were responsible for clinical management of adults with neurological disorders received a survey, by reference to lists of Speech Pathology Area Advisers/Representatives and Managers of Greater Metropolitan Sydney Speech Pathology Services in New South Wales Health. This effectively covered all Area Health Services of New South Wales. In Metropolitan areas, this generally resulted in surveys being sent direct to the relevant service provider. In rural and remote areas, managers of that area were responsible for forwarding the survey to the relevant individual speech pathologist(s). Surveys were sent to a total of 34 speech pathology sites in rural and metropolitan regions across a variety of settings including; private and public services, acute and subacute hospitals, as well as outpatient and community services.

RESULTS

The survey reply rate was 76.5%. Of the 26 surveys returned, 13 respondents were unable to provide any information as they had not been referred any patients with the disorder within the time period stated.

Client demographics

The 13 affirmative responses described 20 individual cases of PPA: 13 females and 7 males. Responses were received from metropolitan and rural areas, from acute hospital, inpatient rehabilitation, outpatient rehabilitation, domiciliary and private services.

Referral and diagnosis

Consultant neurologists were the largest referral agents to speech pathology, responsible for 50% of referrals. 35% of individuals were referred by geriatricians, 10% by their local medical officer, and one individual (5%) had self-referred.

Respondents reported that in 63% of cases their clinical reports were used by the referring specialist to confirm or discard a diagnosis of PPA. Half (50%) of clients and/or carers had been advised of their diagnosis of PPA before seeing the speech pathologist while the other 50% were unaware of their diagnosis of PPA.

Management and intervention

Figure 1 summarises the types of service delivery provided by respondents to referred PPA clients. All clients with PPA or possible PPA were provided with assessment by the speech pathologists to whom they were referred. In addition, the majority (17/20; 85%) were also provided with individual treatment. Of these, six (35%) were given more than five sessions of treatment. One person received both individual and group treatment.

The treatments described could be broadly categorised as remediation techniques focusing on the language impairment, and activities that aimed to facilitate participation. The impairment-focused remediation techniques included semantic therapy, naming therapy, word-finding strategies, fluency treatment, and nonverbal...
language-based treatments. The participation-focused activities included the teaching of total communication techniques and/or development of augmentative and alternative communication (AAC) including life books, personal portfolios, and/or communication books. Other interventions included drawing and facilitated conversation. Following individual treatment, 53% (9/17) received regular review of their language.

In addition to assessment, the majority (85%) of clients and carers were provided with education regarding the nature of PPA and language disorders. All three individuals who did not receive treatment received education. One of these individuals was referred on to another speech pathology service, and one was provided with regular review.

Current service provision: Support groups

Overwhelmingly respondents noted a lack of appropriate sources of support and information for people with PPA and their carers, and commented that no support groups were available. In particular, many remarked that current services were not adequate for this client group. One Speech Pathologist wrote, “Clients do not fit into existing support groups – either stroke support or dementia care.” Another commented, “I think support groups would be very important and wish this service was more readily available in my area.”

Current service provision: Speech pathology intervention

The feedback from the surveys gave a clear picture that speech pathologists viewed PPA as an emerging field of practice, and an area in which they felt intervention was appropriate (“We can be a great resource to this client population and their carers”)

![Figure 1. Types of service delivery provided by survey respondents to referred PPA clients.](image-url)
DISCUSSION

We have presented the results of a survey that aimed to evaluate the referral rate and service provision for people with primary progressive aphasia by all speech pathologists with an adult neurological caseload in the Australian state of New South Wales. In our discussion, we will first reflect on the referral (or lack of referral) of people with PPA to speech pathology services, before moving on to a discussion of the current and the optimal management pathways for such individuals.

Referral patterns

The centres that responded to the survey clearly considered that people with PPA are suitable to receive speech pathology intervention; however, the levels of referral were remarkably low over the specified 12-month period. In fact, several large health facilities and some regional areas had received no referrals for PPA at all. Are we able to assume that significant numbers of people in the regions surveyed are in fact living with PPA but not receiving speech Pathology services?

It is difficult to determine the precise incidence of PPA, as to date we know of no studies of incidence or prevalence of PPA specifically. Mesulam (2001) estimates PPA to account for roughly 20% of all dementias. This is within the bounds of McNeil and Duffy’s (2001) observation that one quarter of all dementias are atypical and that some proportion of these will be PPA. It is also consistent with Harvey, Roques, Fox, and Rossor’s (1996) epidemiological review suggesting that one in seven cases of early-onset dementia (onset before age 65) is likely to be associated with frontotemporal lobar degeneration, the neuropathology most commonly (but not exclusively) associated with PPA. The current incidence of dementia of all types in the Australian population is 1 per 100 (Access Economics, 2005). For the state of NSW an estimate of 1 per 100 with dementia (Access Economics, 2005) would suggest that 67,000 people in NSW have dementia and, if Mesulam’s (2001) estimate is anywhere near correct, this would suggest that perhaps 13,000 people have PPA or a kindred disorder. Yet our survey identified only 20 cases referred to the speech pathologist respondents over the 12-month survey period, in addition to the 6 cases referred to the first two authors’ speech pathology service in the same period. Even given the possibility of major sampling error in our survey, and grossly inaccurate estimates of dementia incidence and PPA incidence, these figures can only suggest that people with PPA are substantially under-referred for speech pathology services.

There is currently a growing recognition of—and evidence for—the role of the speech pathologist in the treatment of individuals with communication disorders associated with dementias—e.g., Royal College of Speech and Language Therapists (RCSLT), 2005a, 2005b. Nevertheless, it is still the case that in service delivery models where a speech pathologist is not typically a member of the dementia care team, service provision can become somewhat of a “chance” event. The results of this survey indicate there is a need to promote the role of the speech pathologist in working with people with PPA to the relevant referring agencies. Appropriate
specialists need to refer every person diagnosed with PPA for speech pathology services.

The question remains as to why our particular speech pathology service experienced a relative surge in referral numbers for PPA, which appears contrary to the experience of similar centres across the state. We can only speculate as to the reasons. One factor may have been that the local area from which referrals originate has a high number of residents from a high socio-economic, tertiary-educated background (Randwick City Council, 2007), a demographic associated with high rates of proactive health consumers (Deloitte Research, 1999) who may have sought speech pathology services even in situations where a referral for speech pathology was not routinely offered. Healthcare providers are advised to expect health consumers to be increasingly proactive as generational change occurs (Brodaty, 2006), so we should be prepared for increasing levels of interest about services for PPA from people with PPA and their carers. A second factor is that over the years the clinic has developed as a centre with some expertise in speech pathology services for communication in aged care, and referrals were made by physicians who had regularly referred to this clinic for speech pathology services.

Management pathways for PPA

The survey revealed that when clients were referred for SLP services, all centres provided assessment services, and most clients were provided with education and treatment (impairment or activity-participation based). Nevertheless, no clear single management pathway emerged and speech pathologists consistently requested further guidance on service provision for this population. It seems unlikely that this need is restricted to the clinicians of New South Wales or Australia. To the best of our knowledge there are no guidelines worldwide for the clinical management of communication in individuals with progressive aphasia. While in the United Kingdom the RCSLT’s Clinical Guidelines publication (2005a) covers a huge range of communication disorders and medical conditions that lead to such disorders, it does not specifically mention primary progressive aphasia. In the section devoted to dementia, the guidelines note that “Dementia is not necessarily a global decline in all functions. In the early stages, some areas of cognition may be relatively spared” (p. 89). The fact that language may be the only area of impairment for some years in some “atypical” dementias is not highlighted, nor are specific clinical guidelines recommended for this group.

There is, however, an RCSLT Position Paper on speech and language therapy provision for people with dementia (RCSLT, 2005b, p. 12) that notes the “crucial role” speech pathologists have in assessing language in frontotemporal dementia, progressive aphasia, language presentations of Alzheimer’s Disease, and corticobasal degeneration, especially to assist with differential diagnosis. It argues for the need to assess articulation disturbance in various neurodegenerative diseases, to monitor progression and response to pharmacological treatments, and for the potential efficacy of specific communication interventions in semantic dementia. Although this paper does not provide detailed guidelines about interventions for progressive language impairment, the important points it raises about speech pathology services for dementia in general are highly relevant for these clients.

What information is available about specific programmes for these individuals? In the United States, one group is at the forefront of the development of coherent and
systematic management pathways for individuals with PPA. Weintraub and colleagues at the Cognitive Neurology and Alzheimer’s Disease Centre, Northwestern University, Chicago, have set up a Primary Progressive Aphasia Program (CNADC PPA Program, Cognitive Neurology and Alzheimer’s Disease Centre, 2002b). This programme is a 3–4-day multidisciplinary approach to evaluation, diagnosis, and treatment of PPA. It comprises neurological, neuropsychological, language, and social work evaluation. An integral part of this programme is feedback and recommendations from the speech pathologist regarding tools for improving communication and compensating for difficulties (and referral to local therapists when appropriate). The individuals with PPA and their families also receive educational materials regarding PPA in the form of a handbook (Cognitive Neurology and Alzheimer’s Disease Centre, 2002a).

The CNADC PPA Program also provides clear recommendations for treatment (Cognitive Neurology and Alzheimer’s Disease Centre, 2002c). In particular, they suggest that direct treatment of the language impairment (particularly word retrieval disorders) should be used. Indeed, there is increasing evidence that direct impairment based treatment can benefit people with progressive language disorders (e.g., McNeil, Small, Masterson & Fossett, 1995; Schneider, Thompson & Luring, 1996, and all papers in this special issue of *Aphasiology*). For example, there is evidence that previously “lost” words can be relearned or re-accessed and that treatment can slow the rate of decline for treated items. In addition, the CNADC PPA program (Cognitive Neurology and Alzheimer’s Disease Centre, 2002c) advises that treatment focusing on the use of augmentative and alternative communication strategies (such as the use of gesture, drawing, and communication books) should be provided even in early stages. Both impairment- and participation-focused treatments are suggested to be important and appropriate, but a key point is that the relative focus of the treatment provided will change as language declines (for a lengthy discussion see Rogers, King, & Alarcon, 2000). The change in a person’s communicative ability over time emphasises the need for regular review and reassessment of the person with PPA in order to ensure that the treatment and advice is appropriate to their needs at all stages of disease progression. From the survey results, in 53% of PPA cases the speech pathologist included regular review as part of the management plan. We would suggest that, for a progressive disorder that not only impacts communication, but also may include dysphagia as a later stage symptom, regular review is a necessary component of the optimal speech pathology management plan for all PPA clients.

Support and education

The structured individual approach used by the CNADC PPA programme seems a good model for best practice. However, like the respondents in our survey, those involved in the CNADC PPA Program also perceived a need for group education and support (personal communication, Darcy Morhardt, 7 December 2005). They therefore developed a three-part education/support series. Each session was half a day in length and began with an hour of educational lectures covering topics of relevance to PPA, such as “Coping with Common Communication and Behavioral Issues”, and “Caring for the Caregiver”. Following the lectures, the attendees were divided into small support groups facilitated by social workers, psychiatrists, clinical neuropsychologists, and graduate students. These support groups were designed to offer participants an opportunity to discuss the challenges of providing care for an
individual with PPA with other families living in similar situations. At the attendees’ request, the programme has been followed by monthly support groups. A similar approach to group education and support has been adopted at other tertiary referral hospitals with large clientele with progressive aphasia. For example, the Pick’s disease support group based at the National Hospital, London (Harvey et al., 1996; Pick’s Disease Support Group, 2007) and the Cambridge Memory Clinic at Addenbrooke’s Hospital, Cambridge, UK (Nestor & Hodges, 2001) also provide support groups and newsletter support for people with progressive aphasia and their carers, and there are education and support programmes linked to major hospitals throughout North America under the umbrella of the Association for Frontotemporal Dementias (2007).

The clinical experience of two of us (Taylor and Kingma) strongly suggests that programmes developed for the carer also need to become an important component of interventions for PPA in Australia. It is clear from the literature on communication in various types of dementia that training the carers of individuals with dementia has positive benefits. For example, Ripich, Ziol, Fritsch, and Durand (1999) looked at training the partners of individuals with Alzheimer’s disease to be better communicators. Their results suggest that communication partners of persons with Alzheimer’s disease can be trained to structure questions that result in more successful communication. Benefits of partner training, both in more successful communication and reduction of anxiety and depression are further supported by qualitative studies (Greene & Monahan, 1989; Shulman & Mandel, 1988). Within the aphasia treatment literature there is also a body of evidence that supports the positive benefits of partner training (Boles & Lewis, 2003; Booth & Swabey, 1999; Hopper, Holland & Rewega, 2002; Kagan, 1998; Kagan, Black, Duchan, Simmons-Mackie, & Square, 2001; Lock et al., 2001).

As the survey had identified a particular need for support and information services for people with PPA and their carers in an Australian context, two of the authors (Taylor and Kingma) developed an education and support training programme. This programme combined elements inspired by the CNADC PPA Program and the literature on the role of training both communicative partners (described above). The initial pilot programme was conducted over three sessions, with involvement by a neurologist and social worker. There was a heavy emphasis on conversation training, as well as information on nature of the disorder, progression, treatment, support, and life-planning issues. The feedback from the attendees was extremely positive, for example the husband of a woman with PPA said, “I feel now I have a better understanding of what I can do to help my wife communicate. There’s a lot more I can do.” The service aims to run the programme regularly, continuing to refine the education and carer-training components in light of ongoing research on PPA, and on social approaches to aphasia intervention (Byng, Pound, & Parr, 2000).

A further important issue that emerged from the survey was highlighted by respondents’ reports that 50% of patients referred were unaware of their diagnosis of PPA at the time of seeing the speech pathologist at initial assessment. There are obvious difficulties in proceeding with education and management when the patient and/or carer are unaware of the diagnosis. This issue has been discussed by McNeil and Duffy (2001, p. 474) who have reported that “the hiatus in the diagnosis can delay aphasia management and general life planning”. Although it is not within the scope of this article to discuss this issue in detail, speech pathologists need to consider the impact of delay in formal diagnosis. As with all of the progressive
communication or cognitive disorders, life-planning issues will factor strongly. We need to consider when intervention to address these issues should begin.

Conclusions

The survey we report here was modest to say the least. It surveyed centres in one state of Australia, receiving 26 responses describing services for 20 clients with PPA. These limitations notwithstanding, the PPA incidence estimates (see above) would suggest that there are people living in the community with PPA who are not being referred to speech pathology services, even though there is an increasing literature that describes the benefits of intervention for this group (e.g., Croft, Nickels Laurence, & Manning, 2008 this issue). Our survey indicates that steps need to be taken to improve this situation. We would like to see increased referrals to speech pathology services and to promote the role of the speech pathologist on dementia care teams. Increasing awareness of progressive aphasia and related disorders among consultant neurologists and geriatricians, combined with an ageing population and increasingly proactive consumers will contribute to an increased referral rate over time. The preliminary goal of the survey was to stimulate dialogue among speech pathologists in New South Wales regarding service provision for people with PPA. Our aim in reporting the survey in this paper is to propagate that discussion internationally within the speech pathology profession. We hope many speech pathologists will take up the opportunity to explore optimal management and support pathways for individuals with PPA and their carers.

We end with a comment made by one speech pathologist in response to the survey, which encapsulates the issues for the speech pathology profession in its emerging role with people with primary progressive aphasia: “We need more services, more awareness and more information.”

REFERENCES


APPENDIX: SURVEY QUESTIONS

1. What type of facility do you work in (e.g., acute hospital, community health team, rehab centre, etc.)?
2. What region of NSW do you work in (area health service or geographical location)?
3. Were you referred a client with confirmed or queried primary progressive aphasia in last year (June 30 2004 – July 1 2005)?
4. If so, how many clients, in this period?
5. How many females? males?
6. Who referred the clients to the speech pathology service? (tick a box)

The tables accompanying the next four questions allow for responses regarding up to ten clients. If you are able to provide information on more than this number please record the extra data in a similar manner on the back of the questionnaire.

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7. Do you consider your clinical findings were used, by the specialist, to confirm or discard a diagnosis of PPA? How many cases did this apply to? (Please give answer as a percentage)
8. Was the patient made aware, by their medical officer, of their diagnosis of primary progressive aphasia?

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8b. If the clients was not made aware of the diagnosis, what other terms / labels were used by the medical officer to describe the condition?

9. Was the primary carer made aware, by the medical officer, of the diagnosis of primary progressive aphasia?

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10. What speech pathology service did you provide?

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<tr>
<th>Assessment</th>
<th>Client 1</th>
<th>Client 2</th>
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<th>Client 7</th>
<th>Client 8</th>
<th>Client 9</th>
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</thead>
<tbody>
<tr>
<td>Was this case referred to you as a queried (Q) or confirmed(C) case of PPA.</td>
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<table>
<thead>
<tr>
<th>Individual Treatment (1)</th>
<th>Client 1</th>
<th>Client 2</th>
<th>Client 3</th>
<th>Client 4</th>
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<tr>
<td>(&lt; 5 sessions)</td>
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<th>Group treatment session (1)</th>
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<th>Education to patient</th>
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11. If you have provided intervention to clients with PPA, could you please describe the types of intervention that were provided? (e.g., naming therapy, life books, AAC, conversation groups, etc.)
12. Do you refer PPA clients to stroke support groups or post-stroke aphasia groups?

13. Can you comment on appropriate existing support groups for patients with PPA and their carers, in your area?

14. Would you like to make any other comments about speech pathology service delivery to clients with PPA and their carers?