



# Group intervention for individuals with primary progressive aphasia and their spouses: Who comes first?



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## ABSTRACT

Primary progressive aphasia (PPA) is a neurodegenerative dementia in which language impairment is the first and most dominant symptom. There is a considerable dearth of interventions for PPA although language rehabilitation has made headway in managing the disorder. Thus far, no comprehensive services have been proposed for PPA clients and/or their spouses. This paper describes the first structured group intervention program designated exclusively for people with PPA and their caregivers. This pilot project originates from a clinical service and presents supporting evidence for initiation of a larger study to establish an evidence-based intervention for PPA. A 10-week intervention program comprised working on language activities, learning communication strategies, counselling and education. Outcome measures administered to participants and their spouses before and after the intervention were compared and showed improvements in quality of communication and coping skills in the PPA group compared to controls. Qualitative comments from all 10 participants in the active treatment group highlighted the necessity of intervention that is tailored specifically to the PPA population and addresses the needs of both individuals with PPA and their caregivers. All participants in the intervention group contributed to the study and are also co-authors of this paper.

## 1. Introduction

### 1.1. Group intervention for post-stroke aphasia

Communication and social participation are some of the most fundamental needs of every human being. Our capacity to engage in society and to develop meaningful relationships is largely dependent on intact communication skills (Parr, Byng, Gilpin, & Ireland, 1997). Language impairments negatively impact person's ability to communicate, and have detrimental influence on psycho-social well-being and quality of life (Berg et al., 2003; Code & Herman, 2003; Davidson, Worrall, & Hickson, 2003; Garcia, Barrette, & Laroche, 2000; Kagan, 1998).

Among different ways of remediating impaired communication abilities, group therapy has been established as a viable option for clients with a post-stroke language disorder, a.k.a. aphasia (e.g., Godecke et al., 2009; Kagan, Cohen-Schneider, Sherman, & Podolski, 2007; Ross, Winslow, Marchant, & Brumfitt, 2006; Brumfitt & Sheeran, 1997; Simmons-Mackie & Damico, 2009). There are numerous advantages of group therapy over more traditional individual approaches. Communication that occurs in the group context promotes not only generalization of language skills through interaction with different group members (Elman & Bernstein-Ellis, 1999; Lyon,

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1992), but also fosters psychosocial functioning and positively influences quality of life (Gaianotti, 1997; Parr et al., 1997; Ross et al., 2006; Simmons-Mackie & Damico, 1996). Group intervention was also found beneficial for families affected by mild cognitive impairment (Dyck, Hendryx, Short, Voss, & McFarlane, 2002; McFarlane, 2002) a disorder that, in its progressive nature, resembles a language disorder known as primary progressive aphasia (PPA). Group intervention offers participants knowledge, coping skills, opportunities for problem-solving experiences, and professional and peer support. It has been found to improve not only cognitive function in patients but also their management of psychiatric and neurological conditions (Rapp, Brenes, & Marsh, 2002; Senanarong et al., 2004; Willis et al., 2006). Most importantly, it leads to decreased usage of health services (Dyck, Hendryx, Short, Voss, & McFarlane, 2002; McFarlane, 2002; Rodgers et al., 2007).

Occasionally, group intervention is offered to family members and/or caregivers of people with aphasia in addition to an intense program for individuals with aphasia (Rose, Cherney, & Worrall, 2013; Rodriguez et al., 2013). Published studies emphasize the importance of providing training on communication strategies (Kagan, 1998; Simmons-Mackie, Raymer, Armstrong, Holland, & Cherney, 2010; Sorin-Peters, 2004), managing caregiver depression (King & Shade-Zeldof, 1995), and alleviating caregiver burden through setting more realistic expectations and access to other resources (Johansen-Horbach, Crone, & Wallesch, 1999). Through a systematic review of literature on training communication partners in post-stroke aphasia, Simmons-Mackie et al. established that “a skilled communication partner is able to facilitate and support the communication of people with aphasia and should be considered as a method of providing environmental support and communication access” (Simmons-Mackie et al., 2010). We wanted to extend this view to intervention for PPA. This research did not receive any financial support from funding agencies in the public, commercial, or not-for-profit sectors.

## 1.2. Background on primary progressive aphasia

While many comprehensive services are available world-wide to individuals with post-stroke aphasia, therapeutic programs offered to those with PPA are often limited to impairment-based approaches. Comprehensive functional interventions are only emerging now and are still in their early development phase (Taylor, Kingma, Croot, & Nickels, 2009; Croot, Nickels, Laurence, & Manning, 2009). Three distinct variants of PPA are recognised: (a) semantic (svPPA); (b) nonfluent/agrammatic (nfvPPA); and (c) logopenic (lvPPA) (Gorno-Tempini et al., 2011). These variants are distinguished by the state of semantics, phonology, and syntax, and show differences in fluency, and rate of connected speech.

The *semantic variant* of PPA (svPPA), a.k.a. fluent progressive aphasia or semantic dementia, is characterized by impaired naming and comprehension of word/object meaning (Hodges, Patterson, Oxbury, & Funnell, 1992; Hodges, Graham, & Patterson, 1995). Because of a significant semantic loss, the resulting language disorder is characterised by fluent and well-articulated, but progressively empty, speech, and whole word substitutions called semantic paraphasias (e.g., *tiger* → “*lion*”) (Breedin & Saffran, 1999; Neary et al., 1998; Warrington, 1975). Sentence comprehension is thought to be largely spared in svPPA (Rochon, Kavé, Cupit, Jokel & Winocur, 2004).

The *nonfluent/agrammatic variant* of PPA (nfvPPA) is characterised by preserved semantics in presence of progressive dissolution of language form (i.e., phonology) and/or syntax (i.e., grammar), (Croot, Patterson, & Hodges, 1998; Croot, Patterson, & Hodges, 1999; Mesulam & Weintraub, 1992; Watt, Jokel, & Behrmann, 1997). Errors made by people with nfvPPA consist predominantly of sound substitutions called phonemic paraphasias (e.g., *window* → “*widor*”), and may be accompanied by syntactic and/or motor speech impairments.

The *logopenic variant* of PPA (lvPPA) is a relatively new addition to the classification of PPA. It is characterised by marked anomia, impoverished (but not abnormal) syntax, decreased oral repetition of sentences, and phonological errors in spontaneous speech and naming (Gorno-Tempini et al., 2004; Gorno-Tempini et al., 2011). The evidence of successful language intervention in lvPPA has only now begun to emerge.

The initially spared hippocampal integrity in PPA (Gorno-Tempini et al., 2011), supports episodic learning and preserved autobiographical memory contributes to the learning process, (Snowden, Griffiths, & Neary, 1994; Snowden, 1999). Other cognitive skills necessary to benefit from therapy, such as ability to attend, concentrate, and rehearse are also well preserved within the first 2–5 years post-onset. For all those reasons, intervention literature suggests that individuals with mild PPA are good candidates for language rehabilitation (e.g., Jokel, Graham, Rochon, & Leonard, 2014).

The low prevalence of PPA results in treatment studies that usually involve a small number of participants. In fact, most published results were based on one to three participants (e.g., Beeson et al., 2011; Henry et al., 2008; Henry, Beeson, & Rapcsak, 2009; Jokel, Rochon, & Leonard, 2006; Jokel, Rochon, & Anderson, 2010; Senaha, Brucki & Nitrini, 2010). Thus far, five publications described group intervention in PPA. Four of them promoted pharmacological intervention with medications that had been found successful as cognitive enhancers in dementia of the Alzheimer's type (Boxer et al., 2013; Farrajota et al., 2012; Kertesz et al., 2008; Reed, Johnson, Thompson, Weintraub, & Mesulam, 2004). The only group study that offered communication skills training via behavioural treatment was published by Jokel and Anderson (2012), in which four distinct therapy approaches were tested in a group of seven patients with svPPA. Each patient received personalized therapy for naming and the aggregated data pointed to errorless learning as a therapy of choice for svPPA. Numerous other studies confirmed the benefits of impairment-based or more functional therapy for PPA (e.g., Bier

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