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## Development of a psycho-educational support program for individuals with primary progressive aphasia and their care-partners

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### Abstract

Primary progressive aphasia is a language-based dementia that initially spares other cognitive domains; however, aphasia interferes with many life roles such as work and interpersonal relationships. Psycho-educational programs, such as support groups have been shown to be effective for persons with Alzheimer's dementia; however, little is known regarding their effectiveness for persons with primary progressive aphasia. This paper describes the development of a program that offers support, education and activities for persons with primary progressive aphasia and their care-partners and its feasibility. Development and structure of pilot and formal intervention groups are described. Thematic analysis of both groups included the following themes: (1) coping with limitations and language decline; (2) dealing with increased dependency; (3) expressing resilience and making adaptations; (4) experiencing stigma (pilot group) and confronting stigma (intervention group); (5) experiencing self-confidence; and (6) feeling a sense of belonging. The knowledge gained from this process may be useful in designing programs for individuals with aphasic dementia and preserved insight. Evidence-based data from supportive interventions for persons with primary progressive aphasia and their care-partners are needed.

### Keywords

frontotemporal dementia; psychosocial support; nonpharmacological intervention; psycho-education; dementia; quality of life; Alzheimer's disease; primary progressive aphasia

### Introduction and background

Primary progressive aphasia (PPA) is a clinical dementia syndrome characterized by a disorder of spoken and written language (i.e. aphasia). The aphasia is caused by neurodegenerative brain disease (i.e. progressive) and is initially the most salient feature and

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the chief cause of daily living limitations (i.e. primary) (Mesulam, 2001). Onset typically occurs in the productive years of adulthood (age: 40–65) but later onset has also been observed. The clinical features of PPA include progressive decline in language abilities but relative sparing of other cognitive domains such as memory, attention, and visuospatial function, for many years (Gorno-Tempini et al., 2011; Mesulam, Rogalski, et al., 2014; Mesulam, Weintraub, et al., 2014). PPA is being recognized with increasing frequency; however, diagnosed individuals and their families remain underserved compared to those with typical amnesic dementias such as amnesic dementia of the Alzheimer type or stroke-induced aphasia (Riedl, Last, Danek, & Diehl-Schmid, 2014; Taylor, Kingma, Croot, & Nickels, 2009). The cognitive impairments associated with PPA interfere with successful engagement in typical life roles, such as parenting, working, and maintaining interpersonal relationships.

Due to the heterogeneity of PPA clinical profiles, particularly as they present initially, and the complex relationships with underlying pathology (Mesulam, Rogalski, et al., 2014; Mesulam, Weintraub, et al., 2014) it is not surprising that diagnosed individuals and families are often confused regarding the trajectory of PPA and what to expect. There is a variable rate of disease progression at the individual level and the underlying cause can be the result of different neuropathologic diseases. PPA can be caused by Alzheimer's disease or a number of neuropathologic entities that fall under the general rubric of frontotemporal lobar degeneration. The research criteria outline three clinical variants of PPA: (1) agrammatic, (2) semantic, and (3) logopenic (Gorno-Tempini et al., 2011); however, subsequent reports suggest that many individuals simultaneously meet criteria for more than one subtype (Mesulam, Rogalski, et al., 2014; Mesulam, Weintraub, et al., 2014; Mesulam, Wieneke, Thompson, Rogalski, & Weintraub, 2012; Sajjadi, Patterson, Arnold, Watson, & Nestor, 2012; Wicklund et al., 2014). Studies have shown that persons with PPA live between five and 20 years after diagnosis (Dickerson, 2011).

Although recognition of the diagnosis is increasing, it is still considered a rare condition and individuals living with PPA may not have the opportunity to know others with similar disease, intensifying their sense of isolation. Medina and Weintraub (2007) found that persons with PPA experience increased depression compared to persons living with Alzheimer's dementia and care-partners report great burden and stress (De Vugt et al., 2006; Riedijk et al., 2006).

There is growing evidence of the positive benefit of non-pharmacological interventions to improve quality of life for individuals diagnosed with dementia and their families (Maslow, 2012; Rogalski et al., 2016). Medical treatments continue to be limited; therefore, non-medical interventions are key to optimizing quality of life for both persons with dementia and their care partners (Brodaty & Arasaratnam, 2012).

Specifically, support groups are known to be important for improving quality of life for care-partners of individuals with a dementia diagnosis, especially in the early stages (Logsdon et al., 2010). A systematic review found that support groups reduce care-partner distress and depression (Goy, Kansagara, & Freeman, 2010). However, little is known about the utility of these groups for persons with language-based dementias such as PPA.

Persons with dementia can benefit from specialized interventions based on symptom presentation and age of onset (Morhardt et al., 2015). Diehl, Mayer, Forstl, and Kurz (2003) found that support group discussions for care-partners of persons with frontotemporal dementia tended to focus on changes in behavior, emotion and language, different from the theme of discussion in groups caring for persons with Alzheimer's dementia, where the focus revolves around changes in memory. They emphasized how families expressed an increased sense of belonging to a group where their concerns were more universally understood and validated and concluded that individuals benefit from support groups that address their situational needs. Similarly, O'Connell, Crossley, Cammer, and Morgan (2014) found that spouses in rural areas caring for persons with young onset atypical dementias benefited from specialized groups tailored to their needs and highlighted the group concept of "universality", or recognition that one is not alone (Yalom, 2005), as key to the group's success.

The PPA support and education program described here was inspired by an individual with a diagnosis of PPA, who requested to meet others with a similar diagnosis. Accounts from people with PPA suggested that a support group combined with educational sessions would be beneficial for them to learn more about the illness and to meet others experiencing similar problems. While groups for persons with early stage dementia of the Alzheimer type, or a more amnesic profile of dementia, have existed for many years; at the time we developed the program, to our knowledge, no face-to-face support group or program tailored specifically to individuals with PPA (the language profile of dementia) was in existence.

We sought to develop the early stage PPA psycho-educational support group with the following project aims: (1) to determine the feasibility of offering a psycho-educational support program for persons with PPA; and, (2) to explore the impact of a talk-based psycho-educational support program on individuals experiencing a progressive loss of language and on their care partners.

There are a number of theories and models that support a psycho-educational group approach (Lukens & McFarlane, 2004). Ecological systems theory (Bronfenbrenner, 1979) provides the framework for helping people understand and cope with their illness in relation to others. It represents the complex interaction of the physiological, behavioral, social, and environmental changes that occur when an illness strikes. Psycho-education has been shown to increase resilience to stresses, coping skills and comprehending life meaning (Landsverk & Kane, 1998) in addition to increased levels of mastery and empowerment (Hayes & Gantt, 1992). The group practice model can expand one's support network, reduce isolation and serve as a forum for recognizing and normalizing the experience of the participants as well as enhance participants' dignity and self-esteem due to the opportunity to develop tools for self-care (Penninx et al., 1999).

The groups described here include two phases: (1) a pilot phase and (2) a formal intervention phase. Both phases emphasize the ability for individuals to adapt to and gain knowledge of their condition, in this case, PPA, and a cognitive framework to better understand the illness and empower coping in the most optimal way.

## Pilot phase methods

Participants for the pilot group were recruited from the Northwestern University Cognitive Neurology and Alzheimer's Disease Center Core registry and/or by referral from the Northwestern Neurobehavior and Memory Clinic, Northwestern Medicine. Interviews were required prior to enrollment to ensure participants met the inclusion criteria described below.

### Inclusion exclusion criteria

Prior to participation, potential group participants were screened using in-person interviews. Inclusion criteria were: a diagnosis of PPA, in the early-moderate stage, as defined by clinician rating or supportive neuropsychological testing, to ensure the person with PPA had adequate language output and comprehension to participate. Although stages of PPA are not well defined, a person with PPA is considered beyond the early-to-mid stage if they exhibit:

- Inability to communicate basic thoughts effectively through speaking
- Inability to comprehend what is being said making it difficult to engage in the group process
- Frequent interruptions or disregard toward others
- Behavioral disturbance, such as impatience or low frustration tolerance
- Significant need for assistance, for example, needing help with toileting
- Persistent somnolence

The Northwestern University Institutional Review Board approved this project and written informed consent was obtained from each participant.

Group sessions were audio-recorded and observational field-note data were collected. All groups were facilitated by trained professionals with expertise in PPA – a masters' level prepared social worker, a PhD cognitive neuroscientist and the program coordinator of the PPA research study who had established relationships with participants and their care partners.

### Qualitative thematic analysis

A research assistant captured observational field notes during each session using a semi-structured format which included: number of participants, group topics discussed, group mood, group member interactions, group facilitation techniques and any special features. Observational field notes by research assistants and a post group evaluation by investigators became the basis for which we determined the impact of the group on participants.

Observational field notes by research assistants were independently reviewed by investigators for emerging themes to understand the group's impact on persons with PPA. Using thematic analysis (Braun & Clarke, 2006; Hsieh & Shannon, 2005), facilitators initially became familiar with the data by reading and rereading all field notes to generate initial codes, listen for emerging themes and define and name the themes (Pope, Ziebland, & Mays, 2000). After themes were identified, explanations were developed. In order to

increase trustworthiness of the data, a clinical faculty member not present for the support group sessions also read the field note data and independently applied codes, themes and participated in discussion with all study personnel to achieve consensus.

### Pilot phase: Session design and rationale

The inaugural pilot study, consisting of five 90-minute bi-monthly sessions (see Table 1), began with an educational lecture followed by a support group using a traditional talk-based support group model (Yale, 1995) and led by the trained facilitators. Six individuals with PPA participated: two females and four males, Age range 53–80 (mean 67.5).

During the first session, facilitators reviewed the purpose of the group and what participants might expect from each session. The facilitators also emphasized that the group milieu was their own to shape and guide and encouraged ongoing feedback on the sessions and ways to improve the program to meet their needs. Individuals were reminded that while each participant was in the early stages of PPA, they were all experiencing different symptoms and facing different challenges.

During the first session, support group guidelines such as confidentiality, turn taking, and acceptance of all points of view were discussed and members were asked to introduce themselves. They shared their names and history including their interests, and details of their careers, and families. Some described how their diagnosis affected their lives and the difficulty they have with word finding and communicating. After introductions, the schedule for the next four weeks was reviewed. This led to a discussion about members' expectations of the group and what they hoped to gain from the experience. Members expressed looking forward to the program. It was observed in this introductory meeting that in the beginning of the session, the group was quiet and composed; however, as they were given the opportunity to speak about themselves, participants became more open and talkative. One member, who had initiated the idea for the group, was especially eager to share and ask questions of others. The participants listened intently to one another and all seemed engaged in the conversation. Themes of loss were raised and the group members expressed support for one another. Overall, the most frequent reasons the participants gave for choosing to attend the group were:

1. To meet others experiencing the same difficulties
2. To learn about what "I can be doing for myself"
3. To give support to others
4. To receive support from others
5. To learn more about the diagnosis.

Sessions 2–4 were structured as a 30–45 minute presentation of a topic related to PPA followed by 45–60 minutes of facilitated discussion and support. Each of the presenters had several years of expertise in the clinical and/or research field of PPA. The second session featured a discussion led by a clinical neuropsychologist on *Understanding PPA*, which reviewed the nomenclature and clinical features, associated neuropathology and the process

of obtaining a diagnosis. A speech-language pathologist (SLP) led the third session, *Communication Tools*, and identified helpful communication strategies, with demonstrations of low-tech and hi-tech communication aids, and discussed potential benefits of speech-language therapy. A cognitive neuroscientist informed the group of the current state of *Research in PPA* during the fourth session. This session described the current understanding of the clinical, neuroanatomic, genetic and neuropathologic features of PPA as well as areas of active research and the development of new biomarkers. The session also reviewed the process of research and clinical trials and provided website resources, such as the Association for Frontotemporal Degeneration.

The perspective of the participants' family care partner regarding their family member's group participation was informally offered when picking up and dropping off the participant to the group meetings. Group facilitators were interested in hearing more in a structured format; therefore, with group participant permission, family care-partners were asked to attend the fifth and final session. The care partner group was held separately from the participant group and facilitated by an additional clinical faculty member for this purpose. The purpose of this session was to discuss the experience, whether expectations were met, and their thoughts on future groups.

## Pilot phase: Results

### Themes

During the five sessions of the pilot group, the following themes emerged:

- (1) *Coping with limitations and language decline.* Participants expressed frustration and sadness surrounding the loss of language abilities, such as “not being able to jump into the conversation” as in the past and having difficulty communicating in crowded places or to more than one person. There were expressions of difficulty coping with progressive changes, loss and feelings of sadness/depression. Group members offered each other their different coping methods to deal with these symptoms, example of which are:

Sometimes when I'm with two people at lunch – at the end – I feel like my head is going to explode – too much.

I understand it all, but I can't jump in the conversation. I avoid social situations because it's difficult to talk.

Yes, it's hard to concentrate.

Moving to a quieter part of the restaurant helps.

One member said that she tells others “I listen slow” when she needs them to slow down in speaking. Participants discussed “reversing words”, mixing up past and future tense and the use of pronouns “I” and “we”.

- (2) *Dealing with increased dependency.* There were mixed feelings regarding the increased dependency on others, particularly family members. While many in the group discussed the support of their spouses and other family members and

their advocacy and help, one individual expressed resentment that his wife “makes me talk and makes me feel stupid”.

- (3) *Experiencing stigma.* The group members used the group to discuss the challenges associated with communicating their changing needs and the experience of PPA to others. There was variability among group members’ willingness to tell their friends about their diagnosis. Some were very open with their friends; others chose to keep it private.
- (4) *Expressing resilience: Adapting and sharing compensatory strategies.* There was generous enthusiasm and sharing of helpful compensation strategies with other group members. For example, listening to audiobooks was suggested as an alternative to struggling with reading. The helpfulness of communication notebooks was discussed and members felt it was important to make one, even if they did not need to use it at the present time, understanding that they might in the future. Some participants found closing one’s eyes to concentrate to be helpful when listening to someone speaking and to make sure to turn off the radio and television when trying to have a conversation. It was suggested that it is important to “push yourself” to talk more and “use your speech, even when you don’t want to”. Members spoke about the importance of participating in research to “feel like I’m contributing.” One member expressed his feelings of hopefulness to another member “I’m going to try to talk more because of you.”
- (5) *Feeling a sense of belonging.* Participants would ask each other if they were experiencing similar symptoms and were comforted to know that they were not alone.

The fifth and final sessions allowed participants to provide feedback on the group intervention. As stated, two concurrent groups, one for persons with PPA and one for their family members were held in separate rooms to conduct these discussions. Participant questions explored their experience in the group, impact on coping with the diagnosis, and elicited feedback on the structure and content of the group and educational sessions. Family members were questioned regarding what they observed in their family member with PPA over the previous weeks.

### Participant feedback

In the final session, facilitators explored whether the six participants felt differently about their diagnosis since participating in the group. One person expressed feeling more comfortable about the diagnosis within the group and expressed gratitude for the group. A couple of members commented on how nice it was to have a place in which they could speak freely with other people who shared their diagnosis. One member shared that he was “very depressed before the group” and “intermediately depressed after the group”. Another, recognizing the reality of the progressive nature of the illness, simply stated, “My words are fading.”

When asked what they believed they had learned from the group, several members commented on the utility of the communication notebooks that the SLP had introduced to



the group. One member was so impressed with another member's communication notebook, she was motivated to make one for herself. One member described that as a result of being a part of the group, she learned what to expect as the disease progresses. Others agreed that they learned more about the future from the lectures and from one another. Learning that they are not alone was also helpful in coping with the illness.

Another member admitted that the group was good for him because it forced him to speak, which was difficult. He found that it was a place where he could "voice" this frustration and experience with the diagnosis. He said that he knew the words and they sounded normal "inside his head" but could not say the words out loud or sound normal to others, which others affirmed.

When asked about the group structure, all members agreed that 90 minutes was a good amount of time to meet. They all agreed that the communication session by the SLP was the most helpful. Members initially said that they liked the education sessions; however, a few of the members commented on how those sessions were depressing to them, providing information about what was going to happen over which they had no control. However, all agreed they would prefer to keep an education presentation component in future support meetings. Current participants were open to the idea of having their family members present during the educational sessions as well as the support group discussion rather than meeting independently. One member commented "no secrets," referring to the idea that he wanted to share the support group experience with his family member.

Participants also expressed interest in incorporating new formats into the sessions including social activities or a project with an end goal, which would provide something to look forward to and a sense of accomplishment when finished. They came up with "The Rules of PPA" which were then shared with their care-partners. This document was published in the Northwestern PPA/FTD Educational Conference Booklet (2011) and reprinted here with permission:

## **Rules of PPA**

### **By the early-stage PPA support group**

1. It's okay to just listen.
2. Difficulties with speaking, writing and reading do not begin at the same time. Some challenges are easier to deal with than others.
3. Write out notes for what you're going to say and practice it.
4. Tell other people about your condition.
5. Carry an "I have PPA card" it's good for emergencies and to quickly explain your difficulty to people. Keep a phone card with emergency numbers.
6. There are good days and bad days, don't be afraid of the bad days.
7. Speech therapy is good practice.



8. It's not the worst thing that is going to happen. It won't get better but there are people out there with other problems.
9. See a good neurologist who is knowledgeable about PPA.
10. Don't be afraid to ask for help.

In conclusion, all members thought the group was worthwhile, appreciated meeting others with the same diagnosis, felt empowered to find strategies to compensate for their limitations and changes, and expressed interest in attending a future group. Some illustrative comments appear below:

This was a great pilot program. I want to see it move forward.

I thought (the group) was very worthwhile. I strongly believe the spouses should be more involved.

I know there are people with the same diagnosis as me, which makes it easier to talk about. A sense of camaraderie.

What I liked best about the group was that there are people with the same diagnosis as me, therefore, they understood when I talked about things, I felt more at ease when discussing problems/issues.

### Care-partners

We engaged care-partners to obtain feedback on their observation of their family member over the group time period. Care-partners agreed that the largest benefit of the group was the opportunity for their family member to meet others with the same illness. Multiple care-partners stated that it was reassuring to see their family member meet others and feel a sense of belonging, which was comforting to them.

There was agreement among care-partners regarding the topics presented. Participants expressed to their family members a preference for "hands on" presentations with readily applicable tips such as the communication presentation by the SLP rather than fact-based presentations. Suggestions for future topics included addressing the social aspects of the illness such as what to do with your time, dealing with job-loss, depression, stigma, and dealing with family and friends. There was interest in developing skills for particular problems such as difficulty surrounding a favorite hobby. One family member summarized it as "how to live with PPA".

Regarding observation of changes, care-partners had little to say. One member's son stated that his mother started bringing her communication notebook to various family members to explain that she may not need it now, but that she would be using it in the future. Another family member sadly stated that she had noticed how significantly her husband's language had declined over the recent months.

Care-partners reported that the participant with PPA did not talk about the group with family members unless specifically asked. As the family members discussed the PPA diagnosis and how they themselves were coping, the feedback session began to evolve into a support group session for the care-partners. Family members indicated that they would like to attend future

educational sessions as well so they could benefit from the information, the opportunity to meet other families and to have a shared experience that they could discuss with their family member at home. Thus, there was a difference in receptiveness to the educational component of the group. The patients were more negative toward the disease education and preferred learning about hands on strategies. However, family members expressed interest in getting the facts so they could help and be more prepared for the future.

### **Pilot phase: Conclusion**

Results of this five-week pilot group for individuals diagnosed with PPA confirmed the feasibility of this intervention for persons with PPA. Feedback from the pilot phase prompted the development of a new set of sessions that offered a care-partner group in conjunction with a group for persons with PPA. However, due to the participants' insistence that they keep meeting in some capacity, three open monthly meetings for diagnosed individuals were provided during an interim period while the program facilitators developed the 5-week closed session for both care-partners and diagnosed individuals.

### **Interim group**

The group for individuals with a diagnosis of PPA continued to meet informally biweekly after the pilot phase at the request of participants. Field notes were not taken during these sessions. During this two month time period, the opportunity for participants to continue to provide and receive support was offered. Based on pilot phase feedback, activities were incorporated (e.g. creative arts: painting picture frames, decorating holiday ornaments, etc.). Facilitators noticed that the group members seemed more at ease and their speech was more fluent and natural during the activity sessions (i.e. when there was less emphasis on talking). Group members discussed recent movies and showed pictures from vacations or trips to see family members. The mood of these sessions was positive and with the group's input and collaboration, the formal intervention group was designed.

### **Formal intervention: Session design and rationale**

The aims of the formal intervention were, (1) to further describe the social, emotional and educational needs of persons with PPA and their care-partners; (2) to test the efficacy of a psycho-educational support program for both persons with PPA and their care-partners; and (3) to explore the benefits and challenges of offering this psycho-educational support program for persons with PPA and their care-partners.

Participants were recruited from the pilot group and again from the Northwestern Alzheimer's Disease Center Core registry and Neurobehavior and Memory Clinic. Interviews were required prior to enrollment, using the same inclusion criteria from the pilot phase. Written and informed consent was obtained from all participants.

Seventeen individuals participated in the formal intervention group; eight care-partners and nine persons with PPA. Five individuals returned from the pilot phase; one did not return, and four individuals were new to the group. Six care-partners were female, two male. Seven

were spouses and one was an adult daughter. There were four female persons with PPA and five male. The age range for persons with PPA was 55–82 with a mean age of 67.2.

Facilitators, with significant input from persons with PPA and their care-partners, offered bimonthly 90-minute groups for five months, facilitated by trained professionals. Groups were held twice a month over a period of 6 months. The first group of each month was a joint education and support session for both diagnosed persons and their care-partners on Tuesday evenings, which we called a “hybrid” group. The person with PPA and family met for a modified educational presentation. While the title of each session was similar to what was offered in the pilot phase, we incorporated participant feedback from that session and simplified the educational information and encouraged more dialogue rather than lecture to the participants. We also focused on practical issues families experienced such as finding meaningful activity and how the illness impacted their relationships.

Following the education portion of the group, participants split into separate discussion and support groups. The second group of the month was devoted to social activity-based groups for the diagnosed person only, on Thursday afternoons (Tables 2 and 3).

Observational field notes were again taken at the group for persons with PPA. Two education groups and support “hybrid” groups were taped and transcribed with participant permission. Thematic analysis was again used to analyze the data. This included immersion in the data; that is, listening to the audio-recordings, reading and re-reading the transcripts and field notes. Themes were then coded, compiled and organized. Coded themes were then compared and discussed among the authors with the independent review of the same clinical faculty involved in the previous data analysis.

## Activity group

During the first activity session of the formal intervention activity group, participants sampled “brain games” provided by *Marbles: The Brain Store*. Games that did not rely on written or spoken language were specifically chosen to engage participants. MindWare® Dizios, a dominoes type game, was one the participants particularly enjoyed. Using brightly colored tiles, players matched up edges to earn points. Some participants had difficulty comprehending the rules of the game; however, this did not deter them as they began to make their own rules to work together as a team. At one point, one of the participants helped out another with a specific piece of the puzzle and when it was put in place everyone cheered.

A teaching artist, from a local theatre, led the participants through improvisational acting exercises for the second session. These exercises were adapted from work with the Memory Ensemble, an improvisational theatre program offered for persons with early dementia (Morhardt, O’Hara, & Dunford, 2012). Adaptations to the exercises were made to rely less on verbal skills and focus more on non-verbal methods of communication, such as sculpting emotions, mirroring, and acting out a story without words.

The third and fourth sessions were led by creative arts therapists (Figure 1). Studies show that arts-based activities have a positive impact on cognitive processes and creative

engagement (Young, Camic, & Tischler, 2016). The third session focused on the creation of individual collages allowing participants to identify pictures and words from magazines that represented their thoughts and feelings regarding the changes they were experiencing. Participants were asked to bring in a picture from home, which was glued on thick posterboard and further decorated with fabrics, magazine pictures/words, and stickers. Most participants brought in a picture of a family member, and expressed pride in what they created. One participant brought in a picture of his nephews, which he decorated with heart stickers. Repeating the word “amazing”, he became tearful when he showed his collage to the group. Another participant, a quilter, brought in fabric swatches and made a poster that looked like a quilt. The fourth session introduced watercolor painting. The artist presented canvases in which she had pre-sketched a mountain scene. The participants were then encouraged to use whatever colors they wanted for the canvas. While participants were engaged in both of these creative arts projects, it was noted how verbal communication seemed more spontaneous and less effortful when the session was focused on the completion of an activity where they were able to create and communicate non-verbally compared to a traditional support group session where the focus was producing speech.

Finally, the fifth and last activity session included a horticultural therapist who engaged the participants in garden and plant based activities. Horticultural therapy (HT) is a practice that has demonstrated therapeutic benefits in rehabilitative care for over 200 years with a variety of populations and settings (Simson & Straus, 2003). The horticultural therapist provided several types of pressed leaves and flower petals. The participants glued the materials to stationary or blank notecards, creating a finished product that could be given as a gift to a loved one. Again, as in the creative arts groups, verbal communication seemed more natural and less effortful.

## Education and support “hybrid” group

The education and support “hybrid” group sessions consisted of a blend of education and talk-based therapy. The first session created an opportunity for persons with PPA and their care-partners to become acquainted or re-acquainted with each other. The first 45 minutes were devoted to an education program with all participants followed by 45 minutes of separate support groups, one for diagnosed persons and another for care-partners. This group’s educational presentation on PPA was significantly simplified per feedback from the pilot study as was the group focused on PPA research. The most well received educational presentation was delivered by the SLP discussing communication skills, demonstrating augmentative devices and ways individuals and their care partners could engage in meaningful activities. The final session was devoted to a discussion regarding what the participants felt they had gained and recommendations for future group programs.

## Formal intervention: Results

### Themes

Themes that emerged from observational field notes and group transcriptions from the formal intervention sessions for persons with PPA were similar to the pilot phase, with some modifications and additions. They are (1) coping with limitations and language decline; (2)

expressing resilience: making adaptations and sharing compensatory strategies; (3) confronting stigma; (4) experiencing self-confidence; and (5) feeling a sense of belonging. The experience of care-partners was not documented in the same detail and therefore, not reported here.

1. *Coping with limitations and language decline.* Again, group participants with PPA readily expressed how they were coping with their progressive language problems and shared their difficulty: For example, “*This is hard, you know? It’s hard. Sometimes it’s ok, Sometimes it’s good. Sometimes it’s not good. It’s hard.*” Another expressed, “*It’s getting worse every week. The language....*” and another described the changes, “*In church it’s hard for me to do it (read prayers and words to songs). Sometimes it’s easy but now I’m silent because it’s hard to do.*” Another participant related to this stating, “*I don’t read the prayers either because it’s too fast.*”
2. *Expressing resilience: making adaptations and sharing compensatory strategies.* In spite of the many challenges faced, participants consistently expressed ways they are adapting to changes and readily shared their strategies of what was working for them. For example, in the formal intervention group, participants stated:

Non-verbal strategies:

I like to sit next to other people that like to talk so I don’t have to talk as much.

I find it easier when I can just relax and just listen. It’s OK to listen.

Have a PPA card. Good to use in emergencies.

Relying on helpful others:

Ask people to repeat questions so you have time to think about the answer. Have people repeat what they are saying.

My family knows I have PPA and they try to say some stuff and they wait for me to express myself. They will talk slower.

If I talk about something and my wife said something, I try to do the stuff. I take 2–3 seconds and if I can’t do it, she tries to help out. If I’m trying to talk about something and it’s hard for me to think about the word and people are trying to help, I tell them to stop and give me a few seconds. If they give me a few seconds, I can try to get it.

There is no problem with having people help you out. I like when they help out.

My wife and I might go through 12 different words, but it’s better than nothing.

Tell other people. I find it much easier for people to know. I was talking over the holidays with a friend who lives in Florida and after 5 minutes, he asked, “Are you OK?” and I told him.

I thought, ‘this is really stupid – just tell him’ and it’s OK.

Planning ahead:

I write down points that I wanted to speak about. I had to plan out what I was going to say. It's still hard, but it works (when talking on the phone).

Use a pre-printed list so you can check it off (for grocery shopping).

Write things down; practice what you want to say.

- (3) *Confronting stigma.* In comparison to the pilot phase, the group was less tentative telling others their diagnosis and expressed a sense of empowerment, especially for those who had participated in the pilot phase. One woman told her story of a humiliating experience in a department store,

You can't answer quickly because I was at the store and she said, 'Do you want these?' and I said, 'No,' but I changed my mind because I can't say 'yes' and she was very rude to me. She was in a hurry so she was very impatient because she was waiting on another person. I should've pulled out the card (I have PPA). I carry it in my wallet.

- (4) *Experiencing self-confidence.* Related to the theme of confronting stigma, rather than being inhibited by it, there was an overall expression of self-efficacy and appreciation for the opportunity the group provided to engage in a social situation; however, challenging. They felt they were helped to use their remaining verbal skills in a place where they felt they ultimately benefited. For example one individual with PPA (articulated with help of spouse):

When leaving the day group, after the activity, I feel a sense of accomplishment that made me feel good about myself. I am taken out of my comfort zone, but in the end it is a positive experience.

- (5) *Feeling a sense of belonging.* While everyone expressed gratefulness for the group process and recognition of the benefit to be with others experiencing the same challenges, there was also unanimity for the group to have been available at an earlier time to have helped their coping over a longer period of time.

After being diagnosed, if I had a group like this, it would have helped (everyone in group agrees). I wish I had someone to talk to in the beginning. It's easier after you get over that hump.

Feedback on the type of group they preferred, the majority of participants requested more discussion among themselves and less presentation. The persons with PPA particularly liked the activity group over the discussion group. The session with the SLP was particularly valued over the information and research on PPA.

## Discussion

Results suggest that offering psycho-educational (support, education, and activity) programs for persons with PPA and their care-partners is a feasible endeavor and valued by the group members. Persons with PPA particularly appreciated opportunities to engage socially while also meeting others with the same difficulty with whom they could discuss their shared experiences and feel a sense of confidence and empowerment as a result. While all

participants in this project generally desired more support than didactic sessions, both were requested in the end as they felt that the education was extremely important. The most appreciated education session was the presentation and discussion with the speech language pathologist who discussed interventions to help maintain and enhance communication to support active participation in daily activity. These practical strategies provided a sense of hopefulness to persons with PPA, in direct contrast to the challenges they experience with the decline in verbal functioning. SLPs are trained to provide compensatory strategies in addition to effective communication for persons with PPA and their families (Khayum, Wieneke, Rogalski, Robinson, & O'Hara, 2012). This individualized approach to tailoring strategies based on remaining strengths is recommended practice for adults with all forms of neurodegenerative disease (Fried-Oken, Mooney, & Peters, 2015).

Results indicate these support and education groups were valued by participants and contributed to a sense of wellbeing and quality of life. This is consistent with a recent integrative review of the benefits of support groups for persons with mild cognitive impairment and early dementia (Jao, Epps, McDermott, Rose, & Specht, 2016) where authors found that the groups were well accepted by participants (and care partners) who experienced a positive impact on participant acceptance of cognitive impairment, satisfaction with meaningful activity, and resilience.

Due to the obvious nature of progressive language impairment, reliance on talk-based groups has its limitations; however, we found that individuals in the early stages of the illness were able to identify ways of connecting with others with similar symptoms and communicate a sense of “universality” (Yalom, 2005) and sense of belonging as a benefit of the support group experience. The merits of focusing on social and creative arts based activities as a method to engage persons with PPA and to promote nonverbal communication opportunities was also demonstrated.

There is a dearth of research documenting the experience of persons living with PPA or other non-amnesic dementias. There is also very little documenting the experience of the care-partner. Further investigation is needed on the relational issues that impact the person with PPA and their care-partners. How are relationships impacted by the loss of language different from and similar to those with more memory-based impairments or other affected cognitive domains? Ultimately, an increased understanding would allow for more tailored approaches in the care for persons with dementia, their care-partners and families.

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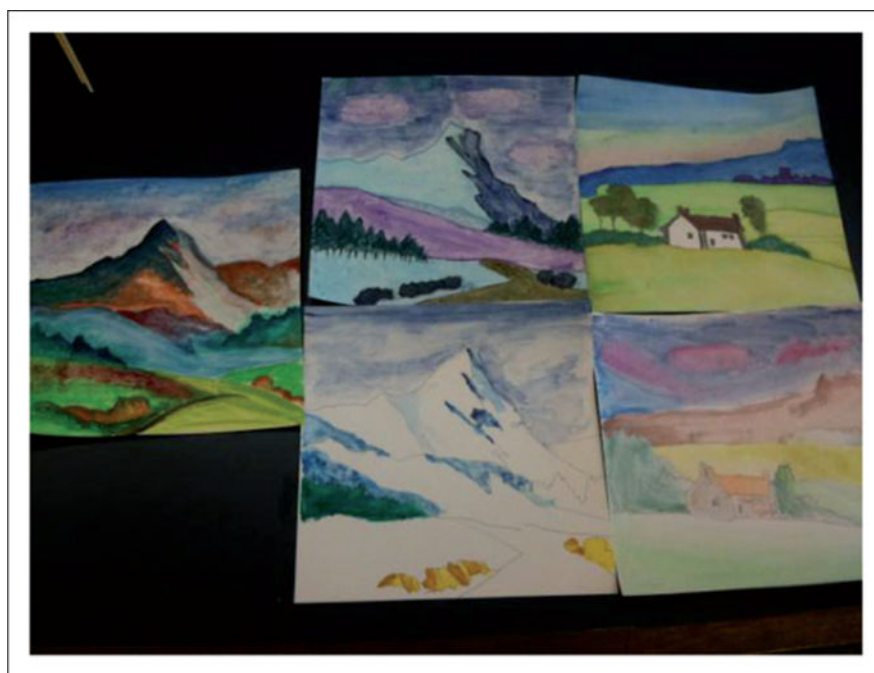
**Emily J Rogalski**, PhD, is a clinical neuroscientist, Associate Professor and Director of Neuroscience at Northwestern University's Cognitive Neurology and Alzheimer's Disease Center. Her research falls under the broad umbrella of aging and dementia and uses a multimodal approach to investigate two aging perspectives: primary progressive aphasia (PPA) in which neurodegenerative disease invades the language network and SuperAging in which individuals are seemingly resistant to the deleterious changes in memory associated with 'normal' or more typical cognitive aging.

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**Figure 1.**  
Art by persons with PPA: The third and fourth sessions.  
PPA: primary progressive aphasia.

**Table 1**

Pilot phase: PPA education and support group.

Session	Topics
(1)	Introduction to the Group
(2)	Understanding PPA
(3)	Alternative Communication Strategies for PPA
(4)	PPA Research
(5)	Group Feedback Session

PPA: primary progressive aphasia.

**Table 2**

Formal intervention: PPA education and support evening “hybrid” group.

Educational Topics for the Evening “Hybrid” Support Group	
(1)	Introduction to PPA Group
(2)	Overview of PPA
(3)	PPA Research (made simple)
(4)	How to Live with PPA: What Helps?
(5)	Evaluations and Group Wrap-Up

PPA: primary progressive aphasia.

**Table 3**

Formal intervention: PPA education and support “activity” group.

Social Activity Groups
(1) Brain exercises and board-games
(2) Improvisational exercises led by Memory Ensemble teaching artist
(3) Art Group – Collage led by teaching artist
(4) Art Group – Watercolor painting led by teaching artist
(5) Horticultural Therapy – led by a trained therapist

PPA: primary progressive aphasia.