Learning about Aphasia through Experience: Descriptions of an Interdisciplinary Patient-Centered Seminar

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Abstract
People with aphasia (PWA) have an insider’s perspective that can help educate and motivate students during their clinical training (Parr, 2001; Purves, Petersen, & Puurveen, 2013). Being involved in educating students through life experiences can also benefit PWA. In this article we describe a program wherein three PWA shared their experiences with first year graduate students in physical therapy, occupational therapy, and speech pathology. The process of preparing, organizing, and executing the program is outlined. One PWA adds his personal insight by describing his participation in the program using his own words. A student leader of the program also adds his perception of the benefits of the program. Reflections of the lessons learned through the program from these two perspectives are also presented. This program presents an example of how partnering with PWA for campus and community education can benefit learners and PWA alike.

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Learning Objectives
1) Describe how people with aphasia can participate in teaching and training students.  
2) Discuss the benefit that people with aphasia can receive when they share their rehabilitative experiences.  
3) Explain how interdisciplinary students can come together to learn about aphasia in a university setting.

One unexpected advantage of speech-language pathology is the opportunity to not only apply knowledge and skills to serve others, but also learn from those we serve. I (e.g., the first author) remember experiencing a paradigm shift while working with my first client with aphasia as a graduate student. I had previously thought that I needed to be in complete control of the sessions and use every moment to do what I thought were “meaningful” activities. Up until that point, however, I had shown little regard for what my client thought was meaningful. This all changed when I decided to spend an entire session conducting an ethnographic interview (Simmons-Mackie & Damico, 1999; Westby, Burda, & Mehta, 2003).
During the interview, I discovered things about my client that went beyond his speech and language abilities. I gained insights into how to make therapy tasks functional. I was inspired by his persistence and resilience. Learning about his life experiences changed the way I viewed him.

We suddenly stood on equal ground and journeyed through speech and language rehabilitation together—as partners. Discovering the life experiences of those we serve can be a powerful catalyst for equalized relationships (Purves et al., 2013).

Drawing on the power of life experiences, the first and third authors created a program that would allow people with aphasia (PWA) to come to the campus of the University of North Carolina at Chapel Hill (UNC-CH) and share their experiences with first year students in occupational therapy, physical therapy, and speech-language pathology. Our belief was that PWA are, indeed, the experts and can participate in educating students through their unique and valuable insider’s perspective (Brown, Worrall, Davidson, & Howe, 2012; Parr, 2001; Purves et al., 2013). The purpose of this article is to delineate the process and describe the benefits of this interdisciplinary, patient-centered education program. We will do so from the perspective of (1) a program leader (i.e., the first author) and (2) a partner with aphasia (the second author). The perspectives of the PWA partner will be interspersed throughout the article (marked by italics). In order to maintain organization and avoid ambiguity, the body of the article is written from the perspective of the program leader who will quote the first-person perspective of the partner with aphasia throughout. The PWA perspective is provided in the second author’s own words. Minor edits for punctuation and grammar have been made to these comments. In two instances, we changed wording of a sentence for clarification; however, this was done in collaboration with the second author to not distort the communicative intent.

Description of Program

Program Commencement

Overview About a year ago, the first and third authors discussed the possibility of bringing people with aphasia to campus to interact with students. The Carolina Center for Public Service at UNC-CH offers a community engagement fellowship to graduate students who are interested in doing work in collaboration with community partners.Securing this fellowship allowed us to bring this idea to fruition. The vision was to establish a mentoring experience between PWA and clinical graduate students in rehabilitation sciences that would be mutually beneficial. The program revolved around the personal experiences of PWA. We thought that such a program would improve participation and quality of life for PWA and provide students with direct patient contact and interdisciplinary educational experiences at an early stage in their training. A central part of this program was the PWA sharing their “stroke story”.

An example of one of these stories follows.

On a Sunday night in January 2013 I was exercising and enjoying playing hockey with friends. I was a 46-year-old man and have played hockey since I was 5 years old. When I finished the game, I went home to prepare to travel to Arizona the next day for work and then went to bed. In the middle of the night, I woke up and suffered a massive stroke on the left side of my brain caused by a hit to my throat by a hockey stick the night before. I didn’t know what was happening to me until I arrived at the hospital a few hours later. I did not have access to tPA medication because of the time that passed since I was hit. In addition to not being able to move the right side of my body, I couldn’t talk. I could speak but nothing was coming out except for saying [unintelligible jargon] to everyone day after day. I was devastated, I could deal with my arm and leg being injured and getting back to normal in time—which has taken a lot longer than I ever would have imagined but it will be back—but not being able to talk when the words were at my lips was awful. I wanted my words back right away.

Currently, I talk pretty fluently, but I need to slow down my speech a lot. I also forget certain words that I would like to use in a conversation and I need to [unintelligible jargon] synonym and then go back to the actual conversation on my own. When tested, I have been told I have almost normal performance of my language. I was tested 8 months after my stroke and scored 93.1 on the Western Aphasia Battery Test.
We felt that personal accounts like this one would help color the book-based learning that students undertake during their first year of graduate school. We also thought that providing PWA an opportunity to tell their story to a friendly, supportive, and interested audience would be, in and of itself, therapeutic.

**Collaborative Team** Prior to initiating the program, we formed an interdisciplinary team to provide leadership from disciplines that are often involved in the rehabilitative care of PWA. Our team included one student from speech, occupational, and physical therapy. These students became the project leaders. Working as an interdisciplinary team to organize, develop and execute this program strengthened the project. Each of us brought differing perspectives that enriched the program at each stage. As a team, we fostered relationships with the UNC-CH Department of Allied Health Sciences and our community partner, Triangle Aphasia Project, Unlimited (TAP; [http://www.aphasiaproject.org](http://www.aphasiaproject.org)). These relationships were vital to the program’s success.

Within the UNC-CH Department of Allied Health Sciences we relied heavily on administrative assistants and faculty members. Secretaries assisted with scheduling. They also helped us communicate with over 90 first-year therapy students as we prepared for the program. Department faculty members assisted us by encouraging and incentivizing student participation in the program.

In addition to our connections within the University, our relationship with TAP was also crucial. TAP is a nonprofit organization based out of Cary, NC that offers group therapy for PWA within the framework of the life participation approach to aphasia (LPAA; Chapey et al., 2000). From the conceptualization of this project, the director and volunteers of TAP were helpful and supportive. Being connected with TAP helped us reach out to many people with aphasia and receive their feedback about the project. Before officially recruiting participants, the project leaders went to TAP communication groups to speak with PWA about the project and receive their feedback. From these sessions we learned that many TAP members were interested in interacting with students, sharing their stories, and answering student questions. The obstacle for many, however, was coming to campus due to transportation, parking, and mobility limitations. In the future, we would like to bring groups of students to the TAP central office so more PWA could participate in the program. For the first year of the program, however, we decided to find PWA who could come to campus to facilitate as much student participation as possible.

With all logistical aspects of the project completed, we were ready to begin recruiting participants. With the help of TAP, we identified three PWA to participate in the program. We considered these PWA our partners in educating students about aphasia through personal life-experiences. We strived to reflect the ideology that we hoped to pass on to student participants in the program, namely that PWA and therapists should share an equalized relationship. The second author was one of these partners. He described his anticipation for participating in the program and interacting with students.

I used to speak quite a bit for my job. I am a sales and marketing executive and got up and spoke for large and small groups every day. I had to get my words back. I started my speech therapy at the hospital right away. When I finally regained some my ability to speak and read after several months of speech therapy I wanted to practice my speech in a friendly environment to a group of people who would understand what I have been through. I was given a format to talk about my story to a small group of students in a class environment, which was great. Six months after my stroke I spoke to 100 family members and friends at my mother’s funeral. That was so difficult for me to do and was so emotional. At that point, I realized I have to speak more and get more comfortable with my words in a friendly environment. I used every opportunity to speak in front of people. I set speech goals for myself every week and every month. Talking to a class of students was what I needed to gain back my confidence to speak in front of people I did not know.

**Program Implementation**

We envisioned a program that would be mutually beneficial for first year therapy students and PWA. PWA would be placed as experts (Purves et al., 2013) and provided with opportunities to share their *insider’s perspective* (Parr, 2001). We anticipated that this meaningful communicative experience had the
potential to increase their communicative confidence and participation.

We found that in order to take full advantage of their interactions with PWA, students should learn some basic strategies to support communication. TAP volunteers were experienced at educating businesses and organizations throughout the community about aphasia. We, therefore, solicited help from TAP to educate students about aphasia and provide training about how to support communication prior to patient interactions.

The end result was a three seminar series, which is outlined below. One seminar was provided weekly with each session lasting 50 minutes. The principle presenter of the first session was a speech-language pathologist that leads groups at TAP. The final two sessions featured the three PWA volunteers.

“Learn to Speak Aphasia”: Session 1. In the first session a volunteer group leader from TAP gave a presentation to students about aphasia and supporting communication for individuals with aphasia. During this session, the group leader began by defining aphasia, explaining common consequences of aphasia, and discussing the rehabilitation process. The volunteer also introduced concrete strategies for successful communication with PWA, which were based on principles from Supported Conversation for Adults with Aphasia (SCA; Kagan, Black, Duchan, Simmons-Mackie, & Square, 2001). Specific strategies addressed included: (1) recognizing that PWA are competent despite their language deficits, (2) verifying information received during conversation with PWA, (3) allowing PWA adequate time to communicate their message, and (4) providing tools to support communication. Students were made aware of the support that gesture, writing, and drawing can provide to PWA and were encouraged to have paper and pencils available during their interactions. In addition, alternative and augmentative communication (ACC) was mentioned briefly and students were shown an example of an AAC binder used at TAP containing laminated alphabet sheets, number sheets, maps, and other pictures.

“I realized right away that I had to prepare for talking in front of people much more than I did before my stroke. I needed to put a summary together about what I wanted to say. From there, I could put some slides together in presentation format. I then needed to sit on it for a day to get my thoughts together. After this I could finish the presentation once and for all. It took a lot more time than I thought, but it was worth it. It helped me get my confidence back. I needed to keep practicing again and again. I needed to practice the speed of my speech so that I could articulate my words and get the right tone in my speech. I had to slow my speech down every time. I started to practice with water beside me so that I could purposely slow down my speech by taking a drink. It also helped me when I got nervous. I was used to talking in front of people before my stroke but now I had to make sure that I remembered the words I was saying. It scared me a little bit that I would possibly forget what I was saying, so I needed to practice all the time.

“Stroke Stories”: Session 2. In the second session our three PWA partners came to campus to share their story with students. These PWA had each prepared a ten-minute presentation that gave a brief history of their stroke and rehabilitation experiences. Prior to this session the student leaders met with the three PWA for a practice session. Each of the PWA practiced telling their story and received feedback from the other PWA and student leaders. They were not given specific instructions about what to include beyond the direction to tell about their stroke or injury and the rehabilitation process. They were also encouraged to include psychosocial aspects of their experience with the students. During the session, each PWA was given a brief introduction by one of the student leaders and then spoke to the entire group of therapy students.

“Question-and-Answer”: Session 3. The third and final seminar was a question and answer session. Small groups of ten to twelve students met with one of the PWA to ask questions. A combination of physical, occupational, and speech therapy students were in each group. The groups were divided into three small classrooms. One student leader facilitated the discussion in each room. This was a unique opportunity for students to learn what they wanted to know about coping with aphasia as it related to their field. They interacted directly with individuals who had experienced living with aphasia. This session also provided students with an opportunity to learn more
about the thoughts and culture of each of the three disciplines represented.

Talking in front of students who were studying to help people with aphasia was amazing. Looking into their eyes and anticipating what questions they would ask excited me and made me feel at ease with my speech. It also helped me get quicker with my responses to questions. Some of their questions surprised me. They were mainly textbook questions and lacked real life experiences, which I’m sure, will come with time. It brought me back to a youthful time in my life when I would look forward to learning every day. They wanted to know why things were happening to me—not just because that’s what happens when you have a stroke—but to really understand why. They asked me so many questions about what I did the days after my stroke. They really made me feel at ease with aphasia.

Maintaining Relationships After the seminar series was complete, the program leaders met with the three PWA. Two caregivers were also present. Together, we held a focus group to review the experience and receive feedback.

The PWA who partnered with us in this project were truly inspiring. We were able to build relationships with them that have extended beyond the program itself. Each of them continues to be involved in the work on campus (i.e., teaching and/or research) in various ways. For example, two have participated as case-studies in a treatment plan assignment for SLP students, two have agreed to participate in emerging research projects, and one has come to campus to share his story with undergraduate students. While I am confident that their involvement benefited students, I believe that it also opened the door to opportunities that they would not have had otherwise. PWA should be viewed as our partners. They have much to share with therapists and students alike. They have been educated through their experiences and can provide insight that can supplement book learning and inspire improved professional service. In addition, having opportunities to share their life experiences can benefit them.

Since I first spoke to an audience, I have been fortunate enough to have additional speaking engagements. I have gotten better with my speaking every time. Participating in this program allowed me to increase my opportunities to speak. Since the time of the program, I have spoken to undergraduate students as well as the graduate students I originally spoke to. I am looking for other speaking engagement throughout the US and my homeland—Canada. I really want to help future therapists know what it’s like dealing with people who have had aphasia. I also want to help stroke survivors know that you can get past aphasia if you work on it and don’t become isolated in your home. You have to get out. You have to talk to people.

Reflection
Organizing a program wherein we partnered with PWA to educate interdisciplinary students about aphasia was rewarding and instructive. Among the many lessons I learned were those about community engagement, aphasia advocacy and education, and the value of learning from life experiences of PWA.

Community Engagement
This program was an example of community-engaged scholarship. In partnership with TAP we addressed participation needs of PWA, while simultaneously educating students and collecting outcome data. This merging of service, teaching, and research is at the core of the scholarship of engagement (Boyer, 1996). By organizing this program I realized that there are many practical needs that can be met through this integrated approach. Teaching, research, and service do not need to be exclusive but can, in reality, be integrated. With that said, I also learned that the integration of research, teaching, and service takes significant time and planning. When more parties are involved, more time must be dedicated to planning and idea exchange. Although this requires time, it can also enhance the overall effectiveness of the project and ultimately save time during execution because the team shares responsibilities. Community-engaged scholarship is well worth the effort required.
Aphasia Advocacy and Education
In addition to the scholarship of engagement, I learned important lessons about aphasia advocacy and education. During the first session, the students were asked to raise their hand if they knew what aphasia was. Only about one-fourth of the future therapists in the audience raised their hand. They were then asked to raise their hand if they had ever met someone with aphasia. Only two of the approximately fifty first-year therapy students in attendance raised their hand.

After the question and answer session, one of the PWA partners told me about a student who—while speaking with him—realized that her grandfather, who had suffered a stroke years previously, had aphasia. It was not until she had learned about aphasia through the lens of a PWA that she was able to connect the word “aphasia” to her own personal and family experience. The need for clinicians, academicians, and PWA to unite their voices in education about aphasia is great. Involving PWA in our endeavors to educate students is one way to augment this effort.

Learning by Experience
This program incorporated two forms of learning based on experience. First, students and PWA learned by experiencing interaction with one another through a question-and-answer session. Second, students learned about aphasia through the life-experiences of PWA. This approach seemed beneficial to all parties involved as evidenced by the second author’s following comment.

I have gotten used to learning every day and I love that feeling of getting better every day. I have been a proponent of getting people with aphasia out and about to live their lives like they did before they had a brain injury. Having people with aphasia speak in a friendly environment, with a purpose, talking about what they love—talking about their family or talking about the work they once did prior to having a brain injury—is so important. Get them excited about talking even if they’re struggling at first. Set goals to improve and work on them every day. Make the environment comfortable for them to struggle at will. Give them a chance to find their words and let them speak again at their own pace.

Learning from the life experiences of PWA can increase understanding, empathy, and motivation. As indicated by recent literature, there is much to learn about living with aphasia (Brown et al., 2012). Involving a PWA can springboard students’ process of learning about aphasia from the beginning of their academic and clinical training.

Conclusion
A seminar series to educate first year therapy students about aphasia was meaningful and beneficial for both a program leader and a PWA partner. Furthermore, this is a program that could easily be replicated to promote student interaction with PWA or others living with disability. We have delineated the steps taken to initiate, plan, organize, and execute this three-week seminar. We have supplemented this description with reflections from a PWA partner and a program leader. It is our hope that the process outlined herein as well as the personal perspective and insight of one of the PWA partners will motivate others to find simple and meaningful ways to involve those living with communication disorders in the education of students and community members. We also submit that the power of personal life experiences should not be diminished but rather harnessed for the education and motivation of students as well as the benefit of individuals with communication disorders. As we partner with these people in teaching and training students, I am confident that we will continue to appreciate the mutual benefit of such relationships.

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