Aphasia intervention: Are we missing the forest for the trees?

Making human communication a human right, accessible and achievable for all. (American Speech-Language-Hearing Association, 2014)

How successful are clinical speech-language pathologists in making human communication a human right, accessible and achievable for people with aphasia? If our recent experience is any indication, this goal is being missed, often by a wide margin.

As a community-based aphasia program, we serve people with aphasia (PWA) at varying times post-onset. Some clients come to us with little to no prior aphasia treatment. Others arrive with many months, or even years, of prior treatment. Some of our clients have limited financial resources. Others have enrolled in a number of different aphasia treatment programs.

What these clients appear to have in common, especially those who are living with a moderateto-severe aphasia, is that they often arrive at our doors with little or no ability to communicate, even their basic wants and needs. When communication breakdown occurs, we are seeing more and more PWA without sufficient strategies or supports to communicate even the most basic information.

These PWA have not learned functional communication strategies. Most do not possess even a "low tech" individualized communication system, such as a communication book. Their family members or other significant others have not been provided with partner training or education in using effective communication strategies. For these people living with aphasia, they do not currently possess the human right of communication. They have been disenfranchised by their aphasia and our healthcare services have not been successful in helping them regain this fundamental human right.

Preliminary findings from a survey of aphasia center participants regarding the education, training, and communication support that PWA and family members have previously received in acute rehabilitative, home health, and outpatient settings support our observations. Final results of this survey will be shared as part of this paper.

A main goal of the present paper is to discuss some possible reasons that our current system may be faltering as well as to suggest some possible remedies. I believe that those of us attending this conference can take actions that will make a real difference in providing the human right of communication to people living with aphasia.

Some possible reasons our current system has faltered:

1). Clinicians are overwhelmed and overloaded with information. As the majority of clinicians are generalists, many may find it challenging to stay informed about all disorders.

2). Graduate coursework and textbooks are expanding in length and detail over time, making it challenging for students and clinicians to discover the most salient information.

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3). Many people with aphasia are receiving fewer authorized sessions of treatment (Elman & Bernstein-Ellis, 1995), and clinicians are being forced to do more with less. In addition, patients may be more acute and there may be more focus on dysphagia or other medical issues in the period immediately following stroke.

4). Clinicians may not be able to communicate a good rationale regarding the need to establish a system of supports and strategies to enhance current communication and participation in activities of choice. Because the initial communication system may include modalities other than speaking, PWA and family members need to understand that this does not preclude spoken language becoming a future or simultaneous treatment target.

Some possible remedies:

1). Clinicians, family members, and PWA would benefit from a roadmap. There are some clinical practice guidelines for stroke, but overall, specific guidelines for aphasia intervention are lacking (Rohde, Worrall, Le Dorze, Hinckley & Cruice, 2012). Specific guidelines that might provide an initial roadmap for PWA, family members and clinicians are unpublished (Beeson, O'Bryan, Henry, Risling, & Kim, 2010). Some type of clinical pathway is needed—perhaps not one with step-by-step instructions, but one that outlines an approach for at least the first few weeks of speech-language intervention.

We need to create and communicate a roadmap that is consistent and simple. What about something like this? Before starting other aphasia treatments, make sure you've worked to establish a system of communication supports and strategies that are effective for each PWA. For those with moderate-to-severe aphasia, this may include partner training to teach supported conversation techniques. This may be asking yes/no questions in a systematic way or creating and demonstrating the use of an individualized low-tech communication book. Once a basic system of communication is established, then move forward with other treatments.

We have begun talking to clinicians, instructors, and students about recommending an initial roadmap or checklist that uses the acronym CAPE: Connecting people; Augmentative and Assistive Communication; Partner Training; and Education and Resources.

2). We need to communicate any roadmap clearly. How can we enhance our own communication with students, professionals, family members, and members of the larger community? Often, the information is accurate, but it is embedded in our chapters and in our lectures, and it may be difficult for the audience to unpack and prioritize. The environment seems very noisy—there are so many trees that it is often difficult to step back and see the forest.

As university educators, continuing education instructors, and authors of books on aphasia, we can do a better job of stressing the need for providing a basic communication system for PWA.

3). We need to provide a simple and clear rationale for this roadmap. Many PWA, clinicians, and family members are concerned that introducing compensatory communication strategies and supports early may impair the ability to use spoken output later (Rose, 2013). Perhaps we should look to other modalities and other rehabilitation disciplines. For example, the rehabilitation

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discipline of physical therapy demonstrates that a goal of walking is not incompatible with using other methods of moving about—a wheelchair, a walker, canes, and/or an ankle foot orthotic, may all be used depending on the individual's specific abilities and needs. Perhaps our rationale can be improved by comparing the supports needed for ambulation to those needed for communication for people with aphasia.

4). We need to contextualize research. Research findings require context so that readers and listeners don't overgeneralize the results. When we write chapters or give classes, we need to ensure that we frame research findings into the overall context of aphasia intervention.

5). We need to consider ways of funding expert clinicians to establish communication systems and supports for PWA using a consultative model. This might be similar to how some Augmentative and Alternative Communication clinics are currently funded and utilized.

These are a few suggested remedies—it is hoped that the discussion period will provide the opportunity to consider additional ideas and suggestions.

Conclusion

As clinical aphasiologists, we have a responsibility to ensure that PWA have a system of individualized communicative supports and strategies in place in order to communicate and participate in activities of choice. As authors and educators, we are in a position to make this a reality, by creating and communicating a roadmap for the first few months of aphasia intervention. Use of this roadmap can provide PWA with the human right of communication, by assisting them, clinicians, and family members to see the forest of aphasia intervention rather than just the trees.

References

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