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Students' Understanding of Self-Management in Aphasia Treatment

An Honors Thesis submitted in partial fulfillment of the requirements for Honors in
Communication Sciences and Disorders.

By
Maryse Azer

Under the mentorship of *Dr. April Garrity*

ABSTRACT

Aphasia is a neurogenic language disorder caused by damage to the language areas of the brain in the left hemisphere, resulting in speech and language impairments. People with aphasia (PWA) often receive services from speech-language pathologists (SLPs) who provide screening, assessment, diagnosis, and treatment to address communication deficits. Aphasia is a chronic condition and PWA experience symptoms throughout their lives. Healthcare costs related to aphasia account for \$46 billion annually. Provider shortages, lack of transportation, insurance constraints, and travel expenses can leave PWA without adequate care. One possible solution to the costs and access issues is the implementation of self-management for chronic aphasia. Through self-management, PWA take responsibility for their care after being educated on how to manage their symptoms and make adaptive communication changes. However, clinicians have limited resources to guide them in implementing this approach. This study utilized a pre-test/post-test design to: 1) assess the knowledge and perceptions of SLP graduate students regarding self-management in aphasia rehabilitation before and after their participation in a training session on the topic, and 2) determine if participants have become more familiar with this concept and if they would consider implementing it in their future practice. Results suggested that participants were more likely to consider implementing self-management in their future practice and were more knowledgeable about this intervention after the training session. Therefore, introducing the concept of self-management to more SLPs can garner their support in building and implementing a formal intervention in their practice.

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Introduction

Aphasia is a neurogenic language disorder acquired due to left hemisphere brain damage. This results in injury to the language areas of the brain, including the region around the Sylvian fissure. Aphasia resulting from damage to the right hemisphere accounts for a minority of cases and is referred to as crossed aphasia. Strokes are the most common cause of aphasia. Other causes of aphasia include: brain infections, surgeries, and tumors, traumatic brain injury, and progressive neurological diseases such as dementia (ASHA, n.d.-a).

Aphasia may result in impairment in one or more of these primary areas: spoken language expression, spoken language comprehension, written expression, and reading comprehension (ASHA, n.d.-a). Impairment in spoken language can include anomia (difficulty finding words), effortful or telegraphic speech, jargon, grammatical errors, and substituting sounds or words. Aphasia symptoms related to spoken language include failing to understand complex utterances, requiring additional time to comprehend messages, misinterpreting figurative language, and not realizing one's errors. Symptoms related to reading and writing include agraphia and alexia. Agraphia refers to a range of difficulties in writing, spelling, and grammar. Alexia is difficulty in comprehension of text, sounding out words, substituting synonyms, and recognition of sight words (ASHA, n.d.-a).

People with aphasia (PWA) experience receptive and expressive language difficulties and are categorized as fluent or nonfluent depending on the extent of their expressive communication ability. The speech of an individual with fluent aphasia remains fluent but is often filled with meaningless jargon, making it incoherent to the

listener. Nonfluent aphasia is characterized by severely limited and laborious speech. Global aphasia is the most severe as both comprehension and expression are limited (National Aphasia Association, 2021). Aphasia does not typically affect nonlinguistic cognitive skills and PWA often retain executive function and memory.

PWA often receive therapy from a speech-language pathologist (SLP) who collaborates with other healthcare professionals to treat the client's deficits. The responsibilities of SLPs are vast and range from screening, assessments, diagnosis, and treatment, to education, prevention, advocacy, research, and administration (ASHA, n.d.-c). The American Speech-Language Hearing Association (ASHA) is the credentialing and governing body of the profession of SLP. ASHA promotes the use of the World Health Organization's (WHO) *International Classification of Functioning, Disability, and Health* (ICF) framework in SLP practice. The ICF framework considers the impact of impairments in structure and function of the body, limitations in daily activities, and contextual factors, such as one's environment, on quality of life for PWA (ASHA, n.d.-a).

Treatments should be person- and family-centered, including the preferences of both PWA and their families in the development and implementation of services (ASHA, n.d.-b). Treatment can focus on restoring impaired function or compensating for deficits. Treatments for aphasia include: community aphasia groups, communication partner training, and individualized interventions (ASHA, n.d.-a). While treatments may manage symptoms and assist PWA in regaining communicative function, aphasia is a chronic condition and cannot be completely cured (Nichol et al., 2019). The rehabilitative outcomes of aphasia are contingent on many factors including the area(s) of the brain

affected, the time course of treatment, and the capability and willingness of the individual to participate in treatment.

Because aphasia is a chronic condition, PWA experience lifelong communication difficulties. The Life Participation Approach to Aphasia (LPAA; Chapey et al., 2000) is an ICF-aligned framework and suggests that SLP services should be available to PWA “at all stages of aphasia.” This means that PWA could opt to participate in SLP services immediately at the onset of aphasia, discontinue treatment once their goals have been met, then opt to participate in SLP services again at a later time to meet a different goal or set of goals. According to LPAA, this pattern of SLP services should be considered normative throughout the life of a PWA. However, PWA often lack support once formal care has ended (Nichol et al., 2019).

An issue in rehabilitation of aphasia after a stroke is the lack of resources available to some PWA to continue receiving treatment. Stroke-related aphasia is on the rise due to the increased life expectancy of the geriatric population. Every year, 795,000 people have strokes (CDC, 2022) and it is estimated that a third of strokes result in aphasia (National Aphasia Association, n.d.). There are over 180,000 new cases of aphasia in the U.S. each year (ASHA, n.d.-a). The cost of strokes and stroke-related services are estimated to be \$46 billion annually (CDC, 2021). These costs place a burden on healthcare spending at both national and individual levels. Increasing numbers of PWA requiring speech and language services can lead to strain on the healthcare system and leave some without care. PWA may also face barriers related to lack of transportation, travel expenses, and provider shortages (Nichol et al., 2019).

One potential solution for expanding access to care and reducing spending is to implement a self-management approach to aphasia rehabilitation. Self-management approaches have been used in treating other chronic conditions such as heart disease, diabetes, asthma, and strokes (Nichol et al., 2019). In aphasia rehabilitation, self-management refers to a treatment approach in which clients take active responsibility for their own care. Implementation of self-management in aphasia includes educating PWA about their condition, as well as how to manage their symptoms and medications and make adaptive communication and lifestyle changes.

An underlying goal of self-management is to establish self-efficacy in order for the clients to invest in their motivation and behavior during treatment. Self-efficacy is the belief in one's capability to modify his behavior as it affects thoughts, motivations, and emotion (Nichol et al., 2019). Self-management approaches prioritize self-efficacy to improve clients' capacity of dealing with emotions regarding their chronic condition. Depending on the severity of aphasia and the available support system, PWA can feel isolated or depressed (ASHA, n.d.-a), making improved self-efficacy a vital part of rehabilitation. Additionally, being in control of one's treatment can help in overcoming symptom burden. This phenomenon refers to the negative emotional and psychological consequences that PWA may experience due to severity and longevity of their chronic condition.

Recent studies of other chronic conditions suggest that self-management can lead to positive rehabilitative outcomes in aphasia (Nichol et al., 2019). Self-management can often be a novel concept for some as the clinician and client engage in a role reversal of sorts. The client takes the lead in facilitating his own care, while the clinician provides

support and education so that the client can continue treatment without needing the clinician present (Nichol et al., 2018). Approaches to self-management utilize existing intervention techniques, including individualized technology-based treatment, group and community-based intervention, and communication partner training (Nichol et al., 2019).

Technology-based treatment can be delivered using various modes of electronic devices such as computers, tablets, augmentative and alternative communication devices, and video recordings (Nichol et al., 2019). Some clinicians may also use apps specifically tailored to their clientele in order to improve treatment outcomes. Stark et al. (2018) investigated the effectiveness and feasibility of a self-delivered iPad-based speech therapy app for PWA, finding that this approach has the potential to supplement long-term rehabilitation. Additionally, Li et al. (2021), conducted a study to explore the effects of self-management programs using planned behavior theory for stroke patients. While their findings were not specific to PWA, they indicated that this approach is beneficial in improving the self-management abilities and quality of life of stroke patients, as well as providing a reference for caregivers and nurses on the implementation of this approach.

Despite the potential benefits of self-management in rehabilitative aphasia, clinicians and clients lack resources to guide them on its implementation. Although self-management research in other chronic conditions provides more specific guidelines, many studies exploring self-management in aphasia focus on broad principles because no specific framework or terminology has been established for aphasia. (Nichol et al., 2019). Studies exploring SLPs' perceptions of self-management in aphasia revealed that SLPs were uncertain of what self-management is and how to implement it. However, once they

understood the concept, SLPs perceived self-management as a potentially beneficial treatment approach that they would implement in practice (Nichol et al., 2018; Wray et al., 2020). Introducing the concept of self-management to future SLPs may be one way to foster its development and use among clinicians and clients. To that end, this study examined the effectiveness of a training workshop for teaching SLP students about self-management for PWA.

The aims of this study are to: 1) assess the knowledge and perceptions of SLP graduate students regarding self-management in aphasia rehabilitation before and after their participation in a training session on the topic, and 2) determine if participants have become more familiar with this concept and if they would consider implementing it in their future practice. It is hypothesized that the majority of SLP students will not be familiar with the term “self-management” as it relates to aphasia prior to participating in the training session. It is predicted that the participants will become familiar with the term and will consider implementing it in practice after completing the training session.

Methods

A pretest-posttest experimental design was used to assess students’ knowledge and perceptions of self-management before and after participation in the self-management workshop. The workshop consisted of a pre-survey, an informational module presentation, and a post-survey. Participants of this study were Communication Sciences and Disorders graduate students at Georgia Southern University. The training workshop was a mandatory event held during the students’ class time, but participation in

the research (i.e., completing the surveys) was voluntary. A total of 19 students participated in the research and completed both surveys.

Participants accessed the surveys via Qualtrics QR codes and completed the surveys on their phones. Surveys were divided into three sections: consent to participate in the study, general perception measured with a Likert-type scale, and a knowledge test based on the informational module presentation (see Appendix A). The general perception section asked participants how familiar they were with the term self-management and if they would consider implementing this approach in their future practice. The post-survey was used to assess any difference in perceptions after the presentation. It also included an additional optional section to provide feedback and comments about the training session and perceptions of self-management. The presentation was created using the CANVA graphic design tool. It included five objectives: 1) define aphasia and its causes, symptoms, and impact, 2) define “self-management” in post-stroke aphasia rehabilitation, 3) identify the benefits of self-management in post-stroke aphasia rehabilitation, 4) identify some of the current approaches of self-management currently used by speech-language pathologists, and 5) explain the limitations of self-management and future direction for research (see Appendix B). Participants were asked seven questions based on the contents of the presentation and their pre- and post- survey scores were compared for improvement.

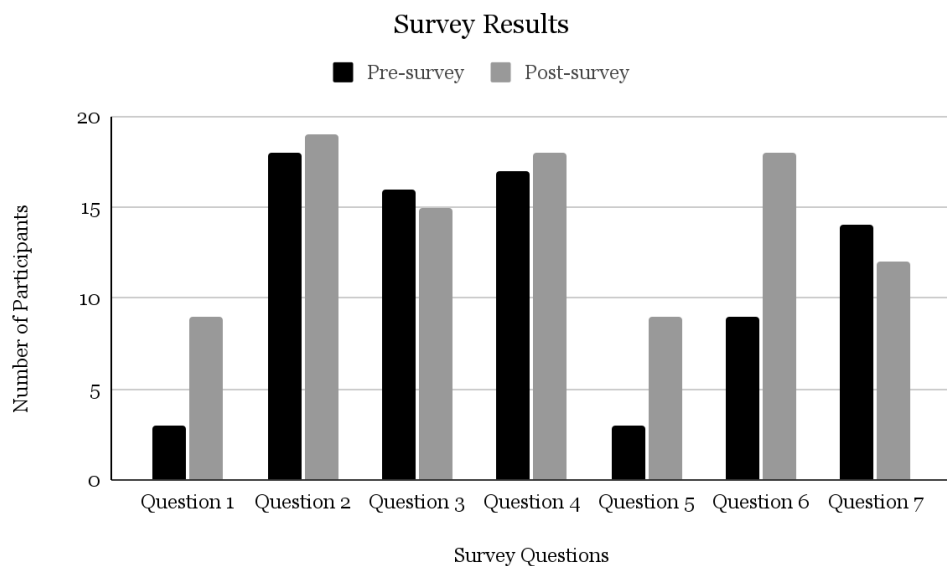
Results

Knowledge Test

Results of the knowledge test are provided in Figure 1. A Wilcoxon Signed-Rank test was run to determine if student scores on the knowledge portion of the surveys

improved after the self-management informational module. This test was selected because data did not meet all of the assumptions for the parametric dependent t-test. The Wilcoxon Signed-Rank test indicated that participants' total scores on the post-workshop survey (M = 4.21, SD = .97) were significantly higher than their scores on the pre-workshop survey (M = 5.47, SD = 1.07), $Z = -2.84$, $p < .01$.

Figure 1. *Results of the knowledge test.*



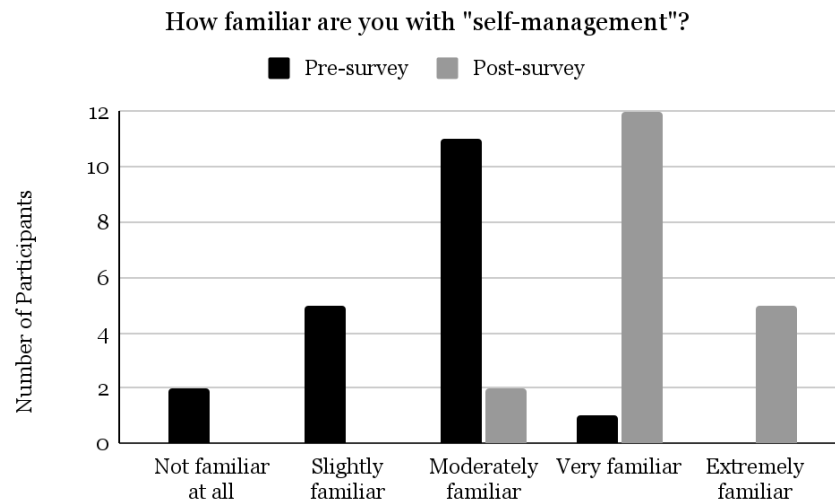
Familiarity

Frequency counts and rates of responses to question 1 of the survey are provided in Table 1 and Figure 2. This question asked participants how familiar they were with the concept of self-management before and after the informational module. Visual inspection of these data reveals that 58% of participants were “moderately familiar” and 5% were “very familiar” with the concept of self-management of aphasia prior to the informational module. After the module, responses to the same survey item indicated that 63% of the participants were “very familiar” and 26% were “extremely familiar” with self-management in post-stroke aphasia rehabilitation.

Table 1. *Frequencies and rates for familiarity question.*

	Pre-Survey		Post-Survey	
	Frequencies	Rates	Frequencies	Rates
Not familiar at all	2	10%	0	0%
Slightly familiar	5	26%	0	0%
Moderately familiar	11	58%	2	11%
Very familiar	1	5%	12	63%
Extremely familiar	0	0%	5	26%
Total responses	19		19	

Figure 2. *Results of familiarity question.*



Implementation

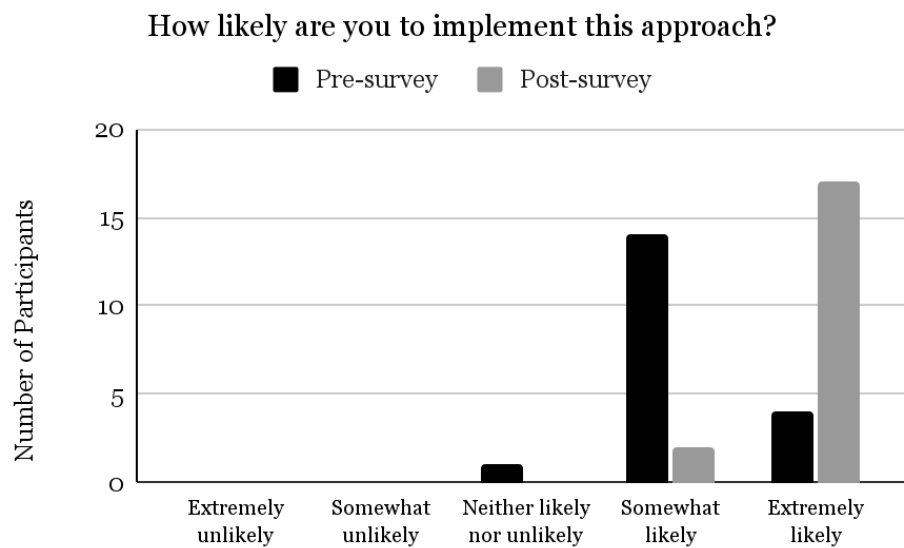
Frequency counts and rates of responses to question 2 of the survey are provided in Table 2 and Figure 3. This question asked participants how likely they were to implement self-management intervention for post-stroke aphasia rehabilitation before and after the informational module. Visual inspection of these data reveals that 74% of

participants were “somewhat likely” and 21% were “extremely likely” to implement self-management prior to the informational module. After the module, responses to the same survey item indicated that 11% of the participants were “somewhat likely” and 89% were “extremely likely” to implement self-management intervention.

Table 2. *Frequencies and rates for implementation question.*

	Pre-Survey		Post-Survey	
	Frequencies	Rates	Frequencies	Rates
Extremely unlikely	0	0%	0	0%
Somewhat unlikely	0	0%	0	0%
Neither likely nor unlikely	1	5%	0	0%
Somewhat likely	14	74%	2	11%
Extremely likely	4	21%	17	89%
Total responses	19		19	

Figure 3. *Results of implementation question.*



Discussion

The aims of this study were to: 1) assess the knowledge and perceptions of SLP graduate students regarding self-management in aphasia rehabilitation before and after their participation in a training session on the topic, and 2) determine if participants have become more familiar with this concept and if they would consider implementing it in their future practice. With respect to the first question, students' results on the knowledge portion revealed a significant increase between pre- and post-surveys, with the Wilcoxon Signed-Rank test score of $Z = -2.84$, $p < .01$. These results suggest that students demonstrated increased knowledge about self-management due to the informational module.

Regarding the second question, students indicated they became more familiar with the concept of self-management and more students considered implementing it in their future practice. Analyses revealed that 58% of participants were "moderately familiar" and 5% were "very familiar" with the concept of self-management of aphasia prior to the informational module compared to 63% rating themselves as "very familiar" and 26% rating themselves as "extremely familiar" after the module. While only 4% of participants were "somewhat likely" and 21% were "extremely likely" to implement self-management prior to the informational module, these rates increased to 11% of participants indicated they were "somewhat likely" and 89% were "extremely likely" to implement self-management strategies after the module. These results reveal that students became more familiar with the concept of self-management after the

informational module and more students came to consider it as a potentially beneficial intervention.

However, despite the generally positive results of this study, several limitations should be noted. First, the informational module and the surveys used in this study were created by the author (an undergraduate student). The content of the workshop could potentially be improved were it created by a more experienced individual, and these improvements could change the perceptions of the participants. Further, this study only used a sample of 19 participants, which limits the use of inferential statistics and the generalizability of the results. Participants of this study were graduate students and not practicing SLPs. Perhaps practicing SLPs with more experience in the field might have a different opinion of self-management intervention in post-stroke aphasia rehabilitation. Future work in this area may be improved by creating a modified workshop and surveys, increasing the sample size, and including a diverse sample of both graduate students and practicing SLPs.

The results of this study suggest that introducing the concept of self-management in aphasia rehabilitation to more SLPs may 1) garner their support in building a formal framework for this intervention, and 2) encourage them to use this intervention in their own practice. SLPs can create a formal framework for post-stroke aphasia rehabilitation based on existing frameworks, such as the Chronic Disease Self-Management Program (CDSMP). In this program, participants engaged in a weekly workshop to learn self-management techniques and develop health goals (CDC, n.d.). Participants included adults with chronic health conditions such as arthritis, diabetes, and heart disease. Participants reported a decrease in pain and depression and an increase in energy,

communication, and confidence in continuing to use self-management techniques to treat their chronic conditions. Although the CDSMP would likely need to be modified somewhat to meet the needs of PWA, the program provides a model for possible next steps towards aphasia rehabilitation self-management.

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Appendices

Appendix A: Pre- and Post- Surveys

Pre-Survey

Part 1: Informed Consent

- Yes, I read the terms above and consent to participate in this research.

Part 2: General Perception Questions:

1. How familiar are you with the term “self-management” as it relates to post-stroke aphasia rehabilitation?
 - a. Not familiar at all
 - b. Slightly familiar
 - c. Moderately familiar
 - d. Very familiar
 - e. Extremely familiar
2. How likely are you to consider implementing a self-management approach for post-stroke aphasia rehabilitation in your current or future practice?
 - a. Extremely unlikely
 - b. Somewhat unlikely
 - c. Neither likely nor unlikely
 - d. Somewhat likely
 - e. Extremely likely

Parts 3: Informational Module Test

1. Which of the following is NOT one of the impacts of aphasia on people with this condition?
 - a. Lifelong communication difficulties
 - b. Consistent deficits in semantics, prosody, and pragmatics
 - c. Lack of formal support once post-stroke symptoms have been treated
 - d. Barriers in accessing care including transportation and travel expenses
2. Which of the following best defines self-management?
 - a. The clinician is completely in control of the treatment
 - b. Clients are educated about their condition, manage their symptom and medication, and make adaptive communication and lifestyle changes
 - c. Clients establish self-efficacy and focus on goal setting, coping and planning strategies, and performing activities of daily living
 - d. All of the above
 - e. Only B & C

3. Which is NOT a benefit of self-management in healthcare and in post-stroke aphasia rehabilitation?
 - a. Increasing symptom burden
 - b. Making it easier for people with aphasia to continue receiving care for their chronic condition
 - c. Decreasing stroke-related healthcare costs
 - d. Successfully treating heart disease, asthma, and strokes
4. What are some ways that technology-based treatment can be delivered?
 - a. Independent practice or face-to-face sessions with an SLP
 - b. Telepractice
 - c. Remote support in real-time from clinicians
 - d. Asynchronous format where clients complete tasks independently and clinicians later review and offer feedback
 - e. All of the above
5. Which is NOT a limitation of self-management in post-stroke aphasia rehabilitation?
 - a. Website search results of “self-management” reveal a lack of information about self-management for aphasia rehabilitation and lack of consistent terminology
 - b. Many clinicians are unfamiliar or have never heard of the term “self-management” as it related to post-stroke aphasia rehabilitation
 - c. Review of the literature revealed a range of approaches to help people with aphasia, but they must pay a large amount of money to access these resources
 - d. There is little to no guidance for clinicians on implementing self-management for post-stroke aphasia rehabilitation
6. How successful was the Chronic Disease Self-Management Program (CDSMP)?
 - a. The program did not succeed and was not implemented by any more organizations
 - b. The program did not yield any conclusive results and more trials need to be conducted
 - c. The program yielded positive results and has been implemented by many health organizations
 - d. This program is in development and has not yet been implemented
7. Why should the concept of self-management in post-stroke aphasia rehabilitation be introduced to more speech-language pathologists?
 - a. To garner their support in building a formal framework for this intervention
 - b. To encourage them to use this intervention in their own practice

- c. To promote them to only use this intervention for all clients with aphasia as it is more cost effective
- d. All the above
- e. Only A & B

Post-Survey

Part 1: Informed Consent

Part 2: General Perception

1. After the informational module, how familiar are you now with the term “self-management” as it relates to post-stroke aphasia rehabilitation?
 - a. Not familiar at all
 - b. Slightly familiar
 - c. Moderately familiar
 - d. Very familiar
 - e. Extremely familiar
2. After the informational module, how likely are you now to consider implementing a self-management approach for post-stroke aphasia rehabilitation in your current or future practice?
 - a. Extremely unlikely
 - b. Somewhat unlikely
 - c. Neither likely nor unlikely
 - d. Somewhat likely
 - e. Extremely likely

Part 3: Informational Module Test (same as pre-survey)

Part 4: Optional Feedback

1. How did your perception of self-management in post-stroke aphasia rehabilitation change after this informational module? Would you consider implementing self-management in your future practice?
2. Do you have any suggestions for improving this informational module or any additional comments?



Pre-Survey QR Code

Please scan the QR code below in order to access the survey. No identifying information will be collected. All results are anonymous.

What is Aphasia?

- Neurogenic language disorder acquired due to left hemisphere brain damage
- Results in injury to language areas of the brain (ASHA, n.d.)

Symptoms

Spoken language
expression

Spoken language
comprehension

Written expression

Reading comprehension

Objectives

After completion of this module, participants will be able to:

- Define aphasia and its causes, symptoms, and impact
- Define “self-management” in post-stroke aphasia rehabilitation
- Identify the benefits of self-management in post-stroke aphasia rehabilitation
- Identify some of the current approaches of self-management used by speech-language pathologists
- Explain the limitations of self-management and future direction for research



Impact of Aphasia



A larger portion of the population is living to an old age and dealing with multiple chronic conditions



Aphasia is a chronic condition, and people with aphasia (PWA) experience lifelong communication difficulties



PWA often lack support once medical intervention has ended



It is estimated that **795,000 people** have strokes every year and **a third** of these strokes result in aphasia (National Aphasia Association, 2022)



Impact of Aphasia



The costs of strokes and stroke-related services are estimated to be **\$46 billion** annually (CDC, 2021)



Barriers in accessing care:

- Lack of transportation
- Travel expenses
- Provider shortages



Result:

- PWA might go without care
- Suffer poor health outcomes
- Lower quality of life (Nichol et al., 2019)



Defining Self-Management



- Clients' role in managing the symptoms of their chronic disease(s)
- PWA are educated about:
 - Condition
 - Symptoms
 - Medication management
 - Making adaptive communication and lifestyle changes
- (Nichol et al., 2019; CDC, 2020)



Defining Self-Management



- Self-efficacy
 - Clients' belief in their own capabilities to modify their behavior
- Client and clinician engage in a role reversal of the sorts
 - Client takes the lead in facilitating his own care
 - Clinician provides support and education
 - Client can continue treatment without the clinician present



Benefits

- A large-scale rapid review including 550 studies of chronic condition
- Indicated that self-management can:
 - Increase quality of life
 - Lead to better medical outcomes
 - Improve use of health services
- (Nichol et al., 2019; Nichol et al., 2018; CDC, 2020)



- Successful in treating chronic conditions such as
 - Heart disease
 - Asthma
 - Strokes
- Being in control of one's treatment can help in overcoming “**symptom burden**”
- PWA to continue receiving care for their chronic condition
- Decrease stroke-related healthcare costs



Current Approaches



- 1** Technology-Based Treatment
- 2** Group and Community-Based Treatment
- 3** Communication Partner Training



Limitations



- Website search results reveal a lack of information and consistent terminology
- Many clinicians are unfamiliar or have never heard of the term
- Review of the literature revealed a range of approaches to help PWA manage their health condition independently, but none mentioned self-management explicitly
- No guidance for clinicians on implementation
- (Nichol et al., 2019)



Future research

Future Direction for Research

- Introducing the concept of self-management in aphasia rehabilitation to more SLPs to:
 - Garner their support in building a formal framework for this intervention
 - Encourage them to use this intervention in their own practice
- Creating a formal framework for post-stroke aphasia rehabilitation based on existing frameworks



(CDC, n.d.)

CDSMP

Future Direction for Research

- Chronic Disease Self-Management Program (CDSMP)
- Participants engaged in a weekly workshop to learn self-management techniques and develop health goals
- Adults with chronic health conditions such as
 - Arthritis
 - Diabetes
 - Heart disease
- Participants reported decrease in:
 - Pain
 - Depression
- Increase in
 - Energy
 - Communication
 - Confidence in continuing these techniques
- Exponential participation in subsequent workshops
- Similar workshops have yielded positive results



Conclusions



- Self-management is an intervention approach in which clients take an active role in managing the symptoms of their chronic diseases, under guidance of a clinician.
- Can be used in post-stroke aphasia rehabilitation to help PWA overcome symptom burden, continue receiving treatment, and cut healthcare costs.
- Some current approaches to this intervention are technology-based treatment, group and community-based treatment, and communication partner-training (CPT).
- As many clinicians are unfamiliar with the term “self-management,” spreading more awareness about this intervention can garner support for the development of a formal framework and encourage more clinicians to implement this approach.

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Post-Survey QR Code

Please scan the QR code below in order to access the survey. No identifying information will be collected. All results are anonymous.