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Lessons on Health Literacy and Communication in Post-Stroke Rehabilitation:

A Primer and Proposal

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Abstract

Health literacy, or the ability to find, understand, and use information to make well-informed health decisions, has been linked to post-stroke rehabilitation outcomes. Importantly, barriers to health literacy stem from stroke survivor characteristics, clinician practices, institutional norms, as well as systemic variables. These barriers impact recovery and rehabilitation outcomes. To address these obstacles, clinicians can learn from the evidence-based practices used by speech-language pathologists in their work with stroke survivors with aphasia, a language impairment that can follow stroke. These methods to overcome communication barriers are appropriate and recommended for patients and family members regardless of stroke impairment, and include a transdisciplinary care model, multimodal approaches to patient education, along with consistent engagement with patients and their care partners. These strategies may be adopted for both personal and organizational health literacy efforts and help optimize the rehabilitation and recovery outcomes of stroke survivors with and without aphasia.

Health literacy is a multidimensional concept characterized as the ability to *access*, *understand*, *appraise*, and *apply* health information.[1] The Office of Disease Prevention and Health Promotion's (ODPHP) Healthy People 2030 initiative[2] identified two types of health literacy: *personal health literacy,* which relates to an individual's ability to engage with health information, and *organizational health literacy*, which describes how health systems equitably enable individuals to make well-informed health decisions. These definitions require both the individual making healthcare decisions and the organization providing that care to co-create an effective dialogue regarding health status. As a Social Determinant of Health, health literacy is a risk factor identified under the social and community domain. Individuals with lower health literacy skills have worse health and poorer health outcomes[3] and ineffective organizational health literacy can negatively impact the health of the communities they serve.[2] These effects are only compounded when organizations with low health literacy serve individuals with low health literacy.

Health literacy rates are a critical consideration in stroke prevention, management, and rehabilitation. According to the American Heart Association's "Get with the Guidelines" initiative for stroke management, acute stroke survivors must receive education on personal risk factors for stroke, warning signs of a stroke, activation of their emergency medical system, the need for follow-up after discharge, and their prescribed medications and treatments, all before they are discharged from acute care.[4] However, Sanders and colleagues identified that 59% of acute stroke survivors have inadequate or marginal health literacy.[5] On average, this group retained *only half* of the stoke education provided to them and several respondents could not name any of their personal risk factors at discharge. Critically, this study excluded 70 of the 189 participants screened for significant cognitive deficits and receptive or global aphasia. This

suggests that a much greater proportion of stroke survivors than previously reported have inadequate health literacy. Low rates of health literacy place stroke survivors, and in particular, individuals with aphasia, in an extremely vulnerable situation for *preventable* poorer health outcomes after stroke.

Flink and colleagues recently studied the relationship between health literacy and stroke survivor outcomes for depression, mobility, perceived stroke recovery, and perceived ability to participate in activities of daily living (ADL) 12-months post-stroke.[6] They found that higher relative health literacy ratings were linked with lower relative rates of post-stroke depression as well as improved mobility, and higher relative perceptions of recovery and participation in ADL, irrespective of age, sex, and education background. This study adds to the body of research that underscores the association between the health literacy of stroke survivors and optimal recovery outcomes.[7–9]

To make a meaningful impact on the health literacy landscape of stroke survivors, it is important to identify the specific skills involved in health literacy tasks, as well as the measures and classifications used in this domain. *Accessing* health information describes the patient's ability to obtain healthcare information and resources (e.g., information shared by their clinician, pamphlet, website), as well as a patient's ability to receive those materials in a way that promotes understanding. For example, health information should be provided in multiple languages and modalities to meet the unique needs of each learner. *Comprehension* occurs when the learner understands information that is presented to them in writing, shared verbally, or through a combination of communication modalities. To support health education comprehension, the American Medical Association recommends that materials be written at a 6th-8th grade reading level.[10] *Appraising* health information requires an individual to decide if the information is reliable and valid and how it might relate to their unique health circumstances. Finally, individuals are asked to synthesize and *apply* the information obtained through these sequential steps in a meaningful way to make well-informed health decisions. Depending on the source, additional domains in this model can include numeracy, or an understanding of measurements used in healthcare, and media literacy.

The US Department of Education and the National Center for Education Statistics conducted the National Assessment of Adult Literacy (NAAL), in which respondents were given ratings of below basic, basic, intermediate, and proficient in their print health literacy and their numeracy. Table 1 provides examples of the skills which accompanied each level of health literacy in this survey.

Table 1. Adapted from the National Assessment of Adult Literacy (NAAL) report,[11] U.S. Department of Education, Institute of Education Sciences, National Center for Education Statistics, 2003 National Assessment of Adult Literacy.

Health Literacy Level	**Print Health Literacy**	**Numeracy**
Below basic	Locating easily identifiable information in short documents and charts.	Identifying numbers and performing concrete and regular math related to healthcare (e.g., how often should someone have a certain healthcare test).

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Basic	Reading and understanding basic information in short documents and charts.	Using easily identifiable quantitative information and completing one-step math equations with this information.
Intermediate	Read and understand moderately dense text and complex documents.	Locate less familiar quantitative information and complete a calculation where the equation is not clearly indicated (e.g., BMI calculation).
Proficient	Read and understand lengthy, complex, and abstract information located on multiple pieces of paper.	Locating abstract quantitative information and using it in a complex, multistep arithmetic equation. (e.g., calculating your share of health insurance costs

The Health Literacy Tool Shed (https://healthliteracy.bu.edu/all) currently provides information on 274 assessments available to measure personal health literacy. Organizational health literacy assessments are not as widely available; however, this landscape is changing.[12] Two commonly used tools to assess personal health literacy are the Short Assessment of Health Literacy (SAHL) and the Rapid Assessment of Health Literacy in Adult Medicine- Short Form (REALM-SF). These brief assessments measure print and oral health literacy, respectively, and identify patients at risk for low health literacy. Results from the REALM-SF also suggest what levels of supports might be successful. These assessments are quick and easy to administer; however, this cursory view comes at a cost. These tools do not robustly examine the sensory, cognitive, and linguistic processes required to engage in the health literacy process. Additionally, for these ratings to be valid for stroke survivors, they must be administered at multiple time points in stroke recovery. As a stroke survivor becomes more familiar with the rehabilitation process and its jargon (e.g., aphasia or hemiparesis), health literacy for these topics may improve. The recovery prognosis for the language and cognitive sub skills involved in health literacy is especially interesting when examined through the lens of aphasia, a language disorder which can occur after a stroke. Speech-Language Pathologists have been engaging in this work for decades and can provide insights into meaningful health literacy gains for stroke survivors with and without aphasia.

A Primer and Proposal for Stroke Rehabilitation Clinicians

Effective health literacy is critical to stroke recovery and rehabilitative success, so how can clinicians support these skills, especially given the complexity of health literacy and its multifaceted solutions? In general, these strategies fall into the *who* and the *how* of health literacy, through 1) using a transdisciplinary model of stroke intervention, 2) integrating supportive communication approaches in patient education, and 3) acknowledging each stroke survivor as an expert member of the care team.

Transdisciplinary Model of Stroke Intervention

In transdisciplinary care, healthcare providers, patients, care partners, and researchers "go beyond or transcend disciplinary boundaries" to address the needs of the individual patients and their health conditions most efficiently and effectively).[13] For health literacy to be maximally

effective for stroke survivors, care must be collaborative and coordinated across disciplines and beyond, actively encouraging members of the stroke team to identify and blur overlapping areas of expertise to maximize patient care and education and support high-quality patient decision-making.

Patient education is within the scope of practice for most, if not all, healthcare providers. In a transdisciplinary model, no one team member bears the full responsibility of patient education. This approach is particularly important when the team is working with an individual with aphasia, but many other patients and their families require measures to support health literacy. For example, Chen and colleagues examined the experiences of first-time stroke survivors and their families as they transitioned between levels of care following their stroke event.[14] Although participants appreciated the role rehabilitation nurses played in care coordination and stroke education, they reported not understanding much about their stroke and rehabilitation plan and expressed concern for a lack of care continuity in the transition between acute care to rehabilitation settings. A coordinated, transdisciplinary approach to stroke management and personal health literacy supports patients' understanding of and engagement in the stroke recovery process.

Speech-language pathologists (SLPs), as experts in communication, are a central part of a stroke transdisciplinary team. SLPs can identify strategies to communicate essential recommendations to stroke survivors. These strategies include, but are not limited to, assessing of language and cognitive skills, identifying communication abilities and challenges, and providing specific, multi-modal communication techniques to maximize patient-clinician information exchange. For example, if an individual with aphasia is unable to understand complex spoken language, but they can read short sentences and key words quickly and accurately, this strength can be leveraged to support the patient in meaningful participation in their recovery. Importantly, stroke survivors without aphasia may also benefit from this type of support. For example, patients (and family members) may be distressed about their health status as well as overwhelmed by the unfamiliar acute care setting, with its startling ambient noise (e.g., alarms, announcements, monitors) and frequent distractions (e.g., team members coming and going). Speaking in (respectful, non-patronizing) short sentences, writing key words, and summarizing key points can help patients and care partners attend to and comprehend the information shared in a distracting setting. Once the patient's optimal modalities of communication are identified, SLPs will communicate these findings with the transdisciplinary stroke team, recommend opportunities to practice strategy use, and optimize educational materials – in collaboration with other members of the care team – to support adherence to discharge recommendations. Overall, the transdisciplinary care team's collaboration combined with the integrated communication expertise of the SLP can move stroke survivors closer to effective self-management of their recovery of post stroke.

Supportive Communication Approaches for Patient Education

Healthcare providers should receive direct instruction on communication techniques that can enhance health literacy for all patients. The FRAME model for patient communication and education was developed by Baylor and colleagues and implemented for medical students interacting with stroke survivors with aphasia and other communication disorders.[15,16] During this model's development, students watched a short, preparatory video followed by a 2-hour training. This seminar resulted in a statistically significant increase in medical students'

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confidence and efficacy when working with patients with varying communication skills and styles.

Specifically, the FRAME model encourages healthcare providers to take the following steps when communicating with patients:

1). Familiarize yourself with how your patient communicates BEFORE starting the interaction. This includes obtaining or preparing communication supports before your discussion with the patient. For example, a provider might read a team or SLP note about communication strengths and challenges and grab a dry erase marker and wipe board before heading in to talk to a patient and provide written key words.

2) Reduce your rate of speech to support your communication partners. It can be challenging to work in a fast-paced setting and commit to a slower rate of speech; however, this strategy improves the patient's comprehension of your education, ultimately decreasing their need for information repetition in the future.

3) Assist the patient with communication. Have supportive communication materials on hand, such as previously mentioned wipe board and marker, a page with Yes / No written to use for pointed responses, and readiness to use gestures to support your verbal message. In moments of communication breakdowns, simply relay "I'm sorry, I don't understand" then try a new strategy to facilitate communication. It is also helpful to verbally acknowledge what you *did* understand by using short paraphrases or summaries of patient's utterances.

4) Mix your communication methods to support effective communication. Write one or two key words to orient the patient and care partners to the topic of the conversation (e.g., "going home"). Provide a brief written summary of plain language points (guidance provided in the next section) to ensure that information is salient and accessible.

5) Engage your patient to respect their autonomy. While stroke care providers educate patients daily about stroke rehabilitation and recovery, the patient is the expert of their life and experiences, and their perspective is essential. Speak directly with the patient, when at all possible, to ensure that the patient feels acknowledged, included, and worthy of respect during all interactions.

The FRAME model provides a foundation for effective communication exchanges. In addition to the basic approach in FRAME, speech-language pathologists employ evidence-based strategies to support spoken and written education for stroke survivors with and without aphasia.

Spoken/Conversational Presentation of Patient Information and Education

Most of the time, clinicians share information verbally with their patients and there are a few key concepts which can maximize the impact of the health education they provide.

Consider HOW You Communicate

Communicating with patients and care partners often requires clinicians to use shorter and simpler sentences, as mentioned previously. Clinicians should also pause periodically to allow for information processing and patient questions. Although using jargon may have ensured good grades on qualifying examinations, minimizing, or eliminating jargon and providing relatable explanations can foster understanding with patients. It is also critical to consider the patient's basic sensory needs for aided communication. Are hearing aids and/or glasses needed? Are they

on the patient and turned on? Do they need to be cleaned or require new batteries? When left unaddressed, these factors can have a significant impact on the patient's ability to learn.

Facilitate Adequate Health Literacy

Literature shows that learners appreciate multiple repetitions of essential information (e.g., medication directions, follow up visits, exercise directions). Repeated information can be phrased differently to support comprehension and the learning style of your patient. Additionally, consider providing multiple opportunities for the patient to ask questions and/or using a respectful, non-patronizing "teach back" method to facilitate patient comprehension. When using "teach back," it can help to have the clinician take responsibility for use of medical jargon unfamiliar to the patient. "Teach back" has been successful when the clinician has used language that resonates with the patient and the patient indicates full comprehension of the relayed information. If there are lapses in the education, the onus is on the clinician to make the repair.

Written Presentation of Patient Information and Education

Most organizations provide written educational material such as pamphlets, brochures, websites, and handouts to reinforce information shared verbally with the patient. Studies show that many of these documents do not meet the literacy levels of the general population and even specific materials designed for individuals with aphasia may not adequately support comprehension.[17] Azios and colleagues found that many educational materials for stroke survivors with aphasia required 13 to 16 years of formal education to read and understand.[18] To improve accessibility of this information, they suggest collaborating with speech-language pathologists to employ effective communication supports for stroke survivors with aphasia and their care partners. Rose and colleagues demonstrated that both individuals with and without aphasia after stroke had improved comprehension of brochures and handouts when written language strategies were in place, such as highlighting keywords and adding picture supports.[19] Moreover, Herbert, et al. reported that font size, concept presentation, and graphics have the potential to significantly improve written material comprehension.[20] Recently, Saylor and colleagues examined how well stroke survivors with and without aphasia understand a standard pharmacy medication handout compared to an aphasia-friendly version with features described above.[21] Their results indicated that both participant groups demonstrated improved comprehension, supporting the idea that aphasia-friendly education materials are beneficial for a broader audience.

Highlighted recommendations to optimize written health information for stroke survivors with and without aphasia are outlined here[19,22–24]:

Reading Level

All printed health education material should be consistent with a 5th or 6th grade reading level,[17] considered slightly below the national average reading level of 7th-8th grade. To achieve a 5th or 6th grade reading level, printed education should feature simple words and short sentences to limit the amount of text on the page. Sentences should have no more than 15 words each and just as with spoken language, medical jargon should be avoided. Simplified vocabulary and syntax in titles and headings are also helpful. A few online readability tools are available to calculate reading level.

Virtual resources, such as informational websites, have even more facets to consider, such as the readability, validity, and user-friendliness of the site.[25] To measure the readability of a website,

Flesch-Kincaid Reading Ease and Grade Level measurements can be calculated (online tools are available), while the SPAT (Site, Publisher, Audience, and Timeliness) and SAM (Suitability of Materials) indices can support the development of stroke survivor friendly web-based resources.

Use of Images/Graphics

Research demonstrates that age-appropriate graphics and pictures strongly support written language comprehension. Graphics should be selected from a professional photo library and the content should be unambiguous, minimizing unnecessary background details. Each picture should feature short captions to describe the content. Ideally, printed education should be on a white background with a contrasting color background and white lettering setting the title of the educational handout apart.[20]

Other Visual Presentation Considerations

Patients prefer the use of large and standard san serif fonts.[20] For example, a title can be printed in Arial Black in 24-point, while content sentences can be written in Arial 14-point font. Highlighting (bold, italicize) important terms and information can draw attention to key content, and blank white space on a page facilitates comprehension and space for writing down questions and clarifying points.

Recent innovations to support health literacy, such as the use of virtual reality in clinical education of stroke survivors,[26] apps for medication management adapted to aphasia-friendly standards,[27] pre-visit digital checklists and tools to support informed discussions related to chronic health management,[28] and short video-based education modules[29] have also incorporated many of the recommendations for aphasia-friendly communication and optimal health literacy.

Cultural considerations are included by some as an important facet of health literacy initiatives. Of note, Appalasamy and colleagues created culturally and linguistically inclusive videos that featured vignettes of stroke survivors speaking several languages and dialects to provide short education about stroke management in their own words.[30] Importantly, when stroke survivors are presented with auditory education, supplemented by written keywords, they can comprehend with increased accuracy and speed.[31] The guidelines and considerations described above for written educational materials can bolster an organizations' efforts to create accessible health information and bridge the health literacy gap for stroke survivors; however, there is no substitute for personal interactions with stroke survivors and their care partners.

Stroke Survivors: Expert Members of the Care Team

Individuals with aphasia, when asked about their post stroke experiences with clinical providers, reported their desire to be an active part of their medical care and decisions.[32] Furthermore, during times of communication breakdowns, stroke survivors and care partners appreciated physicians who attempt to communicate differently or navigate the breakdown, as opposed to ignoring unsuccessful communication or communicating only with the care partner.[33] When communication was directed only to family members, some participants believed that their involvement was not beneficial despite their best efforts. Stroke survivors and their care partners also acknowledged that physicians often appeared to try their best to communicate; however, ineffective communication can damage a provider-patient relationship and therefore optimal stroke recovery. Bottomline, clinicians must work to establish a trusting partnership with each patient and support stroke survivors to be their own best advocates. This effort starts by

observing the needs of the patient and adjusting the supportive communication approach accordingly.

It is also important for clinicians to remember that stroke recovery is not linear. For example, most individuals with aphasia continue to see gains in their language impairments – even 20 or more years following the initial stroke event. Therefore, members of the care team need to dynamically adjust their communication approach depending on the communication abilities of the patient at the present time.[34] Furthermore, aphasia is an impairment that can vary somewhat throughout each day. Clinicians may witness significant shifts in an individual's ability to understand or respond to health information, and these shifts relate to factors such as level of fatigue, stress, or environmental distraction. Each of these factors also may impact stroke survivors without aphasia as well; therefore, the clinician's time and care to ensure comprehension is never wasted.

Future Directions

Although this article focused on the importance of health literacy in stroke recovery, future directions should include stroke prevention-focused health literacy. In the U.S., the annual economic burden of stroke is estimated at 49.8 billion dollars,[35] and the economic burden of living with aphasia is estimated to be over 15.8 million dollars.[36] Since individuals with poor health literacy are at greater risk to experience cardiovascular events,[8] expanded systemic efforts to educate both stroke survivors and the public about modifiable stroke risks is critical. Speech-language pathologists are uniquely qualified to address approaches to improving health literacy (e.g., *accessing*, *understanding*, *appraising*, and *applying* health information), and as communication experts, SLPs are important collaborators in the development of meaningful and accessible healthcare education – but have been underutilized in this role to date. Imagine the human and financial capital saved by implementing an inexpensive and targeted prevention approach centered around health literacy -- it is certainly a proposal worth considering.

Conclusion

Stroke survivors, including individuals with aphasia, have an increased risk for low levels of health literacy and associated poor health outcomes. A transdisciplinary health team that integrates the communication expertise of the speech-language pathologist can support both personal and organizational health literacy efforts to improve patient-provider communication related to stroke prevention, management, and recovery. In addition, all members of the transdisciplinary team can dynamically apply multimodal supportive communication approaches to improve patient comprehension, engagement, and independent decision making. Many of the approaches described in this paper can benefit not just individuals with aphasia but many other stroke survivors and their families. Finally, there is no substitute for deliberate and direct communication with stroke survivors and their care partners as expert members of the care team. Small adjustments in the clinician's communicative approach can support stroke survivors as they access, comprehend, appraise, and apply essential health information to make well informed decisions about their care and recovery after a stroke.

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