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4	The role of the speech-language therapist/pathologist in primary
5	progressive aphasia
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## **Abstract**

In recent years, the role of the speech-language therapist/pathologist (SLT/P) has become increasingly established in the assessment, care, and management of primary progressive aphasia (PPA). Throughout the progression of the condition, the SLT/P's role encompasses five notable domains: behavioral assessment, impairment-based intervention, compensatory strategy intervention, communication partner training, and informational counseling. The SLT/P brings a unique perspective and clinical arsenal to address the linguistic, functional, and psychosocial effects that PPA can have on a person's life. Ongoing training opportunities are warranted to deliver evidence-based and person-centered SLT/P services to people living with PPA. Therefore, in this commentary, our aim is to clarify the SLT/P's role to advocate for our patients and their options for care.

### Introduction

The speech-language therapist/pathologist (SLT/P)<sup>1</sup> plays a crucial role in the assessment, care, and management of primary progressive aphasia (PPA)<sup>2-4</sup>. While the language-led changes in PPA are progressive, much can be done to support and manage the effects of the condition. Here, the SLT/P can provide clinical services that are particularly suited to the unique manifestations of communicative decline in dementia<sup>1</sup>. SLT/Ps have a long history of supporting people with progressive disease, including but not limited to amyotrophic lateral sclerosis, Huntington's disease, Parkinson's disease, and multiple sclerosis<sup>5</sup>. Surprisingly, people with PPA have been comparably neglected, where there are documented discrepancies in the number of PPA patients receiving referrals relative to those who qualify for them<sup>6,7</sup>. Here, to reduce this service gap, we detail the SLT/P's scope of practice as it relates to PPA.

# Diagnostic characterization and classification of symptoms

Comprehensive examination of language function is essential to provide insight on impairments, relative strengths, and to infer a likely diagnosis of PPA<sup>8</sup>. Clinical subtyping of PPA into the nonfluent, semantic, and logopenic variants of PPA relies upon careful evaluation of features of language function<sup>9</sup>. Recent studies of speech and language features in PPA support the clinical sensitivity of behavioral measures—ranging from the Cambridge Semantic Battery<sup>10</sup> to evaluations of motor speech<sup>11</sup> to informativeness of language output<sup>12</sup>—for this population. SLT/Ps have the clinical expertise to evaluate domains of speech, language, and communication beyond the restrictions of standardized assessments and to interpret these results appropriately (e.g., such as by examining semantic processing beyond picture-word matching and instead through multimodal tasks [using gesture, mime, pictures, or objects] with limited linguistic demands; for example, gesturing the use of a spoon when provided with a photo of one). Beyond

establishing a diagnosis, within an assessment, the SLT/P can quickly determine which level of support a person may benefit from to increase their performance accuracy. In a picture naming task for the stimulus "popcorn", hierarchical cueing can begin at the level of sound (e.g., "It begins with /p/"), grapheme (e.g., a "P" on a piece of paper), semantic (e.g., "We often eat it at the movies."), or gestural (e.g., moving your hand in a sweeping motion from an invisible bag to your mouth and chewing). For each cue type, the level of support can be adjusted to best suit the person's needs. This dynamic form of assessment (1) reveals patterns of speech and language difficulties required for a diagnosis, (2) speaks to the likely progression of communicative decline, (3) can help patients and their families understand the condition, and (4) allows the SLT/P to formulate appropriate clinical recommendations.

## Therapeutic impairment-based intervention

As foreshadowed above, assessment is the inception of rehabilitative SLT/P services<sup>13</sup>. The relationship between these two processes is and should be symbiotic: assessment informs intervention targets and intervention informs the outcomes in return. There is a misconception that progressive conditions are ineligible for rehabilitative care. As a result, people living with PPA may be precluded from SLT/P services<sup>6,7</sup>. If a patient chooses to pursue therapy beyond initial evaluation, a SLT/P can offer an impairment-based model to target goals<sup>15</sup>. This option targets improvement—consistent with what the term "rehabilitation" typically evokes—or, in the case of progressive aphasia, maintenance. Naming, an indispensable feature of efficient communication, is a hallmark challenge in PPA. Naming-based interventions can have restorative effects, where results appear most beneficial during the milder stages of condition <sup>4,14-16</sup>. Similarly, script training is proving to be a valuable approach for the nonfluent variant to maintain and improve fluency and grammatical well-formedness<sup>7</sup>. Given the heterogeneity within

a PPA diagnosis<sup>9</sup>, a stage-based approach is not validated, however, impairment-based approaches are likely more effective when initiated early<sup>16</sup>. A person-centered approach, whereby treatment is shaped by joint decision-making, has been advocated by people with PPA<sup>17-19</sup>, their families<sup>17,18</sup> and expert SLT/Ps<sup>1,13,20</sup>. The process of joint decision-making begins when the SLT/P incorporates concepts that the patient identifies as important, and ensures that intervention outcomes, even when limited, are beneficial and transferable to daily acts of living.

### Compensatory and strategy-based intervention

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The overarching goal of PPA intervention is to improve life participation<sup>17</sup>. The relentless decline necessitates practical and person-centered targets<sup>1,13,18,19</sup>. When restorative approaches become increasingly incompatible with a patient's wants and needs, a compensatory approach can be taken in parallel; in fact, employing non-restorative communication strategies at the inception of intervention provides immediate opportunities for improved communication and life participation. For example, as naming becomes more challenging, a patient can employ a range of methods to effectively convey target words, including but not limited to circumlocution (e.g., describing a concept's pertinent features or purpose), writing, drawing, gesturing, using pictures, or playing pre-recorded messages. Augmentative and Alternative Communication (AAC) devices can ameliorate communication breakdowns<sup>20,21</sup>, with options ranging from high tech (e.g., a personalized smartphone application) to low tech (e.g., a paper booklet with fifteen pictures of crucial information). In this therapeutic approach, it is the SLT/P's responsibility to determine and train feasible strategies for a patient to complement their current and future communication<sup>1</sup>. The focus shifts to maximizing functional communication. Collaboratively examining barriers to communication can generate novel solutions, such as a laminated pictographic map of a person's daily walk for them to reference.

### **Communication partners and support groups**

Functional communication is the product of speaker, environment, and communication modality. While we have spoken to the speaker (the person with PPA) and modality (verbal, visual, or gesture-based expression), we have yet to address the role of the environment, or communication partners, in the success of a conversation. The SLT/P can address this issue in two distinct ways: (1) providing communication partner training and (2) facilitating groups intended for people with PPA and/or their communication partners. Often implemented in dyads, communication partner training consists of structured programs<sup>22-23</sup> that aim to enhance interactions by identifying behaviors that obstruct conversations and training strategies to mitigate their effects<sup>22,23</sup>. Whether in-person or virtual, local and national<sup>24</sup> support groups led by SLT/Ps facilitate connections for communities affected by PPA and provide further practice opportunities.

## **Informational counseling**

The role of the SLT/P also entails one-on-one and partner-based counseling to address the emotional and educational needs resulting from a diagnosis and subsequent management of the condition. A diagnosis of PPA compels significant shifts in personal identity, relationships, occupational roles, and daily activities of living, and as such, informational counseling is a pertinent tool for both people living with the condition and those in their direct community<sup>25</sup>. While symptoms are initially restricted to specific language functions, the progressive decline can quite instantly seep into a person's social, professional, and community participation. SLT/Ps have the clinical training and expertise to identify the ways in which PPA can affect behavior and communicative abilities and can therefore provide clinically-informed counseling. Throughout the care journey, counseling empowers patients and their communities by providing

accessible explanations of the condition, recognizing its insidious effects, clarifying the provider team, and introducing concrete strategies to increase engagement and autonomy, problemsolving, and psychosocial support for the acceptance and management of future expectations. As the condition evolves and caregiving demands increase, intensified support for community partners will likely be needed.

#### An evolving role

The role of the SLT/P will evolve as we gain evidence of the SLT/P's impact from clinical trials. In response to these outcomes, training materials and opportunities for ongoing education must be cultivated for future and current SLT/Ps to deliver care that meets the needs of this community. International efforts are required to create accessible and generalizable practice principles and educational resources for SLT/Ps new to this population. Recently, the formation of the International PPA SLT/P network<sup>1</sup> has resulted in collaborations across Australia, Canada, Chile, Hong Kong, India, Norway, Spain, Switzerland, the United States, and the United Kingdom. A recent outcome of this initiative was the creation of best practice principles for SLT/Ps working with PPA<sup>1</sup>. Future work of this network includes the creation of a SLT/P registry for PPA and identification of training needs, with the ultimate aim of improving the PPA patient experience of identifying, receiving, and benefitting from SLT/P services.

#### **Conclusion**

The role of the SLT/P in PPA is imperative to support people living with PPA across all stages of this condition. There is an urgent need for early and frequent referral to SLT/P services for this community, with frequent review (and re-referral if required) to promote maximal benefit from these services. We hope to have illustrated the indispensable nature of this SLT/P in the assessment, care, and management of this condition. A repertoire of evidence-based restorative

interventions for PPA remains to be established to shape procedures of assessment, decision-
making, and informational counseling. These tools will enable patients and their families to
make informed decisions—together—about the support that will benefit them most. Methods to
revise current infrastructures to promote the role of the SLT/P in PPA also remain to be enacted.
The practical implications of this statement are the necessity to (1) heighten awareness of the
SLT/P's clinical expertise and function in working with PPA, (2) connect patients with SLT/Ps
through the means of a registry and referrals, and (3) provide ongoing educational opportunities
for SLT/Ps, neurologists, and neuropsychologists to collaboratively meet the needs of these
shared patients.

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