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Clinical Focus

"Please Don't Assess Him to Destruction": The R.A.I.S.E. Assessment Framework for Primary Progressive Aphasia

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ABSTRACT

Purpose: Speech-language pathologists (SLPs) assess people with primary progressive aphasia (PPA) through measurements of speech, language, communication, and well-being, with the aims of identifying challenges and strengths, monitoring change, and informing treatment directions and supports. The purpose of this clinical focus article is to highlight the necessity for person-centered assessment specific to PPA and to conceptualize a framework that acknowledges the multifaceted nature of assessment for this population. In this framework, the unique challenges posed by a diagnosis of PPA are addressed with the aim to provide practical guidance for clinicians and to support reflection on current practices.
Method: In clinical and research practice, assessment of people with PPA requires an ever-evolving approach that is centered on the client. In this clinical focus article, a discussion-based consensus process was used to synthesize authentic longitudinal experiences of people with PPA to explore assessment approaches, tools, and philosophies.
Results: This analysis of person-centered assessment identifies seven essential components of assessment in PPA that set the foundation for the five steps of the R.A.I.S.E. Assessment framework. These components each contribute to a clear definition of assessment that reveals clients' competencies with a strengths-based focus; prioritizes the reciprocity of benefits; promotes dynamic assessment; and recognizes the complexity, evolution of assessment over time, and advocacy.
Conclusions: This clinical focus article takes a novel look at assessment in PPA by stepping away from assessment practices that focus on revealing deficits and decline and, instead, provides practical recommendations through the conceptualization of a PPA-specific assessment framework. The R.A.I.S.E. Assessment framework is grounded in principles of uplifting clients through person-centered assessment, keeps pace with best practice in PPA intervention, and contributes to a supportive experience for clients and families in the face of a progressive diagnosis over time.

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Case 1

A client with PPA attends the clinic with his spouse. The appointment is led by the medical team, with the speech-language pathologist present. As they sit down, his spouse states, "Please don't assess him to destruction today." When the therapist asks for clarification, the spouse explains that his experience of these

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appointments usually involves a rigorous assessment where the client is drilled into failing and walks away feeling low, dejected, and exhausted. The spouse identified that they already had a diagnosis and were unsure what the experience of assessment added, feeling, if anything, that it was unhelpful.

As in all health care contexts and for all clinical populations, a person-centered approach is essential for the assessment of primary progressive aphasia (PPA), a neurodegenerative and language-led condition, given the multitude of factors that might pervade disease progression, family and care partner support, and client adaptability (Gallée & Volkmer, 2021; Gorno-Tempini et al., 2011; Henry & Grasso, 2018; Marshall et al., 2018; Rogalski & Khayum, 2018; Volkmer et al., 2022). Originally defined in the mid-20th century by the psychotherapist Carl Rogers, we use the term *person-centered* to signify an approach informed and led by the client and guided by the empathetic and responsive clinician (Forsgren et al., 2022; Greene, 2017; Hickey et al., 2017; Kirschenbaum, 2012). This view is consistent with a policy framework put forward by the World Health Organization (WHO, 2007). The then regional director, Shigeru Omi, stated the following on person-centered health care (WHO, 2007):

> As health is influenced by a complex interplay of physical, social, economic, cultural and environmental factors, it must be seen in a broader context, with all stakeholders involved. We need to re-establish the core value of health care, which is health and well-being of all people as the central goal. This entails a more holistic and people-centred approach to health care, and a balanced consideration of the rights and needs as well as the responsibilities and capacities of all health constituents and stakeholders. Health systems, therefore, need to change. (p. 1)

This call for change remains current, and as noted by the WHO (2007), services for people with PPA and their families have not always been experienced as person-centered (Hickey et al., 2017). In this clinical focus article, we outline the necessity for person-centered assessments that serve to lay the foundations for therapeutic services, as well as for life postdiagnosis, and are adaptable to the unique needs and disease progression of every client.

Developing a Person-Centered Approach for PPA

Behavioral assessment of speech, language, and communication is paramount to efficiently and accurately diagnose and subtype PPA as current methodologies to identify biomarkers underlying pathologies in vivo are limited (M. E. Murray et al., 2014; Rabinovici & Jagust, 2009; Rabinovici et al., 2008). As such, premortem clinical phenotyping of PPA depends on behavioral assessment protocols that are reliable and specific to diagnosis and person. While previous work, such as the Living with Aphasia: Framework for Outcome Measurement (A-FROM; Kagan et al., 2008), has addressed the need for assessment in aphasia to be client-directed, we draw attention to the need to consider an assessment framework specific to PPA due to the unique challenges of this progressive condition. While we acknowledge that all diagnoses carry complexity, principles of assessment and treatment developed for chronic aphasia do not address the essential progressive nature of PPA (Volkmer et al., 2021). Moreover, while concepts of person-centered care, informal and formal assessment (Coelho et al., 2005; Hersh et al. 2018), and functional outcomes have been well established in the literature, these concepts have not been comprehensively or specifically applied to the challenges experienced by individuals living with PPA. Although there are overlaps in the symptoms experienced by individuals with both chronic and progressive language-led disorders, the nature of PPA is distinct due its unclear disease onset, progressive trajectory, and the necessity for palliative care considerations. While much of assessment and treatment in chronic aphasia focuses upon improvement and maintenance of language function, an essential aspect of PPA is the continued support needed to accept and appropriately respond to the progressive and terminal nature of the disorder. Consequently, a diagnosis of PPA requires an approach developed specially for this condition.

The purpose of this clinical focus article is therefore to provide a structured framework for assessment that was developed for this target population and to provide support for its necessity. Additionally, we provide clinical guidance to possible assessment approaches and tools, identify the unique role that the speech-language pathologist (SLP; referred to as speech and language therapist by governing boards in Ireland [Irish Association of Speech & Language Therapists, n.d.], New Zealand [New Zealand Speech-language Therapists' Association, n.d.], and the United Kingdom [Royal College of Speech and Language Therapists, n.d.] or as speech pathologist in Australia [Speech Pathology Australia, n.d.]) has in advocating for clients with PPA, share case examples to illustrate the possible range of considerations relevant to assessment in PPA, and, finally, provide clinical tutorials to practice applying our proposed framework to example cases. In tandem with this proposal, we also acknowledge that person-centered assessment can be a challenge and at times feel idealistic, particularly when, for example, clinicians are frequently under time pressure to produce reports containing measures of impairment-level decline. A range of strategies, frameworks,

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tools, and collaborative resources are therefore needed to cultivate best practice person-centered assessment approaches.

Assessment Approaches and Measures

While assessment and diagnosis are inextricably linked, assessment should also be considered a continuous process for monitoring and even potentially skill-building throughout intervention. Hersh et al. (2013) introduced the concept of assessment serving as a therapeutic tool when its usefulness, purpose, and relevancy are made clear to the client. Assessment can take many forms and, when implemented successfully, highlights the client's strengths and capabilities in addition to documenting decline (Hersh et al., 2013, 2018; Korytkowska & Obler, 2016; L. Murray & Coppens, 2013; Thomson et al., 2018). These features are especially important when evaluating change in a continually evolving disease. Conversely, unsuccessful assessment is underspecified, focused on weaknesses, and disconnected from client feedback. Furthermore, inadequate scaffolding and support can result in obfuscating the client's true potential and negatively impacting their perception of assessment and their own outcomes. Formal assessment has been defined as consisting of standardized test protocols (e.g., published assessment tools with outcome norms; Coppens & Simmons-Mackie, 2018; L. Murray & Coppens, 2013; an exemplar being the Western Aphasia Battery–Revised [WAB-R]; Kertesz, 2007). In contrast, informal assessment utilizes clinician observations based on qualitative impressions, client self-report, or quantitative data that cannot be scored relative to a normative sample (Coppens & Simmons-Mackie, 2018; L. Murray & Coppens, 2013; Thomson et al., 2018). Informal assessment might occur within a conversational exchange and often has a relational focus between the clinician and the client. A necessary distinction between assessment and the approach taken must be made; just as a standardized assessment can be utilized in an informal way (e.g., by only administering half the test items in one sitting or not adhering to the scripts provided by the testing manual), a formal approach can be implemented using a test battery consisting of informal assessments. Consistent with this point, the term *informal* is synonymous with *nonstandardized* (Coelho et al., 2005) while remaining deliberate, skill-based, dynamic, and/or in line with the needs of the client (Coppens & Simmons-Mackie, 2018; Hersh et al., 2018; L. Murray & Coppens, 2013).

To be most responsive to clients, the approach and assessment types selected by the clinician are dependent on knowing clients well and being in line with their expectations. This can be achieved through a decision-making process shared by both the clinician and client, where the clinician guides the discussion in response to client requests and input. Ideally, this process would begin with a case history or "ethnographic interview" to foster rapport and get to know the person, and their support needs at the time of the assessment (Douglas & Hickey, 2015; Hickey et al., 2017). Regardless of the assessment tools selected, a crucial component of the assessment approach is the manner in which the tools are introduced and the results of these being subsequently communicated to both the client and care partners. What occurs before, during, and after the assessment is essential to prevent either gatekeeping or overburdening the client with information.

An informal approach to assessment can be the key to incorporating clinician, client, and care partner needs and values. As stated earlier, the term *informal* by no means reflects an aimless, ineffectual, or unstructured approach; instead, we use this term to denote a responsive and flexible pathway to complete a comprehensive assessment of a client's wants and abilities (Hersh et al., 2018; Korytkowska & Obler, 2016; L. Murray & Coppens, 2013; Thomson et al., 2018; Winner & Crooke, 2009). The informal approach is a framework that builds upon a person-centered approach and takes place in collaboration with the client and care partner(s). While it might seem counterintuitive, an informal approach to assessment *can* and *does* include standardized measures of specific cognitive and linguistic capacities. In contrast to a more formal approach, the manner in which the informal evaluation is conducted is largely determined by the affect, communicated needs and values, and observed strengths and difficulties of each unique client in front of the clinician. More often than not, casual conversation to get to know the client and their individualized situation is used to put them at ease (Douglas & Hickey, 2015) to ascertain essential information, ensure that their performance on standardized assessments has been optimized, and guide decisions for the next steps of the assessment process.

In this clinical focus article, we argue that that assessment goes beyond data collection to guide clinical judgment and, instead, poses the opportunity to establish person-centered care, provide clarity, and benefit all members involved in the evaluation by raising the needs of the client to the forefront. We accomplish this by characterizing the many factors that influence assessment for people living with PPA, providing illustrative case examples, and conceptualizing a framework to guide clinicians treating this population.

Method

Participants

The authors and participants of this clinical focus article represent a group of international clinical academics who evaluate and treat individuals with PPA and have

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formed a working group on principles of assessment for this population. Four out of five of these participants collaborated on establishing best practice principles for treatment selection and delivery for people living with PPA using a nominal group technique (NGT; Harvey & Holmes, 2012; McMillan et al., 2016) and two subsequent focus group meetings (please see the study of Volkmer et al., 2022). The NGT was completed in two stages. In the first stage, focus group members shared best practice principles related to treatment selection and delivery. Then, each focus group member provided a ranking for their personal top eight components to create a groupwide ranking. In the second stage, the focus group members provided a reranking of the group-level ranking. A person-centered approach was established as the premier best practice principle for PPA and (re)-assessment as an essential need for this population. The working group described in this clinical focus article was derived from individual members expressing interest in these two topics. The fifth participant was invited to the working group for principles of assessment for PPA based on their clinical expertise and established history of collaborative work for this population.

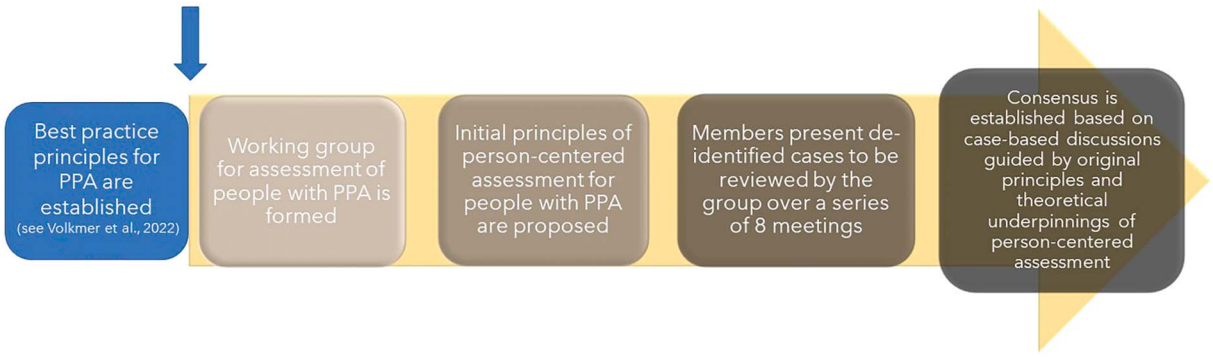
Procedure

Grounded in the process of the NGT and focus group described previously, a consensus process (Hornby et al., 2019) was utilized to continue the discussions to develop principles for assessment with the members of this working group (see Figure 1). The original Delphi consensus process upon which this study is based can be reviewed in work by Hsu and Sanford (2007) and by Hornby et al. (2019). Briefly, the Delphi consensus process is an iterative procedure that can be implemented to achieve various objectives, including but not limited to establishing a consensus and informed judgments on a topic of a particular discipline (Dalkey & Helmer, 1963; Hornby et al., 2019; Hsu & Sanford, 2007) and to identify potential areas that might benefit from improvement (Miller, 2006, as cited in Hsu & Sanford, 2007). The iterative nature of this process is an essential feature, where group members complete a minimum of three rounds (however, more may be completed) to gather and converge expertise on the topic of interest. In order to achieve these, the members of this working group participated in a total of eight meetings between July 2021 and April 2022 to synthesize authentic longitudinal experiences of people with PPA utilizing narrative reviews.

In contrast to the original Delphi consensus process, there was no steering committee to guide the questionnaire process as original conversations were born out of the previously described methods in the study of Volkmer et al. (2022). Furthermore, the initial two rounds of data collection, in the form of discussions related to the components of person-centered assessment, were not anonymous (Hsu & Sanford, 2007). At the initial meeting, a series of statements of essential elements, or components, of assessment in PPA was proposed by the first author. These components were proposed to be the following:

1. Usefulness: the need to create assessment protocols that are not distinct from treatment or treatment goals for the patient, families, and care partners;
2. Dynamism: the need for assessment and treatment to remain relevant and tailored to the individual in the face of a progressive disease;
3. Complexity: the multitude of factors that can affect the *functional impact* of disease process and how this may differ across patients, families, and caregivers;
4. Messiness: based on the definition that messiness describes a situation, object, or event that is "unpleasantly difficult to resolve or settle" (https://www.thefreedictionary.com/messiness; retrieved on September 12, 2022), a diagnosis of PPA is messy from the onset as there is no acute episode that can help backtrack the origin of symptoms; the resulting instability (Marshall et al., 2018) continually grows

Figure 1. The consensus process implemented by the working group to establish a framework for person-centered assessment of people with primary progressive aphasia (PPA).



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over time due to the complexity of factors that can impact a person's trajectory and care; and

5. Specificity: as of now, many assessments used for people with PPA have been adopted from other fields, most commonly poststroke aphasia. While these may be sufficient, these standardized protocols can fail to recognize change from baseline for people with progressive change—particularly as these assessments may not capture individual differences in terms of language capabilities as well as language use.

These statements were then evaluated in detail by each of the group members over time at each of eight working group meetings. At each meeting, group members were asked to present de-identified client cases and personal experiences with assessment and approaches to care. These were then reviewed by the group as a whole to determine the relevancy and appropriateness of these initially proposed statements, or components, of person-centered care for people with PPA. The components of person-centered assessment presented in the results section of this clinical focus article were modified and selected from those originally presented. This process was guided by interactive case–based discussions and theoretical underpinnings of person-centered care. Then, these components were used to formulate a framework for person-centered assessment unique to PPA. Group consensus for the components and framework was established through case analysis and narrative discussions about the themes drawn from each of the longitudinal cases (see Figure 1). Thus, a framework consisting of concrete clinical guidance was born based out of the working group's initial discussions on assessment in the context of best practice principles for PPA (Volkmer et al., 2022), guided by the identification of essential components of person-centered care for PPA, and established through a case and discussion-based consensus process. Meeting notes were taken to document these discussions. Ten cases based on authentic experiences with the discussed clients are included in this clinical focus article to illustrate these themes. The outcomes of these discussions established that assessment itself is a longitudinal process, as evidenced by its role in the multiple time points presented for each unique client in shaping and informing care. Additional case scenarios with reflection questions can be found in the Appendix.

Results

Characterization of the Problem Space

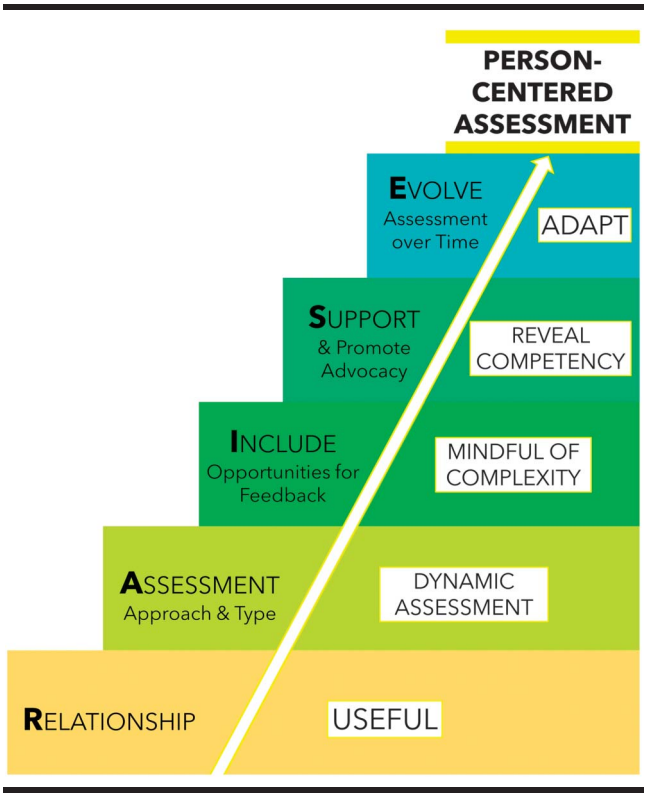
The characterization of the problem space of assessment in PPA is as multifaceted as PPA itself. To guide our considerations, we have identified a framework with five essential steps built upon seven essential components that a clinician must explore to successfully navigate PPA assessment (see Figure 2) and to best advocate for our clients as SLPs. We begin by asking a fundamental question: What constitutes person-centered assessment in PPA? We then offer those components to best guide clinical practices in terms of which assessment measures and approaches to adopt in this process.

Component 1: Defining the Scope of Assessment

Case 2

A client with a diagnosis of logopenic variant PPA (lvPPA) was seen for an initial speech pathology assessment. After the session, she commented to her spouse, "I'm not a kid!" The client perceived the black-and-white line drawings, described as "a seaside scene with a starfish and a bucket," to be out of a

Figure 2. The R.A.I.S.E. Assessment framework. As guided by the clinician's toolkit of creating assessment that is based in the relationship between the client, clinician, and care partners, the R.A.I.S.E. Assessment framework provides concrete recommendations that lead to the "raising" or uplifting and elevation of the client's assessment experience. The five steps of the framework consist of concrete clinical guidance that incorporate the seven components identified in the consensus process by the working group.



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coloring book and felt like the SLP was geared toward children, asking her to "tell stories" and recall fairy tales. The spouse's facial expression when recounting this assessment experience was one of disbelief, acknowledging that while the SLP was "lovely" and meant well, the client did not respond well to the interaction at all. She refused to return to speech pathology services until some years later, by which time her communication difficulties had progressed. Her subsequent experience was more positive because assessment was not structured and more of a conversation; to her surprise, this was something she enjoyed and looked forward to.

Our first component addresses the question of what constitutes assessment itself. We have begun our definition of assessment by providing a distinction between assessment approaches and assessment measures. For the latter, we must also ask ourselves the following question: What kinds of measures are appropriate for assessment of PPA based on current availability? Furthermore, how does the practice context influence the accessibility or availability of certain measures? The overarching advantages of standardized assessment are, first, to provide the clinician with the opportunity to compare performance to normative data and, second, to adhere to standardized procedures that can be compared within and across client samples, factors that are particularly pertinent in diagnostically oriented assessment.

Possible disadvantages of standardized measurement tools include the relative rigidity of testing procedures and selective scopes of isolated subdomains of speech and language, thus giving rise to the possibility that outcomes do not correlate to everyday performance, as well as the well-documented cultural–linguistic bias inherent in many standardized tools (Brown et al., 2011; Centeno et al., 2020; Ellis & Peach, 2017; Milman et al., 2014, 2018; Molrine & Pierce, 2002). It should be noted, however, that not all standardized assessments restrict the domains of assessment; hypothesis-driven assessment used, for example, within cognitive neuropsychological approaches to assessment, and drawing on such tools as the Psycholinguistic Assessment of Language Processing in Aphasia (Kay et al., 1996) or the Comprehensive Aphasia Test (Swinburn et al., 2005) encourage flexibility in guiding, confirming, and revising hypotheses of the language components contributing to the communication difficulties (Nickels, 2008). Such tools do, however, generally remain focused on subcomponents of speech and language rather than the realm of interactive communication. Advantages of informal assessment tools, in contrast, enable the clinician to adapt tools and resources to best meet the client's unique presentation and context, introducing an even greater fluidity to the process. Conversely, informal assessment tools are heavily reliant on the clinician's interpretation and implementation abilities, in addition to their level of experience, confidence, and comfort in working with people with PPA and/or other neurodegenerative conditions. While not exhaustive, a representative set of informal and standardized measurement tools commonly used can be found in Table 1, presented according to formality type (informal versus formal) and the domain(s) assessed by each tool. This categorization aims to guide clinical decision-making regarding which tools may best serve to assess a client for different purposes.

As of now, many assessments used for people with PPA have been adopted from other fields, most commonly poststroke aphasia. While these may be sufficient to identify strengths and weaknesses, these standardized protocols might fail to identify change for people with progressive language loss, particularly as these assessments may not be sensitive enough to capture individual differences in terms of *language capabilities* as well as *language use*.

Furthermore, assessment must be specific enough to reveal a client's competencies in isolated domains (e.g., lexical retrieval, phonological retrieval, and picture–word matching) but broad enough to ascertain the functional contributions of each of these domains in the client's communicative success in a variety of contexts (Gallée & Volkmer, 2021). Most importantly, the strengths we wish to highlight and leverage in our treatment sessions are often revealed through *interaction* and thus dynamic assessments that are activity based are needed (Hersh et al., 2018).

Component 2: Revealing Competency

By first defining our aims of assessment, we can transition to identifying essential components that allow us to cultivate person-centered assessment. We begin with revealing competency in our clients. A predominant focus of standardized assessment is that of identifying areas of weakness or impairments, rather than the capacities and strengths of each person. While identifying impairments is often essential for diagnosis, this approach is rather paradoxical in the face of the well-accepted Life Participation Approach to Aphasia (LPAA), where the aim is to enhance all client experiences rather than solely targeting traditional language goals (Chapey et al., 2000; Rogalski & Khayum, 2018; Ruggero et al. 2019). A conceptual framework that more specifically identifies the need for client and care partner input and relevancy of assessment outcomes to everyday functioning is the A-FROM, where an approach to assessment in aphasia is guided through the lens of the client's aphasia diagnosis and severity, unique identity as it relates to their beliefs and needs, communicative contexts, and participation in everyday activities (Kagan et al., 2008). Standardized assessments of isolated domains of language may tell us about components of the communicative profile of a client; however, the completion of these measurement

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Table 1. Examples of measurement tools commonly utilized in the assessment of individuals with primary progressive aphasia.

Assessment type	Measurement type	Examples
Informal	Self-report	Client's response to prompts related to speech, language, and communication capabilities (e.g., "Tell me about moments of success in your daily communication"; "How do you respond to moments of communication difficulty?").
	Clinician and client collaboration to determine client-specific goals	Living with Aphasia Framework for Outcome Measurement (A-FROM; Kagan et al., 2008) tool
	Clinician ratings and observation	Subjective evaluation from multimodal measures, including but not limited to observation of spontaneous speech, client and partner report, observation during conversation and activities, behaviors and performance on and during standardized assessments (e.g., Progressive Aphasia Severity Scale [PASS]; Sapolsky et al., 2014).
	Personal narrative	A story from childhood, a recent event, or a personal narrative (e.g., "Tell me about a typical Sunday") with or without visual supports or structured elicitation (e.g., Curtin University Discourse Protocol [CUDP]; Whitworth et al., 2015).
	Discourse analysis	A conversation between the client, clinician, and/or familiar conversational partner with or without structured elicitation.
Standardized	Cognition	Systematic assessment of the client's impaired and/or preserved cognitive functions, such as the Montreal Cognitive Assessment (MoCA; Nasreddine et al., 2005); Cognitive-Linguistic Quick Test (CLQT; Helm-Estabrooks, 2001); St. Louis University Mental Status Exam (SLUMS; Shwartz et al., 2019); Mini-Mental State Exam (MMSE; McDowell et al., 1997); and The Comprehensive Aphasia Test "The Cognitive Screen" (CAT; Swinburn et al., 2005).
	Picture naming	Assessment of the client's ability to retrieve words, often manipulating features such as word frequency, imageability, and/or word length. Examples include the Boston Naming Test (30- or 60-item; BNT; Kaplan et al., 2001), CAT "Spoken Language Production: Naming Objects" and "Spoken Language Production: Naming Actions" (Swinburn et al., 2005) subtests.
	Verbal fluency	Assessment of the client's ability to retrieve words within restricted search parameters (e.g., specified category or letter) and in a given time, such as, the WAB-R "Word Fluency" subtest (Kertesz, 2007); categorical (animals) or letter fluency (F, A, S) within 60 s (Eng et al., 2019; Monsch et al., 1992; Rees et al., 1998).
	Articulation	Assessment of motoric aspects of speech production, including intelligibility or a profile of phonemic errors produced (e.g., on the BNT; Kaplan et al., 2001).
	Single-word comprehension	Assessment of the client's ability to identify the meaning of verbally presented words, often measured through picture–word matching such as in the Cambridge Semantic Battery (CSB; Adlam et al., 2010) or Pyramids and Palm Trees (PPT; Howard & Patterson, 1992) test, where the client can use nonverbal responses to identify the corresponding pictures (e.g., pointing).
	Repetition	Assessment of the phonological store of verbal information as it links to articulatory rehearsal, often measured through the client's ability to repeat verbally presented phrases of increasing length utilizing subtests such as the WAB-R "Repetition" (Kertesz, 2007) or CAT "Repetition" (Swinburn et al., 2005) subtests.
	Auditory comprehension	Evaluation of the comprehension of spoken questions or instructions requiring either verbal or nonverbal responses using assessments like the WAB-R "Auditory Verbal Comprehension: Sequential Commands" and "Auditory Verbal Comprehension: Auditory Word Recognition" subtests (Kertesz, 2007) or CAT "Language Comprehension: Comprehension of Spoken Words," "Language Comprehension: Comprehension of Spoken Sentences," "Language Comprehension: Comprehension of Spoken Paragraphs" (Swinburn et al., 2005).
	Syntax	Evaluation of the nonverbal production of specific syntactic constructions given constraints such as in the Northwestern Anagram Test (NAT; Weintraub et al. 2009).
	Reading	Assessment of decoding and reading comprehension skills of sentences and short stories. Examples include the WAB-R "Reading" (Kertesz, 2007) and CAT "Reading" (Swinburn et al., 2005) subtests.
	Writing	Assessment of the client's ability to convey single words, short sentences, or narratives through written expression. Examples include the WAB-R "Constructional, Visuospatial, and Calculation Tasks" (Kertesz, 2007) and CAT "Writing" (Swinburn et al., 2005) subtests.

(*table continues*)

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Table 1. *(Continued).*

Assessment type	Measurement type	Examples
	Procedural, recount, or expository discourse	Evaluation of the client's abilities to communicate a sequence of activities or events in an accurate and communicative manner using prompts, or topics, of commonly known or culturally relevant stories with and/or without visual supports, such as the Peanut Butter and Jelly Sandwich and the Cinderella Story (https://aphasia.talkbank.org/protocol/english/; Stark, 2019). The CUDP (Whitworth et al., 2015) allows comparison of a range of genres, including narrative, procedural, recount, opinions, and conversation, to assess multilevel organization of discourse using a "story grammar" framework.
	Picture description	Evaluation of the client's abilities to communicate a sequence of events describing visual supports in a plausible or appropriate manner. Examples include the "Broken Window" (Menn et al., 1998) and "Cat Rescue" (Hameister & Nickels, 2018; (https://aphasia.talkbank.org/protocol/english/) stories, the WAB-R "Picnic Scene" (Kertesz, 2007), and the CAT "Spoken Language Production: Spoken Picture Description" subtest (Swinburn et al., 2005).
	Clinician rating	Standardized evaluation of the clinician's subjective assessment of the client's communication and participation abilities, such as the Aphasia Severity Rating (ASR; Simmons-Mackie et al., 2018), Measure of Skill in Supported Conversation (MSC; Kagan et al., 2004), and Measure of Participation in Conversation (MPC; Kagan et al., 2004).
	Self-rating	Standardized evaluation of the client's subjective assessment of their communication and participation abilities, such as the Communication Confidence Rating Scale for Aphasia (CCRSA; Babbitt et al., 2011; Cherney et al., 2011), Aphasia Needs Assessment (ANA; Beukelman et al., 2007), Communicative Effectiveness Index (CETI; Lomas et al., 1989), and CAT "The Aphasia Impact Questionnaire."

tools can be arduous, demotivating, and potentially of little use to the client when seemingly removed from the context of everyday communication (Hersh et al., 2018; L. Murray & Coppens, 2013). We often use these assessments to confirm what we and the clients already suspect to be the case: for client performance to be evaluated as challenging or impaired in certain domains of communication. While confirmation can be essential to validate a client's lived experience and to provide optimal care, assessment must be implemented with informed purpose. A more productive approach to assessment that establishes a communicative profile while highlighting the client's dynamic strengths is therefore warranted. Moreover, creating moments of success, such as through a comfortable exchange with a typical conversation partner, might serve to set the client up for success such that they then perform at their best (Walsh, 2007; as cited in the study of Hersh et al., 2018). It therefore follows that a more informal approach to assessment may highlight a client's strengths and heighten their confidence while also gathering necessary data on their capabilities and positive coping strategies to formulate an informed treatment plan. Furthermore, regardless of which tools are utilized in the informal approach, the process of assessment can become person-centered, accessible to the client, and a positive experience that underpins future care and/or intervention. Examples of an informal or person-centered adjustment to an assessment protocol might include eliciting valuable picture description data through a client's personal photograph instead of the WAB-R "Picnic Scene" or through conversation involving a recall of a personal event.

Discourse has been proposed to provide a dynamic, reliable, and adaptable measurement tool in PPA (Beales et al., 2018; Gallée et al., 2021; Gallée & Volkmer, 2021; Nevler et al., 2018; Whitworth et al., 2018; Wilson et al., 2010), as well as a focus and context for intervention (Gallée & Volkmer, 2021; Volkmer et al., 2018, 2021; Whitworth et al., 2018) that can be leveraged to highlight a person's unique strengths and difficulties. Continuous assessment of discourse can provide insight into a client's functional participation in their everyday environments and communicative contexts. However, the lack of unifying theories across the established methods to evaluate the various levels of discourse (Battista et al., 2017), not least influenced by the inherent variability in the nature and use of spoken output, requires further work for consistent comparison across timepoints or across clients to be made (Bryant et al., 2016; Dipper et al., 2021). Therefore, selecting measures that are appropriate to the individual but can also be purposed for a wider range of clients in terms of interests, background, and specific language impairment is essential for the assessment of speech, language, and communication in PPA.

Measures of spontaneous output, frequently elicited in conversation, as well as prompt-elicited discourse (e.g., a picture description or procedural narrative), appear to provide the most comprehensive insight into a client's functional communication abilities in lieu of collecting this information in real-world contexts (e.g., observing the client in shops or in social interactions in familiar contexts; Gallée et al., 2021; Gallée & Volkmer, 2021). Picture descriptions can also provide a blend of spontaneous

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discourse in the context of constraints visible to both the clinician and client through the use of clear visual supports. Furthermore, the client is provided the opportunity to describe features that are most salient to them, allowing for individual differences between clients. However, while the evaluation of a client's ability to describe specific objects, agents, and actions in pictures can be standardized, the descriptions can easily evolve into listing of elements rather than cohesive narratives (Beales et al., 2018; Stark, 2019). Conversely, more open-ended prompts, such as personal narratives, can make it difficult for a clinician to assess the relevance and appropriateness of the content words the client provides, requiring judicious consideration of the most appropriate measures or analytical approach for a particular discourse sample.

While each of the measurement tools listed in Table 1 provide insight into client performance, we caution against an overreliance on numbers and outcomes that may not translate into everyday participation and a person's perception of life satisfaction. For example, while we may acknowledge an assessment's diagnostic and theoretical value, point differences on, for example, elicited responses such as, "It is the girl that the boy is pulling," on the Northwestern Anagram Test (Weintraub et al. 2009; e.g., creating a sentence out of printed words to describe a picture constrained by a specific type of grammar) might provide little clinical insight for progress monitoring or skill-building if a client does not need to use such target grammatical constructions in their daily communication. In contrast, assessments that probe functional communication, such as the Communicative Effectiveness Index (Lomas et al., 1989), may provide more comprehensive insight into a client's successes and difficulties in daily activities of living. Overall, significant differences in performance between diagnostic cohorts or across time must be taken into consideration and interpreted in context (e.g., 25% vs. 30% accuracy on a naming task might be a statistically significant difference but not indicative of a salient change in everyday communication or participation ability to the client and their care partners). It therefore follows that an informal protocol that combines assessment tools to efficiently characterize performance in a manner that is functional and reproducible to the individual client is paramount. This brings us to the need for *reciprocity of benefit* and the assurance that assessments are *useful*.

Component 3: Reciprocity of Benefit

Case 3

A client diagnosed with nonfluent variant PPA (nfvPPA) is scheduled for an 11:00 appointment with an SLP. Due to scheduling changes, the client will be evaluated in a room that is several corridors down from the waiting room. The clinician observes that the client is nervous and initiates informal conversation to relieve tension. The client is responsive to this and provides multiple sentences to every question. Once in the assessment room, the clinician begins the session through open-ended prompts, including, "Tell me about your weekend," and "How has work been treating you?" The client bristles, visibly frustrated, and states, "You already asked me all those questions!" and, when prompted, begrudgingly provides a significantly more pared down version of the original responses. The clinician redirects the assessment to more constrained tasks but observes the client to exhibit limited affect and participation for the rest of the session. In the waiting room, the client is overheard stating, "She didn't listen to me!" when asked how the evaluation went.

As illustrated in Case 3, assessment can be a frightening, as well as confusing, experience for clients, particularly when the intent or purpose of the evaluation measures is left unclear. In such instances, any mutual gains in undertaking the evaluation protocol are obfuscated and can directly impact client performance and trust in the process. Assessments are often viewed as primarily informing the referring agent or the funding body or leading to a more formal care plan that may not be seen as directly related to the client. However, to foster a person-centered approach, assessment must be mutually beneficial for the client, care partners, and the treating clinician and, furthermore, be driven by an ongoing collaboration of these individuals (Hersh et al., 2013, 2018). Regardless of the measurement type used in assessment, usefulness can be instilled or clarified through opportunities for feedback, explanation, and working in partnership with the client and their care partners. Furthermore, assessment protocols should be reflected in intervention and thus should not be distinct from treatment or treatment goals. Instead, assessment should be considered to be the inception of therapeutic support and integrated into the intervention process (Hersh et al., 2013) to proactively support the client and care partners (Volkmer et al., 2022). Therefore, in order to be maximally beneficial, assessment protocols should continually evolve to:

1. incorporate client, family, and care partner feedback (Bright et al., 2012; Denman, 1998; Forsgren et al., 2022; Hersh et al., 2012, 2013; Howe et al., 2012; Ruggero et al., 2020; Sherratt et al., 2011);

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2. reflect and build upon the relationship between the client and the clinician (Bright et al., 2021; Cohen-Schneider et al., 2020; Coppens & Simmons-Mackie, 2018; Forsgren et al., 2022; Hersh et al., 2012; Worrall et al., 2010); and
3. be completed in partnership with the client and others involved in care (Chapey et al., 2000; Coppens & Simmons-Mackie, 2018; Forsgren et al., 2022; Hersh et al., 2012, 2013, 2018; Howe et al., 2012; Kagan et al., 2007).

Case 4

A client with a diagnosis of nfvPPA was seen for a review appointment in the medically led memory disorders clinic. The client was diagnosed with nfvPPA a number of years ago. During the review appointment, the doctor assessed the client's comprehension and expression, asking him to do tasks he found quite challenging, including an oral motor assessment, repeating long sentences, picture description tasks and complicated sentence comprehension tasks drawn from a formal assessment book. Following the assessment, the relative telephoned the SLP and reported that the client typically found these review sessions very distressing. The relative reported that he never recovers from these experiences and that they have noticed a step down in function each time they attend.

In our advocacy of a more informal and person-centered approach, we recognize that the various demands across assessment settings can limit a clinician's ability to implement personalized testing protocols. In addition to the standards or expectations set by the testing environment, the relationship between the clinician and client is highly dependent on plans for prospective care. For example, if the initial evaluation occurs in the context of an assessment-only clinic, assessment goals and plans transition to the subsequent treating clinician, who may utilize an alternative approach to complement the standardized protocols used for diagnosis. Furthermore, the continuity of care may be restricted to annual assessments if the client only seeks diagnosis and forgoes therapeutic support. Regardless of the assessment constraints or imminent therapeutic outcomes, relational building between the clinician and client must remain central to the assessment interaction as it enhances performance and fundamentally aims to benefit the client. Moreover, benefit should begin at the time of assessment and not at the onset of therapy, a concept described as *therapeutic assessment* (Hersh et al., 2013). As such, an informal *approach* to assessment that is responsive to the unique client remains a fundamental aspect of enhancing client care.

Component 4: Dynamic Assessment

Case 5

The clinician has prepared various testing manuals and laid them out on the table across from the client with a year-old diagnosis of lvPPA. Upon viewing the paper protocols, the client exclaims, "Yuck! Not those." When the clinician redirects the conversation toward small talk, the client is notably encouraged and shares, "I feel fabulous! I just finished up building the new bird watching observatory in my gazebo." The clinician observes the client's enthusiasm and motivation to discuss this topic. As such, the session protocol consists of conversation analysis and informal assessment of lexical retrieval, articulation, syntax, and speech fluency through an audio and video-recorded conversation between the clinician and the client. The client's use of visual supports (e.g., pictures of her birds) and gestures are captured through the video recording. The care partner participates sporadically and provides intermittent clarification and verbal supports allowing for indirect assessment of care partner support in conversation. By the end of the allotted time slot, the clinician has gathered a comprehensive picture of the client's strengths and participation in daily activities of living. Additionally, the clinician has gained the client's trust due to the investment in relationship-building. This is particularly apparent when both the client and care partner exit the evaluation in good spirits and warmly state, "See you very soon!" upon saying goodbye.

Assessment, as well as the assessor, must remain dynamic, relevant, and tailored to the individual in light of the progressive nature of the disease and the continually evolving needs of the client, family, and care partners. Successful implementation of these elements can result in optimized outcomes, as demonstrated in Case 5. The heightened need for dynamic assessment is a direct response to the instability of PPA (Marshall et al., 2018). In contrast to impersonal and static procedures, dynamic assessment allows us to capture the iterative nature of assessment throughout treatment (Hersh et al., 2018; L. Murray & Coppens, 2013) in addition to the ever-evolving nature of the unstable, progressive condition. Furthermore, dynamic assessment allows clinicians to layer aspects of assessment with speech and language treatment. In particular, a dynamic procedure allows for the clinician to identify the skills of a client, as well as their learning potential; in an adaptable procedure, the clinician can work to identify and then implement the scaffolds and supports the client may need to achieve a particular language goal.

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Component 5: Mindful of Complexity

Case 6

A client with a likely diagnosis of semantic variant PPA (svPPA) attended an SLP appointment for assessment in the presence of their partner. The client had initially reported a plan for early retirement within the next 4 weeks but stated at the start of the session that they may not retire and that he needed to decide what to do. His partner looked visibly alarmed and shared that the client was best kept busy and that she was unsure as to how to best support him. As a consequence, the assessment was abandoned and the session's focus was a discussion surrounding retirement, personhood, and activities in which the client felt he could engage in. Furthermore, routine planning utilizing a variety of strategies, including visual schedules with step-by-step instructions, was discussed to assist with the transition.

In addition to being adaptable to varying levels of support, evaluations must be reflective of the multitude of factors that can influence the *functional impact* of disease processes and how this may differ across clients and care partners (see Case 6). Therefore, the focus of one person's therapy may greatly differ from another's (e.g., finances, time constraints of the family, and current occupational obligations; Volkmer et al., 2022). Importantly, this consideration must be made in addition to the *clinical complexity* of PPA and the variant-specific disease progressions. Thus, beyond establishing goals for communication, counseling can be implemented continuously to help maintain hope and motivation. While needs and requests for counseling will vary greatly according to client and care partners, dynamic responsiveness to these needs will allow for a better understanding, digestion of, and grieving around the diagnosis and the changes that it brings.

The complexity of a PPA diagnosis is further exacerbated by the possible lack of structure that can characterize disease process and client response. One person with PPA treated by one of the authors provided a powerful reflection when asked about the onset of his symptoms: *"But when did my symptoms start?" he wondered. "Was it when I couldn't say my new hire's name? When I avoided lengthy conversations with my neighbors on my morning walks? When I couldn't count backwards from 93? Or when others began to see?"* As illustrated by this quote, the complexity of a diagnosis of PPA is heightened by the inherent difficulty in establishing a disease onset, as there is no acute episode that can help us backtrack the origin of symptoms. Therefore, a fundamental distinction between injury-related and dementia-led aphasia is that there is no clear onset of the latter. An official diagnosis of PPA likely does not correspond to the true onset of behavioral change as a diagnosis is dependent on when a person seeks and receives assessment, which is, in part, determined by individual differences, variability in symptoms and decline (Khayum et al., 2012), access to resources, and community support, as well as the actual care that clients receive (Besser & Galvin, 2020). Due to the complexity of the many factors involved in shaping a person's trajectory and the received care, disease onset and determination can appear quite random.

At every level of the disorder, there are unique and complex challenges that cannot always be anticipated due to case-specific trajectories; it can be impossible to prepare or anticipate for every individual as the disease, situation, and environments progress. Moreover, staging of disease can be unique to the variant and person and how it unfolds for a particular person, despite our knowledge of what may generally occur within a specific variant (Volkmer et al., 2022). Additionally, the individualized goals of the client and care partners can be distinct from performance on standardized assessments and/or capacity and support needs (Cohen & Hula, 2020; Rohde et al., 2012). This can lead to unique challenges and frustrations for all persons involved in the process. Due to the instability and individual nature of the disorder, assessment, perhaps both in approach and measures, should be dynamic, personalized, and flexible.

Component 6: Adaptable Over Time

Case 7

The clinician prepares a handout requested by a lvPPA client who has been receiving private SLP services for over 2 years. In this handout, all previous and current outcomes on standardized assessments are listed in a table. Changes in scores are indicated in red. The clinician updates this handout on a 3-month schedule in response to the client and care partner's expressed interest in documenting concrete and numerical change in performance.

Finally, for clinicians to be able to appropriately adapt intervention and care to the needs of people living with PPA, an indispensable feature of assessment protocols for PPA is their capacity to monitor change over contexts and time (Gallée & Volkmer, 2021; Volkmer et al., 2022). This means that an assessment at the start of someone's journey might comprise a formal standardized assessment, exploring areas of semantics, lexical access and phonological representations at single word, sentence and conversational level to gain a deep understanding of the cognitive strengths and difficulties, and inform diagnosis

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(Henry & Grasso, 2018). Equally, we may elect to undertake observational assessment during a conversational interaction with the same client, at a later date, when they are no longer able to participate in more formal assessments but continue to benefit from clinical advice to support speech, language, and communication. Furthermore, beyond the changes captured by these protocols, client and care partner requests and needs will equally evolve with time. Our role as clinicians is to determine (a) what information is requested and (b) what we must accomplish and learn in order to provide the requested care.

Case 8

A client had a diagnosis of nfvPPA and has been going to speech and language therapy for a number of months. They had been seen only via teletherapy due to the restrictions associated with the COVID-19 pandemic. They were currently awaiting a face-to-face review appointment with the medical team, which had been canceled a number of times. The SLP observed the client having difficulties with eye blinking, and they were reporting problems in eating and drinking. Aside from an oropharyngeal dysphagia, this included difficulties in using cutlery with the right hand. Further to a thorough dyspraxia assessment and oral motor exam, the SLP raised these concerns with the medical team. The team was able to prioritize a face-to-face appointment with this client and they were diagnosed with an underlying corticobasal syndrome (CBS). The speech and language therapy team then planned to review their swallow needs, alongside their communication needs, on a more regular basis.

We also may need to modify our assessment protocols to capture new emerging symptoms as dependent upon the evolving underlying pathology. A detailed cranial nerve and dysphagia assessment, alongside a motor speech and language assessment, may be critical to informing the medical diagnosis of a nfvPPA with an underlying progressive supranuclear palsy in contrast to a concurrent diagnosis of CBS, frontotemporal dementia, or lvPPA consistent with an etiology of Alzheimer's disease or co-occurring with CBS (Marshall et al., 2018). Moreover, as a consequence, this assessment may differentially inform the guidance on anticipatory care needs for the individual and their family members. Motor concerns, such as swallowing difficulties, are particularly essential to identify to better prepare for future needs or additional assistance within or outside of the home.

Case 9

A client who received a diagnosis of svPPA 5 years earlier attended weekly support group sessions and bimonthly private SLP services upon the request of his partner. The client's partner had also encouraged him to participate in conversation training to boost his communicative success at home. Recently, the partner has sought additional counseling services due to the frequent observation that the client had begun to emotionally withdraw from their relationship and daily routines that used to bring joy. More strikingly, the client had been overheard making statements such as, "Might as well end it now before it's too late," and to repeatedly write lists related to possible life-ending procedures in a small black notebook throughout the day. The partner pleaded that the clinician refrain from sharing recent assessment scores that revealed a significant decline in picture–word matching and verbal comprehension in hopes of promoting motivation for the client. The clinician honored this request and continuously conducted informal assessments of speech and language abilities through their bimonthly interactions.

The nonlinearity of treatment approaches for PPA is informed by the multitude of factors that impact the type of help a person living with PPA seeks and the help that is made available to them. Individualized provision of information is necessary to best meet the needs of the client and their care partners (Beales et al., 2019; Coppens & Simmons-Mackie, 2018). When it comes to a consultation or evaluation for treatment in PPA, there are many contributing influences in the room, ranging from cultural values and economic constraints to mental health (Volkmer et al., 2022). Alongside highlighting our clients' competencies, it is our role as clinicians to meet our clients' needs when it comes to long-term care planning. It might also require us to put aside our personal preferences and backgrounds to recognize what a client is asking for.

Furthermore, assessment timelines and structures are impacted by client availability and factors outside of their control, including but not limited to lengthy waiting lists in public health systems and referrals from general practitioners (McGill et al., 2020; Stute et al., 2020). Due to the potential delay between scheduling and receiving assessment, it is possible that clients might seek private practice services before receiving a formal diagnosis (McGill et al., 2020). In such cases, the need to consider the usefulness and relevance of diagnostic assessment becomes ever more important.

Component 7: Advocacy Within Assessment

Case 10

The spouse of a client with severe lvPPA is considering selling their home and moving as they live on a large property that they are struggling to maintain.

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Rather than presuming that she will not be able to participate in the decision, the spouse raises the topic in speech and language therapy, and with the therapist's assistance in total communication strategies indicates the plans to sell the property. Using a map, the spouse has provided, the client indicates her wish to sell part of the land they own. The spouse recognizes this as a conversation they had many years ago and consequently follows this route of sale.

The case scenarios in this clinical focus article highlight the complex and ethical considerations that arise during the assessment process, such as the determination of decision-making capacity. The need to conduct high-quality assessment in this context clearly applies whether parties are physically present or communicating through a telehealth medium. As communication can be negatively impacted by communicative contexts that involve factors such as time pressure, communication partners that are perceived to be unsupportive or unfamiliar with aphasia, or heightened demands of executive functioning (Cavanaugh & Haley, 2020; Harmon, 2020; Hersh & Armstrong, 2021), self-advocacy can be particularly challenging for all people with communication disorders, including people living with PPA. SLPs can take on a unique role in the assessment by ensuring that the client's capacity to self-advocate is evaluated and supported (Jayes et al., 2021). The disadvantage imposed by a progressive language-led disease and the assumptions surrounding cognitive capacity as based on language-led symptoms cannot be underestimated (Volkmer et al., 2022). In such scenarios, SLPs make broader considerations about the person's rights (Hersh, 2018) and explore ways for assessments to maximize client involvement in decision-making. In particular, capacity to provide informed consent is an essential consideration for assessment in progressive language-based disease (Volkmer, 2016). The focus of assessment should be on functionality and utility of language use, as well as promoting agency and the involvement of the patient and their supporters at every step of the assessment process, noting that self-advocacy becomes increasingly difficult for the person themselves.

As such, van de Ven et al. (2017) highlight that decision-making in the context of dementia should always be considered a relational and interdependent process, and assessment tools must be selected with a focus on minimizing harm. To best advocate for the client, clinicians must understand and disentangle definitions of consent, competency (Darby & Dickerson, 2017; Ganzini et al., 2005), and decision-making capacity (Meulenbroek et al., 2010; Moye & Marson, 2007; Sessums et al., 2011; Tippett & Hillis, 2020; van de Ven et al., 2017) and identify the relevant legislation that applies in their jurisdiction, serving to protect the rights of vulnerable people to make decisions regarding their welfare and finances. An overview of the various legislation and principles is beyond the scope of this clinical focus article; however, references are provided as a useful starting point (Darby & Dickerson, 2017; Ganzini et al., 2005; Hersh, 2018; Meulenbroek et al., 2010; Moye & Marson, 2007; Sessums et al., 2011; van de Ven et al., 2017; Volkmer, 2016). Broadly, to promote the client and care partners agency and best interests, it is essential to identify their abilities to (a) understand and interpret information presented to them about their care, (b) retain this information long enough to make an informed decision, and (c) consistently communicate their decision through their preferred modality. A key takeaway message for clinicians is that assessment needs to be creative, strengths-focused, promote client and care partner agency, and be informed by principles of advocacy and ethically guided practice.

Proposed R.A.I.S.E. Assessment Framework

On the basis of these seven components, we propose an assessment framework that incorporates necessary components of effective, functional, and adaptable assessment for clients with PPA (see Figure 2). Our challenge as clinicians remains to create assessment protocols that are functionally and mutually beneficial to clients, care partners, and clinicians across a wide variety of individuals. The R.A.I.S.E. Assessment framework incorporates the seven components identified above in a set of five pillars of assessment alongside appropriate clinical recommendations for each. Every clinical recommendation put forth addresses at least one of the original components, highlighting that each aspect of assessment delivery incorporates these essential themes. As the name suggests, the aim of the R.A.I.S.E. Assessment framework is to uplift and raise the needs and wishes of clients living with PPA with utmost priority.

1. Relationship

    1.1. Establish a relationship with the client. Assessment should begin with a socially oriented conversation or ethnographic interview, no matter how brief, to allow the person to tell their story or explain their concerns. This "listen first" approach is consistent with the philosophy of narrative medicine (Charon, 2001) and creates a safe space to connect and form the client–clinician relationship (Bright et al., 2021; Cohen-Schneider et al., 2020). Moreover, this philosophy is consistent with the recommendation put forth by an international consensus of expert SLPs on principles of working with individuals with PPA: It is essential to "know people deeply" to provide optimal and personalized care (p. 8, Volkmer et al., 2022).

    1.2. Ask directly about the person's expectations for the session and involvement with speech

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pathology. What do they hope to gain? Frame this discussion around the nature of the assessment referral and service constraints. This transparency ensures that the focus of the session is clear and whether the expectations of the client can be met; if the latter is not the case, this acknowledgment provides the opportunity to discuss further and perhaps refer the client to someone who can respond to those expectations.

2. Assessment Approach and Type

2.1. In the context of an informal approach with relative flexibility in the measurement tools used:

2.1.1. Whenever possible, utilize measurement tools that reflect the natural variation and complexity of our clients. Importantly, dedicate time to planning and thinking this through.
2.1.2. Naturalistic speech samples recorded during assessment can be efficiently collected and used to diagnose, monitor, and treat (in potentially both compensatory and restorative manners) language challenges (Gallée & Volkmer, 2021) in conjunction with standardized assessment, all under the umbrella of an informal approach. Versatile prompts that elicit open-ended responses should aim to reflect the strengths of the individual and allow for a characterization of the person's functional communication abilities and to capture their individual differences.

2.2. In the context of standardized measures but an informal approach:

2.2.1. Prioritize building the relationship prior to initiating standardized assessment.
2.2.2. Take advantage of video recordings throughout the assessment to gather speech samples to reflect more naturalistic speaking environments outside of the standardized materials and to capture compensatory strategies implemented throughout the evaluation to formulate therapeutic goals and scaffolds.

3. Include Opportunities for Feedback

3.1. Provide feedback throughout and provide opportunities for the person/family to ask questions and to share how they are finding the interaction/assessment experience. Remain sensitive to the impact the interaction/assessment has on the person and adjust accordingly. Offer counseling and promote collaborative efforts between clinician, client, and care partners in assessment and intervention.

4. Support and Promote Advocacy

4.1. Through joint client and care partner involvement (Khayum et al., 2012; Mooney et al., 2018; Volkmer et al., 2018, 2020a, 2021), people's agency is encouraged and bolstered leading to better self-advocacy skills, including for care partners as the client's cognitive skills decline (Schaffer & Henry, 2021; Volkmer et al., 2020b, 2022).

5. Evolve Assessment over Time

5.1. As the nature of PPA is progressive, assessment approaches, types, and outcomes will and must evolve over time to best meet the needs and desires of clients and their care partners (Hinshelwood et al., 2016; Volkmer et al., 2022). This can be achieved through dynamic assessment, where domains of speech, language, and communication can be assessed in a hierarchical manner to determine scaffold needs; this is particularly relevant as the unique features of the disease progress toward a more global and less language-specific dementia (Rogers & Alarcon, 1998). The responsive clinician will consistently seek to adapt assessment protocols to efficiently evaluate the client's capabilities while also providing increasing psychosocial and informational counseling to both the client and care partners (Schaffer & Henry, 2021). Attendance of support groups for clients, care partners, or both, is also recommended to enhance opportunities for community-level engagement. Furthermore, the clinician can provide improved support by consistently evaluating whether specific requests or needs might be better met by other providers or services, such as social work.

Discussion

We have proposed a new framework that culminated from an iterative discussion-based consensus-forming process on principles of person-centered assessment for this client group. This framework for PPA is grounded in principles of therapeutic assessment (Bright et al., 2021; Hersh et al., 2013, 2018), relationship and person-centered approaches (Chapey et al., 2000; Forsgren et al., 2022; Hersh et al., 2012, 2013, 2018; Howe et al., 2012; Kagan et al., 2007; Worrall et al., 2010), and existing frameworks for poststroke aphasia and other chronic language-led conditions, such as the LPAA (Chapey et al., 2000; Rogalski & Khayum, 2018; Ruggero et al. 2019) and A-FROM (Kagan et al., 2008), with novel elements addressing the progressive nature of the condition. Our process was twofold: First, we identified seven components of indispensable

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clinical care in the assessment of PPA. Beginning with definitions of assessment approaches and measures in the context of PPA, we suggest that a clinician can facilitate person-centered assessment by adopting protocols that reveal competency, have reciprocity of benefit, incorporate dynamic assessment, are mindful of complexity, and remain adaptable over time. We have further argued that the role for advocacy throughout assessment is currently underrecognized and a necessary feature.

Second, we used the original seven components that resulted from the consensus-forming process as the foundation of the R.A.I.S.E. Assessment framework. Five steps (see Figure 2) were derived to provide concrete clinical guidance on how to approach and cultivate person-centered assessment for people living with PPA. Within each of the five steps of the framework, the original seven components are weaved into the clinical guidance that frames the assessment process. As detailed in the framework, we believe that the assessment process begins with establishing the relationship between the client, clinician, and care partners prior to the selection of the assessment approach and measures. Throughout assessment, opportunities for feedback and advocacy are highly recommended. Finally, assessment must be adapted in response to the changing needs and interests of the client and care partners.

Unique to PPA, this framework incorporates the imperative adaptability to change at every assessment opportunity. First, our framework guides the clinician to consider whether modifications should be made to the assessment tools used or the scaffolds implemented, automatically changing whether a standardized or informal approach is used. Second, we recommend that the clinician continually adapts assessments in response not only to behavioral change but also to the client and care partner feedback. While previous frameworks have promoted person-centered approaches and involving care partners, to our knowledge, the R.A.I.S.E. Assessment framework is the first to acknowledge and provide clinical guidance for the ever-evolving behavioral progression of PPA within and outside domains of communication.

Through the R.A.I.S.E. Assessment framework, we have put forth practical recommendations for clinical practice to best address and evaluate the unique challenges experienced by our clients with PPA. Often clinicians find themselves constrained by the boundaries of standardized protocols, which could diminish opportunities for therapeutic outcomes during assessment sessions. Assessment interactions are significant for people with PPA and their families and are an integral aspect of care. As such, this clinical focus article addresses areas of challenge by introducing a structured framework to guide the creation of dynamic, mutually beneficial, individualized, and evolving assessment protocols for a complex progressive condition.

Clinical Applications of the R.A.I.S.E. Assessment Framework

While the R.A.I.S.E. Assessment framework emerged from discussions specific to PPA, it has wider applications to all acquired neurogenic communication disorders, such as the non-PPAs and possibly other progressive conditions with ongoing and evolving communication support needs. Therefore, possible future directions of this work include additional consensus ratings for other progressive conditions with nonprimary needs for communication support. Nonetheless, we hope to have illustrated the importance of developing a framework specific to the population of interest due to the unique challenges posed by a diagnosis of PPA, including but not limited to the progressive and terminal nature of the diagnosis, and that it remains poorly understood. For training purposes, two case examples with questions related to the R.A.I.S.E. Assessment framework have been included in the Appendix to further illustrate the framework's applicability to the target population.

There is more than one way in which one can make a diagnosis, monitor change, and adapt intervention through assessment; we hope to have provided insight on how this may be achieved using a person-centered approach that is sensitive to the complexities experienced by people with PPA. A person-centered approach that uses informal and standardized measurement tools is likely to be necessary to capture a person's true capabilities and to maximize their outcomes; however, it is the attention to relationship and to the evolving and complex needs of the person and their care partners that is likely to raise the success of assessment in PPA. As clinicians, we have the power to shape the assessment experience of a person's individualized care by incorporating their feedback, creating and maintaining a partnership with them, and building their support networks into the decision-making process that will lead to more uplifting experiences going forward.

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Appendix

Clinical Tutorial: Applying the Recommendations of the R.A.I.S.E. Assessment Framework

The following case scenarios are presented to consolidate understanding and application of the person-centered assessment framework. Respond to the reflection questions and how well the person-centered assessment framework has been applied. You may like to discuss each scenario as a team and reflect on how your responses compare to your current practice or thinking about assessment in the context of PPA.

Scenario 1

A person diagnosed with lvPPA and her spouse relayed a recent assessment experience to her SLP. They were seen by a clinician she hadn't met before and who wasn't the Neurologist. They weren't sure of the clinician's title. The clinician administered a full cognitive assessment using a standardized tool. The spouse described the assessment as a "really bad assessment" because the client felt pressured and did not know who the clinician was. Furthermore, he reported that the client came out of the assessment room flustered and agitated. The spouse was acutely aware that whatever she did and whatever the results were, they would not have been true results. The couple described medical interactions like these to be frustrating and did not value or respect the intelligence of the client, furthermore acknowledging that, for a person who used to be able to do anything, struggling to draw a clock face was demoralizing and that the assessment context set people up to fail.

1) Does this scenario reflect a person-centered assessment? Why or why not?
2) What factors have contributed to the client perception of the assessment?
3) Assuming that the full cognitive assessment is a mandated component of the clinic at which the evaluation took place, how can the seven components of a clinician's toolkit to person-centered assessment be applied here to optimize evaluation outcomes?
4) Which of the five recommended steps of the R.A.I.S.E. Assessment framework are most relevant or appropriate to adopt for the assessment described in this scenario?

Scenario 2

A client with nfvPPA has decided she would like to sell a family home abroad that she inherited from her family. To do this, she must bestow a specific power of attorney to another family member to act on her behalf in the sale. The therapy team has been asked to undertake an assessment of their decision-making capacity to donate. The client has significant oral motor dyspraxia and communicates using total communication strategies including writing and a low tech AAC device. She also has a mild agrammatism in the absence of other significant cognitive difficulties. Given the COVID-19 restrictions at the time, the SLP and the nurse must undertake an assessment via zoom. The SLP and nurse ask the client and her spouse to provide them with information in advance of the assessment about the house, who lives there now, photos of the building and map of its location, and information on the economic value of the home and the options related to the decision (including the role of the person who will be donated power of attorney). The spouse facilitates the environment by setting up two cameras at their home; one so that the client can engage with the SLP and nurse, and another so the SLP and nurse can observe anything she writes down. The client is known to the SLP and nurse, meaning that they are able to use appropriate written and visual prompts to support her comprehension. The discussion demonstrates she understands the information related to the decision, can retain it and weigh up the benefits and negatives of this sale, and express her decision. The team are able to demonstrate that with all practicable support this client has capacity to donate power of attorney to a family member for the purposes of this house sale.

1) Does this scenario reflect a person-centered assessment? Why or why not?
2) What ethical and/or legal considerations apply in this scenario?
3) What factors have contributed to the client perception of the assessment?
4) What is the SLP's role in terms of advocacy in this scenario?

General reflection questions:

1) What further learning is required to best apply person-centered assessment and care to these cases?
2) Are there other components that you would consider essential constituents that have not been considered in our analysis of the clinician's approach to providing person-centered care? Why and how?
3) Which best practice recommendations would you add or modify within the R.A.I.S.E. Assessment framework proposed here?

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