

DEVELOPMENT OF A QUESTIONNAIRE AND SUBSEQUENT INVESTIGATION  
OF STUDENT PERCEPTIONS OF PRIMARY PROGRESSIVE APHASIA

By

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### **Abstract**

Primary Progressive Aphasia (PPA) is a neurodegenerative disorder characterized by language and communication deterioration in the initial stages of the disease (1-3 years). Given that PPA progresses over the course of years, patients with PPA require interdisciplinary teams of practitioners to provide effective care, including physicians and speech-language therapists. These practitioners should be well-educated about and hold respectful attitudes towards PPA so that patients receive optimal care. The goal of this study was to investigate university students' perceptions of PPA as characterized by both baseline knowledge and positivity of attitude. New scales– the PPA Knowledge Scale (abbreviated PPAk; assessing knowledge of PPA) and the PPA Attitudes Scale (abbreviated PPAA; assessing attitudes towards PPA)– were developed for this purpose and administered alongside previously validated scales related to aging and dementia. Pre-health and communication science disorder students were surveyed initially because these students will become the next set of practitioners for patients with PPA. The results indicated that while knowledge of PPA among surveyed students is lacking, attitudes towards PPA are relatively positive. Suggestions for future research include continued evaluation of the PPAk and PPAA scales. There is a need for educational initiatives to provide students with more instruction regarding PPA in the health related fields at the undergraduate level.

## Introduction

### Overview of Primary Progressive Aphasia

Primary Progressive Aphasia (PPA) is a neurodegenerative syndrome characterized by language and communication degeneration at onset. In contrast with more commonly recognized neurodegenerative diseases like Alzheimer's Disease (AD), PPA is a more recently described disorder, first characterized clinically by Marsel Mesulam in 1982, who reported case studies of patients that, "...experienced the insidious onset of an aphasia and its gradual progression for many years in the absence of other behavioral abnormalities," (Mesulam, 1982). Over the last several decades, speech pathologists and neurologists have become more aware of PPA, but even these practitioners are still discerning the best ways to treat patients, with the majority of UK Speech and Language Therapists (90.5% of respondents) reporting that there is no care pathway for PPA within their service (Volkmer et al., 2018).

There are currently three recognized variants of PPA, which include nonfluent PPA (nfvPPA), semantic PPA (svPPA), and logopenic PPA (lvPPA). Though each variant has distinct diagnostic criteria based on language profile and neuroimaging, all share the underlying issue of progressive degeneration of language with initial preservation of other cognitive functions (including working memory and perception). Although there are some overlapping characteristics across PPA variants, each is associated with a specific constellation of symptoms. Specific neuropathological findings as illuminated by neuroimaging can be used as aids in diagnosis. Part of the difficulty with diagnosing and classifying PPA variants stems from an overlap between pathology consistent with PPA and pathology consistent with AD and/or frontotemporal lobar degeneration (FTLD) (Gorno-Tempini et al., 2011). Currently,

Gorno-Tempini et al. (2011) have provided clear and updated classification guidelines for diagnosing PPA and its variants which are briefly summarized below.

nvPPA is classified according to two core criteria, which include agrammatism and effortful speech, and at least one must be present for diagnosis (Gorno-Tempini et al., 2011; Marshall et al., 2018; Montembeault et al., 2018). Patients should show impaired comprehension of syntactically complex sentences, while single-word comprehension and object knowledge should be spared (Gorno-Tempini et al., 2011). Cortical atrophy is observed in the inferior frontal gyrus (Broca's area), which plays a role in motor speech programming and language output (Marshall et al., 2018). Gorno-Tempini et al.'s (2011) guidelines concur that imaging should display neuroanatomical changes in the left posterior fronto-insular region, which may appear as atrophy on an MRI or hypoperfusion/hypometabolism on SPECT or PET. nvPPA patients typically show FTL spectrum pathology (Gorno-Tempini et al., 2011), however some patients do present with AD pathology (Grossman et al., 2013). Given that the underlying neurodegenerative processes can vary, it is crucial that imaging be used in conjunction with clinical evaluation.

lvPPA is characterized by word-finding difficulty and anomia and can share the symptoms of slow speech and speech sound errors with nvPPA, however in contrast there is typically less agrammatism and distorted speech sound production due to the underlying phonological deficit (Marshall et al., 2018; Montembeault et al., 2018). According to current guidelines, patients must present with both core features of impaired single-word retrieval in spontaneous speech and naming and impaired repetition of sentences and phrases to be diagnosed with lvPPA (Gorno-Tempini et al., 2011). Diagnosis also requires at least three of the following features: speech (phonologic) errors in spontaneous speech and naming, spared

single-word comprehension and object knowledge, spared motor speech, and absence of frank agrammatism (Gorno-Tempini et al., 2011). Neuroimaging of individuals with lvPPA typically shows degenerative changes in the left posterior perisylvian area/temporal-parietal junction (Marshall et al., 2018; Gorno-Tempini et al., 2011). The most common pathology underlying lvPPA is associated with AD (Gorno-Tempini et al., 2011; Rohrer et al., 2012).

svPPA is characterized by progressive loss of semantic knowledge, so grammatical structure and articulation are usually preserved, but actual utterances are lacking meaning (Marshall et al., 2018; Montembeault et al., 2018). For clinical diagnosis, patients must present with both impaired confrontation naming and impaired-single word comprehension (Gorno-Tempini et al., 2011). Additionally, at least three of the following must be present: impaired object knowledge, particularly for low-frequency or low-familiarity items, surface dyslexia or dysgraphia, but spared repetition, and/or speech production (grammatical construction and motor speech) (Gorno-Tempini et al., 2011). Neuroimaging in svPPA typically shows predominant anterior temporal lobe degenerative changes and can also include atrophy in the amygdala and anterior hippocampus (Marshall et al., 2018; Gorno-Tempini et al., 2011). Similar to nfvPPA, FTLN pathologic changes are most commonly found in svPPA (Gorno-Tempini et al., 2011).

In spite of defined clinical criteria, PPA is often misdiagnosed because neurodegenerative processes can be difficult to characterize and there is considerable heterogeneity and overlap in symptoms among individual cases. For example, Randall and Larner (2020) in their case report describe two cases in which PPA was misdiagnosed as AD and vascular dementia as a result of neuroimaging misinterpretation. These diagnoses were later revised to nfvPPA, but Randall and Larner (2020) highlight these cases to raise awareness of PPA and emphasize that PPA should be

included when considering possible diagnoses of neurodegenerative disorders. Given that PPA is associated with FTLD and AD pathology depending on the variant, it is logical that neuroimaging alone could lead to an assumption of a more common disease than PPA.

Therefore, Randall & Lerner (2020) strongly suggest correlating clinical findings with any neuroimaging done. However, their case studies also allude to the larger issue of limited PPA awareness among clinicians. As researchers and clinicians elucidate more about each variant, it will be imperative for medical practitioners involved in diagnosis and treatment to be aware of these findings. Building knowledge and awareness needs to start at the educational level.

The present study focused on developing a survey to characterize current knowledge and attitudes about PPA among students who plan to enter health or communication-based professions. To create a supportive framework for care of PPA and other neurological disorders in the future, there is a pressing need to invest in education and cultivate a network of professionals equipped with appropriate knowledge and attitudes.

### **Prevalence of PPA**

Neurodegenerative disorders are becoming increasingly prevalent as our population ages since many are late onset. According to the Alzheimer's Association, 1 in 9 people aged 65 or older have Alzheimer's disease ("2022 Alzheimer's Disease Facts and Figures," 2022), and the burden this will present in coming years is foreshadowed by substantial literature on the subject. By comparison, PPA is less commonly reported than AD. Magnin et al.'s study from 2016 estimated a prevalence of 3.1/100,000 people, which fits reasonably within a figure of 10.8 cases of FTLD per 100,000 people (frontotemporal lobar degeneration syndromes, of which PPA was considered a subtype in this study) (Coyle et al., 2016). It is worth noting that few studies on the prevalence of PPA have been conducted, and given the overlapping characteristics between AD,

FTLD and PPA, it is probable that some cases go undiagnosed or misdiagnosed, so the prevalence may vary from these estimates. Importantly, individuals with PPA may interact with a variety of clinicians, including neurologists, geriatricians, psychiatrists, and speech and language pathologists, all of whom may contribute towards reaching a diagnosis of a specific variant of PPA (Nickels & Croot, 2014). As the population ages, more clinicians will inherently become involved in cases of PPA, and more robust guidelines and treatment plans will be required to properly care for patients.

Beyond clinicians, caregivers, healthcare workers, and family members may be involved in support. It is therefore important to characterize baseline knowledge regarding neurodegeneration, and PPA specifically, within each of these segments of the population to determine where additional educational initiatives are warranted. One particularly important segment of the population includes current health and communication science students (the target demographic for this study) as these are the future practitioners who will care for the aging population and those with neurodegenerative disorders.

### **Current Literature About Perceptions of Aging, Dementia, and PPA**

Given the relatively high prevalence of AD in the aging population, it is not surprising that assessing knowledge of and attitudes towards dementia has become an interest to current researchers. Perceptions of aging and dementia have been relatively well-characterized in literature already, with many studies developing tools or employing existing scales to investigate both the constructs of attitude and knowledge (Basri et al., 2017; Breystpraak & Badura, 2015; Fraboni et al., 1990; Gubner et al., 2020; Palmore, 1980; Scott et al., 2019; O'Connor and McFadden, 2010; Toye et al. 2013). Validated and commonly used tools to investigate dementia perception include the Dementia Attitudes Scale (DAS) (O'Connor and McFadden, 2010) and

the Dementia Knowledge Assessment Tool (DKAT) (Toye et al., 2014). Tools for assessing knowledge of aging and ageism include Palmore's Facts on Aging Quiz (Palmore, 1980), the Fraboni Scale of Ageism (Fraboni et al., 1990) and Kogan's Attitudes Towards Old People Scale (Kogan, 1961). However, no equivalent tool currently exists to assess similar constructs about PPA.

Findings from research regarding perception of both aging and dementia suggest that attitudes are often neutral or negative (Kite et al., 2005; Scott et al., 2019; Oh & Bong, 2021; Oh & Morris, 2020; Basri et al. 2017). A large meta-analysis involving 232 studies concluded that an overall bias against older adults exists, and this bias was largest when stereotypic beliefs and perceptions of attractiveness were assessed (Kite et al., 2005). Investigating medical professional student perception of older people showed students held generally neutral attitudes towards older adults and had relatively low knowledge of dementia (Scott et al., 2019).

Though attitudes are not exceedingly positive towards aging adults and those with dementia, in a different study, students who possessed neutral-to-negative attitudes at the start of a semester ended with more neutral attitudes close to the cutoff score for favorable after regular nursing home observation (Oh & Bong, 2021). This indicates that exposure to and interaction with those with dementia may be related to more positive attitudes towards the population overall. Qualitative reports also demonstrated improvements in understanding towards older adults (Oh & Bong, 2021). Another study concluded that communication science and disorder students who took courses in gerontology and dementia had generally more positive attitudes towards those with dementia when they found such classes beneficial (Oh & Morris, 2020), suggesting that exposure and education may be key factors in improving attitude. These results are confirmed and extended upon by Basri et al.'s (2017) meta-analysis, which analyzed 18



studies with a similar focus on characterizing knowledge and perception of dementia. The authors primarily emphasized that hands-on experience and more curricular exposure to dementia are important in improving knowledge and attitudes among students (Basri et al., 2017).

Taken together, these studies suggest that there is room for improvement in student knowledge of and attitudes towards aging adults and those with dementia, which may be attained through improved curricular and hands-on exposure. While there is available literature regarding knowledge and attitudes about the general concepts of aging and dementia, studies characterizing the constructs of knowledge and attitudes towards people with PPA are currently lacking. Given the neutral-to-negative attitudes and mediocre knowledge level commonly reported regarding aging and dementia, there is likely a need for improvement in education and exposure to PPA as well.

### **Present Study Aims**

The present study aimed to develop new tools for assessing the constructs of knowledge and attitude about PPA. As the population continues to age, it will be important for future caregivers, healthcare practitioners, and speech-language therapists to understand how to interact, assess and treat people with PPA. Understanding current student perception of PPA can help institutions address gaps in knowledge or negative attitudes early in the educational process. Aims for this project included:

1. Assess whether there is a relationship between knowledge of and attitudes towards PPA, and knowledge of and attitudes towards aging and dementia. The present study developed two new tools (the PPA Knowledge Scale and the PPA

Attitudes Scale), so this aim served as a measure of external validity for newly developed PPA scales.

2. Characterize attitudes towards PPA and knowledge of PPA, and determine whether knowledge and attitudes relate.
3. Investigate whether specific demographic variables (i.e., class level, area of study, etc.) relate to knowledge of and attitudes towards PPA, and whether any of these characteristics predict PPA knowledge and attitudes.

## **Methods**

### **Questionnaire Development**

The purpose of this study was to characterize knowledge of and attitudes towards PPA among undergraduate students in pre-health and communication science disorder majors. This initial demographic was broadened to include university students in general as the study progressed to improve response rate. Given that no scales currently exist to measure the constructs of knowledge of and attitude towards PPA, a new set of items was developed to serve this purpose. For external validity, previously validated aging and dementia scales were administered alongside new items written about PPA. PPA items were divided into two new scales: the PPA Knowledge Scale (PPAk) and the PPA Attitudes Scale (PPAa), assessing knowledge of and attitudes towards PPA respectively. A modified procedure of the steps suggested by Artino et al. (2014) in their guide to developing questionnaires for educational research were followed. These steps included:

1. Defining target constructs
2. Searching current literature for existing tools to measure intended constructs

3. Conducting informal email interviews with undergraduate students (labeled “non-experts” about PPA) and several well-respected experts in the field of PPA (labeled “experts” about PPA)
4. Developing items
5. Expert content validation of items and subsequent refinement prior to piloting
6. Constructing the larger questionnaire
7. Conducting pilot testing, factor analysis, and refining

Each of these steps is described in the sections below.

### ***Defining Target Constructs***

The present study assessed knowledge of and attitudes towards PPA among undergraduate students because these are key components of overall perception of PPA. Given that these students will comprise the future workforce of healthcare workers and speech-language therapists that will treat patients with PPA, it is necessary that they develop understanding of and respectful attitudes towards those with PPA. The construct of “knowledge” was defined as factual awareness and familiarity with the symptoms of PPA and assessed with true/false (T/F) statements. “Attitude” was divided into the domains of cognitive, behavioral and affective components following the Dementia Attitudes Scale (O’Connor & McFadden, 2010), and was assessed with Likert style questions. The tripartite model of attitude– including cognitive, behavioral and affective components– is well-recognized and supported (Breckler, 1984). Researchers are encouraged to measure all three aspects or to specify which is of focal concern to avoid ambiguity (Breckler, 1984). Therefore, several items were crafted for each domain with the intent of measuring all three within a set of Likert-style statements.

### ***Current Tools in the Literature***

Perceptions of aging and dementia are well-explored topics in recent literature (Kite et al., 2005; Basri et al., 2017; Scott et al., 2019). Some prominently used tools include the Alzheimer's Disease Knowledge Scale (ADKS), Dementia Knowledge Assessment Tool (DKAT) (version two), Dementia Attitudes Scale (DAS), Palmore's Facts on Aging Quiz, the Fraboni Scale of Ageism (FSA), and Kogan's Attitude Toward Older People Scale (Carpenter et al., 2009; Toye et al., 2013; O'Connor & McFadden, 2010; Palmore, 1980; Breytspraak & Badura, 2015; Fraboni et al., 1990; Kogan 1961). These established scales were referenced as inspiration for the language, scope and difficulty of PPA items. Select scales were also included in the larger questionnaire to establish external validity of new items.

### ***Informal Interviewing and Developing Items***

It is a well-established practice to conduct interviews to elicit information about the constructs to be investigated when developing a new questionnaire (Artino et al., 2014). This is to ensure researchers' conceptualization of a construct matches how respondents think about it (Artino et al., 2014). Prior to drafting items of the Dementia Attitudes Scale, O'Connor and McFadden (2010) conducted interviews with family caregivers and professionals to gain a sense of themes and patterns in attitudes towards dementia in their target demographic. Although Artino et al. (2014) describe conducting interviews verbally, informal interviews were conducted via email for feasibility in this study. Interviewees included small groups of both non-experts (undergraduate students) and experts (professionals who work with individuals with PPA). See Table 1 for interview questions administered.

**Table 1***Informal Non-Expert and Expert Interview Questions*

Non-Expert Interview Questions	Expert Interview Questions
Have you heard of the term Primary Progressive Aphasia before? What do you know about it?	What do you think are the most important aspects of PPA that healthcare professionals and SLPs should know and understand? For example: symptoms of PPA, how to interact with patients with PPA, common signs of progression, differences between PPA and other aphasias, available treatment options for individuals with PPA, other thoughts
How important do you think it is that future Speech and Language Pathologists (also known as speech therapists) and healthcare professionals learn about PPA?	What are some common misconceptions about PPA that you encounter in your work?
How do you think you would react to a person with PPA if they were to talk to you?	Are there specific aspects of PPA that you feel should definitely be included in our questions/statements?
How would you feel if you or a loved one were diagnosed with PPA?	What are the most important facts about PPA that most health professionals should know?  Please provide a few statements about your experience researching and working with patients with PPA.

A general pattern of complete unfamiliarity with PPA emerged among non-experts, with the common confusion that PPA primarily causes progressive memory loss like AD. This general lack of knowledge guided development of PPAk to ensure that items were not so specific that participants would be primarily guessing. Rather, items were designed to assess general knowledge of PPA, with the impression from initial interviews that participants in the target demographic who are somewhat familiar still have limited knowledge. With respect to attitude, many non-experts expressed that it might be frustrating or shocking to be diagnosed with PPA.

Many also found it important that future healthcare and speech-language professionals know how to work with and interact with individuals with PPA. Items assessing willingness to interact with people with PPA and interest in learning about PPA were therefore included in the initial PPAa draft.

Experts included three members of the University of Arizona Speech, Language and Hearing Science Department who have studied PPA and/or worked closely with people with PPA. Experts emphasized the importance of understanding the definition of aphasia and PPA and differentiating between PPA and other dementias. Non-experts confusing PPA with memory-focused dementia confirmed a need to assess these topics. All three experts emphasized a need for professionals to understand diagnosis and treatment options for PPA, although a lack of clear treatment protocols was noted in Volkmer et al.'s 2018 study. Several suggestions from experts were considered when developing items, the most notable including:

1. Probing students for an understanding of the term “aphasia” as well as how it relates to PPA.
2. Skills vulnerable to decline with PPA (awareness that PPA can affect motor speech skill as well as language).
3. The role of neuroimaging in diagnosis.
4. The relationship between post-stroke aphasia and PPA.
5. That treatment can be beneficial in PPA.
6. The benefits of family and caregiver support.

These sub-themes were addressed both in PPAk T/F items and PPAa items.

*Expert Validation & Refinement of PPA Questionnaire*

Items were drafted by the author (EA) and reviewed and refined in collaboration with members of the Language and Neuroimaging Lab at the University of Arizona (Katlyn Nickels- PhD candidate; Dr. Aneta Kielar- principal investigator). Experts were provided with a complete list of 24 T/F items and 16 Likert-Scale items to establish content validity (see Table 2). Experts provided written feedback for select items and a rating of essential, not essential, or not necessary for each item. The initial idea was to calculate Lawshe's Content Validity Ratio (CVR) for each item. Taherdoost (2016) clarifies that the minimum value of CVR for five panelists is 0.99, but given the small population of experts closely available working on PPA, the current study only had three, of which only two provided feedback, and not on all the items. Such limited feedback renders the CVR inappropriate in this case. Items were instead refined based on qualitative feedback.

Feedback was received gradually, and revisions were made as feedback was available. The most substantial revisions were made following the first set of feedback for PPAk (T/F) items. This feedback did not include evaluation of any attitude items. For T/F items, technicalities were amended for factual accuracy. For example, in item 1, the word "speech" was replaced with "language". Additional technical errors were amended as needed to make questions unambiguously true or false. Other items were amended so as not to probe two separate ideas, such as item 16, which was divided into "People with PPA are often unaware of their language decline" and "Individuals with PPA can experience significant frustration associated with their language decline/difficulty". Finally, word choice was amended to ensure more consistent interpretation of items. Technical terms were removed or clarified. For example,

the clarification “brain damage that gets worse over time” was added to item 2 to explain “neurodegenerative disorder”.

After this initial round of revision, the updated T/F items were sent again to two experts for feedback. Only one responded with minimal critiques, likely as a result of the significant improvements on the initial set of items. The first reviewer did not provide feedback on attitude items. The second reviewer found most of the items essential and appropriate, with one modification suggested for item 2 to improve clarity. Small wording adjustments were made to T/F items and attitude items at this stage. The list was finalized by all three team members within the Language and Neuroimaging Laboratory prior to piloting (see Table 3).

**Table 2**

*Initially Drafted Items on PPA Knowledge and PPA Attitude Scales*

Construct 1- Knowledge (PPAk)	Construct 2- Attitude (PPAa)- Likert Scale
True (T)/ False (F)	1- strongly disagree, 2- disagree, 3- slightly disagree, 4- neutral, 5- slightly agree, 6- agree, 7- strongly agree
1. Aphasia is a loss of ability to understand or express speech. T	1. I am familiar with PPA.
2. Primary Progressive Aphasia (PPA) is a neurodegenerative disorder affecting communication. T	2. I think PPA would be a debilitating diagnosis to receive. *
3. Stroke is the main cause of PPA. F	3. People with PPA can make meaningful contributions to our society.
4. PPA occurs because of changes in the brain. T	4. I feel sympathy for people diagnosed with PPA.
5. If trouble with speech and language appears suddenly, it is likely due to PPA. F	5. If a loved one was diagnosed with PPA, I would want to learn how to help them.
6. PPA can cause people to speak slowly and with effort. T	6. I understand the difference between PPA and dementia.



Construct 1- Knowledge (PPAk)	Construct 2- Attitude (PPAa)- Likert Scale
7. Communication difficulties in an older person are almost always due to PPA. F	7. I would like to learn more about PPA.
8. To be diagnosed with PPA, difficulty with speech and language function must be the predominant symptom. T	8. I think supporting people with PPA is important.
9. Trouble finding words is a common early symptom of PPA. T	9. I would avoid a person with PPA who cannot communicate clearly. *
10. PPA affects spoken language but not written language (reading and spelling). F	10. I am afraid of people with PPA. *
11. Speech therapy cannot help preserve language skills in individuals with PPA. F	11. I think it would be rewarding to work with people who have PPA.
12. People with PPA remember specific, less familiar words (e.g., glacier) better than general, more familiar words (e.g., sister). F	12. I feel uncomfortable around people with PPA.*
13. PPA can evolve into dementia. T	13. People with PPA should stop working upon diagnosis. *
14. Individuals with PPA generally have lower life expectancies than individuals of similar age and background without these disorders. T	14. I think it would be frustrating to speak to someone with PPA. *
15. PPA causes memory loss. F	15. I would not like it if a person with PPA approached me. *
16. Patients with PPA are often unaware of their language decline and therefore aren't usually frustrated by their symptoms. F	16. I think treatment for people with PPA would be ineffective. *
17. People in late stage PPA retain the ability to understand others. F	
18. After symptoms of PPA appear, patients can live for several years. T	
19. PPA cannot be cured. T	
20. PPA affects language but not motor skills required for speech production. F	

Construct 1- Knowledge (PPAk)	Construct 2- Attitude (PPAa)- Likert Scale
21. There are multiple variants of PPA, and each is characterized by different language deficits. T	
22. Family counseling and/or attending PPA support groups can be helpful after a loved one is diagnosed with PPA. T	
23. It is possible to distinguish between PPA variants by examining brain MRIs. T	
24. Post-stroke aphasia can transform into PPA. F	

*Note.* \* indicates an item is reverse scored.

### Table 3

#### *Final Set of Items on PPA Knowledge and PPA Attitude Scales*

Construct 1- Knowledge (PPAk)	Construct 2- Attitude (PPAa)- Likert Scale
True (T)/ False (F)	1- strongly disagree, 2- disagree, 3- slightly disagree, 4- neutral, 5- slightly agree, 6- agree, 7- strongly agree
1. Aphasia is the loss of ability to understand or express language. T	1. I am familiar with PPA.
2. Primary Progressive Aphasia (PPA) is a neurodegenerative disorder (brain damage that gets worse over time). T	2. I think PPA would be an upsetting diagnosis to receive.
3. PPA affects communication. T	3. People with PPA can make meaningful contributions to our society.
4. Stroke is the main cause of PPA. F	4. I feel sympathy for people diagnosed with PPA.
5. PPA occurs because of changes in the brain. T	5. If a loved one was diagnosed with PPA, I would want to learn how to help them.
6. If trouble with speech and language appears suddenly (e.g., within a 24-hour period), it is likely due to PPA. F	6. I understand the difference between PPA and dementia.

Construct 1- Knowledge (PPAk)	Construct 2- Attitude (PPAa)- Likert Scale
7. PPA can cause people to speak slowly and with effort. T	7. I would like to learn more about PPA.
8. Difficulty coming up with words in an older person (above 65 years of age) is typically due to PPA. F	8. I think supporting people with PPA is important.
9. To be diagnosed with PPA, difficulty with language must be the predominant symptom. T	9. I would avoid a person with PPA who cannot communicate clearly. *
10. Trouble coming up with words is a common early symptom of PPA. T	10. I am afraid of people with PPA. *
11. PPA does not affect written language (reading and spelling). F	11. I think it would be rewarding to work with people who have PPA.
12. Speech therapy may help improve language skills in individuals with PPA. T	12. I feel uncomfortable around people with PPA.*
13. People with advanced PPA can have problems with memory and changes in personality. T	13. People with PPA should stop working upon diagnosis. *
14. Individuals with PPA generally have lower life expectancies than individuals of similar age and background without these disorders. T	14. I think it would be frustrating to speak to someone with PPA. *
15. The primary symptom of PPA is episodic memory loss (e.g., Remembering names of grandchildren). F	15. I would not like it if a person with PPA approached me. *
16. People with PPA are often unaware of their language decline. F	16. I think treatment for people with PPA would be ineffective. *
17. Individuals with PPA can experience significant frustration associated with their language decline/difficulty. T	
18. People with advanced PPA retain the ability to comprehend written and spoken language. F	
19. PPA cannot be cured. T	

Construct 1- Knowledge (PPAk)	Construct 2- Attitude (PPAa)- Likert Scale
20. Although PPA affects language, some individuals with PPA may also demonstrate impairment with motor skills required for speech production. T	
21. There are multiple variants of PPA, and each is characterized by different profiles of language difficulties. T	
22. Family counseling and/or attending PPA support groups can be helpful after a loved one is diagnosed with PPA. T	
23. Brain imaging (e.g., MRI or PET scans) provide useful information for diagnosing PPA. T	
24. Post-stroke aphasia can transform into PPA. F	

*Note.* \* indicates an item is reverse scored.

### ***Constructing the Questionnaire***

Although the primary goal of the study was to assess perceptions of PPA and predictors of these perceptions, the larger questionnaire administered included previously validated aging and dementia scales to establish external validity of PPAk and PPAa. Inclusion of these questions also provided further insight into the relationships between perceptions of aging, dementia, and PPA. The final questionnaire consisted of three primary sections as outlined below.

#### **Demographic Section.**

Basic demographic information was collected from students to elucidate predictive factors of better knowledge and attitudes towards PPA. Previous studies have included similar sections to assess predictive factors, including Oh & Morris' 2020 study. The goal of Oh & Morris' (2020) study was to assess attitudes towards people with dementia among students

studying communication science and disorders. The current study extends these findings with a focus on knowledge of and attitudes towards PPA. The demographic section of the questionnaire administered in the present study was modeled off Oh & Morris' (2020) to allow for comparable analysis regarding predictive factors of attitude and knowledge. Some identical items were used, and additions were made as needed to assess exposure to PPA through coursework and extracurricular activities. Prior studies documented that curricular engagement and exposure to patients with dementia may be important predictors of student knowledge and attitude (Oh & Morris, 2020; Oh & Bong, 2021; Basri et al., 2017). Therefore, these factors are potentially important to predict perceptions of PPA.

### **Knowledge Section.**

The knowledge section was composed of scales in three primary categories: aging, dementia and PPA. Previously validated scales about aging and dementia were included to assess the external validity of new PPA statements. Participants randomly received either Palmore's Facts on Aging Quiz revised in 2015 (Breytspraak & Badura), or the Dementia Knowledge Assessment Tool (DKAT) Version 2 developed by Toye et al. (2013), which both present items in a true or false format. For easier analysis, Palmore's Facts on Aging Quiz was labeled as 'Palmore-AgeK' to indicate knowledge of aging, and the DKAT Version 2 was labeled as 'DKAT-DemK' to indicate knowledge of dementia.

The original scale developed by Palmore has high group reliability and low item reliability, but high validity as determined by use in a variety of studies (Palmore, 1980). Items in the 2015 version closely mimic those in the original but contain updated language and add items drawn on current research, making them more appropriate for present use.

The Dementia Knowledge Assessment Tool (DKAT) Version 2 developed by Toye et al. (2013) aims to assess foundation-level knowledge of the dementia trajectory with a greater emphasis on late-stage dementia. Though the target demographic for the DKAT includes family caregivers and aged care staff, the statements are general enough to be at the appropriate level for students in the pre-health and communication science disciplines, who are likely to enter care-based professions themselves. Content validity for the DKAT was established by experts (Toye et al, 2013).

PPA items were administered following both the aging and dementia items and were written in a T/F format to maintain consistency in the style of question administered. This scale is titled the PPA Knowledge Scale and is abbreviated as ‘PPAk’ in subsequent sections.

#### **Attitude Section.**

The final section of the questionnaire aimed to assess student attitudes towards PPA, and once again included the categories of aging, dementia, and PPA. Previously validated ageism and dementia scales were included to assess external validity for newly developed PPA items. As in the knowledge section, the questionnaire was configured such that participants received one of two scales at random, either the Fraboni Scale of Ageism (FSA) (Fraboni et al., 1990) or the Dementia Attitudes Scale (DAS) (O’Connor & McFadden, 2010). For easier analysis, the FSA was labeled as ‘FSA-AgeA’ to indicate attitudes towards aging, and the DAS was labeled as ‘DAS-DemA’ to indicate attitudes towards dementia. After piloting, the questionnaire was amended such that participants received either both age-related scales or both dementia-related scales to improve experimental design and increase power. Further explanation is provided in context of the pilot data below.

When developed, the FSA scale was found to have adequate construct validity and high internal reliability (Fraboni et al., 1990). O'Connor and McFadden (2010) also used this scale in their validation of the Dementia Attitudes Scale. The DAS was developed by O'Connor and McFadden (2010) to assess attitudes about dementia in students and direct care workers, so the target population is consistent with that of the current study. The scale assesses affective, behavioral and cognitive components of attitude and the psychometric properties are favorable when compared to similar scales (O'Connor & McFadden, 2010).

PPA items were assessed with a seven-point Likert scale based on standards in prior literature. Artino et al. (2014) state that 6-10 items is typically sufficient to capture the essence of the phenomena in question, and Qualtrics, a well-known survey creation tool, recommends in their handbook that scale points range from 5-9. While fewer points may result in less differentiation between respondents, more points can decrease respondent reliability ("Handbook of Survey," 2020). Additionally, the DAS was developed with a seven-point Likert scale, so choosing a seven-point scale for PPA items maintained consistency for participants. This scale is titled the PPA Attitudes Scale and is abbreviated as 'PPAa' in subsequent sections.

Notably, the Likert scale for the FSA was initially designed with four points (1- strongly disagree, 2- disagree, 3- agree, 4- strongly agree). Scoring ranged from one to five for negative statements and five to one for positive, with unanswered items given three points and higher scores indicating more ageism (Fraboni et al. 1990). The four-point scaling was not changed to maintain validity of the original items, but scores were coded in reverse so that higher scores indicated less ageism. Unanswered questions were not scored because these were unscored in other administered scales. This allowed for easier evaluation of the relationship between attitudes towards aging adults compared to attitudes about people with dementia or PPA.

***Pilot Testing***

Piloting was conducted among undergraduate students in pre-health and communication sciences who comprised the target demographic for the larger study. Initially, the questionnaire was programmed in the Qualtrics XM platform hosted by the University of Arizona such that participants received ten items from Palmore-AgeK, FSA-AgeA, DKAT-DemK, and DAS-DemA in addition to both PPAk and PPAa. With only ten items from each aging and dementia scale, and a small sample size ( $n = 10$ ), the first investigator (EA) and the principal investigator (AK) determined that including the entirety of each of the aging and dementia scales would provide more variance and meaningful results to analyze. The survey was reprogrammed to administer the entirety of either Palmore-AgeK or DKAT-DemK, and either FSA-AgeA or DAS-DemA in addition to both PPAk and PPAa. Pilot responses were analyzed to establish baseline reliability and validity for PPAk and PPAa items and guide adjustment prior to distribution of the final questionnaire. These findings are described below.

***Validation, Reliability and Refinement***

Content validity of PPAk and PPAa were established by expert review as discussed above. To assess the external validity of PPAk and PPAa items, correlations between aging and dementia scales and PPA scales were computed. It is worth noting that pilot responses were very limited, with only a usable sample size of 17 responses included in analysis. Additional responses beyond these 17 were not included because they were incomplete or submitted after changes were made to the programming of the questionnaire. Notably, not all respondents received all scales, so correlations are based on varying sample sizes (for example, of the 17 useful responses, 7 responded to Palmore-AgeK).



Scores on the DKAT-DemK were significantly and positively correlated with PPAk scores, ( $r = .76, p = .007$ ). Palmore-AgeK scores did not significantly correlate with PPAk scores. Within the construct of attitude, DAS-DemA scores positively correlated with PPAa scores, but FSA-AgeA scores did not correlate significantly with PPAa scores. (DAS-DemA  $r = .81, p = .014$ ). In conjunction with prior expert review, these results confirmed external validity of the new PPA scales because dementia and PPA are related constructs.

Cronbach's alpha was computed for PPAa items to assess internal reliability of the Likert scale, and  $\alpha = .778$  confirmed acceptable internal reliability of the PPAa items.

Principal components analysis was employed to simplify the number of potential constructs within the PPAa scale, as well as adapt items based on the inter-item correlation matrix generated. Oblimin rotation was used given that the overall purpose of the PPAa scale is to assess positivity of attitudes towards PPA, and therefore it is likely that constructs underlying item response patterns correlate. In total, five factors with eigenvalues greater than one were identified. With a relatively small sample size for the pilot, these were not interpreted to have specific meaning, rather, used to confirm that the PPAa scale measures constructs relevant to attitude.

The correlation matrix demonstrating inter-item relationships was used to refine items. Item 2 in the PPAa scale was originally reversed scored (a higher rating indicating a more negative attitude), but this matrix demonstrated negative correlations between item 2 responses and most other items on the PPAa scale. Item 2 states "*I think PPA would be an upsetting diagnosis to receive.*" This item is unique because it evaluates a person's attitude towards having PPA themselves rather than interacting with others who have it, which are different concepts. Being upset about the diagnosis could mean that participants are aware of the potential struggles

they might have (more knowledge of PPA) and care about it (somewhat of an indicator of positive attitude). Given these preliminary results, this item was scored regularly in the administration of the final questionnaire, such that being more upset (higher ratings) indicated a more positive attitude.

PPAa item 1, assessing familiarity with PPA, was also removed from the overall PPAa score, as those who are unfamiliar may still hold a relatively positive attitude. Instead, this item was used in analyses as predictive of knowledge and attitude.

Finally, this piloting process revealed a sample size caveat to the original method of aging and dementia scale administration: the original method for randomization resulted in four unique groups of respondents. This would require a very large sample size to reach acceptable power. To reduce the possible combinations that the participants could receive, the final version of the questionnaire included either both Palmore-AgeK and FSA-AgeA, or DKAT-DemK and DAS-DemA, in addition to PPAk and PPAa, yielding two groups of respondents. The survey was programmed to administer either combination at random but in equal frequencies to generate two approximately equal groups of respondents. This is demonstrated in Table 4.

**Table 4**

*Final Questionnaire Distribution*

Scale Administered	Group 1 ( $n = 73$ )	Group 2 ( $n = 76$ )
Palmore-AgeK	Received	Not Received
FSA-AgeA	Received	Not Received
DKAT-DemK	Not Received	Received
DAS-DemA	Not Received	Received
PPAk	Received	Received
PPAa	Received	Received

### **Administration of Final Questionnaire**

The final Qualtrics questionnaire was initially distributed to faculty in the University of Arizona Physiology and Speech, Language and Hearing Science Departments, as these departments were expected to have a large population of pre-health and communication science and disorders students within them. Faculty were provided with a brief paragraph introducing the purpose of the study and the link to the questionnaire to share with students. The link was also shared via student group chats and on social media platforms to increase response yield. Data was collected throughout September and October 2023.

After collecting responses for several weeks without high yield, distribution was expanded to include university students as a whole group, given that social media distribution may have already resulted in student responses from outside the pre-health and communication science disciplines and/or the University of Arizona overall. While not all university students will become caregivers to the aging population and those with neurodegenerative disorders, this age group represents the future family members and caretakers to these populations. Demographic filtering allowed analysis of only pre-health and communication science students within the aggregate data, but having more responses overall allowed for more accurate analysis of primary trends and outliers within the age group as a whole.

### **Data Organization and Cleaning**

Data was filtered within Qualtrics by two criteria: completion of the questionnaire (programmed as proceeding to the final screen), and scores equivalent to or above the minimums possible for each attitude scale. Because the attitude scale minimums are nonzero (the minimum score per question is one point), participants who did not answer all scales but proceeded to the end screen were still filtered out. The net result was exclusion of participants who either did not

finish the questionnaire, or who skipped attitude scales later in the survey. Knowledge scale scores were not included in filtering given that it is possible for a participant to receive a score of zero despite answering all questions. Data was then examined by hand to eliminate outlier participants or those who completed enough questions to pass the filter.

This filtering was employed because it was crucial that each participant complete all four assigned scales in order to accurately assess relationships between scale scores. In total, 49 respondents were excluded from data analysis via this filter. One additional subject was excluded because despite answering three assigned scales, PPAk was completely unanswered. Therefore 74.87% of responses were included in the final analysis. A few subjects who skipped less than or equal to four questions (leaving not greater than 5% of scale questions unanswered) were included because their scores were not noticeably lower than other participants, and the occasional skipped question appeared to be random. In total, 149 responses were analyzed, with 73 responses for the aging and PPA scales combination, and 76 responses for the dementia and PPA scales combination. Some demographic questions were optional in nature and many participants left these blank. Completion of the demographic section was not a criteria for filtering. Within item and within participant means and standard deviations were computed with no significant outliers emerging, confirming that small numbers of skipped items were not significantly impactful in aggregate data. Interestingly, the PPAk item 3 (“PPA affects communication”) was answered correctly by all but one participant, but given how straightforward the item is, this trend was not considered erroneous.

## Results

### Demographic Data Analysis

Table 5 shows the demographic characteristics of respondents. Most participants were Caucasian, women, and between 19 and 21 years of age. This reflects the demographic of students at the University of Arizona and those most likely to see and respond to the survey after outreach initiatives through advisors and professors. Most students were in their junior or senior years (71.8%). Notably, 46.3% identified as pre-health students and 29.53% identified as communication sciences students. Thus, approximately 75% of the data came from the target demographic despite broadening distribution to all university students.

There was a small but significant correlation between respondents' ages and their PPAk scores ( $r = 0.162, p = .049$ ). However, age did not correlate significantly with PPAa scores ( $r = .146, p = .075$ ). Correlational analysis was not appropriate for other demographic variables given that these were categorical in nature with few categories overall (i.e., sex had three possible categories). Additionally, there were no statistically significant differences in means for PPAk or PPAa score by sex, gender, or race/ethnicity (see Appendix B for ANOVA table).

**Table 5**

#### *Demographic Characteristics of Respondents*

	Number	Percent		Number	Percent
<b>Age</b>			<b>Gender</b>		
17	2	1.34%	Man	20	13.42%
18	7	4.70%	Woman	127	85.23%
19	34	22.82%	Nonbinary/third gender	2	1.34%
20	50	33.56%	Prefer not to say	0	0.00%
21	39	26.17%	<b>Race/Ethnicity</b>		

	Number	Percent		Number	Percent
			American		
22	7	4.70%	Indian/Alaskan Native	0	0.00%
24	1	0.67%	Asian/ Pacific Islander	8	5.37%
			Black or African		
25	3	2.01%	American	1	0.67%
26	2	1.34%	Hispanic	26	17.45%
27	1	0.67%	White/Caucasian	95	63.76%
			Multiple		
30	1	0.67%	Ethnicities/Other	19	12.75%
37	1	0.67%	<b>Class Level</b>		
38	1	0.67%	Freshman	9	6.04%
<b>Mean (SD)</b>	20.55	(2.63)			
<b>Sex</b>			Sophomore	28	18.79%
Male	18	12.08%	Junior	59	39.60%
Female	130	87.25%	Senior	48	32.21%
Prefer not to say	0	0.00%	Master's Student	4	2.68%
<b>Track</b>			Doctoral Student	1	0.67%
Pre-health	69	46.31%			
Communication					
Sciences	44	29.53%			
Neither	36	24.16%			

*Note.* Participants were included irrespective of whether they answered all demographic questions, hence,  $n = 148$  for the question probing sex; all other questions displayed above were answered by all 149 respondents.

Table 6 shows descriptive statistics (means and standard deviations) for PPA<sub>k</sub> and PPA<sub>a</sub> scores by class level (freshman, sophomore, junior, senior, master's student, or doctoral student) and track of study (pre-health, communication sciences, or neither). Table 7 shows Analysis of Variance (ANOVA) results for PPA<sub>k</sub> and PPA<sub>a</sub> scores by class levels and tracks of study.

ANOVA indicated no significant differences in PPAk and PPAa scale scores between class levels, but there was a significant difference in average PPAa score between tracks of study (pre-health, communication sciences, neither) (see Table 6 for F and p values). Students in communication sciences had the highest PPAa score average at 84.61%, followed by students on the pre-health track at 81.82%, and those indicating neither scored 79.47% on average.

**Table 6**

*Scores on PPAk and PPAa Scales by Track of Study and Class Level*

		<b>Indicated Track of Study</b>			
		N	Mean	Std. Deviation	Std. Error
PPAk	pre-health	69	74.88	9.85	1.19
	communication sciences	44	77.08	8.92	1.34
	neither	36	74.54	8.84	1.47
	Total	149	75.45	9.34	0.77
PPAa	pre-health	69	81.82	8.86	1.07
	communication sciences	44	84.61	7.19	1.08
	neither	36	79.47	11.58	1.93
	Total	149	82.08	9.30	0.76
		<b>Class Level</b>			
PPAk	freshman	9	78.70	7.92	2.64
	sophomore	28	72.62	11.31	2.14
	junior	59	76.34	8.46	1.10
	senior	48	75.35	8.28	1.20
	master's student	4	76.04	20.23	10.12
	doctoral student	1	75.00		
	Total	149	75.45	9.34	0.77

PPAa	freshman	9	80.74	3.08	1.03
	sophomore	28	77.38	11.42	2.16
	junior	59	83.20	9.38	1.22
	senior	48	83.12	8.11	1.17
	master's student	4	88.33	4.75	2.38
	doctoral student	1	84.76		
	Total	149	82.08	9.30	0.76

**Table 7**

*Differences in Mean PPAk and PPAa Scores By Class Level and Indicated Track of Study*

Class Level	df <sup>a</sup>	df <sup>b</sup>	F	p
PPAk	5	143	0.840	0.523
PPAa	5	143	2.225	0.055
Indicated Track of Study				
PPAk	2	146	0.972	0.381
PPAa	2	146	3.165	<b>0.045*</b>

Note. \*=  $p < 0.05$

<sup>a</sup>between groups; <sup>b</sup>within groups

### Descriptive Statistics for Scale Scores

Table 8 shows the means and standard deviations for scores across all six scales administered within the questionnaire. The aging scales administered were Palmore-AgeK and FSA-AgeA, and randomly distributed to half of respondents. The dementia scales administered were DKAT-DemK and DAS-DemA and also randomly distributed to half of respondents. PPAk and PPAa were administered to all participants.



**Table 8***Scale Scores in Both Participant Groups*

Scales	Group 1- Aging and PPA		Group 2- Dementia and PPA		All Participants	
	Mean (%)	Standard Deviation	Mean (%)	Standard Deviation	Mean (%)	Standard Deviation
Palmore-AgeK	63.53	9.08	-	-	-	-
FSA-AgeA	75.92	8.43	-	-	-	-
DKAT-DemK	-	-	79.32	8.68	-	-
DAS-DemA	-	-	74.19	9.03	-	-
PPAk	73.8	9.88	77.03	8.57	75.45	9.34
PPAa	80.99	8.59	83.12	9.03	82.08	9.30

**Bivariate Relationship Between Aging and Dementia Scores and PPAa and PPAk Scale****Scores**

Table 9 shows correlations between aging or dementia scale scores (Palmore-AgeK, FSA-AgeA, DKAT-DemK, and DAS-DemA) and PPA scale scores (PPAk and PPAa). Scores on the PPAa scale correlated significantly with both attitudes towards aging (FSA-AgeA) and attitudes towards dementia (DAS-DemA) in each respective group of respondents. These were  $r = .595, p < .001$  for aging and PPA, and  $r = .651, p < .001$  for dementia and PPA, indicating that more positive attitudes towards aging (or dementia) relate to more positive attitudes towards PPA.

Scores on the PPAk scale correlated significantly with scores for knowledge of aging and knowledge of dementia, but these correlations were weaker at  $r = .328, p = .005$  and  $r = .276, p = .016$  respectively. Still, this demonstrates that slight increases in knowledge of PPA align with increases in knowledge of aging or dementia. These correlations also confirm external validity of the PPAk scale, given that aging, dementia and PPA are related constructs.

Scores on knowledge and attitude for aging, dementia and PPA showed small but significant correlations. The correlation between knowledge of aging and attitude towards aging was  $r = .297, p = .011$ . Between knowledge of dementia and attitude towards dementia,  $r = .226, p = .050$ . Between knowledge of and attitude towards PPA,  $r = .162, p = .048$ . These correlations suggest that an increase in knowledge is associated with more positive attitudes for aging, dementia and PPA.

**Table 9**

*Correlations Between Scale Scores*

	Palmore-AgeK	FSA-AgeA	PPAk	PPAa	DKAT-DemK	DAS-DemA
Palmore-AgeK	1	0.297*	0.328**	0.225	-	-
FSA-AgeA	0.297*	1	0.117	0.595**	-	-
PPAk	0.328**	0.117	1	0.162*	0.276*	0.200
PPAa	0.017	0.595**	0.162*	1	0.158	0.651**
DKAT-DemK	-	-	0.276*	0.158	1	0.226*
DAS-DemA	-	-	0.200	0.651**	0.226*	1

*Note.* all correlations involving aging scales  $n = 73$ ; all correlations involving dementia scales  $n = 76$ ; correlation between PPAk and PPAa  $n = 149$

\*  $p < 0.05$ ; \*\*  $p < 0.01$

### **Predictors of Knowledge and Attitude Towards PPA**

Linear regression was used to explore potential models that may predict PPAk or PPAa scores. Table 10 describes five regression models with variables that predicted knowledge of and attitude towards PPA.

**Table 10***Regression Models for PPAk and PPAa Scores*

<b>Dependent Variable</b>	<b>Regression Input</b>	<b>Standardized <math>\beta</math></b>	<b>Significance (<math>p</math>)</b>	<b>Adjusted <math>R^2</math></b>
Model 1- PPAk Score				0.141
	FSA-AgeA Score	-0.195	0.185	
	Palmore-AgeK Score	0.380	<b>0.002**</b>	
	PPAa Score	0.335	<b>0.019*</b>	
Model 2- PPAa Score				0.405
	PPAk Score	0.232	<b>0.019*</b>	
	Palmore-AgeK Score	-0.25	<b>0.015*</b>	
	FSA-AgeA Score	0.642	<b>0.000**</b>	
Model 3- PPAa Score				0.429
	PPAk Score	-0.068	0.468	
	DKAT-DemK Score	0.028	0.765	
	DAS-DemA Score	0.659	<b>0.000**</b>	
Model 4- PPAa Score				0.480
	PPAk	-0.067	0.459	
	DKAT-DemK	-0.06	0.518	
	DAS-DemA	0.535	<b>0.000**</b>	
	Rated Interest in Aging	0.083	0.526	
	Rated Interest in Dementia	0.209	0.109	
	Class Level	0.217	<b>0.015*</b>	

*Note.* \* $p < 0.05$ , \*\* $p < 0.01$

Model 1 predicted knowledge of PPA (PPAk) based on PPAa, Palmore-AgeK, and FSA-AgeA scores,  $F = 4.95 (3, 69), p = .004$ . The two statistically significant predictors were Palmore-AgeK and PPAa scores, with an adjusted  $R^2$  of 0.141. (Refer to Table 10 for the standardized beta coefficients for PPAa and AgeK). This model suggests that knowledge of PPA was predicted by knowledge of aging and attitudes towards PPA, but not attitude towards aging.

For attitudes towards PPA, several models were generated. In Model 2, the significant predictors were PPAk, Palmore-AgeK and FSA-AgeA scores, and  $F = 17.34 (3, 69), p < .001$ . Model 3 predicted attitudes towards PPA from DKAT-DemK, DAS-DemA, and PPAk as independent variables,  $F = 18.00 (3, 72), p < .001$ . The adjusted  $R^2$  was .429, and attitudes toward dementia (DAS-DemA) was the only significant predictor in this model. A larger model (Model 4) including PPAk, DKAT-DemK, and DAS-DemA scores, as well as rated interest in aging and dementia, and class level, was constructed to predict PPAa scores,  $F = 12.545 (6, 69), p < .001$ . Attitudes towards dementia (DAS-DemA) and class level were significant predictors.

Generally, knowledge scale scores were likely to predict knowledge of PPA, and attitude scale scores were likely to predict attitudes towards PPA. This confirms the validity of the newly developed PPAk and PPAa scales given that knowledge of aging and dementia were related to PPA knowledge, and attitudes towards aging and dementia were related to attitudes about PPA. Overall, most other reported participant information (classes taken related to aging or dementia, interest in these classes, interest in aging or dementia, and others) did not predict knowledge or attitude towards PPA.

### **Discussion**

The purpose of this study was to characterize undergraduate students' perceptions of PPA as assessed by their knowledge of and attitudes towards this syndrome. Results suggest room for

improvement in knowledge of PPA. Relatively positive attitudes towards PPA exist among undergraduate university students already. Results on aging and dementia scales align with results reported in prior literature (Damron-Rodriguez et al., 2004; Basri et al., 2017; Kite et al., 2005; Scott et al., 2019; Oh & Bong, 2021; Oh & Morris, 2020).

### **Student Knowledge of Aging, Dementia and PPA**

Initial interviews with non-experts revealed a general lack of familiarity and confusion about symptoms associated with PPA. The mean PPAk score was ~75%, which is higher than would be predicted by guessing alone (50%) and demonstrates that students have some level of knowledge of PPA. No prior literature has established a typical level of student knowledge level of PPA, but lack of familiarity among interviewed students in addition to these results suggest that increased education about PPA at the undergraduate level is warranted. Prior literature has reported that hands-on exposure to people with dementia and classes about aging can improve knowledge and attitudes (Damron-Rodriguez et al., 2004; Basri et al., 2017), so additional exposure and education at the undergraduate level may similarly help increase knowledge of PPA.

Mean scores for knowledge of aging and knowledge of dementia were 63% and 79%, respectively. This aligns with previous literature suggesting room for improvement in knowledge of aging and dementia (Damron-Rodriguez et al., 2004; Basri et al., 2017) and provides further evidence of a need for educational initiatives about all three constructs at the undergraduate level.

### **Student Attitudes Toward Aging, Dementia and PPA**

Despite room for improvement in knowledge of PPA, the mean score on the PPA attitudes scale was ~82% (higher score indicating more positive attitude). No specific cutoffs were

defined to indicate negative, neutral, or positive attitudes towards PPA, however Likert style PPAa items included a range from “strongly disagree” (1 point) to “strongly agree” (7 points), so an average greater than 50% indicates overall more agreement with positive statements about PPA (and disagreement with negative statements). This is a promising result given previous reports of negative to neutral attitudes towards older adults and those with dementia in prior literature (Kite et al., 2005; Scott et al., 2019; Oh & Bong, 2021; Oh & Morris, 2020; Basri et al. 2017), although there is still room for improvement. Prior literature suggests that experiential exposure (such as nursing home observation) may improve attitudes towards aging adults and those with dementia (Oh & Bong, 2021; Oh & Morris, 2020; Basri et al., 2017). This study found that attitudes towards aging, dementia and PPA relate (moderate positive correlations). Given that exposure to older adults and those with dementia can improve attitudes towards both populations, exposure to PPA at the undergraduate level may be beneficial for student attitudes towards PPA.

Mean scores for the FSA-AgeA and DAS-DemA were 76% and 74%, respectively. This aligns with prior literature suggesting room for improvement in attitudes towards older adults and those with dementia (Kite et al., 2005; Scott et al., 2019; Oh & Bong, 2021; Oh & Morris, 2020; Basri et al. 2017).

### **Relationships Between Knowledge and Attitude**

The correlation between PPAk and PPAa was small. This indicates that having additional knowledge of PPA does not strongly relate to positivity of attitude toward PPA. This might be partially due to the demographic of respondents surveyed. Most respondents (~75%) considered themselves to be on the communication sciences or pre-health tracks. As students anticipating careers in care or therapy-based professions, they may hold positive attitudes towards PPA

despite lacking knowledge about it at this stage of education. Additionally, given that PPA is diagnosed much less frequently than dementias like Alzheimer's Disease, students likely hear about PPA less often than dementia or aging. This might mean that while they do not know much about PPA, they hold positive attitudes about serving populations in need overall, which manifests as higher PPAa scores.

Although assessing student knowledge of and attitudes towards aging and dementia were not the primary foci of this study, knowledge of aging correlated weakly but positively with attitude towards aging. Knowledge of dementia also correlated weakly but positively with attitude towards dementia. This result aligns with previous literature describing that educational initiatives (which would increase knowledge) may improve attitudes towards people with dementia (Oh & Morris, 2020; Basri et al., 2017), however the correlations in this study were weaker overall and suggest a less robust relationship between the two constructs than has been found previously.

### **Regression Models**

Aligning with significant correlations between attitudes towards aging or dementia and attitudes towards PPA, linear regression generated the most robust models for predicting attitudes towards PPA, despite generating only a few statistically significant predictors. Most notable was Model 2, a model including PPAk, Palmore-AgeK and FSA-AgeA scores (knowledge of PPA, knowledge of aging, and attitudes towards aging) as predictors of PPA attitude, which were all statistically significant predictors. Standardized beta coefficients for PPAk and AgeK were positive, suggesting that more respectful attitudes towards aging adults and more knowledge of PPA would predict more positive attitudes towards PPA. Unexpectedly, *lower knowledge of*

*aging tended to predict a higher PPAa score* (i.e. less knowledge predicting more positive attitude). Limitations of this model are further discussed below.

### **Limitations**

The PPAk and PPAa tools were newly developed for this study. Content validity was established by experts in the University of Arizona Speech, Language and Hearing Sciences Departments, and external validity was established by significant correlations between knowledge of aging or dementia and PPA, and attitudes towards aging or dementia and PPA. Reliability was confirmed with Cronbach's alpha during piloting. However, given that these are new scales, additional studies are needed to confirm replicability in additional student populations.

It is also worth noting that nearly all scale scores were clustered within an approximate 20% range. Minimal spread within the data may have made clear correlations more difficult to elucidate, hence weaker correlations overall made significant by large sample size.

Although it is promising that averages across all three attitude scales were skewed toward positivity (all means >50%), these results may be artificially inflated. The questionnaire was optional and long, so those who submitted complete responses may already care more about topics like PPA and hold more positive attitudes than university students not in these disciplines.

Regression models were generated but not very robust for predicting knowledge of PPA (adjusted  $R^2 < 0.2$  for Model 1). Models predicting PPA attitude were more robust, with the best model (Model 2) generating three statistically significant predictors (knowledge of aging, attitudes towards aging, and knowledge of PPA). However, within this model, less knowledge of aging predicted more positive attitudes towards PPA. Lack of spread within the data, generally weak correlations aside from those between attitude scales, and overall high variation as a result



of the subjective nature of Likert scales limits the power of these regression models. This model should not be interpreted to mean that less knowledge of aging predicts a more positive attitude toward PPA, rather, as an indication that knowledge of aging may indeed play a role in predicting attitude towards PPA, but further investigation is warranted.

### **Future Directions**

It is important that future initiatives address how to better prepare students to work with the population of individuals with PPA, given that there is room for improvement in knowledge of PPA overall. Future research should also include continued assessment and refinement of both the PPAk and PPAa tools, and further investigation into educational initiatives that may improve baseline knowledge. Even if students lack sufficient knowledge of PPA at the undergraduate level, relatively positive attitudes towards PPA among students are promising. These attitudes should help foster respectful and genuinely compassionate healthcare teams in the future. Additional research could include investigation into how attitudes are shaped by exposure to individuals with PPA, similar to Oh & Bong's study assessing student attitudes toward older patients before and after nursing home observation (Oh & Bong, 2021).

### **Conclusion**

As the population of the United States ages, it is inevitable that the prevalence of age-related disease will increase, including neurodegenerative disorders. Continued investigation into the pathology, clinical presentations and courses of these disorders is therefore critical. In addition to increasing scientific knowledge, however, it is crucial to empathize with the experiences of each patient, prioritizing excellent levels of care until potential cures are found. Intuitively, in order to provide effective care, practitioners and therapists should have minimum baseline knowledge of and respectful attitudes towards disease manifestation in their patients.

Thus, the focus of this study was to characterize university student perception (primarily pre-health and communication science students) of one such neurodegenerative disorder: Primary Progressive Aphasia, given that these students will become the next generation of caregivers treating people with PPA.

Results indicate that there is some room for improvement in both knowledge of and attitudes towards PPA, although student attitudes lean towards positive already. Given that both PPAk and PPAa scales were newly developed for this study, future directions should include continued verification of their validity as well as refinement and use in additional studies to further characterize perceptions of PPA.

Previous studies assessing student perceptions of dementia as a general construct have demonstrated that nursing home observation and taking coursework in gerontology and/or dementia can improve student knowledge and attitude towards dementia (Oh & Bong, 2021; Oh & Morris, 2020; Basri et al., 2017). This suggests that educational initiatives to provide more exposure to and experience with PPA and its clinical manifestations at the undergraduate level may be an efficacious way to similarly improve perceptions of PPA. These studies support a rather intuitive idea that learning more about a subject may help eradicate unconscious bias or spark interest in it such that more respectful and positive attitudes are fostered. Similar to Oh & Bong's (2021) study, student perception could be assessed prior to and after exposure to patients with PPA.

Ultimately, future healthcare providers and speech-language therapists have a dual responsibility to both understand and seek continued knowledge in their respective fields while also translating this knowledge into compassionate care, which starts with developing respectful and positive attitudes towards the patient populations with which they will work. Characterizing

current students' perceptions of PPA who intend to enter these fields was an initial step towards creating interventions to achieve this goal, and the hope is that this work will inspire additional investigation into provider perceptions of PPA and ways to improve care overall.

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**Appendix A**

## Complete Questions and Key for Administered Questionnaire

## Block 1-

1. Consent

## Block 2- Demographics

*0. Demographic section instructions*

1. What is your age? [number entry]
2. What was your sex assigned at birth? [male, female, prefer not to answer]
3. What is your gender identity? [woman, man, non-binary/third gender, prefer not to say]
4. Which race or ethnicity best describes you? (Please choose only one.)
  - a. American Indian or Alaskan Native
  - b. Asian/Pacific Islander
  - c. Black or African American
  - d. Hispanic
  - e. White/Caucasian
  - f. Multiple ethnicities/Other
5. What is your class level?
  - a. Freshman
  - b. Sophomore
  - c. Junior
  - d. Senior
  - e. Master's student
  - f. Doctoral student
6. What is your area of study? [fill in the blank]
7. Would you consider yourself to be on a pre-health track, communication sciences track, or neither? [pre-health track, communication sciences track, neither]
8. Please rate your interest in the aging population. [Low Interest, Slight Interest, Moderate Interest, Significant Interest, Extreme Interest]
9. Please rate your interest in the population of persons with dementia. [Low Interest, Slight Interest, Moderate Interest, Significant Interest, Extreme Interest]
10. How many academic courses on aging or gerontology have you taken (i.e., Physiology of Aging)? Please list all of the course titles. [fill in the blank]
11. How many academic courses with specific focus on dementia have you taken? Please list all of the course titles. [fill in the blank]
12. How many academic courses with specific focus on communication disorders have you taken? Please list all of the course titles. [fill in the blank]
13. Were any of these courses required in your program of study? [Y/N]

14. If so, which courses? [fill in the blank]
15. If you took any classes related to aging, dementia, or communication disorders, how much did you enjoy these classes? [I did not enjoy these classes at all, I minimally enjoyed these classes, I somewhat enjoyed these classes, I moderately enjoyed these classes, I enjoyed these classes very much].
16. Please rate the benefits of these courses to your present or future career path. [no benefits, few benefits, some benefits, significant benefits, very significant benefits].
17. Do you believe you will eventually pursue a career in which you will work with people with dementia? [Y/N/Maybe]
18. Do you believe you will eventually pursue a career in which you will work with people with communication disorders? [Y/N/Maybe]
19. Do you have personal experience interacting with family members or friends who have dementia? [Y/N]
20. Do you have personal experience interacting with family members or friends who have PPA? [Y/N]
21. Do you have any volunteer or work experience with people with dementia? [Y/N]
22. Do you have any volunteer or work experience with people with PPA? [Y/N]
23. How involved are you in non-work or academic-related groups (volunteer groups, church, social groups) that involve older adults? [not at all involved, minimally involved, somewhat involved, moderately involved, very much involved]

### Block 3- Palmore's Facts on Aging Quiz

#### 0. Instructions

1. The majority of old people (past 65 years) have Alzheimer's disease. **F**
2. As people grow older, their intelligence declines significantly. **F**
3. It is very difficult for older adults to learn new things. **F**
4. Personality changes with age. **F**
5. Memory loss is a normal part of aging. **T**
6. As adults grow older, reaction time increases. **T**
7. Clinical depression occurs more frequently in older than younger people. **F**
8. Older adults are at risk for HIV/AIDS. **T**
9. Alcoholism and alcohol abuse are significantly greater problems in the adult population over age 65 than that under age 65. **F**
10. Older adults have more trouble sleeping than younger adults do. **T**
11. Older adults have the highest suicide rate of any age group. **F**
12. High blood pressure increases with age. **T & F**
13. Older people perspire less, so they are more likely to suffer from hyperthermia. **T**
14. All women develop osteoporosis as they age. **F**
15. A person's height tends to decline in old age. **T**
16. Physical strength declines in old age. **T**

17. Most old people lose interest in and capacity for sexual relations. **F**
18. Bladder capacity decreases with age, which leads to frequent urination. **T**
19. Kidney function is not affected by age. **F**
20. Increased problems with constipation represent a normal change as people get older. **F**
21. All five senses tend to decline with age. **T**
22. As people live longer, they face fewer acute conditions and more chronic health conditions. **T**
23. Retirement is often detrimental to health--i.e., people frequently seem to become ill or die soon after retirement. **F**
24. Older adults are less anxious about death than are younger and middle-aged adults. **T**
25. People 65 years of age and older currently make up about 20% of the U.S. population. **F**
26. Most older people are living in nursing homes. **F**
27. The modern family no longer takes care of its elderly. **F**
28. The life expectancy of men at age 65 is about the same as that of women. **F**
29. Remaining life expectancy of blacks at age 85 is about the same as whites. **T**
30. Social Security benefits automatically increase with inflation. **T**
31. Living below or near the poverty level is no longer a significant problem for most older Americans. **F**
32. Most older drivers are quite capable of safely operating a motor vehicle. **T**
33. Older workers cannot work as effectively as younger workers. **F**
34. Most old people are set in their ways and unable to change. **F**
35. The majority of old people are bored. **F**
36. In general, most old people are pretty much alike. **F**
37. Older adults (65+) have higher rates of criminal victimization than adults under 65 do. **F**
38. Older people tend to become more spiritual as they grow older. **T**
39. Older adults (65+) are more fearful of crime than are persons under 65. **F**
40. Older people do not adapt as well as younger age groups when they relocate to a new environment. **F**
41. Participation in volunteering through organizations (e.g., churches and clubs) tends to decline among older adults. **F**
42. Older people are much happier if they are allowed to disengage from society. **F**
43. Geriatrics is a specialty in American medicine. **T**
44. All medical schools now require students to take courses in geriatrics and gerontology. **F**
45. Abuse of older adults is not a significant problem in the U.S. **F**
46. Grandparents today take less responsibility for rearing grandchildren than ever before. **F**
47. Older persons take longer to recover from physical and psychological stress. **T**
48. Most older adults consider their health to be good or excellent. **T**
49. Older females exhibit better health care practices than older males. **T**
50. Research has shown that old age truly begins at 65. **F**

## Block 4- DKAT

*0. Instructions*

1. Dementia occurs because of changes in the brain. **T**
2. Brain changes causing dementia are often progressive. **T**
3. Alzheimer's disease is the main cause of dementia. **T**
4. Blood vessel disease can also cause dementia. **T**
5. Confusion in an older person is almost always due to dementia. **F**
6. Only older adults develop dementia. **F**
7. Knowing the likely cause of dementia can help to predict its progression. **F**
8. Incontinence always occurs in the early stages of dementia. **F**
9. Dementia is likely to limit life expectancy. **T**
10. When a person has late-stage dementia, families can help others to understand that person's needs. **T**
11. People who have dementia may develop problems with visual perception (understanding or recognizing what they see). **T**
12. Sudden increases in confusion are characteristic of dementia. **F**
13. Uncharacteristic distressing behaviors (for example, aggressive behavior in a gentle person) may occur in people who have dementia. **T**
14. Difficulty swallowing occurs in late-stage dementia. **T**
15. Movement (for example, walking or moving in a bed or chair) is limited to late-stage dementia. **T**
16. Changing the environment (for example, putting on a CD, opening or closing the blinds) will make no difference to a person who has dementia. **F**
17. When a person who has dementia is distressed, it may help to talk to them about their feelings. **T**
18. It is important to always correct a person who has dementia when they are confused. **F**
19. A person who has dementia can often be supported to make choices (for example, what clothes to wear). **T**
20. It is impossible to tell if a person who is in the later stages of dementia is in pain. **F**
21. Exercise can sometimes be beneficial to people who have dementia. **T**

## Block 5- PPAk

*0. Instructions*

1. Aphasia is a loss of ability to understand or express language. **T**
2. Primary Progressive Aphasia (PPA) is a neurodegenerative disorder (brain damage that gets worse over time). **T**
3. PPA affects communication. **T**
4. Stroke is the main cause of PPA. **F**
5. PPA occurs because of changes in the brain. **T**

6. If trouble with speech and language appears suddenly (e.g., within a 24-hour period), it is likely due to PPA. **F**
7. PPA can cause people to speak slowly and with effort. **T**
8. Difficulty coming up with words in an older person (above 65 years of age) is typically due to PPA. **F**
9. To be diagnosed with PPA, difficulty with language must be the predominant symptom. **T**
10. Trouble coming up with words is a common early symptom of PPA. **T**
11. PPA does not affect written language (reading and writing). **F**
12. Speech therapy may help improve language skills in individuals with PPA. **T**
13. People with advanced PPA can have changes in personality. **T**
14. PPA can limit life expectancy. **T**
15. The primary symptom of PPA is struggling with retrieval of memories from the past (e.g., remembering names of grandchildren). **F**
16. People with PPA are often unaware of their language decline. **F**
17. Individuals with PPA can experience significant frustration associated with their language decline/difficulty. **T**
18. People with advanced PPA retain the ability to comprehend written and spoken language. **F**
19. PPA cannot be cured. **T**
20. Although PPA affects language, individuals with PPA may also demonstrate impairment with motor skills required for speech production. **T**
21. There are multiple variants of PPA, and each is characterized by different profiles of language difficulties. **T**
22. Family counseling and/or attending PPA support groups can be helpful after a loved one is diagnosed with PPA. **T**
23. Brain imaging (e.g., MRI or PET scans) provides useful information for diagnosing PPA. **T**
24. Post-stroke aphasia can transform into PPA. **F**

## Block 6- FSA

### 0. Instructions

1. Teenage suicide is more tragic than suicide among the old.
2. There should be special clubs set aside within sports facilities so that old people can compete at their own level.
3. Many old people are stingy and hoard their money and possessions.
4. Many old people are not interested in making new friends preferring instead the circle of friends they have had for years.
5. Many old people just live in the past.
6. I sometimes avoid eye contact with old people when I see them.

7. I don't like it when old people try to make conversation with me.
8. Old people deserve the same rights and freedoms as do other members of our society. \*
9. Complex and interesting conversation cannot be expected from most old people.
10. Feeling depressed when around old people is probably a common feeling.
11. Old people should find friends their own age.
12. Old people should feel welcome at the social gatherings of young people. \*
13. I would prefer not to go to an open house at a senior's club, if invited.
14. Old people can be very creative. \*
15. I personally would not want to spend much time with an old person.
16. Most old people should not be allowed to renew their driver's licenses.
17. Old people don't really need to use our community sports facilities.
18. Most old people should not be trusted to take care of infants.
19. Many old people are happiest when they are with people their own age.
20. It is best that old people live where they won't bother anyone.
21. The company of most old people is quite enjoyable. \*
22. It is sad to hear about the plight of the old in our society these days. \*
23. Old people should be encouraged to speak out politically. \*
24. Most old people are interesting, individualistic people. \*
25. Most old people would be considered to have poor personal hygiene.
26. I would prefer not to live with an old person.
27. Most old people can be intimidating because they tell the same stories over and over
28. Old people complain more than other people do.
29. Old people do not need much money to meet their needs.

## Block 7- DAS

### 0. Instructions

1. It is rewarding to work with people who have ADRD.
2. I am afraid of people with ADRD. \*
3. People with ADRD can be creative.
4. I feel confident around people with ADRD.
5. I am comfortable touching people with ADRD.
6. I feel uncomfortable being around people with ADRD. \*
7. Every person with ADRD has different needs.
8. I am not very familiar with ADRD. \*
9. I would avoid an agitated person with ADRD. \*
10. People with ADRD like having familiar things nearby.
11. It is important to know the past history of people with ADRD.
12. It is possible to enjoy interacting with people with ADRD.
13. I feel relaxed around people with ADRD.
14. People with ADRD can enjoy life.

15. People with ADRD can feel when others are kind to them.
16. I feel frustrated because I do not know how to help people with ADRD. \*
17. I cannot imagine taking care of someone with ADRD. \*
18. I admire the coping skills of people with ADRD.
19. We can do a lot now to improve the lives of people with ADRD.
20. Difficult behaviors may be a form of communication for people with ADRD.

#### Block 8- PPAa

##### 0. Instructions

1. I am familiar with PPA. (not included in overall score)
2. I think PPA would be an upsetting diagnosis to receive.
3. People with PPA can make meaningful contributions to our society.
4. I feel sympathy for people diagnosed with PPA.
5. If a loved one was diagnosed with PPA, I would want to learn how to help them.
6. I understand the difference between PPA and Alzheimer's Disease.
7. I would like to learn more about PPA.
8. I think supporting people with PPA is important.
9. I would avoid a person with PPA who cannot communicate clearly. \*
10. I am afraid of people with PPA. \*
11. I think it would be rewarding to work with people who have PPA.
12. I feel uncomfortable around people with PPA.\*
13. People with PPA should stop working upon diagnosis. \*
14. I think it would be frustrating to speak to someone with PPA. \*
15. I would not like it if a person with PPA approached me. \*
16. I think treatment for people with PPA would be ineffective. \*

\* indicates an item was scored in reverse.

Survey flow proceeded through blocks 1 and 2, either block 3 or block 4, block 5, either block 6 or block 7, and finally block 8. Participants receiving the 1-2-3-5-6-8 flow were in the aging and PPA group. Participants receiving the 1-2-4-5-7-8 flow were in the dementia and PPA group. These groups were determined at random.

As noted in the text, the FSA was originally coded as: Strongly Disagree= 1, Disagree= 2, Agree= 4, Strongly Agree= 5 (3= no answer), with higher scores indicating more ageism (more negative attitudes towards aging). For the purposes of this investigation, choices were coded in reverse so that higher scores correspond with less ageism (more positive attitudes

towards aging) to allow for easier assessment of relationships between attitudes towards aging and PPA. Therefore, Strongly Disagree=5, Disagree=4, Agree=2, Strongly Agree=1. (Blank answers were not scored given that other Likert scale questions administered did not score unanswered questions. Leaving questions unanswered could also falsely skew the resulting score for positivity of attitude given that ‘unanswered’ does not necessarily equal ‘neutral’ and an intermediate point credit may not be an accurate reflection of a student’s attitude).



**Appendix B**

## Supplemental Table

*Analysis of Variance Across Demographic Variable Groups for PPAk and PPAa Scores*

	PPAk				PPAa			
	df <sup>a</sup>	df <sup>b</sup>	F	p	df <sup>a</sup>	df <sup>b</sup>	F	p
Sex	1	146	0.025	0.874	1	146	2.37	0.126
Gender	2	146	0.371	0.691	2	146	1.131	0.325
Race	4	144	1.786	0.135	4	144	0.792	0.325

*Note.* There were no significant differences in PPA knowledge or attitude by the demographic variables of sex, gender, and race.

<sup>a</sup>between groups; <sup>b</sup>within groups