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RESEARCH REPORT

Access, referral, service provision and management of individuals with primary progressive aphasia: A survey of speech-language therapists in Italy

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Abstract

Background and Objectives: In Italy, approximately 650 individuals receive a diagnosis of primary progressive aphasia (PPA) every year. Unfortunately, the frequency with which patients are referred to speech-language services is suboptimal, likely due to skepticism regarding the value of speech-language therapy in the context of neurodegeneration.

Materials and Methods: We conducted a virtual survey of speech and language therapists (SLTs) across Italy, to collect information about the assessment, intervention and management of patients with PPA. To ensure that as many SLTs as possible received the survey, the Italian Federation of SLTs (Federazione Logopedisti Italiani, FLI) aided in disseminating the survey.

Results: In total, 336 respondents participated in the online survey, 140 of whom had previous experience with PPA patients. Respondents indicated having seen a total of 428 PPA patients in the previous 24 months (three patients on average, range: 0–40). SLTs who reported never working with PPA identified underdiagnoses, low referral rates and the rarity of the clinical syndrome as major reasons for their lack of experience with PPA. SLTs with experience working

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with PPA indicated that patients may not have accessed services because of service dysfunction and geographical barriers. Respondents reported using informal interviews during assessments and tests developed for post-stroke aphasia, while impairment-based/restitutive interventions were utilised most often.

Conclusion: Findings may serve to inform health policy organisations regarding the current shortcomings and needed recommendations for improving the care of individuals with PPA in Italy. Improving awareness of the utility of rehabilitation among SLTs and other clinical service providers may serve to facilitate access to intervention, which in turn will serve to better support individuals living with PPA.

KEYWORDS
assessment, clinical service, intervention, PPA, rehabilitation, speech and language therapy

What This Paper Adds

What is already known on the subject

Speech and language therapists (SLTs) play a crucial role in the assessment, diagnosis and treatment of people with primary progressive aphasia (PPA). However, the frequency with which individuals with PPA are referred for speech and language services is suboptimal due to skepticism regarding the value of speech and language therapy in the context of neurodegeneration, the scarcity of SLTs with expertise in the treatment of PPA and the lack of awareness of the SLT role amongst referrers.

What this paper adds to existing knowledge

In recognition of the lack of published information on the provision of speech and language therapy services and clinicians' approaches to the assessment and treatment of individuals with PPA in Italy, we conducted an online survey to evaluate the current referral patterns for speech and language therapy services and to examine the current barriers to access these services for individuals with PPA in Italy.

What are the potential or actual clinical implications of this work?

The data presented here support that SLTs view treatment as useful for individuals with PPA and other professional figures and may serve to improve access to intervention, which in turn will serve to better support individuals living with PPA. The results highlight the need to inform health policy organisations about current gaps and aid in developing recommendations for improving the care of individuals with PPA, in order to understand how SLTs can best support individuals with PPA and their families.

INTRODUCTION

The World Health Organisation estimated that there were around 50 million people affected by dementia in 2020, and the total number of people living with dementia is projected to reach 152 million in 2050, painting an even more concerning picture (www.who.int/news-room/fact-sheets/setail/dementia). In Italy, the total number of patients with dementia is estimated to be over 1 million and about 3 million people are directly or indirectly involved in the care of loved ones living with dementia (Raggi et al., 2022). Frontotemporal dementia (FTD) is one of the lead-

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ing causes of younger-onset dementia, often diagnosed in individuals who are in their 50s–60s who may still be employed, with dependent family members (Knopman & Roberts, 2011). Therefore, the economic cost and societal burden of FTD are significant, posing a major public health challenge.

Primary progressive aphasia (PPA) is an umbrella term used to refer to several clinical variants that manifest as an insidious deterioration of speech/language skills, usually due to frontotemporal lobar degeneration and/or Alzheimer's disease (Mesulam & Weintraub, 2008). Consensus criteria have been proposed by an international community regarding the sub-classification of PPA into three variants (Gorno-Tempini et al., 2011): (1) semantic variant PPA, characterised by impaired confrontation naming and single-word comprehension; (2) logopenic variant PPA), characterised by word-finding difficulties and sentence repetition deficits; and (3) non-fluent variant, characterised by agrammatism with or without apraxia of speech. The incidence rate of FTD in Italy is 3 per 100 000 person-years and 34.9% of new FTD cases are estimated to be PPA (Logroscino et al., 2019). The incidence of PPA is therefore approximately 1 per 100 000 person-years. Assuming a conservative incidence of aphasic variants of Alzheimer's disease of 1.5 per 100 000 person-years, we expect an overall PPA incidence rate of 2.5 per 100 000. Assuming an average duration of the disease of 10 years (Coyle-Gilchrist et al., 2016; Onyike, 2011), we would expect that in Italy, there is an approximate prevalence of 0.025%, corresponding to 15 000 cases of PPA; with around 650 people receiving a diagnosis of PPA every year.

A recent report edited by the Italian Federation of Speech Therapists (Federazione Logopedisti Italiani, FLI) and realised by the public research institute specialized in the Health area, Datanalysis (*Libro Bianco Della Logopedia*, 2021) estimated that the number of SLTs working in Italy is approximately 15 000, which does not fully cover the healthcare needs of the population. One of the consequences of this shortage is that patients may not receive adequate attention from SLTs when a diagnosis of PPA is confirmed. This scenario is even worse considering that no pharmacological treatments that counteract or slow disease progression and subsequent loss of speech/language abilities are currently available (Taylor-Rubin et al., 2021).

Speech and language therapists (SLTs) play a crucial role in the diagnostic process and in setting a therapeutic path along with monitoring the evolution of the clinical picture. The assessment of speech and language is an important first step for diagnosis and intervention planning in PPA (Henry & Grasso, 2018). Multiple assessments are needed for a comprehensive evaluation (e.g., confrontation naming, repetition ability, motor speech exam, grammar testing, reading/writing and testing of semantic knowledge). Moreover, a careful and detailed analysis of connected speech, elicited via picture description or personal narrative, can highlight speech alterations (i.e., reduced articulatory agility; altered prosody; the presence of pauses, self-corrections and false starts); impairment at the morphosyntactic level (production of simple structures, grammatical omissions, morphological errors); lexical-semantic deficits (anomia, semantic paraphasias) and phonological errors (Gallée et al., 2021; Wilson et al., 2010).

Recently, many research studies have documented the importance and benefits of speech-language treatment for PPA (e.g., (Henry et al., 2018, 2019; Machado et al., 2021; Suárez-González et al., 2021)). More specifically, evidence supports both restitutive and functional interventions for improving communication abilities in individuals with PPA (Henry et al., 2019; Machado et al., 2021; Suárez-González et al., 2021). Restitutive intervention approaches, such as lexical retrieval treatment, are geared towards rebuilding lost skills. Approaches that address functional communication aim to improve everyday communication and the individual's ability to function in their day-to-day life. These approaches include environmental modifications (e.g., working with families and caregivers) and activities focused on engagement in everyday tasks or situations. For SLTs as well as individuals with PPA, improvement in the level of functional communication is often the main desired outcome and is central foci to collaborative goal-setting (e.g., Hersh et al., 2012; Volkmer, Spector, Meitanis et al., 2020).

Despite growing evidence supporting the benefits of speech-language intervention, the frequency with which individuals with PPA are referred for speech and language services, is suboptimal likely due to skepticism regarding the value of speech and language therapy in the context of neurodegeneration, the scarcity of SLTs with expertise in the treatment of PPA, the lack of awareness regarding the role of the SLT amongst referrers, and the geographical barriers that impede access to in-person speech and language services (Taylor et al., 2009; Volkmer, Rogalski et al., 2020).

Few reports have investigated access to and utilisation of speech and language services in different countries; nevertheless, the evidence from these studies indicates that there is a serious need to increase service provision for individuals with PPA. In Australia, SLTs reported via survey indicated that only a small proportion of clients with PPA are referred to SLTs, highlighting the need for more accessible information for clinicians and individuals with PPA (Taylor et al., 2009). In Germany, Riedl et al. (2014) collected data from family carers of patients living with PPA and found that the majority of individuals did not receive adequate or sufficient in-home SLT services, with only 9% of patients indicating that they were receiving

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speech therapy. More recently, in the United Kingdom, two reports concerning the nature of services delivered by SLTs to individuals with PPA reported inequities in access to SLT services, such that individuals from high socioeconomic backgrounds were predominately referred for services due to a higher likelihood of seeking support (Volkmer et al., 2019; Volkmer, Spector, Warren et al., 2020). In the Italian scenario, patients with PPA are rarely offered treatment options due to a lack of understanding of the disorder on the part of health professionals and erroneous assumptions regarding the utility of treatment in patients facing an ever-worsening prognosis. Italy has a particular cultural and linguistic background, with 20 geographically distinct regions, as well as a regionally-based national health service. The national healthcare system provides universal coverage to citizens and residents, with public healthcare largely free of charge. However, little is known about care pathways available to individuals with PPA and current barriers to accessing speech and language services in Italy.

In this descriptive study, we aim to examine the provision of SLT services to individuals with PPA, characterize clinicians' approaches to assessment and treatment and identify referral patterns and current barriers to speech and language services in Italy. We distributed an online survey to SLTs working in Italy in order to (1) conduct an in-depth analysis of the current referral patterns to SLT services for clients with PPA and (2) to examine how to best facilitate access to SLT services for individuals with PPA in Italy.

MATERIAL AND METHODS

Design, setting and participants

For the purpose of this study, we collected data using an online survey that conforms to the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) survey reporting checklist (Eysenbach, 2004). The survey was made available for 2 months, from 21 October to 21 December 2021, and targeted SLTs practicing in Italy who were enrolled in the professional registry (n = approximately 15 000). Although all Italian SLTs were given the option to respond to the survey, only respondents with experience working with PPA patients were instructed to complete all survey sections (all others exited the survey after the first section). The first section of the survey was made available to all Italian SLTs in order to collect data regarding the reasons why some SLTs do not see individuals with PPA in their clinical practice. To ensure that as many SLTs as possible received the survey, we contacted the Italian Federation of SLTs (i.e., FLI) and worked with them to disseminate the survey. To further increase dissemination across Italy, we distributed the survey link through social media channels, including WhatsApp, LinkedIn, Facebook, Telegram, Instagram and Twitter. The survey link was also emailed to 20 relevant service providers, across different settings including private providers and public institutions, outpatient services and hospitals, in metropolitan as well as remote areas. We sent a reminder to complete the survey via these channels 2 weeks before closing the survey. The survey was further promoted via several local and national news websites. On the initial page of the online survey, participants were required to give informed consent before proceeding to the remainder of the survey. No personal data were collected and all responses were stored anonymously. The study was approved by the internal Clinical Scientific Institutes 'XX's' committee. Participants were not offered any financial incentive to participate in the online survey.

Online survey instrument

We selected questions from a previous survey developed by Volkmer et al. (2019) and Volkmer, Spector, Warren et al. (2020), which was specifically designed to assess SLTs' engagement with people with PPA across the United Kingdom. The survey was translated from English to Italian by the first author and was reviewed by two other Italian-speaking SLTs. The survey was then shared with a small panel of Italian-speaking SLTs, who provided further feedback on the understandability of the translation, before public dissemination. The English version comprised 37 questions; however, a few questions were slightly modified to best capture the Italian context and to ensure their relevance. Thus, items regarding clinical background, occupation and geographical location were refined. Moreover, respondents without previous experience working with individuals with PPA were asked to specify the reasons for not having worked with this population. The final survey consisted of 34 items across five sections: (1) eight questions regarding the clinical background and geographical location of participants; (2) 16 questions on the number, type and source of patients seen in the last 24 months; (3) four questions about the care pathway available for individuals with PPA; (4) two questions regarding assessment tools and interventions; and (5) four questions on the outcome measures used in therapy, as well as information regarding locally available caregiver support groups and associations locally available. Additionally, respondents were asked to provide an email address if they were interested in receiving the results of the survey. On the landing page, participants were briefed about the aims of the study and on the final page, participants were debriefed about the study and thanked for their

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contribution. The final survey is reported in Appendix S1. Survey data were collected and stored confidentially online using the database management system Qualtrics (Version March 2020, Qualtrics, Provo, UT, USA).

Data analysis

Following the elimination of duplicates (the last entry was used), completed surveys were extracted and analysed. Response rates were calculated in accordance with the CHERRIES definition (Eysenbach, 2004). We present the results of the survey items, including sociodemographic characteristics of SLT respondents, using descriptive summary statistics. Categorical variables were described and displayed using frequencies and percentages (or proportions), while numeric variables were summarised using mean, median and range.

Because responses divided by each geographical region (20 regions) resulted in small sample sizes, data were grouped into three larger geographic areas: Northern Italy (Valle d'Aosta, Piemonte, Liguria, Lombardia, Veneto, Trentino Alto Adige, Friuli Venezia Giulia, Emilia Romagna), Central Italy (Toscana, Marche, Lazio, Umbria, Abruzzo, Sardegna) and Southern Italy (Campania, Puglia, Basilicata, Molise, Calabria, Sicilia). Non-parametric Kruskal–Wallis test was used to assess whether the number of PPA cases seen in the last 24 months reported by the respondents differed between these larger regions. Data were analyzsd using R v4.0.3 and R studio 2021.09.1.

RESULTS

Demographics of speech and language therapist respondents

As of 21 December 2021 (the closing date of the survey), a total of 445 unique respondents had opened the survey; however, only 336 of these respondents completed the survey. Of the 336 respondents who completed the survey, 140 indicated experience working with individuals with PPA (see flow chart, Figure 1). Based on the estimate of 15 000 working SLTs in Italy (*Libro Bianco Della Logopedia*, 2021), the survey coverage (i.e., how well the sampling units included in a sampling frame account for a survey's target population) was approximately 2.2%.

Descriptive sociodemographic characteristics are presented in Table 1 and refer to responders who completed the survey. A relatively small percentage were new graduate (1.8%, n = 6) or within 1–2 years post-graduation (9.5%, n = 32), or within 2–3 years post-graduation (16.4%, n = 55). Almost one-third of respondents were

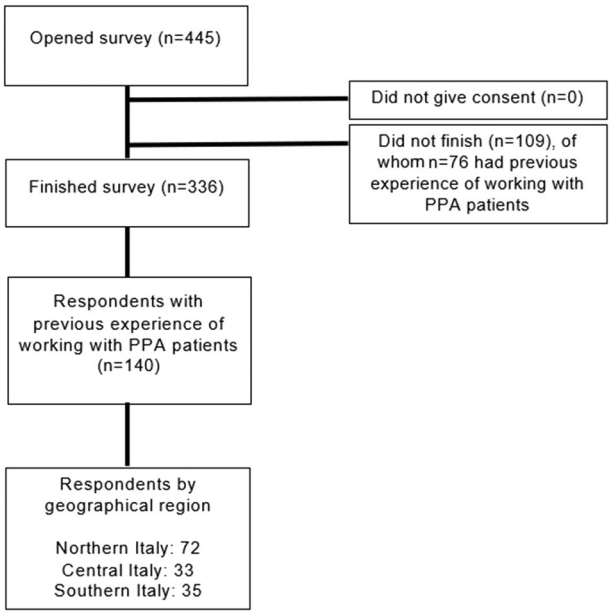

FIGURE 1 Flow chart of respondents from the online survey (closed on 21 December 2021).
Abbreviation: PPA, primary progressive aphasia.

within 5–10 years post-graduation (24.4%, n = 82). One hundred sixty-one respondents (47.9%) had 10 or more years of clinical practice experience. A bachelor's degree (which is the minimum degree to practice as an SLT in Italy) was the most represented educational qualification (38.4%, n = 129), followed by post-graduate degree (25.9%, n = 87), master's degree (23.5%, n = 79), other post-graduate courses (6.8%, n = 23), other degrees (4.8%, n = 16) and doctor of philosophy (0.6%, n = 2) (Table 1). A total of 105 (31.2%) reported working with local health authorities, and 96 (28.6%) reported working as independent contractors, 69 (20.5%) of the respondents reported working in hospitals or clinical-scientific institutes, 48 (14.3%) reported working in other settings, 10 (3.0%) of the respondents reported working in care homes and 8 (2.4%) reported working in semi-residential facilities for day care. When comparing the number of respondents across Italian regions, the highest number of respondents were from Northern Italy (n = 164; 48.8%), followed by Southern Italy (n = 91; 27.1%) and Central Italy (n = 81; 24.1%).

Characteristics of patients referred to SLT

The 140 SLT respondents who had previous experience working with individuals with PPA reported seeing a total of 428 individuals during the 24 months preceding their completion of the survey. On average, respondents reported seeing three individuals with PPA during this

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TABLE 1 Sociodemographic characteristics of SLTs respondents on 21 December 2022

Years post qualification (%)	
New graduate	6 (1.8)
1–2	32 (9.5)
3–4	55 (16.4)
5–10	82 (24.4)
10+	161 (47.9)
Highest educational qualification (%)	
Bachelor's degree (BSc)	129 (38.4)
Master's degree (MSc)	79 (23.5)
Doctor of philosophy (PhD)	2 (0.6)
Post-graduate degree	87 (25.9)
Other degrees	16 (4.8)
Other	23 (6.8)
Healthcare service (%)	
Hospital and/or clinical and scientific institutes	69 (20.5)
Local health authority (Azienda Sanitaria Locale)	105 (31.2)
Care home (Residenza Sociosanitaria Assistenziale per Anziani)	10 (3.0)
Semi-residential facilities for day care	8 (2.4)
Independent contractor	96 (28.6)
Volunteering	0 (0)
Other	48 (14.3)

Abbreviation: SLT, speech-language therapist

period of time (median: 2, range: 0–40). Although geographical variation was observed, no statistically significant difference was found in the number of PPA patients reported to be seen in the previous 24 months ($p = 0.26$), between geographical areas. The 72 respondents from Northern Italy reported seeing a total of 231 PPA patients, an average of 3.2 per respondent (median: 2, range: 0–20). The 33 respondents from Central Italy reported a total of 72 PPA patients (average: 2.2, median: 2, range: 0–9), while the 35 respondents from Southern Italy reported a total of 125 PPA patients (average: 3.6, median: 1, range: 0–40). The average number of reported PPA patients by geographical region is displayed in Figure 2. Respondents reported seeing patients with PPA in local health authorities (Azienda Sanitaria Locale, n = 69, 49.3%), in research-oriented hospitals (Istituti di Ricovero e Cura a Carattere Scientifico, n = 36, 25.7%) at a specialty center for neurodegenerative diseases (n = 12, 8.6%), in private settings (n = 29, 20.7%), in acute clinical settings (n = 21, 15.0%), in care home (Residenza Sociosanitaria Assistenziale per Anziani, n = 9, 6.4%), and in facilities for day-care (n = 2, 1.4%). Most respondents reported seeing Italian-speaking patients only (n = 130, 92.9%) and seeing most patients in the age category of 60–70 years (n = 73, 52.1%) or 70 or older (n = 33, 23.6%).

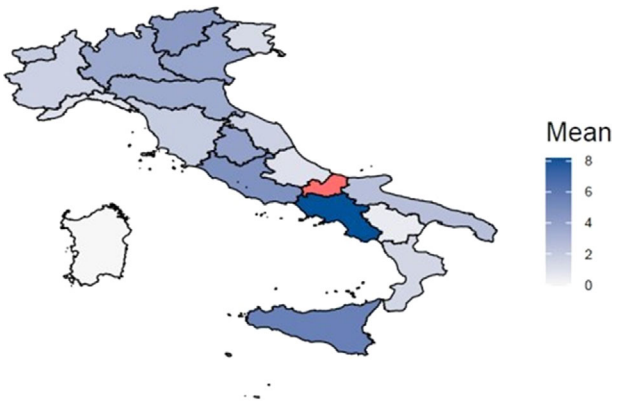

FIGURE 2 The average number of PPA patients seen within the last 24 months by SLTs across Italy by region. No respondent from the region displayed in red (e.g., Molise) completed the online survey.
Abbreviations: PPA, primary progressive aphasia; SLT, speech-language therapist.
[Colour figure can be viewed at wileyonlinelibrary.com]

Access to SLT services

Of the 336 respondents, 196 (58.3%) SLTs indicated no experience working with individuals with PPA. Among the reasons provided for not having previously worked

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with individuals with PPA, more than half of the respondents indicated that they only work with children and teenagers (n = 106, 54.1%), 35 (17.9%) reported that they do not work with PPA although they work with older adults (e.g., a different sub-specialty such as voice disorders), 33 (16.8%) reported that PPA patients are not referred to them, although they work with older adults affected by neurodegenerative diseases (e.g., amyotrophic lateral sclerosis, Parkinson's disease). Twenty-two respondents (11.2%) reported other reasons for not seeing individuals with PPA; most of them reported probable underrepresentation of PPA in their caseloads due to a lack of referrals and lack of awareness amongst clinicians (e.g., referring doctors and SLTs) regarding the utility of SLT interventions; under-diagnosis of PPA or overall rarity of the clinical syndrome as causes for the underrepresentation of PPA patients on their caseloads.

We also asked about the barriers that patients are likely to encounter when attempting to access SLT services. Amongst the SLT responders who indicated previous experience working with individuals with PPA, 40 (28.6%) cited service dysfunction (e.g., long wait time before starting treatment, treatment postponed until patients reach a specific severity threshold or other unspecified issues), 37 (26.4%) indicated geographical barriers and 26 (18.6%) indicated that patients declined SLT services. Other common barriers to access that were identified included patients' poor knowledge of technology (e.g., patients' limited technological proficiency, particularly if they do not have a laptop and have never used one before) (n = 15, 10.7%), high cost of treatment (n = 14, 10.0%) and lack of access to technological devices in the home (n = 7, 5.0%). Respondents reported that they receive a large number of their PPA referrals from neurologists (n = 110, 78.6%), and/or geriatricians (n = 35, 25.0%) or other SLTs (n = 33, 23.6%). Most of the SLTs reported word-finding difficulties as one of the first prominent symptoms for which they receive referrals (n = 130, 92.9%). Ninety-six (68.6%) reported that if the patients or the family were provided a diagnostic label from a physician/specialist, a label of PPA was used. Half of the respondents (n = 70, 50.0%) reported that PPA patients were referred for SLT services within 2–3 years of symptom onset. Table 2 displays data summarising access to SLT services for Italian individuals with PPA.

Care pathways

Respondents were asked if they have the possibility of directing individuals with PPA to a care pathway and 36 (25.7%) indicated that they do indeed have the ability to do so. As a follow-up, they were also asked to describe this pathway. The majority of respondents listed an onward referral process to another SLT service. Fewer respondents described their service's care pathway as comprising only rehabilitation (e.g., not assessment). One respondent reported referring patients to another institution where research projects are carried out. Two respondents provided an overview of the care pathways they offered by giving some examples of intervention modes that included sessions with transcranial current stimulation. Figure 3 displays the average number of sessions spent on assessment and treatment/management of individuals with PPA (or their families). On average, respondents spent 12.0 sessions (range: 0–30), with an average duration of 45 min on intervention for the speech-language deficit and 4.9 sessions (range: 0–24), on functional communication-focused interventions; 2.3 sessions (range 1–5) for assessment of speech, language and communication; 0.6 (range 0–7) on cognitive assessment but only 0.7 sessions (range: 0–5) on contribution to PPA diagnosis (in terms of sessions discussing education about the diagnosis) and 0.7 sessions on dysphagia assessment. The results show that respondents spent more time on interventions than on any other activity. An average of 2.6 sessions were dedicated to family education, while those dedicated to education for persons with PPA were 3.0. A small amount of time was spent on group therapies, on average 0.5 sessions. Finally, when respondents were asked how often they referred patients to community-based organizations and support groups, more than half of the respondents (n = 78, 55.7%) reported they never make such referrals; (i.e., Associazione Italiana Afasici, AITA, n = 42; 30%; Associazione Italiana Malattia Frontotemporale, n = 13; 9.3%; Federazione Alzheimer Italia, n = 11; 7.9%; other local support groups n = 6; 4.3%).

Assessment tools

Respondents rated on a 5-point scale (never, occasionally, sometimes, often, always) the frequency with which they used a selection of 10 listed assessment tools for the evaluation of speech and language impairments. The most commonly used tool was the patient and family informal interview which was rated as always used by 100 respondents (71.4%) and never used by zero respondents. The second most commonly used tool, informal assessment of communication, was rated as never used by six (4.3%) respondents and as always used by 86 (61.4%) of respondents. Commonly used formal published tests and batteries included the Aachener Aphasia Test (AAT, Luzzatti et al., 1994), always used by 28 (20.0%) respondents and never used by 37 (26.4%) respondents; the Esame Neuropsicologico per l'Afasia (ENPA, Miceli et al., 1994), always used by 25 (17.9%), often used by 51 (36.4%) respondents, and never used by 25 (17.9%) respondents; the

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TABLE 2 Access to and provision of speech and language therapy services

Source of referrals (%) multiple responses allowed	
Neurologists	110 (78.6)
Geriatricians	35 (25.0)
Other SLTs	33 (23.6)
Other	25 (17.9)
General practitioners	23 (16.4)
Psychologists	19 (13.6)
Psychiatrists	3 (2.1)
Referral reason (%) multiple responses allowed	
Word-finding difficulties	130 (92.9)
Slurred speech	58 (41.4)
Swallowing difficulties	42 (30.0)
Low intensity of vocal sounds	24 (17.1)
Other	12 (8.6)
Most common time since symptom onset (%)	
Within 1 year	38 (27.1)
Within 2–3 years	70 (50.0)
Within more >4 years	22 (15.7)
Cannot tell	10 (7.1)
Terms used when the patients had been informed of their diagnosis(multiple responses allowed)	
PPA	96 (68.6)
FTD	56 (40.0)
Semantic dementia	23 (16.4)
Logopenic variant PPA	19 (13.6)
Non-fluent variant PPA	14 (10.0)
Semantic variant PPA	10 (7.1)
Other	18 (12.9)
Barriers to accessing SLT services(multiple responses allowed)	
Service dysfunction	40 (28.6)
Geographical barrier	37 (26.4)
Offered but declined	26 (18.6)
Poor knowledge of technology	15 (10.7)
Low access to technology from home	7 (5.0)
High costs	14 (10.0)
Other	40 (28.6)

Abbreviations: FTD, frontotemporal dementia; PPA, primary progressive aphasia; SLT, speech-language therapist

Screening for Aphasia in Neurodegeneration (SAND; Battista et al., 2018), always used by 33 (23.6%), often used by 24 (17.1%), and never used by 65 (46.4%) respondents; the Boston Naming Test (Vestito et al., 2021), always used by 7 (5.0%), often used by 20 (14.3%), and never used by 54 (38.6%) respondents; the Esame Neuropsicologico Breve (Mondini et al., 2011), always used by 5 (3.6%), often used by 20 (14.3%) and never used by 76 (54.3%) respondents. The least used instrument in clinical practice was reported to be the Pyramid and Palm Tree Test (Gamboz et al., 2009) rated as never used by 81 (57.9%) respondents and always used only by 3 (2.1%) respondents. The survey includes an open question where clinicians could list additional tests they used in the clinical practice. We extracted the names of other tests and found that respondents reported to use the Batteria per l'Analisi dei Deficit Afasici (Miceli et al., 1994), The Communicative Effectiveness Index (Lomas et al., 1989) or the American Speech-Language and Hearing Association—Functional Assessment of Communication Skills (Muò et al., 2015) or the Italian version of the Communication Outcome after Stroke scales for patients and caregivers (Bambini et al., 2017). Very few respon-

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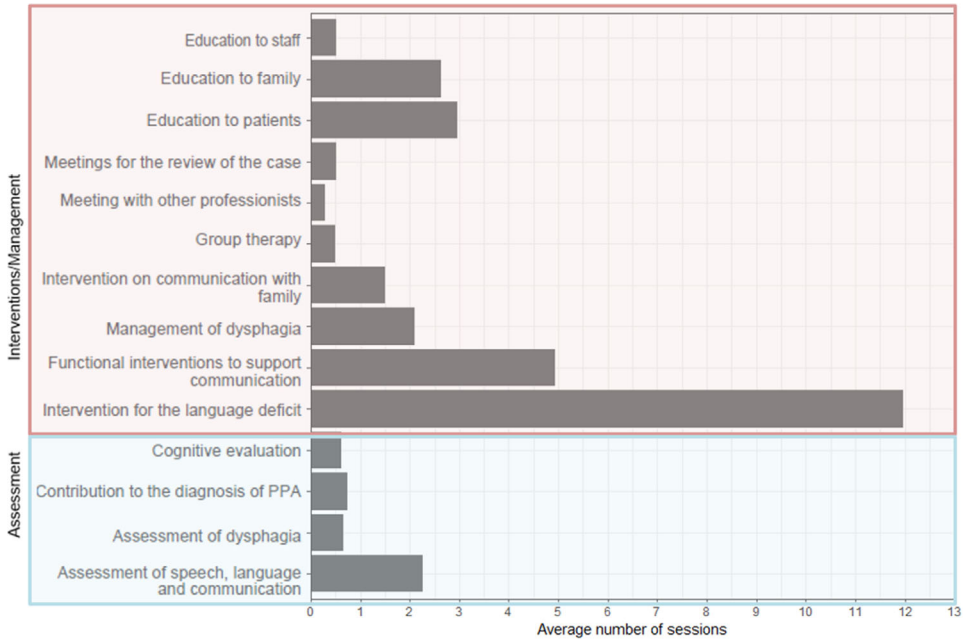

FIGURE 3 The average number of sessions spent by SLTs with individuals with PPA. In the red box, interventions and management activities are highlighted, and in the blue box assessment sessions are reported.
Abbreviations: PPA, primary progressive aphasia; SLT, speech-language therapist.
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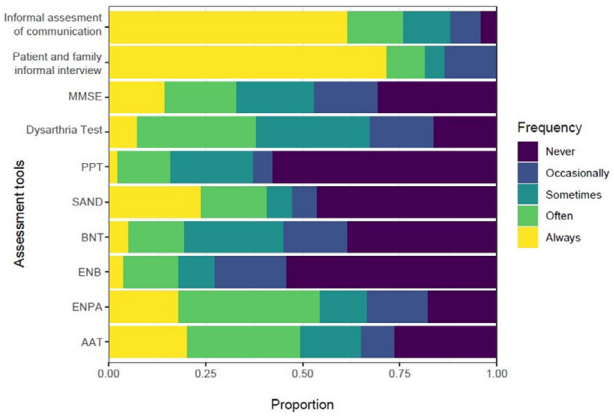

FIGURE 4 Frequency of speech, language and communication assessment tools used with individuals with PPA.
Abbreviations: AAT, Aachener Aphasia Test; BNT, Boston Naming Test; ENB, Esame Neuropsicologico Breve; ENPA, Esame Neuropsicologico perl'Afasia; MMSE, Mini Mental State Examination (Measso et al., 1993); PPA, primary progressive aphasia; PPT, Pyramid and Palm Tree Test; Profilo di valutazione della disartria;SAND, Screening for Aphasia in Neurodegeneration.
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dents reported using the Cookie Theft description task. Figure 4 shows the reported frequency of use of speech and language assessment tools.

Intervention approaches

Respondents were asked to rate on a 5-point scale the frequency (never, occasionally, sometimes, often, always) with which they used eight listed intervention approaches. The most used intervention types, impairment-based interventions, were rated as always used by 66 respondents (47.1%), often used by 64 (45.7%) and never used by 3 (2.1%) respondents. Functional communication-focused interventions were rated as always used by 46 (32.9%), often used by 43 (30.7%) and never used by 9 (6.4%) respondents. Communication training for families and caregivers was rated as always used by 49 (35%), often used by 49 (35%), and never used by 3 (2.1%), respondents. The least used intervention approach among the listed options, introducing patients and family to support groups, was rated as occasionally used by 30 (21.4%) and never used by 28 (20.0%) respondents. When asked to report on other intervention approaches used, 10 respondents identified communication books and cards, whilst script training was listed by only four respondents. Figure 5 shows the reported frequency of use of intervention approaches. Finally, we explored whether SLTs explicitly address planning for the future with patients with PPA. We found that almost all respondents (n = 131; 93.6%) addressed concerns related to deterioration of communication that patients experience. Other topics included family care support

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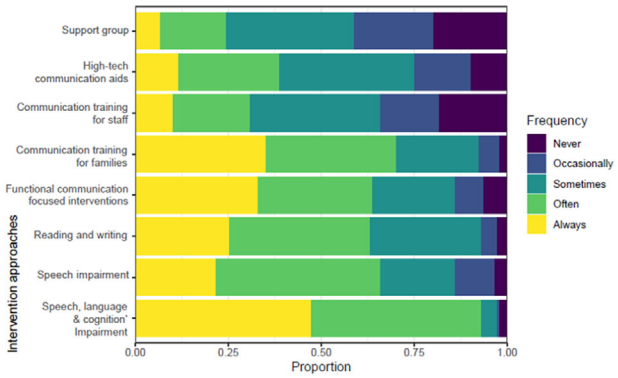

FIGURE 5 Frequency of speech, language and communication intervention approaches used with individuals with PPA. Impairment (speech etc.) indicated interventions directed to articulation deficits, and impairment-based intervention indicated interventions directed to cognitive and linguistic deficits [Colour figure can be viewed at wileyonlinelibrary.com]

(n = 75; 53.6%); legal and financial, health and social care issues (e.g., assessment of capacity; n = 60; 42.9%); driving issues (n = 56; 40%) and family financial support (n = 7; 5%).

Measuring outcomes

When asked which outcome measures SLTs used to document progress in therapy, respondents were able to choose multiple options from a list of four options. Language testing was reported as the most commonly used measure (n = 111, 79.3%), followed by a picture description or naming task (n = 110, 78.6%), self-rating scales completed by the patient or their communication partner (n = 54, 38.6%) and transcriptions of video-recordings of conversation (n = 53, 37.9%). Respondents provided examples of other outcome measures that they used which included analysis of audio recordings, an ad hoc scale developed to rate apraxia of speech and use of gesture or drawing in conversations. Respondents also provided examples of the types of goals they set in clinical practice. Of the 122 examples, 58 (47.5%) provided examples based on impairment-based interventions (e.g., word retrieval and/or semantic knowledge improvement); 44 (36.8%) indicated that functional communication goals are typically used (e.g., being able to order a coffee or a pizza at the restaurant); 12.2% (n = 15) of respondents reported use of communication aids (such as books, cards, technological devices, phone) and less than 4% of respondents reported teaching strategies and including a partner to enable patients to communicate about specific topics.

DISCUSSION

In this study, we reported the results of a survey administered to SLTs, which identified the current speech and language clinical practices available for individuals with PPA in Italy. The results of the survey identified current utilisation patterns for speech and language rehabilitation services, referral sources, barriers to services, available care pathways and the most common assessment and intervention tools and procedures employed by SLTs in Italy. We believe these insights are not only valuable towards improving awareness about PPA but also may serve to inform governmental and health policy organisations regarding current gaps and aid in developing recommendations for improving the care of individuals with PPA.

Access, referral and service provision

Of the 336 SLTs participating in the survey, 58.3% indicated that they had not seen individuals with PPA for assessment or treatment. Our findings indicate that in Italy, the main reasons that SLTs have not served individuals with PPA, despite the fact that they work with older adults, include a focus on other diseases and a lack of awareness among clinicians regarding the utility of SLT interventions, followed by issues related to the underdiagnosis and rarity of the clinical syndrome. Among SLT responders indicating previous experience working with PPA individuals, 29% indicated that individuals with PPA may not have received SLT services due to service dysfunction (e.g., long wait time before starting the treatment, or treatment not beginning until patients reach a specific severity threshold, or other unspecified issues). In Italy SLT is funded by the national healthcare system with only negligible differences across regions in the amount of copayment required for a 'package' of SLT sessions. The national healthcare system provides universal coverage to citizens and residents, with public healthcare largely free of charge or with a small amount of copayment. On the contrary private SLT treatments are not covered by the national healthcare system. The long waiting times at national healthcare system lead patients to choose private treatments to access therapy sooner in spite of higher costs (Bloder et al., 2021). Eligibility criteria to access public healthcare services represent a primary barrier as it is typically the case that patients with severe chronic conditions, such as those with post-stroke aphasia or advanced stages of neurodegenerative disease, are prioritised. A second barrier is the geographical distance from service providers. This barrier may be mitigated by capitalising upon alternative treatment modalities, such

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as teletherapy (Dial et al., 2019; Grasso et al., 2021; Henry et al., 2018, 2019; Rogalski et al., 2016), which has shown to result in equivalent outcomes compared to traditional, in-person delivery in mild-to-moderate PPA (Dial et al., 2019; Rogalski et al., 2022).

Patients with PPA may be under-referred to speech and language services, and referrals are likely to occur after 2–3 years of living with PPA. This delay between symptom onset and referral for intervention services means that the patient may arrive with concomitant cognitive impairments which, in turn, make it more difficult to implement a comprehensive treatment plan. In Italy, individuals with PPA are essentially forced to wait until their symptoms are significant in order to be prioritised for treatment because the overburdened healthcare system rarely accepts patients who are in the earliest stage of the disease. In fact, guidelines for rehabilitation care issued by the Italian Ministry of Health (Gazzetta, 1998) defined two different pathways: (1) intensive care, carried out in public or private hospitals, adopted in the post-acute phase of a disease; and (2) extensive care, which represents all the interventions that are not intensive (i.e., long-term hospitals, outpatient settings, semi-residential homes). Overall, in order to gain admission to a public health service, a patient first needs to make a request to the local health authority, presenting a general practitioner's (GP) referral for the service; the GP then fills out the formal application and the assessment unit evaluates whether or not the patient should be admitted (lo Scalzo et al., 2009). The physician in charge of the rehabilitation program defines the number of rehabilitation sessions needed for each patient and is in charge of developing the 'piano individuale personalizzato' (tailored rehabilitation plan) which includes the number of sessions for physical therapy, speech therapy and occupational therapy. This number varies depending on the functional autonomy of the patient; therefore, patients with more significant impairments are prioritised.

As a consequence of the aforementioned strict eligibility service criteria, individuals with PPA experience long wait times, which overall is the most significant problem facing the Italian national healthcare system (Siciliani et al., 2014). These waiting lists may be due to large demand for SLT services which cannot be addressed by the limited SLT availability. This issue can be managed by increasing the availability of resources and services. In fact, it has been estimated that the number of SLTs working in Italy is 24 per 100 000 inhabitants, compared with the European average of 40 per 100 000. Considering that, in Italy, there are 60 million inhabitants, it has been estimated that about 10 000 additional SLTs are needed to account for this shortage (*Libro Bianco Della Logopedia*, 2021). As such, if the caseload of each SLT is at capacity, the SLT will be forced to refer the patient to another colleague out of necessity. Our results demonstrate that this referral pattern is indeed taking place, as we observed that 'other SLTs' were indicated by 24% of respondents as the most common source of referral. Because of this SLT shortage, we can assume that a large number of individuals living with PPA are likely not receiving speech and language therapy.

Role of SLT in the management of individuals with PPA

Considering that speech-language difficulties are the main cause of functional decline while non-language cognitive abilities are relatively spared for years, it is challenging for patients with PPA to be admitted to rehabilitation in public service or extensive care. Yet speech and language intervention is critical in the early phase of the syndrome as this is when patients may more easily learn new communication strategies (Volkmer et al., 2022). Speech and language interventions can be crucial to counteract language decline and the associated frustration and isolation individuals with PPA often experience (Taylor-Rubin et al., 2021). SLTs offer a range of potential benefits for individuals with PPA, which include maximising effective communication for as long as possible, providing communication strategies and educating individuals living with PPA as well as their family members. Several studies have demonstrated the utility of treatments designed to facilitate significant, generalised and lasting improvement of speech-language function in PPA, as demonstrated by comparing the performance of trained versus untrained targets at a 1-year interval (e.g., Henry et al., 2013, 2018).

As previously described, a handful of studies have investigated SLT practices via survey dissemination in other countries including Australia, Germany and the United Kingdom (Riedl et al., 2014; Taylor et al., 2009; Volkmer et al., 2019). Consistent with these studies, our results revealed variability and limited access to SLT service provision. More specifically, our results indicated that in the Italian context the main factors prohibiting service delivery include reduced awareness of the SLT role, limited clinician experience in working with PPA, and limited funding to offer proactive and long-term services. Taken together, survey results across Australia, Germany, the United Kingdom, and now Italy indicate that barriers to accessing SLT services are a shared issue that warrants advocacy and attention.

It is also worth noting that more than half of the respondents (55%) reported that they never refer patients and their families to any nonprofit organization or third-sector organizations. This likely reflects lack of collaboration

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between relevant organizations and the SLTs working within the dementia field. When SLTs refer patients to third-sector organisations, they usually address patients to AITA. However, AITA is largely focussed on supporting and connecting, through meetings and seminars, individuals with post-stroke aphasia and their families. Given the different needs that people with post-stroke aphasia and progressive aphasia have, it will be important to implement new strategies to connect the Federazione Alzheimer Italia or the Associazione Italiana Malattia Frontotemporale with patients and families of individuals with PPA.

Interventions and assessment in PPA

With respect to intervention, the most frequently used approaches were impairment-based interventions, including approaches targeting lexical retrieval. Moreover, SLTs reported frequently using communication training for caregivers and functional communication-focussed interventions intended to prepare patients to leverage and maximise use of all forms of communication as soon as possible. The intervention approaches in the current study are largely aligned with a recent consensus paper on best practice principles in the selection and delivery of SLT interventions for individuals with PPA (Volkmer et al., 2022). This PPA consensus working group examined expert opinions among 15 SLTs regarding approaches to intervention. Although impairment-based interventions were ranked as highly relevant, person-centered approaches including education, conversational training and hybrid approaches were ranked as having greater importance. The results garnered from expert opinion in comparison to the results of the current study indicate convergence regarding the importance of both impairment-based interventions (which serve to address primary communication difficulties), and education, support and counselling (which serve to empower the patient and family and provide tools to cope with the symptoms of PPA) (Volkmer et al., 2022). The consensus paper also calls for continued SLT monitoring over the lifespan of the disease. As a consequence, individuals with PPA and their caregivers need to be supported by SLTs both at the time of diagnosis, and with disease progression (Volkmer et al., 2022). Therefore, in Italy, an overhaul to the care pathway is required for PPA services provided by SLTs so that intervention may occur across the severity continuum.

With respect to therapeutic goals, five main themes emerged from the respondents' responses: impairment-based interventions, functional communication, communication aids, use of strategies and involving communication partners. These themes are aligned with the type of interventions that respondents claim to use in clinical practice. Even though the majority of the provided example goals were about impairment-based interventions, more than half of SLTs also reported that the words treated in the therapy sessions are often selected by the patient, giving rise to functional selection of treatment targets. With respect to the number of sessions spent across assessment, patient and family education and treatment, the lowest number of sessions were dedicated to education about the diagnosis. The low number of sessions spent on comprehensive assessment may be due to the fact that SLTs are poorly informed on the best formal assessment to use with this patient group coupled with the fact that there is a lack of assessments that are specialised and available for clinicians working with PPA clients. In fact, SLTs reported that the most frequent assessment tools used were informal interviews along with a selection of speech and language tests (selected based on clinical judgment). Historically, the only speech and language tests available for the assessment of PPA in the Italian clinical context were borrowed from the post-stroke aphasia literature (Battista et al., 2017). Among the traditional aphasia instruments, respondents reported using the AAT (Luzzatti et al., 1994), or the ENPA (Capasso & Miceli, 2001), which are standardised on post-stroke aphasia patients. Selecting tests that were not designed to identify the core clinical features of PPA may diminish clinicians' ability to identify the correct PPA variant, given that these features may be neglected when using tools not developed ad hoc (Henry & Grasso, 2018). Moreover, the paucity of instruments designed for Italian-speaking patients makes it difficult to plan a tailored intervention program. Although a new screening battery capable of capturing the key language features for the classification of PPA, the SAND (Battista et al., 2018), was recently developed, almost half of respondents reported that they have never used this battery in their clinical practice. The SAND represents one of the briefest batteries available, although a few other tests have recently been validated for Italian speakers with PPA, including the Semantic Association Task (Luzzatti et al., 2020) and the Northwestern Anagram Test (Canu et al., 2019).

Limitations and future research

We should acknowledge some limitations of the current study. First, it was a challenge to try to reach all SLTs working with older adults and PPA patients in Italy, therefore some geographical regions may be under-represented or not represented at all (such as the Molise region, see Figure 2). Also, some SLTs with little knowledge of technology may have not taken part in this online survey, preventing us from collecting a representative sample of Italian SLTs. In future studies, gathering the perspectives

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of individuals living with PPA will be important in order to further understand the barriers these individuals face. Finally, future studies may consider examining the difficulties experienced by SLTs when selecting and delivering interventions in order to understand how they can best support individuals with PPA and their families.

CONCLUSIONS

In Italy, individuals with PPA are under-referred to SLTs for rehabilitation services. On our survey, SLTs that reported never working with this population identified underdiagnosis, low referral rates, focus on other diseases and the rarity of the clinical syndrome as major reasons for their lack of experience with PPA. SLT responders with previous experience working with PPA indicated that individuals with PPA may not have accessed their services because of geographical barriers, service dysfunction, high costs or poor knowledge of technology. Assessment tools used by SLTs when working with individuals with PPA are mainly derived from the stroke-induced aphasia literature. Concerning interventions, impairment-focused interventions and interventions based on functional communication were the most frequently used amongst SLTs. Improving awareness of the utility of rehabilitation among SLTs and other allied health professionals may serve to facilitate access to intervention, which in turn will serve to better support individuals living with PPA and their families.

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CONFLICTS OF INTEREST

M.P. reports outside the submitted work having received partial funding for a self-initiated research project from Novartis Pharma and being awarded a research grant from the Center for Stroke Research Berlin (private donations). The other authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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