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Supporting people with post#stroke aphasia to live well: A cross#sectional survey of Speech & Language Therapists in Ireland

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TITLE

Supporting people with post-stroke aphasia to live well: A cross-sectional survey of Speech & Language Therapists in Ireland.

KEY WORDS

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Language Therapy

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Health services research

Community-Based Participatory Research

Cross-Sectional Survey

ABSTRACT

Living well with post-stroke aphasia is supported by responsive, collaborative health and related services, aphasia information and training for people with aphasia (PWA) and their social networks, and opportunities to contribute and participate autonomously in their communities. Several international surveys indicate shortcomings in the provision of long-term support and, in Ireland, while there is a lack of data around service provision for PWA, there is evidence that post-acute stroke services are fragmented and under-resourced. The aim of this study was to survey Speech & Language Therapists (SLTs), due to their unique role in aphasia management, to understand what SLT and related support services and aphasia information and training are currently available to support living well with aphasia in Ireland. We developed and piloted a self-administered, web-based cross-sectional

survey with questions informed by a systematic review and qualitative evidence synthesis around living well with aphasia, and with input from a Public and Patient Involvement aphasia advisory group. Data from 95 SLTs working with PWA were analysed using descriptive statistics. Though SLT was generally available for PWA, the results highlight access barriers and evidence-practice gaps in terms of the amount, intensity and timing of SLT to be maximally effective and there was a lack of PWA input into service design and evaluation. Access to other relevant supports such as mental health services was inconsistent and there was a lack of community support for families. There were shortcomings in access to aphasia information / training for PWA, families, friends and other healthcare professionals. There is a need for a coordinated and standardised approach to supporting PWA across Ireland. This study addresses an evidence gap around the provision of stroke services for PWA and is part of a larger project aiming to produce recommendations for improving person-centred support to facilitate living well with aphasia.

WHAT IS KNOWN ABOUT THIS TOPIC

- Living well with aphasia is supported by: Speech and Language Therapy (SLT); support with mental health; support for families; aphasia information and training for PWA, friends and families and healthcare professionals; and opportunities for participation.
- Several international studies indicate shortcomings in the provision of long-term support and SLT for PWA.

WHAT THIS PAPER ADDS

- This is the first clinician survey of post-stroke support for PWA in Ireland designed with Public and Patient Involvement.
- Access to SLT and mental health support was inconsistent; there were shortcomings in

support for families and aphasia information / training.

- There is a need for standardisation in the provision of holistic, flexible and integrated support for PWA.

BACKGROUND

Aphasia is an acquired communication impairment following damage to the language centres of the brain which affects any combination of speaking, understanding, reading, writing and gesture, and occurs in about one third of people with stroke (Engelger et al., 2006; Flowers et al., 2016). People with post-stroke aphasia (PWA) are systematically excluded from stroke research leading to a relative lack of guidance around service planning and delivery (Brady, Fredrick, & Williams, 2013; Engelger et al., 2006; Flowers et al., 2016; Wray, Clarke, & Forster, 2017).

Aphasia management is typically the remit of Speech and Language Therapists (SLTs) (Brady, Kelly, Godwin, Enderby, & Campbell, 2016). Speech and Language Therapy (SLT) is effective at improving functional (everyday) communication, receptive (understanding, reading) and expressive (speaking, gesture, writing) language, particularly when delivered at higher intensity (Brady et al., 2016). In addition to assessment, diagnosis and rehabilitation, SLTs play a unique role in aphasia care advocating and connecting people with other health care and social support services (Clinical Centre for Research Excellence (CCRE) in Aphasia Rehabilitation, 2014). Several 'best practice' aphasia recommendations aim to improve the quality and consistency of care (Aphasia United, 2018; CCRE in Aphasia Rehabilitation, 2014). Aphasia United recommends that: PWA have access to information about aphasia and treatment options at all recovery stages; PWA have the option of intensive, individualised, culturally appropriate SLT; families / caregivers are included in the rehabilitation process; and families and health and social care professionals (HCPs) working with PWA to be provided with "Communication Partner Training" (Simmons-Mackie, Raymer, & Cherney, 2016) and aphasia

information (Aphasia United, 2018). Complementing these, the Australian Aphasia Rehabilitation Pathway emphasises: collaborative goal-setting; self-management strategies; social support for PWA, families and caregivers; planning for transitions (e.g., discharge); access to a liaison person for post-discharge and self-referral queries; raising awareness of aphasia; and opportunities to meet others affected by aphasia (CCRE in Aphasia Rehabilitation, 2014).

In recent years, there is growing emphasis on empowering patients to actively shape health policy, guidelines and services through public and patient involvement (PPI) and qualitative health research evidence (Carroll, 2017; Langlois, Tunçalp, Norris, Askewb, & Ghaffara, 2018; World Health Organisation (WHO), 2016). Involving patients and families in shaping health services has potential benefits in terms of improving quality of care and health outcomes (Prior & Campbell, 2018). Communication is central to human existence and participation, so living with a chronic communication impairment has far-reaching negative effects on health-related quality of life, self-identity, mental health, social networks and relationships, return to work, social and community participation, stigmatisation, disadvantage, access to digital technology and “third-party disability” for family members (FMs) (Baker, Worrall, Rose, & Ryan, 2019; Black-Schaffer & Osberg, 1990; Grawburg, Howe, Worrall, & Scarinci, 2013; Hersh, 2017; Hilari, Needle, & Harrison, 2012; Kelly, Kennedy, Britton, McGuire, & Law, 2016; Morris, Franklin, & Menger, 2011; Northcott, Marshall, & Hilari, 2016; Northcott, Moss, Harrison, & Hilari, 2016; Parr, 1997; Shadden, 2005). Advocates have shifted focus to providing holistic support targeting personally meaningful outcomes and removal of barriers to participation in society more generally, for example using the International Classification of Functioning, Disability and Health (ICF) framework (WHO, 2001). Treatment outcomes prioritised by PWA and their families span all ICF domains in contrast with rehabilitation that emphasises impairment-based outcomes; this further highlights the need for collaborative goal setting (Wallace et al., 2016).

The findings of a recent systematic review and qualitative evidence synthesis of the perspectives of

PWA illustrate how living well with aphasia is promoted via responsive, flexible and long-term access to health and related support services for PWA, their friends and family and the wider community, and through opportunities for people to participate autonomously and to make a genuine contribution to their communities (Manning, MacFarlane, Hickey, & Franklin, 2019). PWA identified that increasing awareness of aphasia and communication strategies among service providers and the general public would help support participation (Manning et al., 2019). Access to accessible information and aphasia-aware health and social care professionals helped empower PWA to direct their recovery, organise care and collaborate in decisions about their treatment (Manning et al., 2019). The review findings were in keeping with stroke and aphasia research emphasising the need for psychosocial support for depression, grief and changes in life participation (Ayerbe, Ayis, Wolfe, & Rudd, 2013; Baker et al., 2017; Chapey et al., 2001; Simmons-Mackie & Damico, 2007; Walsh, Galvin, Loughnane, Macey, & Horgan, 2015; Wray & Clarke, 2017).

There remains however a lack of consensus and high-quality guidance around the optimum approach to aphasia rehabilitation, for example in relation to goal-setting, counselling and patient/caregiver support, and this may impact on care quality and consistency (Brady et al., 2013; CCRE in Aphasia Rehabilitation, 2014; Rohde, Worrall, & Le Dorze, 2013; Shrubsole, Worrall, Power, & O'Connor, 2017). This evidence gap is compounded by an evidence-practice gap including the provision of aphasia-friendly information, support with depression and SLT of adequate intensity to maximise effectiveness (Code & Petheram, 2011; Foster, Worrall, Rose, & O'Halloran, 2015; Hickey, Shrubsole, Worrall, & Power, 2019; Hilari et al., 2015; Rose, Worrall, McKenna, Hickson, & Hoffmann, 2009; Shrubsole, Worrall, & Power, 2019; Shrubsole, Worrall, Power, & O'Connor, 2018; Thomas et al., 2013; Trebilcock et al., 2019). Surveys of SLTs in Australia and Hong Kong highlighted that PWA received sub-optimum dosage for effective therapy (Kong, 2011; Kong & Tse, 2018; Rose, Ferguson, Power, Togher, & Worrall, 2014; Verna, Davidson, & Rose, 2009). This echoes earlier surveys in Australia, Canada, the United Kingdom and the United States (Katz et al., 2000; Mackenzie

et al., 1993; Verna et al., 2009). A lack of SLT intensity and dosage in the United Kingdom was reported by Palmer and colleagues, who asked PWA about the care that they had received in a 3-month period in 2014-2016 (Palmer, Witts, & Chater, 2018). They noted that access to SLT was variable (a “post-code lottery”), with better access in the first year (Palmer et al., 2018). A lack of aphasia education and training for PWA, caregivers and other healthcare professionals was reported in the Hong Kong survey (Kong & Tse, 2018); and there was a lack of aphasia information for friends in Australia (Rose et al., 2014). A lack of access to group and intensive therapy, limited follow-up, and a general lack of community support services particularly in rural areas was also reported in the Australian survey (Rose et al., 2014). Although SLTs in Australia commonly practiced counselling, many did not feel sufficiently prepared for this role (Rose et al., 2014).

In Ireland, there is evidence that access to post-stroke support including SLT, psychological support and support for families/caregivers, for people affected by aphasia is variable and front-loaded (Community Services Subgroup of the National Stroke Working Group, 2011; HSE Quality and Clinical Care Directorate, 2012; Horgan, Walsh, Galvin, Macey, & Loughnane, 2014; McElwaine, McCormack, & Harbison, 2015; McElwaine, McCormack, & Harbison, 2016). Access to healthcare in Ireland has been described as inequitable (Burke, Normand, Barry, & Thomas, 2016). Its 2-tier system comprises a largely tax-funded public system and a private health sector accessed by about half of the population (European Observatory on Health Systems and Policies, 2016). About one third has medical card status or means-assessed entitlement to free public health services; the rest make some payment when using services such as General Practice and public hospitals (European Observatory on Health Systems and Policies, 2016). Plans to implement a universal single-tier health and social care system are underway (HSE, 2018).

In the last decade, a National Clinical Programme for Stroke and improved acute stroke services has meant fewer preventable deaths and admissions to long-term care (McElwaine et al., 2015). However, post-acute services are identified as particularly fragmented (McElwaine et al., 2015) and there is a

lack of access to rehabilitation services (both public and private) for people with acquired brain injury (Muldoon, Walsh, Curtin, & Kinsella, 2017). A 2011 neuro-rehabilitation strategy remains unimplemented (Burke, McGettrick, Foley, Manikandan, & Barry, 2020). A 2011 survey revealed significant gaps in access to early supported discharge and allied health professionals (Community Services Subgroup of the National Stroke Working Group, 2011). Community SLT was of sub-optimal intensity and duration; access was inconsistent, often with long waiting lists (Community Services Subgroup of the National Stroke Working Group, 2011). Access to services varied by location, age and medical card status (Community Services Subgroup of the National Stroke Working Group, 2011). A 2013 survey highlighted long-term, often unmet psychosocial needs of community-dwelling people with stroke, including PWA (Horgan et al., 2014). A majority (77%) reported emotional problems; however, only 11% of these had received psychological support. In 2016, a survey of post-acute rehabilitation units highlighted inadequate provision of therapy, psychology, vocational rehabilitation, self-management support and caregiver training (McElwaine et al., 2016). Reliance on the voluntary sector for essential services including neurorehabilitation and community support was noted (McElwaine et al., 2016).

Overall there is a lack of data in relation to the long-term experiences of people with stroke in Ireland, with implications for service planning and development (Community Services Subgroup of the National Stroke Working Group, 2011; McElwaine et al., 2016; Wren, Gillespie, Smith, & Kearns, 2014). While some PWA were included in the stroke surveys mentioned above, to the best of our knowledge, no aphasia-specific study of service provision has been conducted to date. Brady and colleagues caution that a relative lack of evidence around care for PWA may lead inequitable access to stroke support (Brady et al., 2016, p. 195). We need a better understanding of current support for PWA to identify how best to implement change (Shrubsole et al., 2018).

The aim of this study was to survey SLTs to understand what SLT, related health and social care support and aphasia information / training are currently available for PWA and FM to support living well with

aphasia in Ireland. We surveyed SLTs due to their unique role in rehabilitation, information and training, advocacy and connecting PWA with other relevant support (CCRE in Aphasia Rehabilitation, 2014). The survey content was developed with input from a PPI aphasia advisory group and covered themes relating to promoting living well with aphasia synthesised from 31 articles reporting on qualitative interview or focus group studies with PWA (Manning et al., 2019).

METHODS

This study follows the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) (Eysenbach, 2004) and the STROBE (STrengthening the Reporting of OBservational studies in Epidemiology) Statement (von Elm et al., 2007) (See Supporting Information, Appendices A-B). The design was a self-administered web-based cross-sectional survey using Survey Monkey.

Participants

We purposively targeted qualified SLTs currently involved in the delivery of services to PWA in Ireland in any care setting. Exclusion criterion was working with PWA less than 1 year.

Ethical approval

Approval was obtained from the Research Ethics Committees of the REDACTED and REDACTED. Completion of the survey signified consent.

Recruitment

No national database of eligible SLTs exists in Ireland. To maximise access, recruitment was via several sampling frames. SLT Managers were contacted via phone call and e-mail attaching study information and survey web-link and asked to alert their team members to the research study. The Irish Association of Speech & Language Therapists (IASLT) and IASLT Special Interest Groups (SIG's) for Dysphagia and Adult Communication Disorders were contacted by e-mail and asked to circulate the study information and web-link to members via e-mail and social media (Facebook and Twitter). Study information was also published in the Adult Communication Disorders SIG newsletter.

Survey development

To increase relevance and content validity, the questions were informed by: (1) the findings of a recent systematic review and qualitative evidence synthesis looking at how best to promote 'living well' with

aphasia (Manning et al., 2019); (2) a Public and Patient Involvement (PPI) aphasia advisory group; and (3) a pilot study with SLTs. The PPI aphasia advisory group comprising 4 PWA had been convened in the Mid-West region of Ireland as part of a larger study looking at living well with aphasia.

A set of draft questions was initially prepared by the first author informed by the systematic review findings and contributions previously generated by the PPI advisory group in discussing and validating these findings. In addition, the other authors each compiled 20 draft questions by considering the systematic review findings. The first author then compiled the 4 sets of questions, grouping and merging overlapping questions as necessary.

In March 2018, we sought further input from the PPI advisory group (see Appendix C, Supporting Information). A participatory learning and action (PLA) research approach and adapted PLA tools used previously to successfully create communication ramps for PWA helped to create a collaborative research space (Mc Menamin, Tierney, & Mac Farlane, 2015a, 2015b; O'Reilly-de Brun et al., 2018). We also used aphasia-friendly communication strategies such as supported conversation techniques, accessible written materials, informed consent processes, slides and agendas and giving people the opportunity to identify strategies they find helpful (Dalemans, Wade, van den Heuvel, & de Witte, 2009; Kagan, 1998; Luck & Rose, 2007; Pearl, 2014; Pound, 2013; Rose, Worrall, Hickson, & Hoffmann, 2012). The survey instrument was also piloted in order to assess its face validity, usability, clarity and comprehensiveness (Burns et al., 2008). Two SLTs experienced in working with PWA and working in the University of Limerick completed the draft instrument within Survey Monkey and gave written feedback in April 2018. The instrument was subsequently refined further.

The final instrument was administered from May-August 2018. It contained 38 questions presented in fixed order over 37 screens with 1-4 items per screen (see Supporting Information, Appendix D). Participants were asked questions about: their care setting, post-stroke aphasia caseload and service delivery characteristics; aphasia information for people affected by aphasia in their area and other

HCP'S; support services for PWA and FMs in their area including mental health support; and support for social and community participation for PWA. To explore geographical spread of service availability, whilst maintaining respondent anonymity, SLTs were asked to identify which of the 9 Community Health Organisation (CHO) they worked in, as a proxy for their approximate location; however, we targeted SLTs working in all care settings including those outside of the CHO system (i.e., acute, rehabilitation settings).

We used a mix of response formats including binary, nominal and interval closed responses, and indeterminate response options (e.g., "this information is unavailable to me") to capture respondent uncertainty (Burns et al., 2008). Open-ended free text responses ("Other") were also permitted to capture unanticipated issues, elaboration and explanation (O'Cathain & Thomas, 2004). Most questions were mandatory (n=30); the remaining 8 were sub-questions conditional on the answer given to the previous question (e.g. Q10 "If **no**, what are the common barriers to accessing SLT", Supporting Information, Appendix D). Respondents were unable to review answers to questions on previous screens.

Data analysis

The data were downloaded from Survey Monkey in Excel and inputted into StataIC-14 for data cleaning (checking for missing data, labelling variables and assigning values) and analysis. Categorical data, binary and multiple responses, were analysed in StataIC-14 to obtain frequency statistics. All data were included for analysis. Open-ended responses not captured in the given response options were grouped in similar categories and included descriptively. The results were then presented back to the advisory group for their comment and interpretation using the PLA techniques described above.

RESULTS

Sample characteristics

As no database of SLTs currently exists it is not possible to determine the precise response rate. Based on combined SIG membership of about 254, we estimate a response rate of 44% based on 111 consented respondents. As responses were anonymous, non-respondent analysis and efforts to identify multiple entries from the same individual were not possible. Of 111 consented, 98 participants were eligible and a further 3 discontinued after initial screening questions; hence, 95 datasets were included in the analysis. Unless otherwise stated, all figures are expressed as a percentage of the respondents who answered that question. The completion rate was 81%. A summary of respondent characteristics is in Table 1. More than half had been working with PWA for over 10 years and the majority worked in community, inpatient or rehabilitation settings. Each of the 9 CHOs was represented.

(insert table 1 here)

SLT service provision for PWA

Availability and access

Most respondents (n=67; 74%) reported that SLT was 'readily available' to PWA in their area; 26% reported that SLT was not. At the same time, 54% identified that PWA experienced barriers in accessing SLT including service constraints (n=43), practical barriers like getting to clinic (n=28), geographical barriers (n=19), informational barriers or lack of awareness of service (n=8) and/or financial barriers (n=4). Open-ended responses primarily identified service constraints as a barrier to accessing SLT. Two SLTs identified SLT dysphagia input was prioritised in community and inpatient settings; another observed that access to rehabilitation was dependent on having concomitant Occupational Therapy or Physiotherapy needs: *"Often if they are younger people or have no other OT / Physio needs they are rarely referred to the rehab facility and are therefore discharged home, or if they do make it to rehab they are d/c once OT /Physio needs have been met, d/c is never based on SLT needs"*.

Frequency and duration

In community settings most PWA were offered 1 x 30-60-minute session per week; in acute settings most were offered 3 sessions, and in rehabilitation services most had 5 sessions (see Fig. 1).

(insert figure 1 here)

In acute settings the majority of SLTs were able to provide an average of less than one month of treatment; in community and rehabilitation settings this rose to 1-3 months of treatment (see Fig. 2).

(insert figure 2 here)

Respondents discharged PWA when they were moving to another facility (n=56, 64%), achieved their goals (n=56, 64%), reached a 'plateau' (n=48, 55%), self-discharged (n=38, 44%) and/or due to service constraints (n=25, 29%).

Collaboration and choice

When asked how post-stroke aphasia care in their service was organised to maximise collaborative support, SLTs selected options including: involving FMs (n=63; 72%) and/or PWA (n=60; 69%) in management decisions; having a team of rehabilitation therapists involved (n=35; 40%); and/or case conferences (n=31; 36%). A minority identified that post-stroke care was not collaborative (n=13; 15%).

More than half identified that PWA were not involved in the design of local SLT services (n=49, 56%). Involvement was generally asking PWA for feedback on the service they had received (n=34, 39%), consulted on service delivery decisions (n=16, 18%), asked what information should be given to other PWA (n=14, 16%) and/or consulted on therapy outcome measures (n=6, <1%). More than half selected that PWA had choice in time of day of therapy (n=60, 69%) and/or who is present for therapy (n=56, 64%). Less than half identified that PWA had choice in terms of therapy session length (n=38, 44%),

venue (n=25, 29%), how often they would be seen (n=22, 25%), group or individual treatment (n=19, 22%) and/or the therapist they would see (n=6, <1%).

Support for PWA in the community including support with mental health

Respondents reported a range of available community supports including: charities and voluntary organisations (n=53, 68%); stroke groups (n=43, 55%); conversation partner programs (n=31, 40%); conversation groups (n=22, 28%); aphasia cafes (n=19, 24%); social media groups for people with stroke (n=9, 12%) and PWA (n=8, 10%); disability-friendly sports facilities; (n=6, 8%) and/or aphasia-specific charities or shops (n=1, 1%). SLTs referred PWA to Occupational Therapy (n=48, 62%), Social Work (n=30, 39%) and/or return to work services (n=21, 27%).

SLTs reported a range of support for mental health including: counselling (n=27, 35%); medical social work (n=26, 33%); clinical psychology (n=22, 28%); support from a trained SLT (n=18, 23%); occupational therapy (n=17, 22%); and/or couples counselling (n=2, 3%). 18 (23%) reported no mental health support for PWA in their area. In open-ended responses, SLTs commented on support from GP's (n=3), Psychiatry (n=4) and the Community Mental Health team (n=1). Three SLTs reported that mental health support was limited with long waiting lists; 2 observed that access to primary care counselling was medical card dependent and, therefore, only free for some. Five SLTs noted the lack of psychological support suitable for PWA and suggested that access was dependent on the supported conversation skills of individual counsellors and the level of communication difficulty. One SLT noted that Psychology referrals were rarely accepted given communication difficulties despite SLT offering to co-attend to support communication access.

Support for families and friends

Thirty-nine per cent identified that FMs in their area had access to Social Work and 36% to conversation partner training (CPT). SLTs also reported that FMs had access to mental health supports

including counselling (n=22, 28%), clinical psychology (n=3, 4%), children's counselling (n=3, 4%) and/or family support groups (n=3, 4%). A minority reported spaces for relatives of PWA to meet each other (n=16, 21%) and/or Citizens Support / Financial Advice (n=9, 12%). Ten respondents (13%) identified that FMs were not supported. In open-ended responses, SLTs noted that: family support was provided by voluntary agencies (including the Volunteer Stroke Scheme, local stroke support groups, Headway and Irish Heart Foundation) (n=5); and family support was generally limited and/or basic (n=2). One SLT commented that families may be supported in the acute / rehabilitation setting "in terms of their loved one's progress but not beyond that". Another noted that support usually depended on FMs' "own network of friends/family".

Aphasia information and training

PWA

Most respondents reported that aphasia information for PWA was verbal as the situation arises (n=77, 93%) and/or leaflets (n=71, 86%). Over half identified aphasia cards (n=53, 64%) and/or opportunities to meet other PWA (n=47, 57%). About a third reported the availability of general online information (n=28, 34%). In open-ended responses 7 SLTs commented that information was also available about local stroke, aphasia and SLT groups, conversation partner schemes and voluntary organisations. Information was mainly available in the acute (n=58, 70%) and/or rehabilitation stages (n=57, 69%); and less on an ongoing basis (n=39, 50%), in the long-term (n=25, 30%) and/or accessible directly at any time (n=16, 19%). In open-ended responses one SLT commented: *"I often find they arrive with limited understanding. This may be related to not processing information while in hospital. Many say that no one explained to them"*.

Families and friends

Information was mainly verbal (family n=39, 89%; friends n=43, 55%), leaflets (family n=61, 78%; friends n=31, 40%) and/or general online information (family n=35, 45%; friends n=24, 31%). A little over a quarter identified CPT was available for FMs (n=21, 27%); only 9 (12%) identified CPT for friends. Less than a quarter reported FMs had opportunities to meet other families (n=18, 23%), access talks (n=15, 19%) and/or attend case conferences (n=17, 22%). Friends had less access to talks (n=6, 8%), opportunities to meet other friends/families (n=5, 6%) and/or case conferences (n=2, 3%).

Information was mainly available in the acute (n=45, 58%) and rehabilitation stages (n=42, 55%); and less so on an ongoing basis (n=33, 43%), directly at any time (n=29, 38%) and/or in the long-term (n=28, 36%).

Other healthcare professionals

A little under half (48%) identified that other HCP's such as other Allied Health Professionals, Doctors, Nurses and Healthcare Attendants in their area were given aphasia information and / or training. Over a third (n=29; 34%) reported that this was not given to HCP's. In open-ended responses, SLTs commented on the ad hoc, case-by-case and/or informal nature of information / training (n=9); and/or that aphasia training had been discontinued (n=3).

Where information / training was given, this was predominantly leaflets (n=40, 49%) and/or Conversation Partner Training (n=16, 20%) and mainly to other stroke professionals. More rarely Medical Social Workers (n=12), other voluntary/community organisations (n=9) and/or mental health professionals including counsellors (n=2) and psychologists (n=4) were selected. From open-ended responses SLTs also provided education sessions, in-service training talks and/or presentations for example at primary care or ward meetings, stroke training days and journal clubs (n=14). Aphasia information and / or training was also available to all site staff including household staff, catering staff,

nursing home staff and other ward staff (n=3); GP's (n=2); and home help agencies (n=1).

SLT support with social and community participation

Most SLTs practised individualised goal setting (n=68, 87%), included hobbies (n=60, 77%) and/or referred to voluntary organisations (n=56, 72%). SLTs also provided information and/or training for FMs (n=49, 63%) but rarely for friends (n=17, 22%). From open-ended responses, SLTs also involved families in therapy and/or referred PWA to aphasia groups (n=2). One SLT commented that supporting participation goals was hampered by caseload demands, working in a hospital environment and the impact of multiple medical co-morbidities.

Some SLTs were involved in raising awareness of aphasia, for example giving public talks (n=24, 31%) and/or supporting PWA to raise awareness (n=9, 12%). A little over a third were not involved in raising awareness (n=28, 36%). From open-ended responses, one SLT was involved in a project in which people with communication difficulties co-train café workers (n=1); another was setting up information stands and planning radio segments (n=1); another invited key workers and nursing home activities coordinators to communication groups (n=1); and two facilitated communication groups in voluntary organisations (n=2).

DISCUSSION

Summary of results

This study revealed several findings in relation to the current availability of SLT, related health and social care support and aphasia information / training to support living well with aphasia in Ireland. Whilst three quarters of SLTs considered SLT readily available to PWA, one quarter did not, and more

than half identified barriers to accessing SLT. PWA were offered between 1-5 sessions per week depending on setting. More than a quarter of SLTs discharged patients because of service constraints. More than half identified that PWA were not involved in service design; involvement was mainly asking PWA for feedback. Access to mental health support was variable and the wide range of services and professionals selected by respondents suggested a lack of consistency, agreement and standardisation in providing comprehensive, communicatively accessible mental health support for PWA. Counselling, medical social work and clinical psychology were reported by less than half of SLTs; a quarter reported no mental health support. Over a third reported that FMs had access to Social Work and CPT; over a quarter considered that FM had access to mental health support, only 3 reported counselling for children. Access to appropriate psychological support for PWA often depended on the supported conversation skills of individual counsellors and/or the level of communication difficulty.

The main community supports were charities and voluntary organisations and stroke groups, reported by more than half of SLTs. Over half identified that PWA had opportunities to meet others. Most SLTs supported social and community participation, but there was little consensus in how this was achieved in practice. Difficulties in addressing social and community participation due to caseload demands, acute environments and multiple medical co-morbidities were acknowledged. There was a lack of access to aphasia and self-management information for PWA in the long-term. Most SLTs identified that information was mainly verbal or leaflets and in acute or rehabilitation settings. Less considered information to be available on an ongoing basis or accessible directly at any time. Most SLTs provided aphasia information and/or training to family members, but this was substantially less for friends. Under half of SLTs reported information and / or training for other healthcare professionals, over a third reported that there was none.

Connections with the literature

The results show significant gaps in the provision of SLT and other relevant for PWA and families in

Ireland. Short-comings in the amount and timing of available SLT and variation in access to other support services mirror that previously described internationally (Code & Heron, 2003; Katz et al., 2000; Kong, 2011; Kong & Tse, 2018; Mackenzie et al., 1993; Palmer et al., 2018; Rose et al., 2014; Verna et al., 2009) and in Ireland (Community Services Subgroup of the National Stroke Working Group, 2011; Horgan et al., 2014; IHF et al., 2014; McElwaine et al., 2016). A lack of flexible access to SLT and other social supports hampers efforts to support PWA to adapt and to achieve life goals in the long-term post-stroke. Short-comings in dosage and intensity of SLT may reduce potential benefits (Brady et al., 2016) and front-loading access may not suit some individuals who might prefer to engage with SLT at a later stage when their health has improved, or to support evolving life goals (Manning et al., 2019). The survey did not examine the non-aphasia caseloads of respondents; however, prior reports of dysphagia prioritisation at the expense of aphasia services (Foster, O'Halloran, Rose, & Worrall, 2016; Rose et al., 2014) were echoed in open-ended comments from 2 SLTs, and should be further explored in future research.

The lack of collaboration with PWA on service design and delivery initiatives runs counter to the inclusion of people with chronic conditions in decisions around their health care and service design and evaluation (Carroll, 2017; Langlois et al., 2018; WHO, 2016). There is a clear need for studies addressing the involvement of people affected by aphasia in service development, implementation and evaluation.

We know both that the incidence of mental health problems among PWA is high and that psychological care is effective, (Baker et al., 2017; Northcott, Burns, Simpson, & Hilari, 2015; Northcott, Simpson, Moss, Ahmed, & Hilari, 2018; Santo Pietro, Marks, & Mullen, 2019), however the results illustrate a lack of consistent support, in keeping with previous Irish research (Community Services Subgroup of the National Stroke Working Group, 2011; Horgan et al., 2014; IHF et al., 2014; McElwaine et al., 2016). There is a clear need for more equitable, standardised access to communicatively accessible support for depression and other mental health problems

for PWA.

Best practice aphasia support involves accessible information on aphasia and treatment options at all stages of recovery (Aphasia United, 2018), which helps to empower PWA to direct their recovery, organise care and collaborate in decisions about their treatment (Manning et al., 2019). A lack of self-management information is counter to best practice (CCRE in Aphasia Rehabilitation, 2014), as is a relative lack of general online information and/or a lack of signposting of online information, in keeping with findings from Hong Kong and Australia (Kong & Tse, 2018; Rose et al., 2014). There is a clear need to develop accessible information in a range of aphasia-friendly formats that are available to PWA in the long-term post-stroke (Aphasia United, 2018; CCRE in Aphasia Rehabilitation, 2014; Manning et al., 2019).

Inconsistent access to support for families runs counter to best practice (Aphasia United, 2018; CCRE in Aphasia Rehabilitation, 2014) and may exacerbate negative relationships and “third-party disability” (Grawburg et al., 2013; Manning et al., 2019). This was compounded by a lack of access to aphasia information /training (Aphasia United, 2018) and has potential implications for maintaining positive social relationships and social and community participation (Manning et al., 2019). Less information and training for friends mirrors findings in the literature (Rose et al., 2014) and is concerning because it is non-kin relationships that are most severely impacted by aphasia (Hilari & Northcott, 2006, 2016). While many SLTs were involved in supporting participation, there is room to develop efforts to increase awareness of aphasia and to proactively support the rights of PWA to communicative access and life participation (Aphasia United, 2018; CCRE in Aphasia Rehabilitation, 2014; Hersh, 2017).

Finally, reduced awareness of aphasia and communication strategies among HCP’s is counter to best practice recommendations (Aphasia United, 2018; CCRE in Aphasia Rehabilitation, 2014) and has potential implications in terms of empowering PWA to be able to access and capitalise on formal support and rehabilitation (Burns, Baylor, Dudgeon, Starks, & Yorkston, 2015; Manning et al., 2019;

O'Halloran et al., 2019).

Methodological critique and limitations

To maximise content validity, we developed the survey instrument drawing on the findings of a rigorous, qualitative evidence synthesis and with input from a PPI aphasia advisory group (Burns et al., 2008). We piloted the questionnaire to determine comprehensiveness, usability, clarity and face validity and captured “unanticipated answers” via open-ended responses (Burns et al., 2008). We adhered to the STROBE standardised reporting guidelines to standardise the conduct and reporting of the research.

The estimated response rate (44%) falls short of 70% recommended for maximising external validity and generalisability of self-administered surveys to clinicians (Burns et al., 2008). However, the denominator is estimated based on the combined membership of relevant SIG's, which likely includes joint-members and ineligible SLTs. Difficulties determining the true response rate (which may be substantially higher than our estimate), reflects the need for better data capture in terms of the SLTs (and other resources) working in this area. The completion rate (81%) may reflect the large number of questions which can reduce likelihood of completion (Burns et al., 2008; Fox, 1994). Lack of clarity of survey choice options (e.g. “long-term”, Q38, Supporting Information, Appendix D) limited interpretation of the findings. Respondent geographical location data were collected using a crude proxy of Community Health Organisation (CHO). These were not explored further partly to protect respondent anonymity, but also because the CHO structure is not aligned with acute hospital services and therefore provides limited information about the health context that most respondents are working in.

Conclusion

This is the first clinician survey looking at post-stroke support for living well with aphasia in Ireland

and helps to address an evidence gap around planning person-centred aphasia care. Though SLT was generally available, the results highlight access barriers and evidence-practice gaps in terms of the amount, intensity and timing of SLT to be maximally effective and there was a lack of PWA involvement in service design and delivery. Access to other supports such as mental health services was inconsistent and there was a lack of community support for families. There were shortcomings in access to aphasia information including self-management and online resources for PWA, and a lack of aphasia information and training for families, friends and other health care professionals. This study complements findings from previous surveys of stroke services in Ireland and services for PWA internationally. The results will be integrated with an interview study with PWA in order to produce some provisional recommendations aimed at supporting living well with aphasia.

SUPPORTING INFORMATION

Appendix A: Checklist for Reporting Results of Internet E-Surveys (CHERRIES) (PDF)

Appendix B: The STROBE (STrengthening the Reporting of OBservational studies in Epidemiology) Statement (PDF)

Appendix C: Supporting the contribution of the advisory group to enhance the quality and relevance of the survey instrument (PDF)

Appendix D: Final Survey Instrument (PDF)

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TABLES

Summary of responses	
Total consented	111
Total eligible	98
Discontinued after screening	3
Summary of respondents included in the analysis	
Total datasets	95
Completion rate, n (%)	77 (81)
Years qualified, n (%)	
1-4	24 (25)
4-9	21 (22)
10+	50 (53)
Years working with PWA, n (%)	
1-4	32 (34)
4-9	26 (27)
10+	37 (39)
Working in multiple settings, n (%)	42 (44)
Main work setting, n (%)	
Community	36 (38)
Inpatient	33 (37)
Rehabilitation	18 (19)
ESD	2 (2)
Private practice	2 (2)
Outpatients	1 (1)
Long-term older adults service	1 (1)
Community Health Organisation, n (%)	
1	2 (2)
2	9 (10)
3	8 (8)
4	19 (20)
5	13 (14)
6	11 (12)
7	13 (14)
8	8 (8)
9	12 (13)

Table 1. Respondent characteristics

FIGURE LEGENDS

Fig 1. Frequency of SLT by setting

Fig 2. Duration of SLT by setting