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How do Speech and Language Therapists address the psychosocial well-being of people with aphasia? Results of a UK on-line survey

Abstract

Background and Aims: The psychosocial impact of stroke and aphasia is considerable. We aimed to explore UK speech and language therapists' clinical practice in addressing psychological and social needs of people with aphasia including their experiences of working with mental health professionals.

Methods and Procedures: A 22-item on-line survey distributed to UK speech and language therapists via British Aphasiology Society mailing list and Clinical Excellence Networks. Results were analysed using descriptive statistics and qualitative content analysis.

Outcomes and Results: UK speech and language therapists (n=124) overwhelmingly considered that addressing psychological well-being (93%) and social participation (99%) was part of their role. To achieve this they frequently/very frequently used supportive listening (100%) and selected holistic goals collaboratively with clients (87%) including social goals (83%). However, only 42% felt confident in addressing the psychological needs of clients. Main barriers to addressing psychosocial well-being were time/caseload pressures (72%); feeling under-skilled/lack of training (64%) and lack of on-going support (61%). Main barriers to referring on to mental health professionals were that mental health professionals were perceived as under-skilled working with people with aphasia (44%); were difficult to access (41%); and provided only a limited service (37%). A main theme from the free text responses was concern that those with aphasia, particularly more severe aphasia,

received inadequate psychological support due to the stretched nature of many mental health services, mental health professionals lacking skills working with aphasia, and speech and language therapists lacking the necessary time, training and support. Main enablers to addressing psychosocial well-being were collaborative working between speech and language therapists and stroke-specialist clinical psychologists; speech and language therapists with training in providing psychological and social therapy; and ongoing support provided by the voluntary sector.

Conclusions and Implications: The vast majority of speech and language therapists consider the psychosocial well-being of their clients, and work collaboratively with people with aphasia in selecting holistic goals. It is, however, of concern that most respondents felt they lacked confidence and received insufficient training to address psychological well-being. In order to improve psychological services for this client group, there is a strong case that stroke-specialist mental health professionals should strive to make their service truly accessible to people with even severe aphasia, which may involve working more closely with speech and language therapists. Further, improving the skills and confidence of speech and language therapists may be an effective way of addressing psychological distress in people with aphasia.

What this paper adds

What we already know

People with aphasia are at risk of becoming depressed and socially isolated. It is not known how UK speech and language therapists experience delivering psychosocial therapy, nor how they perceive working with mental health professionals to address psychological distress. Having a clearer understanding of current clinical practice may provide useful information leading to improvement in stroke services.

What this paper adds

Our survey of UK speech and language therapists (n=124) found that the main barriers to speech and language therapists delivering psychosocial support were time/caseload pressures, feeling under-skilled/lack of training, and lack of specialist on-going support. The main barriers to referring on to a mental health professional were the perception that they were under-skilled in aphasia and difficult to access.

What are the clinical implications of this work

Mental health services need to ensure that they are accessible and responsive to the needs of people with aphasia. Speech and language therapists, as the professionals most skilled in facilitating communication, potentially have a key role to play in meeting the psychological and social needs of people living with aphasia, including working with and training other healthcare professionals.

Introduction

It is estimated that around one third of stroke survivors will have aphasia, a language disability, early post onset (Engelter et al., 2006), and for 15% it will persist as a chronic life-long condition (Wade, 1994). UK stroke guidelines state that addressing the psychological consequences of stroke should be considered as important as addressing the physical consequences (NHS Improvement, 2011). The current project aimed to explore how speech and language therapists (SLTs) address the psychosocial needs of people with aphasia; the extent to which they considered it part of their role; and their reflections on working with others such as mental health professionals in delivering psychosocial care to this client group.

Rates of depression following a stroke have been estimated at 31% (Ayerbe, Ayis, Wolfe, & Rudd, 2013), and those with aphasia appear to be particularly at risk. Kauhanen et al. (2000) found that at three months post stroke 70% of people with aphasia were depressed, classified using DSM-III-R criteria; by 12 months this figure had dropped only slightly to 62%. The qualitative literature also documents the frustration, anxiety and feelings of hopelessness that aphasia can cause (Worrall et al., 2011). The social consequences of having a language disability can also be profound. Those with aphasia take part in fewer social activities, and are less satisfied with those they do engage in (Cruice, Worrall, & Hickson, 2006). They are also disproportionately likely to lose contact with friends, and have smaller social networks (Northcott & Hilari, 2011; Northcott, Moss, Harrison, & Hilari, 2015). A recent stroke study found that aphasia was the only stroke-related factor measured at the time of the stroke that predicted poorer social network functioning six months later, suggesting that aphasia, more than stroke severity, physical disability or psychological distress, challenges a person's ability to maintain strong social networks (Northcott, Marshall, & Hilari, in press).

There is consensus that it is within the role of health service provision to consider the psychosocial consequences of health states. The World Health Organisation defines health as 'a state of complete physical, mental and social well-being' (World Health Organisation, 2013), and this emphasis on broader psychosocial well-being is reflected in current stroke guidelines. For example, UK guidelines state that 'services for stroke should be commissioned with the same emphasis on provision of psychological care as for physical care and rehabilitation' (p.5) (NHS Improvement, 2011). It is therefore of concern that a recent survey of 1,774 UK stroke survivors found that only 20% felt they were given information, advice and support in coping with the emotional aspects of stroke, and two-thirds felt that their emotional needs were not as well looked after as their physical needs (Stroke Association, 2015). The UK National Audit Office (2010) of stroke care found that psychological care was rated the least satisfactory service in the long-term, with only 24% of respondents rating it as good or very good. While those with aphasia may be particularly at risk of adverse psychological consequences, it is not known to what extent they are able to access stroke psychological services in the UK.

We were particularly interested in the role of SLTs in addressing the psychological and social well-being of people with aphasia. Communication is intricately linked to the social context within which communicative exchanges occur, and there is an increasing recognition that SLTs should consider social participation and involve communication partners, particularly family members, in therapy (Holland, 2007; Worrall et al., 2011). Further, it has been argued that communication goals can be more successfully achieved through SLTs acknowledging the impact of aphasia on a person's life and identity (Holland, 2007; Simmons-Mackie & Damico, 2011). This is now reflected in professional guidelines. For example, in the UK the Royal College of Speech and Language Therapists (2005) state that SLTs working with those who have aphasia should 'address emotional health, and enable participation in an

individual's social context' (p.98). The American Speech-Language-Hearing Association has adapted the ICF-WHO biopsychosocial model (World Health Organisation, 2001) to guide therapy, and state that it is within the scope of an SLT's role to provide counselling regarding communication-related issues (American Speech-Language-Hearing Association, 2007).

In terms of the current practices and beliefs of SLTs, a recent international survey (n=579) found that 74% of SLTs considered quality of life to be the main aim of aphasia rehabilitation (Hilari et al., 2015). In the UK, Brumfitt (2006) found that 97% of SLTs (n=173) stated that psychosocial aspects were important or very important to their management of clients with aphasia, while an Australian survey found that 98% of SLTs (n=111) felt that they had a role to play in addressing psychological well-being (Sekhon, Douglas, & Rose, 2015). In terms of how often SLTs provide psychological support, 66% of Australian SLTs reported providing counselling either frequently or very frequently (Rose, Ferguson, Power, Togher, & Worrall, 2014).

Stroke guidelines in the UK suggest that low level mood problems (Level 1), commonly experienced post-stroke, should be addressed by stroke-specialist staff, for example, through 'active listening' and providing advice and information; for mild/moderate symptoms of impaired mood (Level 2), clinical psychologists should supervise stroke staff in providing support; and that severe and persistent mood disorders (Level 3) require intervention from clinical psychology and/or psychiatry (NHS Improvement, 2011). We wanted to investigate to what extent UK SLTs feel confident and well-equipped to deliver Level 1 and Level 2 psychological care and support; to what extent they feel supported by or have access to clinical psychology; and whether they perceived that people with aphasia were able to access psychological services when necessary, as per UK guidelines.

The purpose of the current study was to capture a broad range of experiences from SLTs working in a variety of settings, encompassing the different stages in the stroke journey from acute to more long-term. In order to reach a large number of SLTs in geographically diverse locations, we ran an on-line survey. The specific aims of the study were to investigate current SLT practice in delivering psychological and social care; perceived barriers and facilitators; SLT training in delivering psychosocial care; SLT experiences of working with mental health professionals, including barriers and facilitators; and perceptions surrounding the scope of the SLT role.

Methods

Procedure and participants

We developed a 22-item questionnaire to explore the current practices and beliefs of SLTs in delivering psychosocial therapy and support to people with aphasia (see on-line appendix 1). The survey was anonymous and delivered on-line through SurveyMonkey to speech and language therapists (SLTs) working with people with aphasia in the UK. The survey was open for one month (June 2015) and was distributed via the mailing list of the British Aphasiology Society (approximately 300 members), as well as interested Clinical Excellence Networks (for example, North West Aphasia Clinical Excellence Network, with around 100 members). We also used snowballing, so anyone who received an email inviting them to participate was invited to forward it on to other SLTs working with people with aphasia. Ethical approval to conduct the study was obtained from the School of Health Sciences Research Ethics Committee, City University London.

Survey

The survey was developed by the first author based on a review of the literature and similar measures (Sekhon et al., 2015). It was reviewed by the co-authors for appropriateness, comprehensiveness, relevance and clarity. Adjustments to format and wording were made based on their recommendations.

The survey collected information on the following:

(1) Background information: demographics and information on SLTs' workplace setting and their experience of working with people with aphasia
(2) SLTs' training in delivering psychosocial therapy or support
(3) The extent to which SLTs believed their caseload were experiencing psychological distress
(4) Psychosocial approaches currently used by SLTs and consideration of the SLT role
(5) Barriers and enablers to delivering psychosocial therapy and support
(6) SLTs' experiences of working with mental health professionals.

Response formats included: selecting from a range of options; 5 point rating scales, for example, to indicate frequency (never to very frequently) or agreement (strongly disagree to strongly agree). In addition, some questions allowed respondents both to select an option and also to add free text. For example, one question explored what training they had received. If they selected 'Other' they would be prompted to write a free text response. There were two optional free text responses at the end of the survey in order that respondents could add more reflective comments.

Data analysis

Descriptive statistics were used to describe the data on closed questions. Qualitative content analysis was conducted on the free-text responses (Graneheim & Lundman, 2004). The material was coded, the coding system having been derived from repeated readings of the data. The coded units were then distilled and placed with other material similarly coded. All material was allocated to at least one category therefore no material was omitted. The process of developing higher order categories was iterative, and involved the primary analyst (SN) frequently reviewing the raw data to ensure it was adequately represented in the final framework. In order to increase trustworthiness and reduce potential bias a second analyst (BM) reviewed the raw data and analytic process. Any disagreements (for example, on category structure) were resolved through discussion until consensus was achieved. Furthermore, different professional backgrounds were represented in the research team, further reducing bias: SLT (SN and KH), mental health nursing (AS and NA), and clinical linguistics (BM).

Results

A total of 124 people responded to the survey. It is not possible to give a precise response rate, due to the snowballing methodology used. A reasonable estimate may be that around 500 eligible SLTs working in the UK received the invitation (British Aphasiology Society mailing list plus Clinical Excellence Networks) suggesting a response rate of around 25%. Response rates to individual questions ranged from 61% to 100% (18/20 questions >82%). Of the two free text questions (framed as ‘optional’), 57% left a comment about their experiences working with mental health professionals (MHPs); 30% used the final free text box to make additional comments.

Participant characteristics

Participants' demographic characteristics are detailed in table 1. The majority of participants were female (96%) and white (96%) which reflects the demographics of UK SLTs (Parity, 2013). Over half were aged between 30 to 49 years old (52%), and had been working as an SLT for more than ten years (56%), thus were relatively experienced. Participants worked across a variety of settings, with the most frequently endorsed responses being community (56%), inpatient rehabilitation (54%), outpatient rehabilitation (42%), and acute/subacute (37%). The majority either agreed or strongly agreed that they were knowledgeable (93%), confident (92%) and experienced (89%) in their work with people with aphasia.

*** table 1 about here ***

SLTs' training *(n=115)*

Respondents were asked how much training they had received in delivering psychosocial therapy or support (response options: none; 1 day or less; short courses < 3 months; certificate/ diploma; it was not specified whether training was pre or post registration). Respondents were most likely to have received training in counselling, with 67% having received at least some training, and 25% having gone on either a short course or studied for a certificate/diploma. 66% had also received some training in social approaches (e.g. facilitating peer support, working with family) with 19% having received more than one day of training. Respondents also indicated they had received at least some training (majority less than a day) in solution focused brief therapy (45%), cognitive behavioural therapy (29%), motivational interviewing (15%), and narrative therapy (20%).

Proportion of caseload experiencing psychological difficulties *(n=90)*

Exactly half of respondents considered that between 70% and 100% of people with aphasia were experiencing psychological difficulties; 38% of respondents put this figure at between 40% to 60%; and 12% estimated that 30% or less of clients were experiencing difficulties.

SLTs' beliefs and experiences in delivering psychosocial therapy and support *(n=111)*

Respondents were asked how often they used specific approaches (see figure 1). In terms of supportive listening (defined in the survey as empathising, active listening, exploring emotional issues), 100% indicated that they used supportive listening frequently/very frequently. Other approaches commonly used included selecting holistic goals (88% frequently/very frequently); working on social support e.g. facilitating peer support or selecting social goals (83% frequently/very frequently); work with family/significant others (81% frequently/very frequently). Less commonly, SLTs created opportunities for their clients to share their stroke or life story (43% frequently/very frequently). Occasionally, SLTs used specific psychotherapeutic approaches such as cognitive behavioural therapy or solution focused brief therapy (11% frequently/very frequently).

figure 1 about here

Respondents were also asked to agree or disagree with statements asking about how confident they felt in delivering psychosocial therapy and support (n=109). SLTs appeared to feel more confident addressing the social needs of clients (73% strongly agreeing/agreeing; 21% neutral; 7% disagreeing/ strongly disagreeing) than the psychological needs (42% strongly agreeing/ agreeing; 34% neutral; 24% disagreeing/ strongly disagreeing).

SLT's role *(n=109)*

The majority of respondents agreed/strongly agreed that the following areas were part of an SLT's role: client's psychological well-being (93% agreed/strongly agreed); client's social support/relationships (97% agreed/strongly agreed); client's participation/ engagement in social activities (99% agreed/strongly agreed); client's confidence (99% agreed/strongly agreed).

Barriers and enablers to SLTs addressing the psychosocial needs of their clients

(n=102; 106)

The main barriers were: time/caseload pressures (72%); feeling under-skilled/lack of training (64%); lack of on-going specialist support (61%); and worries that they may get out of their depth (40%). Also endorsed by 17% was the perception that psychosocial therapy/support was a low priority for their service (see figure 2).

figure 2 about here

When asked what would help them to improve their delivery of psychosocial therapy/support, the three most endorsed responses were: provision of more training (80%); being able to access on-going specialist supervision (74%); and having adequate time to address psychosocial well-being (63%). Recognition from senior staff of the value of addressing psychosocial well-being was also endorsed by 25%, as was having a role definition that encouraged SLTs to take on this work (25%).

Working with Mental Health Professionals (MHPs) and other services

Referring on to other services to address psychological and social well-being (n=106)

SLTs were most likely to refer to voluntary sector organisations (for example, Headway, the Stroke Association) in order to address the social or psychological well-being of clients (85% frequently/ very frequently). Other services they referred to less frequently included: psychology (38% frequently/ very frequently); social work (31% frequently/ very frequently); GP (17% frequently / very frequently); counselling (14% frequently/ very frequently); or mental health nursing (6% frequently/ very frequently).

Barriers to referring to MHPs (n=101)

The most commonly barriers cited were: the view that MHPs feel under-skilled when working with people with aphasia (44%); MHPs being difficult to access (41%); MHPs providing only a limited service (37%); referral guidelines being unclear (34%); long waiting list (32%); no MHPs in the team (29%); and person with aphasia declining onward referral (28%) (see figure 3).

figure 3 about here

Collaborative working with MHPs

SLTs did not commonly work collaboratively with other MHPs, for example, running joint sessions or educating MHPs on supported communication (n=106). The proportion who selected frequently/very frequently were as follows: psychology, 28%; mental health nursing, 6%; counselling, 6%; psychiatry, 2%.

Respondents were also asked how frequently they had a positive experience of referring to or working collaboratively with a MHP (n=76). The most common response was 'occasionally' (46%); 29% selected 'never/rarely'; 25% selected 'frequently/very frequently'.

Qualitative data: themes from the free text responses

There were 71 responses to Q21 (experiences of working with MHPs); 37 responses to Q22, (any further comments on addressing the psychosocial needs of people with aphasia); and 64 free text responses to six earlier survey questions where the response format allowed respondents to add comments as well as select from pre-specified options. Free text responses were analysed together, and fell into four main categories: prevalence of psychological difficulties; barriers and enablers to addressing psychosocial needs; observations on the SLT role; and recommendations.

Prevalence of psychological difficulties

A common theme in free text responses was the inevitability of a person experiencing psychological difficulties in response to such a big and unwelcome life change. Respondents commented on the threat to identity posed by losing language, and the close link between communication impairment and mental health issues.

> *Q10R4: 'I don't think anyone with aphasia escapes without psychological difficulties – either frustration or adjustment or sorrow.'*

Respondents also described variation in how their clients responded to the stroke and aphasia. Factors perceived to mediate a person's psychological response included: levels of insight

and awareness; coping mechanisms (both internal, and also support received from those around them); having a history of mental health issues; and the stage a person had reached on their post-stroke journey.

A further theme was that it could be difficult to identify distress in people with aphasia, particularly where a person also experienced cognitive difficulties. They thus considered it a possibility that stroke professionals underestimated prevalence.

> *Q10R17. 'I think [the proportion experiencing psychological distress] perhaps more than we realise; inconsistent approaches to identifying those people and at what points in their aphasia journey.'*

Barriers to addressing the psychological needs of people with aphasia

The two most frequently cited barriers were that MHPs were under-skilled working with this client group; and that there was limited mental health service provision. Respondents also had concerns about the referral process, and the challenges of joint working. Additional barriers included SLT caseload pressures, lack of training and support for SLTs, the poor evidence base, and the wider multi-disciplinary team's limited knowledge of aphasia.

MHPs limited knowledge and skills when working with people with aphasia

A common theme was that SLTs perceived MHPs to lack confidence and skills when working with people with aphasia. SLTs had experienced MHPs declining to offer a talking therapy as they suggested someone with aphasia would not benefit; or saw the person with aphasia but discharged them after one session due to lack of success facilitating communication; or only offered services, such as 'living with stroke' groups, that required

good language abilities. While lack of training and experience with aphasia was particularly problematic for MHPs who were not specifically attached to stroke services, SLTs reported that stroke-specialist clinical psychologists also lacked skills and poorly understood the impact of aphasia on a person's life.

> *Q22R22: 'often referred on to counsellors/psychologists who then appeared unable to work with my clients because of the communication issues. Only successful referrals were those where the client could fully express themselves.'*

Some respondents expressed concern that on occasion clinical psychologists overestimated their ability to work with people with aphasia, and declined SLT input. This was perceived to lead to incorrect judgements and unsuccessful sessions.

> *Q21R68: 'I find that MHP especially psychologists often feel that they know how to work with people with aphasia and decline our involvement, then they have unsuccessful sessions and discharge the person.'*

A consequence of the perceived undertraining of MHPs in aphasia was that SLTs felt that this client group often had only limited or no access to mental health services. There was particular concern that the needs of those with more severe aphasia were not well identified or treated.

Limited mental health service provision

A strong theme was that SLTs perceived mental health services to be limited or overstretched. Respondents working in a variety of settings (acute, community, early supported discharge) stated they had limited or no access to mental health services. The lack of long-term community support appeared to be a particular concern.

Q22R5: '[Need] more MHP in community as almost impossible to find.'

As a result of the pressures on mental health services respondents commented that some services only provided crisis management. This precluded the longer term work which SLTs felt many of their clients needed. Respondents also commented that the focus of clinical psychology's involvement often appeared to be assessment only, sometimes with an emphasis on assessing cognition rather than mood. Meaningful intervention to address low mood was perceived to be less frequent.

Q21R52: 'no psychology service available beyond initial assessment. Need therapy too.'

Referral process

The referral process was described as unnecessarily complex. It was perceived as particularly difficult when the mental health service was in a different National Health Service (NHS) Trust (where an NHS Trust is an organisation providing health services). SLTs described being unsure which service to refer to, not knowing how to refer, feeling unclear about when it is appropriate to refer and which referrals would be accepted. As a consequence some respondents said that in practice they did not make referrals.

Q21R28: 'it can be difficult to know which service to refer to (which is most appropriate and if a referral will be accepted), and how to refer.'

Further, some mainstream counselling services required telephone self-referrals reducing accessibility for many with aphasia. A number of respondents felt that it was their role to raise concerns and input into discussions; however, they stated within their team it was a doctor's role to make the referral.

Challenges to joint working/ lack of collaborative working

Although joint working was perceived to be a mutually beneficial model (see below), there were difficulties making it work in practice. It was perceived as challenging for both the SLT and MHP to find time to run the session together. This was exacerbated when services were stretched or joint working was perceived as a low priority by a particular manager or service.

> *Q21R10: 'When I have worked with a psychologist it has been a positive experience and has greatly helped the client however finding the time to work together (both the practicalities of finding a time to run a joint session and planning and reviewing) was challenging.'*

Another challenge was a lack of understanding about each other's roles. The different backgrounds and approaches of SLT and psychology could also present obstacles. SLTs felt that they took a more flexible, client-led approach, whereas they perceived some clinical psychologists to be more rigid, for example in their approach to standardised assessment, or in insisting on restricting their involvement until a person reached a certain level on the stepped care pathway.

> *Q21R32: 'I feel that some mental health professionals can be quite rigid in their approach e.g. standardised formal assessment rather than the more holistic approach needed with aphasia.'*

More generally, the lack of collaborative working was perceived as a barrier in addressing the psychological as well as social needs of individual clients.

> *Q15R9. Barriers to addressing psychosocial well-being: 'Lack of collaborative working with social workers and psychologists and the MDT'*

Barriers to SLTs addressing psychosocial needs

Caseload pressures meant some SLTs did not feel they had time to support their clients' psychosocial well-being as much as they would like. Other aspects of the job were prioritised, such as working directly on language and managing dysphagia. Flexibility, such as seeing clients outside clinic in more functional settings, while seen as desirable was impractical due to the extra time this would involve.

> *Q22R19: 'The predominance of dysphagia management in acute and community services may mean the psychosocial needs of people with aphasia are not prioritised.'*

Another emerging theme was that some SLTs lacked confidence in addressing the psychological well-being of clients. They saw it as challenging to deliver psychological therapies effectively and sometimes felt 'out of their depth'. It was also common that SLTs expressed a desire to improve their skills and the lack of accessible or suitably in-depth training courses and supervision was another barrier to SLTs delivering psychosocial support.

> *Q22R9: 'I have thought about improving my skills and knowledge in this area, however, I have struggled to find anything that is local to my area. I do spend time during sessions when clients show that they need to address such issues and use my limited knowledge of counselling to try and support them.'*

A related point was that while they had developed creative ways to support clients, they did so in the absence of a strong evidence base. Further, although providing emotional support was perceived as valuable, they found it difficult to document the 'outcomes' of this type of work. Managers also did not always support SLTs in addressing the psychosocial needs of clients.

Q22R23: 'find it a very valuable area of work that we focus on a lot… but sometimes struggle to capture the work done (outcomes)'

Underfunded voluntary organisations

While the services offered by charitable organisations were welcomed, it was also observed that these were variable across the country, and in some areas there was little available to support people at the end of rehabilitation. Funding cuts were observed to have negatively affected these services.

Q22R25: 'Where I work now there is so little available to help people access activities in their community and to support them to do so as so much has been cut.'

Multi-disciplinary team lacking knowledge about aphasia

SLTs commented that where the multi-disciplinary team lacked knowledge about aphasia this negatively impacted on psychosocial well-being. This particularly applied to staff that were in regular contact with the people with aphasia such as nurses and those providing homecare services.

Q22R29: 'I feel that nursing staff would also benefit from having a better understanding of the impact of aphasia on patients' psychological well-being.'

Inherent difficulties of supporting this client group

A further theme to emerge was that SLTs perceived that it could be challenging to access the 'inner world' of someone with a severe communication difficulty and enable them to express their emotions. The situation was particularly challenging when a person also had a severe cognitive impairment. Non-verbal psychological therapy and support felt challenging, beyond

their capabilities, and an area in which there *'aren't a whole lot of service/options available.'* (R15R7).

> *Q22R1. 'It's so hard for a person with aphasia to explain how they feel and sometimes I feel like I'm putting words into their mouths.'*

Overall lack of service for people with aphasia

Taken together, the lack of mental health service provision, the undertraining of MHPs with this client group, the difficulties SLTs faced in delivering support, and the variable nature of charitable provision, meant that SLTs perceived many people with aphasia, particularly those with more severe aphasia, received an inadequate service.

> *Q22R3: 'I feel this is a gap in stroke services, particularly the long-term lack of psychosocial support.'*

> *Q22R36: 'I feel this is an area that is not addressed well.'*

Failing to address a person's psychosocial needs was perceived to lead to poorer rehabilitation outcomes, create other health problems, and leave people with aphasia to *'suffer unnecessarily'* (Q22R8). It was also observed that knowing there was no long-term support or services made it challenging to discharge people.

Enablers to addressing psychological needs of people with aphasia

The main themes to emerge were: joint working between SLTs and MHPs; having a psychologist embedded in the multi-disciplinary team; SLTs providing support themselves; voluntary sector provision.

Joint working

Respondents gave many examples of SLTs and MHPs working together successfully. This encompassed carrying out joint sessions, discussing cases, and MHPs offering on-going support and advice. SLTs appreciated it when MHPs valued SLT observations, opinions, and advice on how best to facilitate communication. When it went well, joint working was perceived as mutually beneficial for the professionals involved, and as leading to the best outcomes for the person with aphasia.

> *Q21R42: 'Good working relationship with our neuropsychologist who will ask me generally what I think is going on for the person before going to see them and then how I can support the interaction with the neuropsych and indeed what I can put in place after with the person.'*

Clinical psychologist embedded in the team/ psychology input

Many SLTs reported that having a clinical psychologist within the multi-disciplinary team was helpful. It facilitated joint working and made accessing psychological input and advice easier.

> *Q21R66: 'We have a psychologist as part of our team who provides invaluable support.'*

SLTs perceived the following aspects of the clinical psychologist's role to be valuable: supporting and advising the person with aphasia and their family; acting as a liaison point for other mental health services; conducting assessments e.g. mental capacity assessments; delivering therapy, working closely with SLT; and providing indirect support to people with aphasia via the SLT.

SLTs delivering psychosocial support

Where SLTs had relevant training, and were skilled in delivering psychological support, this was perceived as enabling even those with severe aphasia to access appropriate psychological therapy.

> *Q22R2: 'In our service having a dual trained SLT-counsellor works very well for both 1:1 and group work enabling those with severe aphasia to access psychological support.'*

SLTs also reported a variety of ways in which they addressed the psychosocial needs of people with aphasia. These included setting up support groups (e.g. 'living with aphasia' groups; conversation groups); working on communication indirectly through building confidence; using aphasia-accessible psychosocial assessments as a starting point for a conversation about emotions; conversation partner or befriending schemes; facilitating people in accessing courses at further education colleges; use of commercially available tools such as 'Talking Mats'; and finding other creative ways to enable people with limited language to express their emotions during speech and language therapy sessions. SLTs also worked with people with aphasia to deliver some of these services, who acted as positive role models.

> *Q22R16: 'We run an emotional support group on our unit for in-patients which is of great benefit. This is usually led by SALT plus an ex stroke patient.'*

Voluntary sector and other models of service provision

Services run by the voluntary sector such as stroke charities, particularly those offering long-term support, were valued highly by SLTs. At best, the person with aphasia could access

groups where they met other stroke survivors, and receive one to one advice and support, as well as help in accessing other services in the community.

> *Q15R14. 'Local stroke association provide support in partnership with SLT.'*

SLTs without access to a psychologist described working with a variety of other professionals in order to address the psychosocial well-being of their clients. These included a psychosocial occupational therapist and a mental health nurse specialising in stroke support.

The SLT's role

Respondents also reflected on the nature of the SLT's role. Many respondents expressed the strong belief that it was part of the SLT's role to address the psychosocial needs of the people with aphasia, and this was a valuable part of their work. They also considered that their role included supporting the family.

> *Q22R23: 'the role of the SLT [is] addressing any aspect of a person's life that relates to communication/interaction – which includes psychological support (as we are often the one to truly ask a person with aphasia 'how they are' due to difficulty communicating).'*

Others conceptualised their role as enabling people with aphasia and their families to access appropriate support from other professions such as social work and psychology. Some respondents felt that the SLT's role was to work on language, and that they should address the psychological needs only indirectly through improving language skills. There was also concern that SLTs should not *'cross professional boundaries' (Q15R2).*

Q22R11: 'I feel that our role is to reduce psychosocial needs indirectly secondary to aphasia via aphasia therapy (impairment based and functional) …. however I do not feel it is within our role to directly address psychological needs of patients with aphasia.'

A variation on this position was that while SLTs did not consider addressing psychological needs to be their role, it had nonetheless become part of their job as no-one else was able to provide this support due to the language difficulties.

Recommendations

Respondents suggested a number of ways in which they felt services could be improved:

More joint working between SLTs and MHPs; better understanding of each other's roles

Respondents suggested services should be configured to make joint working easier. Suggestions included more time in NHS Trusts to build up relationships; joint training at universities; managers viewing this as a priority; closer working pathways.

Q21R44: 'More joint working is needed so that we understand each other's roles and the MHP understands how best to help the person with aphasia.'

More training for MHPs; improved access to mental health services

A common theme was that SLTs felt MHPs should receive more training on aphasia and make their services accessible to this client group. They also called for more mental health service provision at all stages in the pathway including the longer term, and suggested that

referral pathways should be made simpler and SLTs educated on when and how to make appropriate referrals.

> *Q22R21: 'need more mental health specialists trained in aphasia.'*

Increase skill-set of SLTs

Improved access to both local and national training for SLTs in order to improve their skills in this area was another recommendation. It was felt that reading, short courses and trial and error were inadequate, and access to more specialist and in-depth training and support was required. More generally, a number of respondents felt that the importance of addressing psychosocial needs should be promoted within the speech and language therapy profession.

> *Q22R15: 'Further training/promotion within SLT would be beneficial to highlight this as part of our role as appropriate, to help more consistently integrate into therapy plans.'*

Improve services in the community that address psychosocial well-being

Respondents recommended more universal provision of peer support and other on-going social and community support.

> *Q16R4 'more supported social opportunities, and appropriate services to liaise with in the geographical area I work in e.g. Headway, &/or buddy system.'*

Improve the evidence base

It was suggested that the evidence base in this area, particularly for those with severe aphasia, should be improved. Furthermore, evidence-based resources should be developed to facilitate SLTs in addressing the psychosocial needs of their clients.

Q22R32: 'Lack of evidence base for those with severe aphasia and addressing their needs.'

Discussion

This on-line survey obtained the views of 124 UK speech and language therapists (SLTs) on their clinical practice in addressing the psychosocial well-being of people with post-stroke aphasia. The majority of respondents considered that over half their clients were experiencing psychological distress as a result of their stroke and aphasia, and 93% agreed that the client's psychological well-being was a part of the SLT role. However, only 42% felt confident in addressing psychological needs. The main barriers were time/caseload pressures (72%), feeling under-skilled/lack of training (64%) and lack of on-going specialist support (61%). The most common barriers to referring on to mental health professionals (MHPs) were that MHPs were perceived as under-skilled in working with people with aphasia (44%); difficult to access (41%); and provided only a limited service (37%). Main themes from the free text responses reflected these results, in particular, there was concern over the lack of aphasia-accessible mental health services in the longer-term.

In-line with previous surveys (Brumfitt, 2006; Sekhon et al., 2015), SLTs overwhelmingly considered that addressing the psychological needs of their clients was a part of their role. However, even though the majority felt confident working with people who have aphasia (92%) only a minority (42%) felt confident in addressing psychological needs. This was also found in a survey of Australian SLTs, where 95% felt confident working with people with aphasia although only 31% felt confident managing psychological well-being (Sekhon et al., 2015). Mirroring the Sekhon et al. (2015) survey one of the main barriers was that

respondents felt under-skilled (endorsed by 64% of respondents in both surveys). Further, 40% of SLTs worried that they might get 'out of their depth', a theme also reflected in the free text responses. Other research has found that SLTs feel uncomfortable in taking on a 'counselling' role (Rose et al., 2014), and tend to avoid emotional issues in therapy (Holland, 2007). Simmons-Mackie and Damico (2011) analysed discourse used in therapy sessions and found that SLTs employed several strategies which enabled them to avoid engaging with client distress, such as shifting to 'objective' therapy tasks, deflecting emotion with humour, initiating superficial staged conversations, and focusing on 'facts'. It has also been observed that the predominance of 'SMART' (Specific, Measurable, Achievable, Realistic, Timely) goals in rehabilitation can steer SLTs away from spending time listening to client distress in order to work on more 'objective' goals (Hersh et al., 2012). Yet according to this survey SLTs overwhelmingly aimed to engage in supportive listening, which was defined as empathising and exploring emotional issues, *despite* poor training, support, and work place pressures (72% cited time/caseload pressures as a barrier; 61% cited lack of ongoing support; 80% stated they needed more training). Rose et al. (2014) found providing counselling while feeling under-skilled came at a personal cost to the SLT: dealing with client grief was reported as draining and a major personal challenge. In common with the present study, they found that SLTs reported the need for better education, training and support in this area, and the authors signpost this as a 'critical need' (p.178) for the profession to consider. Caseload pressures, service priorities and potentially rehabilitation culture may also need to be considered carefully if SLTs are to provide psychological support to clients in line with clinical guidelines.

SLTs were more confident addressing social well-being (72%) than psychological well-being (42%). Many had received training in social approaches (66%), had internalised this as part of their role (99%), and this was reflected in their clinical practice e.g. SLTs frequently/very

frequently worked on social support (83%); and worked with family/significant others, for example, providing emotional support or working on communication strategies (81%). This is in line with research exploring what people with aphasia and their family members want from therapy (Howe et al., 2012; Worrall et al., 2011). Previous research has found that SLTs often struggle to involve family members beyond sharing information (Halle, Le Dorze, & Mingant, 2014), and that family members can feel excluded from aphasia therapy (Howe et al., 2012). It is therefore encouraging that this survey suggests family members were mostly included within the therapy process.

Another aim of this research project was to explore SLTs' perceptions about working with MHPs. A main theme from the free text responses was SLT frustration over the limited mental health service provision, particularly in the community, mirroring the results of the UK national audit of stroke services (National Audit Office, 2010). In terms of the longer-term psychological well-being of people with aphasia, community care UK guidelines state that physical and mental health care should be integrated, with mental health care provided in primary health care settings where possible, for example, mental health nurses affiliated to GP practises (Joint Commissioning Panel for Mental Health, 2012). Having a designated MHP within community primary care settings who is supported to work with people with stroke and aphasia may facilitate a longer-term, more flexible meeting of this clients group's psychological needs.

Respondents also expressed concern that MHPs found it difficult to adapt their services for people with aphasia. It is noticeable that current UK clinical practice guidelines do not state that stroke-specialist clinical psychologists need to develop skills in aphasia in order to enable those with a communication disorder to access their services (NHS Improvement, 2011). In Canada, a study explored the experiences of a comparable profession, social work,

in addressing the needs of people with aphasia. It documented the challenges social workers faced as many of their taught skills were problematic when working with someone with aphasia (e.g. reliance on open-ended questions, use of vocabulary which reflects client emotion but is difficult for someone with aphasia to access) (Rowland & McDonald, 2009). Generic supported conversation in aphasia training was perceived as helpful but insufficient. The report recommended more specific training modules for social workers should be developed. Formal training in aphasia for MHPs is one option for delivering aphasia-accessible mental health care. Primary care guidelines also stress that key to integrating mental and physical health provision is better collaborative working practices (Joint Commissioning Panel for Mental Health, 2012). Only around 28% of respondents stated that they worked collaboratively with psychology services frequently/very frequently, and less than 7% with a mental health nurse or counsellor. Nonetheless, this still represents an increase from ten years earlier, when Brumfitt (2006) reported only 3% of UK SLTs reported working collaboratively with a psychologist and/or social worker. There may be challenges to developing effective collaborative working practices, such as anxiety about professional boundaries, different philosophical approaches, workload pressures, and structures and procedures that do not facilitate collaborative working (Simpson, 2006). Various strategies have been found to facilitate inter-professional practice including: open discussion of roles and responsibilities, including role shadowing; joint learning, care-planning and decision making in a safe, respectful environment; identifying areas of potential conflict and establishing mechanisms for resolving differences; and strong consensual leadership that values the different professions (Simpson, 2006). Free text responses from this study suggest that where SLTs and MHPs were able to work closely together, this led to positive outcomes for the client.

Strengths and limitations

One limitation is the self-selecting nature of those who choose to take part in a survey. We estimate that around 500 eligible SLTs received the survey, and that 25% elected to take part: it is likely that the clinicians most interested in the psychosocial aspects of their role would be inclined to complete the survey. Further, the manner of recruitment meant the survey was distributed to SLTs with a specialist interest in aphasia, rather than more generalist SLTs.

A more general limitation of survey methodology is that responses cannot be further explored. For example, it may be difficult for an individual to acknowledge that they do not engage in supportive listening or holistic goal setting: the subtleties and challenges cannot be probed with this methodology. There were also responses which raised further questions: for example, 28% of respondents selected 'person with aphasia declines onward referral' to a MHP. This theme was not picked up in free text responses, so it is unclear why onward referral was declined, although may suggest there is a stigma attached to seeing a MHP for some people, or that some preferred to talk over the emotional aspects of having the stroke with their SLT. Nonetheless, survey methodology enables researchers to canvas a broad range of views and the anonymity may have given respondents freedom to raise controversial viewpoints or acknowledge clinical weaknesses that they might avoid disclosing face-to-face or in front of peers.

Arguably a further limitation is that we chose not to provide definitions of concepts such as psychological distress at the start of the survey. This approach meant we could explore how SLTs themselves related to these concepts during the free text responses. However, it is possible that respondents interpreted core constructs in different ways.

Future directions and implications

This survey documents SLTs' perceptions of working with MHPs. It would be useful to explore how stroke-specialist clinical psychologists and other MHPs perceive delivering care and support to people with aphasia, consider the barriers they face and their recommendations for how services could be improved. Research developing and evaluating training for MHPs working with people with aphasia or the implementation of a shared care protocol may also be a useful future direction.

Scott and Barton (2010) make the distinction between psychological treatment (to be delivered by MHPs, or with the support of MHPs) and psychological care which they argue is the responsibility of the whole health care team, including allied health professionals and nurses. They define psychological care as monitoring a person's psychological well-being, providing accessible information, and emotional care, such as acknowledging distress and anxiety and listening with empathy. They argue psychological care 'should be a routine, integral part of caring for a patient in a holistic way' (p.158), requiring initial training for staff as well as ongoing advice and support. A theme in the free text responses of the current survey was that respondents felt the psychological well-being of people with aphasia would be improved if healthcare staff, including homecare services, had increased knowledge of aphasia and the psychological impact of living with aphasia. Further research is needed into how best to achieve a whole team approach to delivering psychological care at all stages post stroke.

As the professionals most skilled in facilitating the communication of people with aphasia, SLTs potentially play a key role in supporting the psychological well-being of this client group, either directly through developing skills in delivering psychological support (Holland, 2007; Northcott, Burns, Simpson, & Hilari, 2015), or indirectly, through supporting MHPs

and other healthcare staff. A less acceptable outcome is where MHPs and the wider MDT lack training in aphasia, SLTs lack training in psychological therapies/care, and those with aphasia slip through the psychological net and are left with no service.

Conclusion

People with post-stroke aphasia are at risk of depression and social isolation. This study suggests that speech and language therapists overwhelmingly consider the psychosocial well-being of their clients, engage in supportive listening and set holistic and social goals in collaboration with the person with aphasia. It is of concern, however, that the majority of SLTs lack confidence in addressing psychological distress, as well as skills and ongoing support for this work. A further concern is that mental health professionals are perceived to be underprepared for working with people with aphasia. Services need to ensure that the psychological well-being of people with both mild and severe aphasia is addressed, and that mental health services are accessible to this client group.

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Table 1: Participant characteristics

Age (n=124)	Gender (n=124)	Ethnicity (n=122)	Years of SLT experience (n=106)	Workplace setting* (n=119)
20-29: 19.3%	Female: 96.0%	White British: 88.5%	<1: 5.7%	Acute/subacute: 37.0%
30-39: 29.0%	Male: 4.0%	White non-British: 9.0%	1-2: 7.6%	Inpatient rehabilitation: 53.8%
40-49: 23.4%		Mixed ethnic background: 1.6%	3-5: 13.2%	Outpatient rehabilitation: 42.0%
50-59: 22.6%		Asian/ Asian British: 0%	6-10: 17.9%	Early supported discharge: 22.7%
60 or older: 5.6%		Black/African/ Caribbean/Black British: 0.8%	>10: 55.7%	Community: 56.3%
				Long-term care: 16.0%
				Nursing homes: 28.6%
				Private practice: 4.2%
				University: 7.6%

*multiple response options allowed

Figure1. Frequency of clinical approaches used by SLTs in managing psychosocial well-being (n=111)

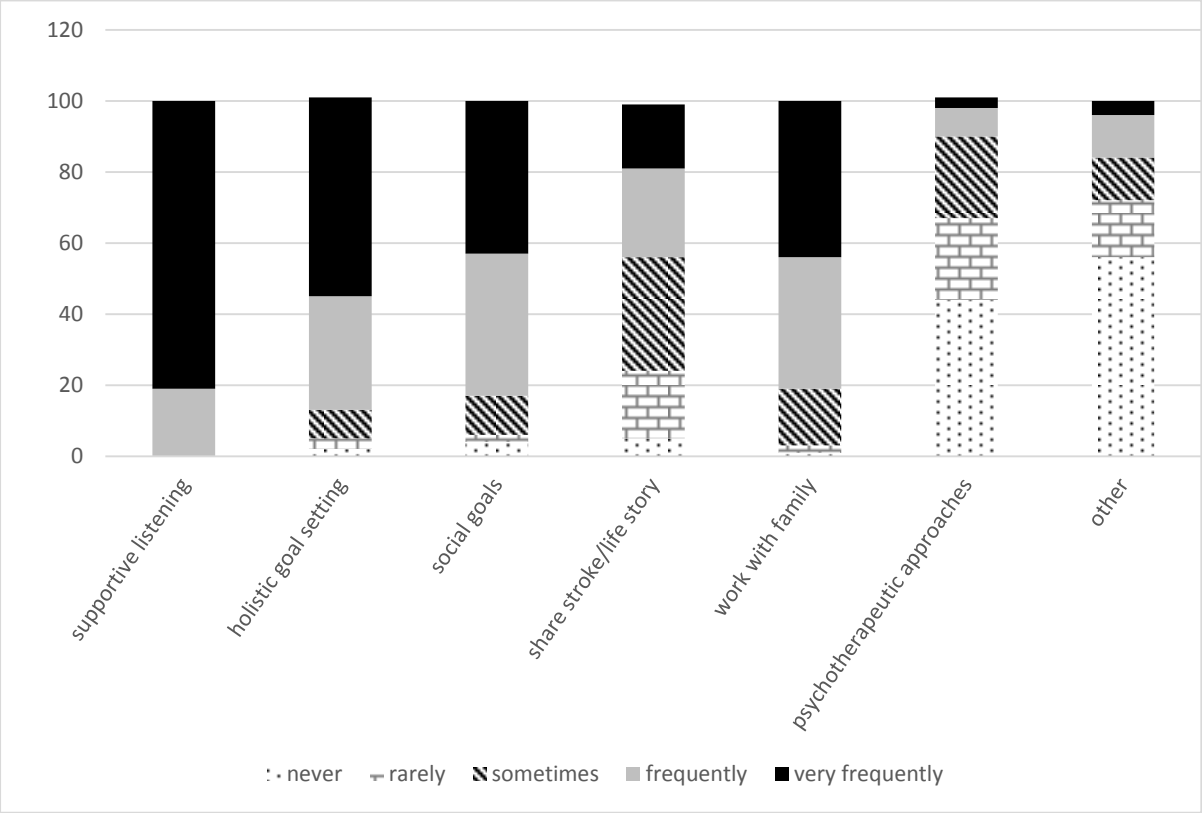


Figure 2. Main barriers to SLTs delivering psychological or social support/therapy (n=102)

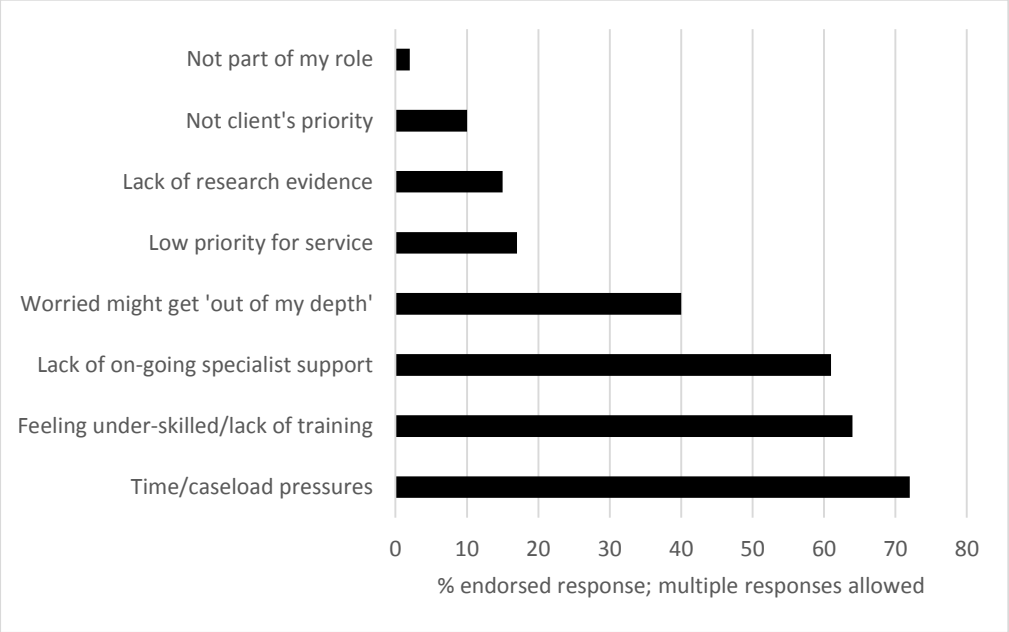
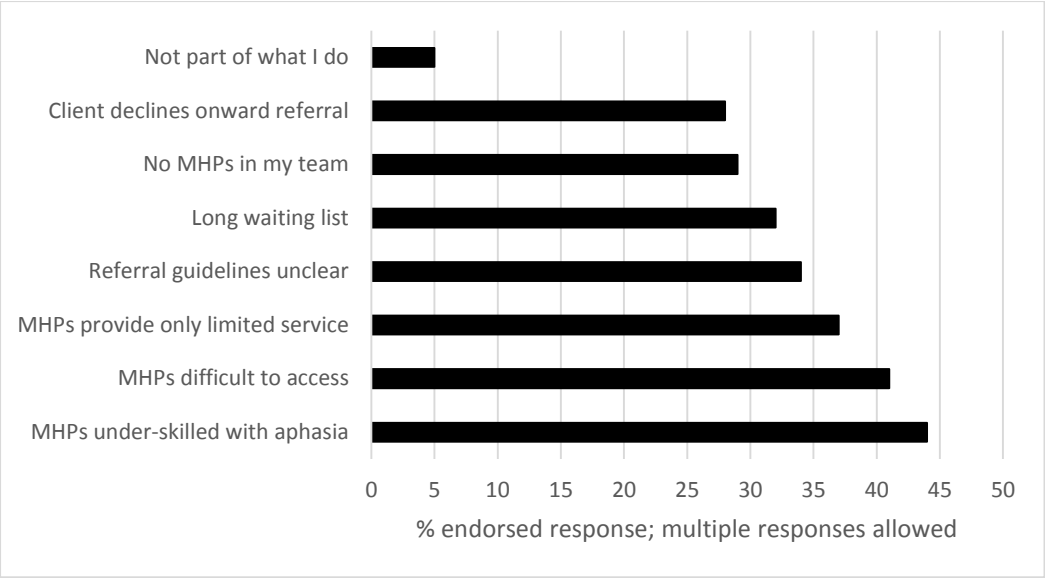


Figure 3. Main barriers to referring to a mental health professional (n=101)



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