Citation: Cruice, M. & Ten Kate, O. (2019). Clinicians’ views and practices in quality of life in aphasia rehabilitation: a preliminary study. Aphasiology, 33(11), pp. 1293-1318. doi: 10.1080/02687038.2019.1632787

This is the accepted version of the paper.

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Permanent repository link: https://openaccess.city.ac.uk/id/eprint/22454/

Link to published version: https://doi.org/10.1080/02687038.2019.1632787

Clinicians' Views and Practices in Quality of Life in aphasia Rehabilitation: A preliminary Study

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Abstract (285 words)

Background: Quality of life (QOL) is important to people with aphasia and their family members and is influenced by a range of factors within the scope of practice for speech and language therapy. Interestingly though, clinicians largely assess patients'/ clients' QOL informally through discussion, and rarely measure QOL as an outcome from aphasia rehabilitation. Research is needed to understand why there is relatively little consideration of QOL in clinical practice and little use of formal assessments.

Aims: This study explores aphasia clinicians' views and reported practices regarding QOL as a concept and its assessment.

Methods & Procedures: Nineteen practising speech and language therapists working in rehabilitation with adult clients with neurogenic communication disorders volunteered and completed the study. They completed an online survey of 48 questions with a range of response options, including free text. Descriptive and inferential statistics were used for count and categorical data, and content analysis for text responses.

Outcomes & Results: These clinicians felt initially unprepared for practice, and had limited awareness, knowledge and confidence in using QOL assessments, but nonetheless thought QOL was important in clinical management. They considered QOL as being individualized, pertaining to life satisfaction and enjoyment, and additionally considered it as communication, participation in activities, education, and emotional support. The majority used informal methods, although some formal assessment use was reported. Many perceived barriers related to lack of resources (physical, staff, and time). Clinicians also reported scope of practice issues with the broader multidisciplinary rehabilitation team and specifically clinical psychology.

Conclusions: Training and access to existing available QOL assessments are clear implications from this study. Further research is needed to assess the extent to which these findings are representative of the broader aphasia clinician community in England.

Keywords: quality of life; wellbeing; clinical expertise; aphasia; speech and language therapist.

Introduction (word count: 8,331)

Speech and language therapy aims for “better lives for people with communication and swallowing needs” (Royal College of Speech and Language Therapists, 2016, p. 7). According to the national clinical guideline for stroke (fourth edition) in the United Kingdom, stroke rehabilitation should aim to “maximize patient’s sense of well-being (quality of life)” (Royal College of Physicians, 2012, p. 11). How speech and language therapists (SLTs) working in stroke and aphasia rehabilitation achieve this remains unclear. Synthesis of randomized controlled trials (RCTs) of speech and language therapy for aphasia following stroke demonstrates effectiveness of speech and language therapy compared to no speech and language therapy for functional communication, reading, writing, and expressive language (Brady, Kelly, Godwin, Enderby, & Campbell, 2016); however the inclusion of QOL as a secondary outcome measure is a recent development, and thus largely restricted to *in progress* RCTs (Brady et al., 2016). As such, there is no such evidence that demonstrates superiority for speech and language therapy treatment A over B, or informs provision of treatment (e.g. dose, intensity, duration, format). Aphasia researchers and clinicians are thus relying on a different evidence base (as reviewed below) to inform practice, which they would implement idiosyncratically depending on their work context.

Evidence-based practice is the integration of best research evidence, patient values, and clinical expertise into the decision-making process for patient care. In this context, best research evidence comprises quantitative literature reporting predictors or factors that influence QOL, and qualitative literature reporting individuals’ views on QOL, living successfully, and priority outcomes for aphasia rehabilitation research. Patient values are easily identified through the use of patient-reported outcomes such as QOL instruments but are also highlighted through the afore-mentioned patient-derived studies. Finally, clinical expertise (and reported practice) in this field has only recently been studied, and as such is the focus for the research study reported in this paper.

With reference to best research evidence, Hilari and colleagues' systematic review (2012) concluded that the existing evidence base was not strong enough to determine the predictors of health-related QOL with aphasia following stroke; however the authors did state that emotional distress/ depression, and extent of aphasic impairment and communication disability, consistently emerged as important across the 14 studies reviewed. Presence of other medical problems, activity levels, and social network and social support were also important. A more recent Australian study of 58 adults with aphasia at 1-year post-stroke (Worrall, Hudson, Khan, Ryan, & Simmons-Mackie, 2017) found that low mood was consistently associated with all domains (participation, impairment, environment, personal factors, and life with aphasia) in the Assessment for Living with Aphasia (Simmons-Mackie et al., 2014).

Patient values and preferences, as well as priorities for treatment, are essential in the decision-making process. Understanding the determinants of QOL from the user's perspective is core to this. Research from individual structured interviews with 30 older people with mild to moderate chronic aphasia focused on their QOL revealed ten factors that contribute quality to, and detract from QOL: activities, verbal communication, people, and body functioning (core); as well as stroke, mobility, positive personal outlook, in/dependence, home and health (Cruice, Hill, Worrall, & Hickson, 2010). Additionally, research from individual semi-structured interviews with 25 adults with predominantly mild chronic aphasia demonstrated four themes related to living successfully with aphasia: doing things, meaningful relationships, striving for a positive way of life, and communication (Brown, Worrall, Davidson, & Howe, 2010). Shifting to a more acute time period, 15 adults with moderate-mild aphasia who were three months post-stroke took part in semi-structured interviews, also focused around living successfully with aphasia (Grohn, Worrall, Simmons-Mackie, & Brown, 2012). Several themes were identified: a need to do things in order to be actively engaged in rehabilitation; increase independence and have a purpose in life; the important of social support; the value of rehabilitation; a need to adapt and make adjustments; and having a positive outlook (Grohn et al., 2012). These studies collectively demonstrate that QOL is multifactorial, relevant to people with aphasia regardless of time post-stroke, and demonstrates that people with aphasia can participate in such discussions making their views known to interviewers (albeit with trained SLTs in each case).

More recent research continues to confirm the importance of QOL in aphasia. Consensus studies undertaken at an international level with people with chronic aphasia (N=39), their family members (N=29), and aphasia clinicians and managers (N=318), identified wellbeing[1] is an important outcome from aphasia rehabilitation research. In the case of service users, the outcome was *emotional* wellbeing, and family members wished for the person with aphasia to have more positive feelings (reduced frustration, maintain good mood, increased optimism and appreciation of others), and people with aphasia wished to have more self-confidence, dignity and determination (Wallace et al., 2017a). In the case of service providers, the outcome was good *psychosocial* wellbeing, and included improved QOL, mood and wellbeing; coping with aphasia; feeling in control and empowered; having a sense of identity, self-worth and self-esteem; feeling confident when communicating; having increased independence and supportive relationships; and accepting and adjusting to life post-stroke with aphasia (Wallace, Worrall, Rose, & Le Dorze, 2017).

Over the past 10-15 years, there has been a growing evidence base in QOL in aphasia (i.e. tool development, insider perspective literature), however, this has not been mirrored or it is not easily seen how this has been considered in clinical practice. In 2005, a survey of 94 aphasia clinicians, mostly from the United States, reported on outcome assessment practices, and QOL assessments accounted for only 4 of the 336 reported assessment tools listed by respondents (Simmons-Mackie, Threats, & Kagan, 2005). A survey of 70 Australian aphasia clinicians, undertaken in 2006 and reported in 2009, revealed that only 1/180 reported assessment tools was a QOL measure (the Visual Analogue Self-Esteem Scale: VASES, Brumfitt & Sheeran, 1999), and was used by only 3/70[2] respondents (Verna, Davidson, & Rose, 2009). In the intervening years, some change has occurred in clinical practice, demonstrated by the following two studies. A survey of 111 Australian aphasia clinicians revealed that between 5-20% of respondents formally assess clients' psychological wellbeing using a recognized mood or QOL measure (Sekhon, Douglas, & Rose, 2015). Finally, an international survey of SLTs working in aphasia, conducted in 2012-2013 (Hilari et al., 2015), considered clinicians were well informed on what constitutes QOL, viewing it as health, participation, in/dependence, communication, personal factors and environmental factors. Clinicians considered it important, but practised informally, considering QOL in clinical discussions with patients and families, and a minority used formal QOL instruments (between 10-27%). Clinicians reported concerns around a lack of professional guidelines and their own competency in practising in this area. The top three research priorities emerged from clinicians' votes as: efficacious treatments to improve aphasia, knowing the factors that influence it, and knowing how QOL is affected by aphasia. Hilari and colleagues (2015) highlighted education and training as needed for SLTs to learn to use formal QOL instruments to assess patients and measure outcomes from aphasia intervention; this implication is clearly also substantiated by the evidence above from other reported practice surveys. Finally, an Australian study of 34 aphasia clinicians reporting on goals for patients with aphasia revealed an emphasis on communication, education, participation and evaluation goals (Sherratt et al., 2011). Very few ‘coping’ goals were described, and included reducing frustration, facilitating increased acceptance of aphasia, confidence, and independence. No goals appeared to be framed around QOL or mood.

In summary, although there are limitations (bias towards chronic and mild-moderate aphasia, and English-speaking WEIRD[3] countries, with less from the acute stage, and none from people whose aphasia is severe), there are sufficient quality descriptive studies available that justify the use of QOL instruments and focus in aphasia rehabilitation. It is unclear why this literature has not influenced clinical practice to date. Research is needed to understand clinicians’ views and practices.

This paper reports baseline data (pre-workshop) for a preliminary intervention study (day workshop educational intervention), aiming to change knowledge about QOL in aphasia generally, as well as knowledge and awareness of formal QOL instruments, with the view to changing practice. Change data is the subject of a separate manuscript in preparation. Thus, this part of the study aimed to gain an appreciation of how clinicians understood QOL in a professional context, and the barriers and facilitators to applying it in clinical practice; and how they addressed and assessed QOL with clients.

Methods

The research employed a descriptive study design using an online survey to explore clinicians’ views and practices. Ethics approval was granted on 21/04/2013 by the Division of Language and Communication Science Proportionate Review Committee, under the School of Health

Sciences at City University London. Participants were recruited in two locations: in London in the South-East, and in Manchester in the North-West of England. Participants were recruited via advertising in the national professional magazine and the British Aphasiology Society newsletter, and via advertising through special interest groups and social media (Twitter). Participants met the following inclusion criteria: qualified speech and language therapist (SLT) with minimum 2 years of clinical practice; currently working in the National Health Service (NHS), independent or voluntary service as a SLT with adult clients with neurogenic communication disorders, working in rehabilitation. Thirty-eight expressions of interest were received via email (and assigned participant number identifiers), and 32 individuals completed the first survey. Of the 32, four individuals did not meet inclusion criteria, five did not attend the educational intervention and/or complete the second survey, and four did not complete the third survey. The total number of included participants was 19.

The survey was designed specifically for this study and was informed by similar surveys of aphasia clinicians' views and assessment practices (Brumfitt, 2006; Simmons-Mackie et al., 2005), and health care professionals' views of QOL (McKevitt, Redfern, La-Placa, & Wolfe, 2003). The survey was loaded in Survey Monkey and comprised 48 questions incorporating closed questions (yes/no and multiple choice), rating scales with anchors, and free text questions (See Appendix 1). Questions included: participant demographics (Q1-17); views, specifically knowledge and understanding of QOL, importance, relevance, support, and barriers and facilitators to applying it in clinical practice; and reported practices, specifically time spent addressing QOL, and assessments used (what, why, and with whom used). Four miscellaneous questions at the end of the survey (Q45-48) recorded participants' 'other comments' regarding the topic, knowledge gaps (areas participants wanted addressed in the intervention), and consent to publish free text responses. Survey questions are referenced by number in brackets in the reporting of each of these four sections, e.g. (Q18) refers to question 18 from Appendix 1. Descriptives were used to characterize numerical data and calculated for questions: 1-14, 16, 17, 20, 21, 24, 27-29, 31, 33, 35 39, 40, 42, 43, 48. Select post-hoc analyses were undertaken using Q42(a,b,c) as the dependent variables (awareness, knowledge, and confidence in using QOL measures) and the following as independent variables: Q3 Extent of experience (length of time qualified), Q11 Contract type (full/part-time), Q14 NHS Professional Band, Q20 Importance, Q21 Qualification preparedness, Q28 Workplace encouragement, Q29 Time spent on QOL, and Q31 Satisfaction. Binary response options either existed or were created for the independent variables (see notes in Appendix 1 under these survey questions), and Mann-Whitney U non-parametric statistics calculated. Some survey questions which would have been of interest as independent variables, such as type of experience, could not be statistically evaluated because of the nature of the data derived from the survey wording and response options (i.e. Q8 and 13 are ‘tick all that apply’ questions). Regarding the free text responses, content analysis was used (Patton, 2002), where semantically similar units of data in participants’ responses to each question were identified and then categorized into broad themes. Qualitative analysis was undertaken on questions: 15, 18, 19, 22, 23, 25, 26, 30, 32, 34, 36-38, 41, 45-47. Given the limitations of the data (i.e. participants responded to each question online restricting length and subsequent depth of explanation, with no interactive probing), findings are presented descriptively with no intention of explanatory analysis. Participants’ quotes are reported noted by their participant number. Frequency counts are also included in the qualitative reporting, indicating the extent to which the issue arose for participants within the sample. Overall, the findings are reported in terms of clinicians’ views of QOL and how this is applied in practice; views regarding preparation for practice; reported assessment practices including barriers and facilitators; and identified learning needs (i.e. expectations of the workshop).

Results

Eighteen (18) females and one (1) male aged 21-49 participated in the study (Q1, 2 see Table 1). Participants had on average 8.5 years' experience in adult neurology in total (Q7 mean= 8.53, 2-17yrs) having worked on average three adult neurological posts (Q6 mean= 3.17, 1-10) since qualifying. Participants were primarily Band 6 and 7 clinicians (Q14), currently worked across a range of clinical settings (Q8), the majority in inpatient and/or community rehabilitation[4], and had worked an average of 4.1 years in their current post (Q10 4 months – 12 years). Regarding current work setting (Q9), 8 participants worked solely in National Health Service (NHS) Inpatients, five (5) worked solely in NHS Community, and the remaining 6 participants worked across NHS (Inpatients, Outpatients, Community) and the voluntary sector, and across a range of geographical areas (Q14). Participants in part-time posts (Q11, *n*=9) worked on average 3 days per week (Q12 2-4 days). Participants had on average 17.4 clients on their current caseload (Q17 6-33[5] clients).

[Table 1 about here]

Views: Defining and Applying QOL in Speech and Language Therapy

Participants had quite varied views in how they defined QOL (Q18), however some consensus was noted around individualization, cognitive (satisfaction) or affective interpretation, and activities and participation. Most participants gave responses that implied individualization, and several participants (*n*=7) specifically highlighted this: e.g. "*It's a very personal judgement that will be different for each person we work with*" (P7). Several participants (*n*=6) interpreted QOL as personal satisfaction with life/ with participation in life/ from participating in activities/ from physical, psychological and social life aspects – and one participant was very specific how satisfaction was derived:

> “*The extent to which an individual can participate in all 'life' roles and opportunities - social, education, vocational, spiritual, 'everyday life', within a family, friendship etc. - the amount of satisfaction that this provides & how congruent this is with an individual's aspirations/ hopes/ dreams/ ambitions/ ideal 'self*'” (P4)

Some participants (*n*=5) referred to QOL in affective terms of joy/ enjoyment, happiness, and pleasure (two of whom also referred to satisfaction) and often explained this in relation to participating in activities:

> “*The joy you get from living/ life. Personal satisfaction. It's not just about living (a means to an end), its more than that, it's about waking up every day and stepping out into the world, with the belief that your life is worth living, having the self belief that you will make a difference however small, and finding joy in what you do*” (P5)
>
> “*The amount of pleasure you are able to derive from your activities, related to your level of participation in the things you enjoy*” (P37)

Several participants (*n*=9) referred to activities and participation in defining QOL, highlighting carrying out/ participating in activities, level and extent of participation, participating in relationships/ community life/ society/ life roles and opportunities; and a few participants noted that this included choice/ control of activities and achievement of them:

> “*Quality of life encompasses having choices in life (e.g., from everyday mundane choices relating to food preferences to more complex issues relating to opportunities to engage in paid work or volunteer roles). It is the ability to exert influence over daily activities, to shape what you can get out of life, to feel empowered/facilitated to achieve something*.” (P6)

Finally, some participants' (*n*=4) definitions conveyed an understanding of the domain construction of QOL listing physical, psychological, social and emotional aspects/ health/ wellbeing. A couple of participants made reference to functioning or achievement in spite of difficulties or poor health, and one participant defined QOL as the meeting of basic and personal needs.

Participants were asked to consider the place of QOL in speech and language therapy (Q19), and described QOL as central, integral, essential and very important to practice. Several (*n*=7) considered QOL across *all practice*, i.e. QOL should guide all input, be considered in all assessment and management, and be incorporated into all interventions. There was specific reference to goal setting. Responses indicated participants considered it part of the SLT role to be maximizing/ achieving/ enhancing/ improving/ or maintaining QOL (*n*=4). Participants (*n*=4) considered QOL as optimizing communication opportunities for clients with aphasia, enabling them to communicate functionally and participate in activities, educating family and carers, and providing emotional support for the client and family. Some considered QOL more broadly as meaningful and relevant intervention and outcomes that were person-centred. Some participants (*n*=6) also made reference to swallowing and safe/enjoyable eating and drinking alongside communication.

All but one participant believed strongly that the psychosocial status of the client affects *overall outcome* (Q35; *n*=1 *fairly*). The majority (*n*=13) also considered client QOL of *utmost importance* in overall client management, and the remainder considered it *very important* (Q20). The majority (*n*=17) also considered QOL as *entirely multidisciplinary*, or *somewhat multidisciplinary* (*n*=1), and one participant considered it *mainly therapy domain-specific* (Q43). A key advantage of considering QOL a multidisciplinary team (MDT) concern was that professionals can work collaboratively to help clients to achieve goals, provide holistic provision (coordinated, efficient and effective input) that meets the needs of clients, consider factors or barriers outside the SLT domain, and enable support and input from appropriate and relevant other professionals (e.g. psychology), that results in input that is beneficial and improves patient care (*n*=8). Other advantages included information sharing and communication across team, support when difficult decisions need to be made (e.g. regarding feeding), raising awareness of QOL amongst the team, addressing patient priorities, and benefits for staff in terms of supervision/ support and shared risk. Disadvantages of considering QOL as a MDT concern were the challenges that arise when team members have different views, values and appreciation of QOL and disability (*n*=6), and difficulties pertaining to role (*n*=4) specifically not knowing own and others' roles in addressing QOL, being challenged to move outside SLT comfort zone, no clear responsibility for assessing QOL, and need to acknowledge professional role boundaries e.g. clinical psychologist and SLT. Other potential disadvantages were that information may not be passed on between team members, and inadequate training to address QOL. Some participants perceived only advantages (*n*=7), some only disadvantages (*n*=2), and the remainder (*n*=10) a mixture of both:

> *"Advantages may be that professionals can work collaboratively to help clients achieve goals. Input may be better coordinated, efficient and effective. Disadvantages may be that information about quality of life is not passed on between professionals or because the information is dispersed between the team individual professionals may not know their own and their colleagues role in targeting it."* (P34)

Views: Training and Preparation for Practice

Four (4) participants agreed their qualification training adequately prepared them to manage QOL issues with clients[6], however the majority (*n*=15) did not, indicating training could have been improved with more experience, case studies, and teaching (Qs21&22). More practical experience in placement, talking to patients, and hearing their personal experience was desired.

Participants reported more teaching on the concept of QOL, how to assess it, how to integrate it into goal setting and treatment, and discussion of the ethical issues and decision-making, would improve qualification training. Most participants who felt inadequately prepared had sought further training (Q23). Participants reported: (1) attending formal *Connect – the communication disability network* and SCA^{TM} courses, conferences and talks by experts, as well as communication skills training (training to ask clients 'difficult questions', Talking Mats, and Sage & Thyme®[7]) and patient-centred goal negotiation training; (2) training in other areas namely end of life care, dysphagia, and dignity; (3) independent study or learning by reading literature and/or shadowing workplace colleagues; and (4) learning by discussing personal experiences with clients. They perceived further training to be beneficial specifically because: (1) they had more experience leading to more understanding, meaning, and confidence; (2) relevance of training had immediate application to current practice; and (3) training was grounded in a client-focus and workplace context (Qs24&25). In response to the final question concerning preparation for practice (Q26), some participants (*n*=5) considered QOL training should be at pre-qualification level, two participants (*n*=2) considered it as post-qualification level, and the majority (*n*=12) participants considered it should be incorporated in both. Those advocating pre-qualification training cited QOL as just as important as direct therapy, essential to client care, and would aid students and newly qualified clinicians take a broader view in client management:

> *"Pre-qualification level would be better. It would help students and NQTs to view their management in the wider perspective of the individual. It would also give permission for them to, for example, not discharge someone who has plateaued in terms of scores*

> *on assessments but who might have potential in terms of more functional, quality of life-oriented goals, e.g., catching a bus, ordering a coffee in Starbucks, etc."* (P6)

Those favouring post-qualification training cited opportunities in current practice to apply training, and clinical experience to which they could relate knowledge. Those advocating training at both levels generally distinguished between introductory awareness at pre-qualification, and more detailed training capitalizing once working. Participants reported: (1) having an overview of basic awareness/ principles of the QOL concept, assessment and management would enable clinicians to adopt a more holistic view, support clinicians to improve patients' QOL as a newly qualified therapist, and be patient or person-centred in all their management; and (2) later training would increase clinicians' skills in the context of greater awareness of the issues that arise gained from practical clinical experience and skills developed that support QOL:

> *"Discussing QOL issues also requires very rounded communication skills as a SLT, which will be easier to do once you have some clinical experience"* (P33)
>
> *"Understanding how QOL fits into therapy and practice is something that I believe is only truly understood with experience"* (P15)

Reported Practice

All participants indicated they engaged with QOL issues primarily as a result of a *personal* philosophy of care, rather than that of their organisation (Q27). Many (*n*=10) participants reported being 'neither encouraged or discouraged' by their organisation to consider QOL (*n*=8 encouraged; *n*=1 strongly encouraged) (Q28). Four participants (*n*=4) considered they spent a *small part* of their clinical time addressing QOL, eight (*n*=8) reported they spent *half* their time, six (*n*=6) reported *most* of their time, and one (*n*=1) reported *all* of their time (Q29). The majority of participants (*n*=11) were *not satisfied* with how much time they devoted to QOL (Q31). When estimating their time (Q30), 10 participants reported reflecting on their clients in relation to functional communication, goals (participation/social), therapy/intervention, and provision of support, education, advice and recommendations as pertaining to QOL; one participant also considered clinical aspects but the more indirect elements (multidisciplinary meetings, ward rounds, case conferences and progress meetings). Some participants (*n*=5) raised dysphagia and swallowing issues when responding, indicating it was either their reason for focusing on QOL or it prevented them from focusing more on QOL (interpreted to mean communication). Five participants (mainly acute[8]) also cited the impact of clinical setting on their QOL focus, reporting patient ill health, dysphagia, and focus on impairment in assessment and treatment, as reasons for not spending more time addressing QOL.

Barriers and facilitators

Analysis of Q32 revealed several barriers influencing clinicians from applying QOL further in their clinical practice. Nine participants (*n*=9) reported these barriers 'sometimes held them back', and seven (*n*=7) reported they posed a hindrance; two (*n*=2) reported they don't hold them back at all, and one (*n*=1) reported no barriers in existence (the latter three participants reported spending *most of their time* addressing quality of life issues and *were* satisfied in doing this) (Q33). Eight participants reported time pressures, lack of time generally, and insufficient time specifically to fully discuss issues with clients (including severely aphasic clients) or practically support clients or explore agencies to support clients, e.g.:

> *"Time. I would like to spend more time with patients looking into functional communication. However, the multidisciplinary team want to know assessment results of comprehension and expressive language tests. Therefore, time spent exploring the patient's mood and more functional aspects of communication can sometimes be taken*

> *over by more structured assessments. This of course is less helpful to a patient in the first instance”* (P8)

Five participants cited varied barriers pertaining to the setting and role:

> “*Prioritisation decisions (e.g. how many sessions to offer someone) are becoming less down to clinical decision making (ax of individual needs) and more to standard "packages of care*" (P16)
>
> “*Possibly preconceived ideas of what the role of the SLT is, e.g., table-top therapy tasks rather than community visits with the client to the gym or McDonalds to assess their communication and put in place devices or therapy that might improve this*” (P6)

A few clinicians reported a lack of knowledge and skills in how to address/ measure/ manage/ and work on quality of life: “*Lack of vocabulary to describe accurately a client's QoL status, lack of skills & confidence in how to follow this up within own scope of practice & within the remit of the service that has been commissioned*” (P4). Finally, some points were raised by only one or two participants but were nonetheless important, and clearly conveyed the impact of the lack of resources e.g.:

> “*Not having access to psychological support for my clients. If you discuss some of these issues you need to be able to deal with them appropriately. You may raise a lot of psychological, adjustment issues that I would struggle to address without the support from a psychologist*” (P33)

Participants identified a range of potential facilitators that would enable them to apply QOL more in practice including knowledge/ training, tools, team, role, staffing, time and acknowledgement of QOL (Q34). Participants (*n*=7) reported training to gain more knowledge (and skills), specifically knowledge of frameworks, tools and how to functionally help patients, and the opportunity to discuss and reflect on training with senior colleagues. Participants (*n*=5) articulated a range of specific needs with relation to tools (assessment and outcome measures), namely tools that enable QOL to be considered in all interventions, that measure impact of impairment or functional therapy, that provide evidence for the effectiveness of speech and language therapy intervention, and importantly tools that provide cost-effectiveness of addressing QOL issues: "*Robust measures re: the cost effectiveness of addressing QOL issues, i.e. if you improve QOL for the Pt this will save the NHS money!*" (P15). Participants (*n*=4) reported facilitators pertaining to team, specifically that multidisciplinary team members were more knowledgeable about QOL and dignity issues; understood why quality mattered and prioritised quality when appropriate (sometimes even over safety and ability); worked with a more joined up approach; and supported clinicians to develop their clinical decision making in relation to QOL, moving beyond being restricted in what they are allowed to offer patients. A few participants mentioned facilitators pertaining to role, including greater awareness of the SLT role in supporting QOL (citing decision making with respect to mental capacity assessment, consent, and general discussion of patient wishes), that other professionals better understood the SLT role, and that SLTs themselves had flexibility in treatment goals contrasting impairment-based therapy with social approaches. Two participants wanted better staffing in speech and language therapy and multidisciplinary teams, and a further two participants desired more time to spend with clients and families/ carers (specifying joint family sessions), and other professionals. Two participants identified the need for wider acknowledgement of QOL and its impact on outcomes in the NHS, and the need for QOL to be on the forefront of planning care in multidisciplinary contexts.

Assessment practices

Participants reported a range in *awareness*, *knowledge*, and *confidence* about QOL measures they could use with clients with aphasia (Q42a,b&c, Figure 1, X axis *n* of participants, Y axis response scale). Most participants (*n*=17) used informal means to assess QOL, i.e. conversation, discussion, and interview with the patient/ client, family/ carer, relatives, friends, and three participants specifically mentioned multidisciplinary staff, one highlighting the neuropsychologist (Q36). Some described (*n*=7) what they wanted to find out about including communication (situations and views on difficulties); social (situations and history); current and desired activities; personal interests, hobbies, and what enjoyed in life; concerns, priorities, wishes, health beliefs; confidence; mood; goals; family, relationships, environment, and wills/ advance directives. Three participants used supported conversation techniques and solution-focused brief therapy principles during their informal discussions with patients/clients, and some (*n*=4) indicated they would observe the client. Some participants (*n*=4) reported occasionally using published assessments (names not specified) including disability questionnaires and mood screens, and a further four participants used patient rating scales/ visual analogue scales, a communication history form, and the ‘tree people’ (Blobby Men image). Finally, two participants reported using a wide range of tools including the Stroke and Aphasia Quality of life Scale (SAQOL-39g; Hilari et al., 2009), the EQ-5D from Euroqol.org, the Stroke Impact Scale (SIS; Duncan et al., 1999), the VASES (Brumfitt & Sheeran, 1999), the Communication Disability Profile (CDP; Chue, Rose & Swinburn, 2010), the Stroke Aphasic Depression Questionnaire (SADQ; Lincoln, & Sutcliffe, & Unsworth, 2000), and the Depression Intensity Scale Circles (DISCS; Turner-Stokes, Kalmus, Hirani, & Clegg, 2005). A subsequent question revealed greater usage of published assessments i.e. by more participants, specifically the VASES (*n*=6), the Comprehensive Aphasia Test Disability Questionnaire (CAT DQ; *n* = 5[9]), the CDP (*n*=4), and the one mention each of SAQOL-39g, EQ-5D, SIS, SADQ and DISCS (Q37). Participants additionally reported communication history questionnaires/forms, life story questionnaires, goal attainment scaling, unnamed mood assessment, ‘tree people’, social circles, and unspecified questionnaires.

[Figure 1 about here]

A few participants used their QOL tools/ assessments with *all* clients (*n*=3), several used them with *most* clients (*n*=7) or *some* clients (*n*=8), and one participant reported *never* (as did not use formal tools/ assessments); and several (*n*=6) reported using tools/ assessments with family members (Q39). The majority of participants (*n*=10) considered the patient’s language and communication abilities, and cognitive abilities, when choosing QOL assessments (Q38). Several participants (*n*=6) additionally reported other factors pertaining to the patient, including awareness, needs, medical status, prognosis, time post stroke, mood, and family support. Four participants (*n*=4) indicated that availability and perceived value determines whether they consider using a QOL tool: “*How useful a formal assessment will be and if it will tell me anything I can't glean from a more natural discussion*” (P6). How well the SLT knew the client, personal choice, time, and setting also determined whether and which assessments used. The majority (*n*=11) agreed they explored clients’ understanding of QOL during the course of therapy (across assessment, intervention and outcome measurement), and eight participants did not (Q40).

Barriers specific to QOL assessments

Participants (*n*=8) raised time as a barrier including time (and caseload) constraints and pressures to get patients out of hospital, the time-consuming nature of QOL assessments administration, and balancing time between impairment and QOL assessments (Q41). Several participants raised the linguistically complicated nature of QOL assessments, identifying the need for accessible aphasia-friendly tools that were easy to use. Some participants (*n*=6) reported a lack of knowledge of appropriate tools and how to interpret the findings, some (*n*=5) reported fit for purpose issues (relevance for patients/ clients with aphasia, validity), and four (*n*=4) highlighted lack of available tools and resources. Other incidental barriers were patient-related factors (cognition, distress, family support), the value of the assessment, i.e. "*whether having a 'score' will affect the outcome/enable access to support services or not*" (P4), and role boundaries and service provision, specifically the role of speech and language therapy versus clinical psychology, and what to do when QOL assessment raises issues that cannot be addressed in speech therapy or are not related to communication.

Identified Learning Needs

Most participants (*n*=16) approached the workshop (Q46) with a view to learn about the range of appropriate and relevant assessments and approaches available. Several (*n*=7) specifically wanted to learn about appropriate outcome measures for evidencing value and role of speech and language therapy:

> *"…how to measure (as I think SLTs have a significant role to play in improving QoL but we are not capturing this data and therefore showing our worth!)"* (P19)

Some participants (*n*=3) wanted a greater knowledge and understanding of the theory and definition of QOL, some (*n*=3) wanted to know how to link QOL to goal setting, some (*n*=3) how to manage QOL and address in therapy, and some (*n*=3) more confidence. Finally, a couple of participants wanted "*re-assurance that it is a valid part of our work…guidance on limits of our role*" (P37) and "*consensus on what can be provided within our own scope of practice*" (P4). Participants specifically wanted the following addressed in the workshop (Q47): tools for assessing and measuring outcomes (*n*=7); how to address QOL in terms of stage of patient recovery, goal setting, addressing in treatment and measuring impact of therapies on QOL (*n*=4); and recommendations for people with severe aphasia and/or cognitive issues (*n*=3).

Post-hoc Analyses

Post-hoc analyses were undertaken to examine whether participants' reported awareness, knowledge and confidence in using QOL measures (Q42a,c,b) differed depending on (1) educational factors (perceived preparedness for practice in QOL by pre-registration qualification or not, Q21); work-related factors (length of time qualified as a SLT Q3; whole-time equivalent contract, Q11 fulltime or part-time; NHS band indicating specialist skills Q14; work-place encouragement to address QOL or not, Q28; and time spent on QOL with clients Q29); and (3) personal factors (perceived importance of QOL in client management, Q20; and satisfaction with time dedicated to QOL, Q31). Mann Whitney U statistical analyses revealed no significant differences in participants' awareness, knowledge or confidence for educational (Q21) and most work factors (Q3, 11, 14, 28). For time spent on QOL with clients (Q29), participants who spent *all* or *most* of their time reported were significantly more aware of QOL assessments than those who spent *half* or a *small* amount of time (p=.013; and NS for knowledge and confidence). Regarding personal factors - perceived importance (Q20), significant differences were noted in awareness (p=.001), knowledge (p=.003), and confidence (p=.012), and higher for those who rated *Of utmost importance* than those who rated *Very important*. Finally, regarding personal factors - satisfaction, a significant difference was noted for confidence only (p=.033), meaning participants who reported being satisfied had greater confidence than those who were not.

Summary of results

Clinicians who self-selected into this study held a strong belief that psychosocial status of the client affected overall outcome, believed QOL was important, and engaged with QOL issues as result of personal philosophy of care (with half the sample also encouraged by their organisation to consider QOL). Strength of belief in the importance of QOL impacted on clinicians' awareness, knowledge and confidence in using measures. The majority considered QOL a multidisciplinary concept, seeing several advantages of this. The key advantage was that collaborative working enables holistic provision addressing patients' needs, with benefits to staff and patients in information sharing. However, clinicians also reported concerns around potential conflict generated by different views and values of QOL amongst team members (and between team and patient), and a potential for role confusion and lack of designated responsibility for taking QOL forward. Clinicians held a range of views about what constituted QOL and how it was applied in practice. Most consensus was noted in an individualized interpretation of QOL; one that defined QOL as satisfaction and enjoyment with life; and recognized activities and participation (with some acknowledgement of choice/ control over these). Later survey responses suggest that clinicians consider QOL in their practice with reference to functional communication, optimizing communication opportunities, participating in activities, education (including advice and recommendations), and emotional support. Approximately half the sample considered QOL applicable to *all practice* (with a quarter clearly articulating the SLT role as maximizing or maintaining QOL).

Most clinicians were unprepared by their qualification training to address QOL, however this had no bearing on awareness, knowledge or confidence in currently using measures. This is possibly because most had pursued further learning through courses and skills training (communication, patient-centred goal setting), independent study, and learning through discussing with patients. They highlighted the importance of introducing the concept of QOL in pre-registration training, specifically how to assess QOL, integrate into goal setting and treatment, and consider ethical issues in decision making, with the opportunity to hear more patient stories in clinical placements. However, there was strong emphasis on post-qualification training with the value of clinical experience for better skills, confidence, and understanding of QOL for patients, and grounding training in direct clinical application in current client and workplace context. Just less than half the sample rated themselves as not aware of the range of QOL tools that can be used, and similarly did not have sufficient knowledge to use them in practice; almost half rated themselves with neutral (mid-point response option) levels of awareness, knowledge, and confidence. Clinicians' awareness, knowledge and confidence did not differ for most workplace factors (experience, specialist skills level, fulltime vs part-time, or workplace encouragement) but did differ for time spent on QOL (awareness), and personal factor satisfaction impacting on confidence. The dominant pattern of QOL assessment was informal through conversation, and some observation, and some use of informal rating scales. There was some use of the following formal assessments from a minority: VASES, CAT DQ, CDP, as well as SAQOL-39g, EQ-5D, SIS, SADQ, and DISCS. Patients' language, communication and cognitive abilities primarily contributed to clinicians' decision-making in choice and use of QOL assessments, as did other patient factors (time post onset, medical status, prognosis, mood, family support), and the availability of and value gained by assessment (i.e. access to a future/ other service or support).

Finally, consistently reported barriers were: (1) lack of time; (2) clinician lack of knowledge (and skills) of appropriate, relevant QOL assessments, including outcome measures in order to demonstrate the value of speech and language therapy intervention to others; (3) lack of resources (QOL assessments and access to clinical psychology); (4) lack of communicatively-accessible, relevant and valid QOL assessments for patients with aphasia; and (5) lack of clarity and support around speech and language therapy scope of practice, specifically the boundary with clinical psychology roles, how to manage issues that are raised but not able to be addressed in therapy or by the SLT professional, and how to enable the MDT to better understand SLT contribution to QOL. Clinicians considered increasing knowledge through training, having assessments/ tools, increasing MDT knowledge of QOL and of the SLT role in QOL, increasing speech and language therapy and MDT staffing for more time, and acknowledgement of QOL by the NHS would enable QOL to be applied more in practice.

Discussion

These self-selecting clinicians who felt initially unprepared for practice in this area, and with limited awareness, knowledge and confidence in using QOL assessments, nonetheless thought QOL was important in the management of their clients and this influenced how they delivered rehabilitation. Clinicians considered QOL as being individualized, pertaining to life satisfaction and enjoyment, which reflects a more wellbeing than health-related interpretation of QOL; and additionally considered it as communication, participation in activities, education, and emotional support. Overall, clinicians' understanding of QOL largely reflected the factors that are known to influence QOL that were discussed earlier in this paper (Brown et al., 2010; Cruice et al., 2010; Grohn et al., 2012; Hilari et al., 2012), although some may be worded or framed slightly differently, e.g. 'emotional support' was reported as how clinicians perceived to address QOL rather than being considered as emotional health, distress or low mood as a known factor influencing QOL. Similar to clinicians in an international study of practice (Hilari et al., 2015), it is possible that emotional health or affect is a lower consideration in clinicians' minds. This is a concern as research discussed earlier in this paper indicates emotional health is a key determinant of QOL. Clinicians did not clearly identify physical health, body functioning, and mobility as contributing to QOL, nor did they raise independence or environmental factors (e.g.

standards of living, safety and security) (Cruice et al., 2010; Hilari et al., 2015). These findings suggest that clinicians might have been more constrained in their view of QOL and may not have considered or have under-estimated the contribution of these other components in life quality.

In line with existing research (Hilari et al., 2015), the majority of clinicians in this study reported informal methods – conversation/ discussion, interview, and observation – as the method of evaluating a client's QOL. This is a fairly persistent finding in QOL research (Hilari as per above) and also in psychological wellbeing (Sekhon et al., 2015). Informal practices however, can lead to inconsistency in practice, unintentional under-identification of the needs and concerns of people with aphasia, and also unintentional mis-directed goal setting and treatment planning. Such practices also offer no opportunity for outcome measurement if no formal baseline has been undertaken. It would appear that clinicians favoured informal methods in the context of limited awareness and knowledge of what QOL assessments are available, limited access to available QOL assessments, limited knowledge and confidence to interpret findings, perceived inappropriateness of QOL assessments (relevance, validity, information accessibility), or inappropriateness for clients due to cognitive and emotional distress issues. Whilst some of these criticisms leveled at QOL assessments are appropriately directed (e.g., measures have negatively framed items, inconsistent response options, linguistically complex terminology) and are often measures used in broader *stroke* research, measures designed specifically for people with aphasia *have* generally considered linguistic and cognitive issues and *can* be used.

Some clinicians reported using some QOL assessments in their practice, including measures of health-related QOL (EQ-5D, SAQOL-39g, SIS) and emotional health/ mood (SADQ, DISCS, VASES), as well as measures that elicit the client's perception of their communication disability (CAT DQ, CDP). It is interesting to note that this list includes a generic health-related QOL measure (EQ-5D), stroke measures (SAQOL-39g, SIS, SADQ), measures with content specifically tapping aphasia/ communication (SAQOL-39g, SIS, SADQ), and measures specifically designed to be accessible for clients with aphasia (VASES, CDP, and DISCS as arguably appropriate for its visual representation). Three of these measures were also reported as used by clinicians internationally, SAQOL-39g, VASES and CDP (Hilari et al., 2015), suggestive of their popularity within the profession.

Clinicians reported a number of barriers affecting their practice, and posited facilitators that could improve the situation. Using a Theoretical Domains Framework (Cane, O'Connor, & Michie, 2012) and Behaviour Change Wheel (Michie, van Stralen, & West, 2011) lens, these factors can be seen to relate to Capacity, Opportunity and Motivation in relation to the behavior under consideration (using QOL measures). Barriers thus pertained to *Opportunity - Environmental Context and Resources* (lack of time; lack of resources i.e. QOL assessments and access to clinical psychology services within the team; lack of appropriate assessments for patients with aphasia i.e. communicatively-accessible, relevant, valid; and lack of outcome measures[10] that demonstrate value of intervention); *Capacity - Knowledge & Skills* (lack of clinician knowledge and skills of QOL assessments); and *Motivation - Social/ Professional Role and Identity* (lack of clarity and support around scope of practice, specifically the boundaries of SLT and clinical psychologist roles, how to manage issues that are raised but not able to be addressed in therapy or by the SLT, and how to enable MDT to better understand speech and language therapy contribution to QOL). Perceived facilitators were *Capacity* (increasing knowledge through training on QOL assessments), *Opportunity* (getting the resources, increasing staffing for more time), *Motivation* (increasing MDT knowledge of QOL and of the SLT role in QOL), and again *Opportunity* (organizational culture/ climate - acknowledgement of QOL by the NHS would enable QOL to be applied more in SLT practice). Several of these barriers and facilitators are shared with clinicians internationally (Hilari et al., 2015), however unique to this study were the emphasis on scope of practice or professional boundaries between SLTs and clinical psychologists, and the explicit recognition of the MDT involvement in improving patients' QOL.

Clinical Implications

Despite the small participant sample, providing training and facilitating access to existing and available QOL assessments are still clear implications arising from this research. Training needs to address individual clinicians' knowledge gaps and consider the construct of QOL broadly, the relationship between communication dis/ability and QOL and factors that influence QOL in people with post-stroke aphasia, and relevant QOL assessments including their development (involving people with aphasia or not), content, design, scoring, and psychometrics. Beyond reliability and validity of an assessment, sensitivity to change in response to treatment is crucially important and is an emerging area in aphasia rehabilitation QOL outcomes. Identifying what QOL assessments are available and where is not straightforward, as some are freely available and as such not included in commercial platforms that would otherwise promote visibility. The SAQOL-39g (Hilari et al., 2009) is freely available from https://cityaccess.org in both download and online versions. Quasi-QOL assessments also exist: the Communication Confidence Rating Scale for Aphasia (CCRSA: Babbitt, Heinemann, Semik & Cherney, 2011) is freely available through personal contact with authors Cherney lcherney@sralab.org and Babbitt ebabbitt@sralab.org; and the Aphasia Impact Questionnaire (AIQ: Swinburn et al., 2018) is available for download (with multiple resources) for a nominal fee online from https://www.aiq-21.net/.

Scope of practice, including being clear about the SLT’s role and contribution to QOL as well as overlap in professional boundary with clinical psychology, was clearly identified in this research and chimes with other recent findings in psychosocial wellbeing. A significant minority (40% of 102) of clinicians working with people with aphasia in Northcott and colleagues’ study had worries they may be out of their depth, and analysis of qualitative responses from clinicians highlighted a concern in ‘crossing professional boundaries’ (Northcott, Simpson, Moss, Ahmed, & Hilari, 2017). SLTs also reported limited or no access to mental health services, and a lack of collaborative working and poor understanding of roles between SLTs and mental health practitioners (Northcott et al., 2017). Whilst there are implications for formal and professional roles clarification and guidance, there is an obvious question as to what is appropriate for SLTs to engage in within their role when addressing QOL. It is here perhaps that SLTs can be guided towards Baker and colleagues’ review (2018) of interventions that adopt a stepped psychological care approach in stroke. Stepped psychological care is defined as “the delivery of routine assessment and interventions for psychological problems” (Baker et al., 2018, p1870) and outlines which interventions might be appropriate for which patients provided by professionals with different degrees of training, framed as four different levels. Here, there are evidence-based preventative and stroke rehabilitation interventions at level 1 appropriate for all people with post-stroke aphasia with sub-threshold mood symptoms (i.e. interventions that enhance mood such as individualized goal setting, self-management workbook, communication partner training, and psychosocial group support). At level 2, there are treatment interventions for people with post-stroke aphasia with mild depressive symptoms (such as behavioural therapy, web-based psychosocial support, and telephone-based problem solving) (Baker et al., 2018). This review suggests that appropriately-trained stroke specialist SLTs can take a clear role in intervention before levels 3 and 4 stepped psychological care are needed where interventions require specialist mental health services. In terms of behavior change, action is needed here not at an individual clinician level but rather at an organisational level, outlining the relevant input of both speech and language therapy and clinical psychology professions and establishing clear roles. There is also indication in the data that when referring to the MDT, SLTs meant physiotherapy and occupational therapy, in addition to singling out clinical psychology, and overall there is a need to clearly outline disciplinary involvement in the multifactorial nature of QOL after stroke. Similarly, organizational level initiatives may be needed to address time pressures/ staffing levels enabling clinicians to begin to engage in assessing QOL, in the knowledge that there is sufficient time to address it.

Limitations and Directions for Future Research

This was a small-scale study of self-selecting SLTs who likely engaged because of personal interest in the topic, which restricts generalization of these findings and limits the conclusions that can be made. The survey nature of the data collection prohibits probing of respondents' views to gain a deeper understanding of their responses, and the survey structure and wording of questions has limited the statistical analyses that could be conducted. Furthermore, data are derived from reported practices, and indeed, clinicians may not actually do what they report they do. Future research should be undertaken with much larger samples of SLTs, ideally employing a range of data collection methods, including online survey methods to reach geographically dispersed clinicians and also individual semi-structured interviews for deeper insights, and documentation of *actual* QOL practices. Future survey research would also benefit from a clearly motivated design investigating the factors that predict SLTs' use of formal QOL assessments. There is also suggestion in these findings that it would be valuable to investigate stroke multidisciplinary health professionals' views, rather than SLTs' views in isolation, given the significant multifactorial nature of client's needs and QOL, and the multidisciplinary input in stroke rehabilitation.

Conclusion

SLTs in this study considered QOL important in clinical management, and oriented towards addressing it in their rehabilitation of patients with aphasia, primarily through informal means of conversation and discussion with patients, family, and members of the stroke team. There was some limited use of QOL assessments, as well as other assessments of emotional health and patient-reported communication disability, both of which are contributing factors in QOL. Perceived inappropriateness of QOL assessments for patients with aphasia, lack of knowledge, lack of resources (QOL assessments and time), and scope of practice (boundaries with clinical psychology and contribution of MDT to QOL) were the main barriers affecting these clinicians' practice. Future research is warranted with a much larger sample, and potentially should explore team and organizational issues in addition to investigating SLTs' own practices.

Footnotes:

[1] Wellbeing is considered a related concept of QOL. Admittedly, this outcome was lesser in priority than other outcomes specifically improved communication and increased life participation (Wallace et al., 2017b)

[2] This is in the context of 65/70 respondents using impairment-based language assessments.

[3] Participants are Western, Educated and from Industrialized, Rich and Democratic countries.

[4] The 5 participants (Table 1) who reported working acute settings (and additionally worked in sub-acute settings) also worked in inpatient *rehabilitation*, an inclusion criteria for the study.

[5] One outlier was noted (n=169 clients) and was removed from analysis.

[6] Participants had been qualified across the entire range from 0-20yrs, so no link evident.

[7] Training for professionals to listen and respond to patients and carers who are distressed or concerned.

[8] Two participants were in community/ residential care setting with one specifically referring to swallowing issues for clients with dementia.

[9] A further 2 participants reported using the CAT but were not specific that this implied the Disability Questionnaire component of the assessment.

[10] This can also be considered *Capacity* reflecting a lack of clinicians' knowledge as some measures *can* be used to capture treatment effects.

Acknowledgments: We are grateful to Professor Karen Sage, at the time employed at the University of Manchester, for her support in recruitment to this research via the Manchester Aphasia Group.

Declaration of interest: The authors report no conflict of interest.

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Appendix 1: Survey

Background Questions

1. What is your age? (please select)

   21-29

   30-39

   40-49

   50-59

   60 or older

2. What is your gender? (please tick)

   Female

   Male

3. Length of time qualified as an SLT:

   0 to 5 years

   6 to 10 years

   11 to 15 years

   16 to 20 years

   21 to 30 years

   31 years or more

   Reader note: This question was used as an IV and binary response created by collapsing data in ‘0-5years’ (n=6) and ‘6-10years’ (n=3) into one group, and comparing with ‘11-15 years’ (n=6) summed with ’16-20years’ (n=4) as another group

4. Length of time working as an SLT (please deduct any years away from the profession):

0 to 5 years

6 to 10 years

11 to 15 years

16 to 20 years

21 to 30 years

31 years or more

Reader Note: Data not reported as not informative i.e. not substantially different to Q3

5. Number of positions held since graduating (please provide number):

   ____

   Reader Note: Data not reported as not informative i.e. not substantially different to Q6

6. Number of posts/ positions/jobs held in adult neurological clinical areas (please provide number):

   ____

7. Time worked in adult neurological areas in total:

   ______years _______ months

8. Settings or stages of service provision worked in during employment history (please tick all that are relevant):

   Acute

   Sub-acute

   Inpatient rehabilitation

   Early supported discharge team

Community rehabilitation

Nursing home/ residential care

9. Current work setting (please tick):

Acute

Sub-acute

Inpatient rehabilitation

Early supported discharge team

Community rehabilitation

Nursing home/ residential care

10. Time in your current position:

______years   _______ months

11. Is your current position full-time or part-time? (please tick)

Full-time

Part-time

Reader note: This question was used as an IV with no alteration to data collected as binary response option present

12. If part-time, please state how many days you work per week?

_______ days

13. What setting description best fits your current position? (please tick all that are relevant)

NHS inpatients

NHS outpatients

NHS Community

Independent Practice

Voluntary Sector in SLT role

14. If you work for the NHS, please state the band of your current role:

5

6

7

8

Reader note: This question was used as an IV and binary response created by collapsing data in Bands 5 and 6 (n=2+8) into one group, and comparing with Bands 7 and 8 (n=8+1) as another group

15. Without revealing where you work, can you please generally indicate geographically which part of England you work in? (Please do not name your specific workplace or trust)

16. Number of patients/ clients on current caseload:

________ clients

Reader Note: Data not reported as not informative i.e. not substantially different to Q17

17. Typical number of patients/ clients on caseload (take average over last 3 months or thereabouts)

________ clients

Quality of life

18. What does the concept “quality of life” mean to you?

19. What do you believe to be the place of this concept within SLT practice?

20. How important do you believe client quality of life is to your overall management of the client? (Please select)

    Not important at all
    Of minor importance
    Quite important
    Very important
    Of utmost importance
    Reader note: This question was used as an IV with no alteration to data collected was needed to create binary response option as the data were distributed across ‘Very important’ and ‘Of utmost importance’ only

21. Did you feel adequately prepared by your pre-qualification training to manage quality of life issues?
    YES
    NO
    Reader note: This question was used as an IV with no alteration to data collected as binary response option present

22. If not, how do you feel this training could have been improved? (Please give details)

23. Have you undertaken any further training post-qualification that has helped you in addressing your clients' quality of life? (Please give details)

24. Was this further training more or less beneficial to you than your pre-qualification training?

    More

    Less

25. Can you give more details about why it was more or less beneficial?

26. Do you believe training in management of quality of life issues should be at the pre-qualification level or post-qualification? (Please indicate and outline your reasons)

27. Is your engagement with these issues a result of your personal philosophy of care or that of your organisation?

    Own philosophy

    Organisation's philosphy

28. To what extent are you encouraged or discouraged by your organisation to include quality of life considerations in your practice? (Please select)

    Strongly encouraged

    Encouraged

Neither encouraged or discouraged

Discouraged

Strongly discouraged

Reader note: This question was used as an IV and binary response created by collapsing data in 'Strongly encouraged' (n=1) and 'Encouraged' (n=8) into one group, and comparing with 'Neither encouraged or discouraged' (n=10) as another group

29. As a rough estimate, how much of your time with clients is spent on quality of life issues?

    None of my time

    Only a small part

    About half of my time

    Most of my time

    All of my time

    Reader note: This question was used as an IV and binary response created by collapsing data in 'None of my time' (n=0), 'Only a small part of my time' (n=4) and 'About half my time' (n=8) into one group, and comparing with 'Most of my time' (n=6) summed with 'All of my time' (n=1) as another group

30. Roughly, how did you gauge this amount? Please outline.

31. Are you satisfied with the amount of time you are able to dedicate to quality of life issues?

    Yes

    No

Reader note: This question was used as an IV with no alteration to data collected as binary response option present

32. What, if any, do you believe are the barriers to further application of a consideration of client quality of life to your practice? (Please describe)

33. If you believe barriers exist, to what extent do they hold you back from applying quality of life to your practice?

    Stop me from applying it altogether
    Sometimes hold me back
    Sometimes pose a hindrance
    Don’t stop me at all
    I don’t believe barriers exist

34. What would enable you to apply quality of life more in your practice? (Please give details)

35. Please indicate how strongly you believe the psychosocial status of the client affects the overall outcome:

    Very important
    Fairly important
    Neither important or unimportant
    Fairly unimportant
    Very unimportant

Tools/ Measures

36. How do you find out about your clients' quality of life?

37. If any, specifically what tools and assessments do you use to do this?

38. What informs your choice of assessment tool?

39. With whom do you use them? (Please select all that apply)

    With all clients

    With most patients

    With some patients

    Never

    Family members

40. Do you explore individual clients' understanding of quality of life during the course of therapy (assessment, intervention and outcome measurement?) (Please tick)

    Yes

    No

41. What, if any, do you believe are the barriers to further use of quality of life measures/ tools? (Please give details)

42. Please rate yourself on the following statements, where 1 = Disagree and 5 = Agree

a. I am aware of a range of quality of life measures I could use with clients with aphasia
b. I know some quality of life measures sufficiently to use them in my practice
c. I am confident in using quality of life measures with clients with aphasia

43. To what extent do you think that a consideration of quality of life issues is a multi-disciplinary concern? (Please select)

    Entirely multidisciplinary

    Somewhat multidisciplinary

    Entirely therapy domain-specific

    Mainly therapy domain-specific

    I'm not sure

44. If you believe that it is a multidisciplinary concern, do you believe this shared responsibility has any advantages or disadvantages? Please give details.

45. Do you have any other comments you would like to make about working with clients with aphasia in relation to quality of life issues?

46. What do you hope to gain from the CPD workshop on quality of life and wellbeing?

47. Are there any specific topics or aspects you would particularly like to see addressed in the workshop?

48. Are you happy for us to include selected excerpts from your free text responses in publications and in the disseminated results of this project? (Please select)

    Yes

    No