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Title: Practitioners' perspectives on quality of life in aphasia rehabilitation in Denmark

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Abstract

Objective: This study reports on Danish speech and language therapists' knowledge and understanding of quality of life (QOL) in aphasia, including therapists' views on education and training in relation to preparedness for working on QOL, use of measures, and barriers to applying QOL in practice.

Methods: 14 Danish clinicians completed a 48-item online questionnaire regarding their views, perspectives and practices that included multiple-choice questions, rating scales, and boxes permitting free text responses. Descriptive statistics were used to characterize the numerical data, and content analysis was applied to text responses.

Results: The clinicians interpreted QOL as subjective wellbeing and participation, and explored it with most clients and relatives using informal methods, primarily conversation, for the purposes of identifying relevant goals to direct treatment. Clinicians perceived a need for greater theoretical, practical and experiential knowledge regarding QOL. They also identified a need for translated QOL instruments and training in these measures in practice.

Conclusion: Despite a reported lack of knowledge about and tools for measuring QOL, Danish clinicians are applying QOL issues in their practice and perceive these issues as valuable and important in assessment and therapy. The findings have clear implications for tool development, and workforce education.

Running Head: Danish practitioners' perspectives on quality of life

Introduction

Within the quality of life (QOL) field, research has generally prioritized the development and validation of QOL instruments, at the expense of theoretical and conceptual development [1]. Whilst the WHOQOL Group definition of QOL (see editorial this issue) is considered the gold standard of definitions, not all researchers use it to guide their research, nor do all researchers provide a definition of QOL in their publications. Subsequently, there is a lack of explicitness and conceptual development in the QOL field, and this is also reflected in different fields of professional practice, where improved QOL is a desired outcome. As McKeivitt et al. [2] has shown, there is a no general consensus among medical and allied health professionals on how to define the concept of QOL in stroke rehabilitation, nor is there a shared understanding of how the concept may be integrated into professional practice. Furthermore, knowledge and understanding of QOL by health professionals and SLTs is unknown. For speech language therapists (SLTs) working with patients or clients with aphasia, QOL is emphasized in various clinical guidelines for stroke and aphasia rehabilitation. For example, in the United Kingdom, clinical guidelines advocate maximization of a patient's sense of wellbeing (quality of life) as a core aim of rehabilitation [3, 4]; and the remaining aims of maximizing social rehabilitation, and minimizing stress on and distress of family [3] are also associated with QOL [5, 6]. Similarly, the American Speech-Language-Hearing Association (ASHA) states that "the overall objective of speech-language pathology services is to optimize individuals' ability to communicate and swallow, thereby improving quality of life" [7:3]. How this is achieved in speech and language therapy (SLT) practice in aphasia is largely unknown.

Our knowledge and understanding of aphasiology practice and research has been influenced over the centuries by localization theory, behaviourism, and the stimulation approach, and more recently by models in linguistics, psycholinguistics, cognitive neuropsychology, and by psychosocial and social approaches to aphasia [8]. Worrall and colleagues have described aphasiology as challenged by these different approaches and lacking in a universally accepted single theory of aphasia therapy [9].

In addition to the theories, models and approaches outlined by Code [8], Worrall et al. [9] also note the pragmatic/ functional, and the biopsychosocial approach, to aphasia. Whilst none of these approaches explicitly targets QOL, the pragmatic/functional, social, and biopsychosocial approaches align most closely with QOL. Amongst these approaches, the social approach to aphasia has generated consensus value statements such as the Life Participation Approach to Aphasia (LPAA) [10] and models such as Living with Aphasia: Framework for Outcome Measurement (A-FROM) [11] which clarifies how different rehabilitation goals, methods and outcome measures relate to the generally accepted framework of the World Health Organization International Classification of Functioning, Disability and Health (ICF) [12]. Various practice-scoping surveys have been undertaken in recent years, and whilst these don't report clinicians' QOL knowledge and understanding, they do provide information on the approaches clinicians ascribe to, which in turn reflect their assessment and intervention choices in aphasia practice. In Australia, a survey of aphasia clinicians' practice revealed that 85% of clinicians follow a functional approach to intervention, 61% use a cognitive neuropsychological approach, and 26% follow a life participation approach [13] (respondents were permitted to select more than one response). A more recent Australian study shows the same preference for the functional approach, but almost equal usage of social and cognitive neuropsychological approaches [14]; and the majority of clinicians reported 'good-very good' knowledge and 'confident-very confident' application of these approaches in practice.

Practice surveys elsewhere highlight how clinicians view specifically the psychosocial aspects of aphasia. In Britain, aphasia clinicians placed high importance on psychosocial aspects in rehabilitation, and considered the client's psychosocial status as important in influencing outcomes [15]. Clinicians recognized the importance of QOL; associated it with self and identity, anxiety and depression, client-reported communication ability, and self-esteem; and measured it using primarily informal methods: 98% reported using informal scales or methods; 80% used communicative history forms; and only 39% used published scales or methods [15] (respondents were permitted to select more than one response). Although no specific QOL instruments were reported, clinicians did report

using the Hospital Anxiety and Depression Scale (HADS) [16], the Stroke Aphasic Depression Questionnaire (SADQ) [17], the Communication Disability Profile (CDP) [18], and the Visual Analogue Self-Esteem Scale (VASES) [19]. In New Zealand, Gibson and Purdy [20] found that SLTs also rated psychosocial aspects highly in management, but additionally that the majority of clinicians felt unqualified and unprepared to manage these in practice. Simmons-Mackie and colleagues [21] investigated outcome assessment practices of aphasia clinicians from the United States, and found that of the 336 measures and methods reported as used, only 4 measures pertained to QOL. One study of Australian aphasia speech pathologists [13] revealed that whilst 52% of respondents reported assessing QOL when measuring intervention effectiveness, only 3 of the 70 respondents reported using a formal QOL measure (the VASES), suggesting other informal means must have been used. Such approaches to exploring and assessing QOL are neither standardized nor sufficiently robust to be compared across clients or across time. Furthermore, they do not align with the World Health Organisation's recommendation for more rigorous data collection on disability and consequences in the health arena [22].

Given the focus of this paper on Danish clinicians' practices, a brief overview of the Danish context is appropriate. The Danish SLT profession originally developed with a strong foothold in pedagogical approaches to adult learning. Historically, Danish SLTs were educated as public school teachers, who subsequently (after at least one year of practice in the school system) pursued a 2-year diploma in speech and language therapy. For many SLTs, their diploma training provided them with a general humanistic pedagogical approach combined with knowledge of speech language disorders. This integration of philosophy and humanistic psychology [23-25] has led to a strongly client-centred approach in aphasia rehabilitation. The 2-year diploma degree was subsequently replaced with a 1-year curriculum, and in 1982 was augmented by a dedicated university five-year (3+2 according to the Bologna process) degree programme, which nowadays is offered at two universities in Denmark. The undergraduate and graduate curricula both promote a general research orientation and focus on evidence-based practice in speech and language disorders. Today, most SLTs in

neurorehabilitation are university graduates, but the organizational structure of the field of SLT outside the hospital system is still to a large extent characterized by the original pedagogical terminology: 'teaching' is used rather than 'intervention' or 'therapy', and 'student' or 'citizen' is used rather than 'patient' or 'client'; and the services are provided in accordance with *Law about special education for adults* [26].

In Denmark, very little has been officially documented about the field of SLT practice in aphasia rehabilitation. In general, much aphasia rehabilitation occurs during hospital or rehabilitation units where the SLT is part of an interdisciplinary team in stroke rehabilitation. Aphasia rehabilitation after hospital discharge predominantly takes place at institutions, where the large majority of SLTs are hired as special teachers or consultants, and constitute the only or predominant group of professionals with little or no collaboration with other professionals involved in rehabilitation, e.g. physiotherapists, occupational therapists, social workers, and (neuro)psychologists. A minority of SLTs are hired in private clinics, such as the influential Centre for Rehabilitation of Brain Injury (CRBI) in Copenhagen, which has pioneered the interdisciplinary approach in the community. Outpatient aphasia rehabilitation is funded by the municipality, and in many places SLTs are required to submit individual funding applications for each client and wait for approval. These applications must have explicit ICF-related goals, since the ICF is as a frame of reference by the funding authorities. Accordingly, the ICF has come to play a very important role in goal setting by SLTs [27]. Regarding the evidence base in aphasia, Isaksen [28] examined evaluation practices among Danish SLTs and found that SLTs find it meaningful to involve clients in informal outcome evaluation after therapy, but are less prone to using formal evaluation tools, such as questionnaires or tests. As far as how Danish SLTs perceive the relevance of QOL as a concept to their own practice or have developed methods of integrating the concept, this has not previously been investigated. One obvious challenge is that there are virtually no existing Danish translations of evaluation tools, which address QOL or participation in clients with aphasia [29, 30].

The lack of a unified approach in the Danish practice field to understanding, assessment and management of aphasia means that there is no coherent picture of the current status of QOL within SLT practice. This is echoed on a global level at which there is very little evidence for how aphasia clinicians apply QOL in clinical practice (this issue excluded). In-depth studies are lacking, which address how the concept of QOL fits with clinicians' visions for their own practice and with the organizational framework within which their practice is situated. As yet, there exists no agreed pathway to the inclusion of considerations of QOL into the practice of SLTs in Denmark or internationally. As such, measuring QOL, setting goals and working on these in therapy, as well as measuring one's efficacy in achieving these and being able to share results, is a difficult and disjointed process. In a system in which both time and resources are limited, it is likely that clinicians would choose to focus on an area in which they feel better trained and more able to make a difference, and indeed able to demonstrate that they *have* made a difference. The increasing pressure on clinicians to rationalise and provide evidence for the efficacy of their work may lead to their feeling uncertain as to how QOL can be justifiably included in their work. With this in mind, the first author developed a brief educational intervention (one day workshop) for SLTs in neurological rehabilitation to provide a scientific approach to QOL, present and discuss the range of measures and methods available in the area, and relate measures to clinical practice. This paper presents baseline data from Danish aphasia clinicians, participating in this research, on (1) their knowledge and understanding of QOL, (2) their views on education and training in relation to preparedness for working on QOL in practice, (3) reported use of QOL measures, and (4) barriers to the QOL concept, broadly in relation to practice, and specifically in relation to tools. It was done via an empirical approach to QOL aiming to describe the practice and reflections of Danish SLTs within an open theoretical framework, which might accommodate several different theoretical approaches to QOL.

Methods

Recruitment and participants

Participants were required to meet the following inclusion criteria: qualified SLT; minimum of two years' clinical practice since graduating; and currently working as a SLT with adult clients with neurological communication disorders. There were no age or gender inclusion criteria. Clinicians also agreed to participating in an educational intervention and completing two post-intervention questionnaires as part of a broader project (data not reported here), in addition to the pre-workshop questionnaire reported in this paper. Participants were recruited through the Danish researchers' professional network via emails that could be forwarded to other colleagues. Fifteen participants signed up for the workshop, which was held in Odense, Denmark, in January 2014 by first author. Prior to the workshop, the first questionnaire was completed online. Participants completed the questionnaire anonymously and were assigned participant numbers (P1-P15) for identification (note participant 10 withdrew during the study leaving 14 participants in total). These codes are used throughout the results to identify participant quotes.

All participants were female and ranged in age from 26 to 60 years with an even spread. Participants had an average work experience of 9.76 years as SLTs (range = 4.08 – 21; SD = 5.56) with 8.06 years of average experience within adult neurological areas (range = 4.08 – 16, SD = 3.41). All regions of Denmark were represented, with the exception of Nordjylland. Nearly all participants were employed in the public sector (regional or municipality-driven outpatient clinics and/or hospitals), with only two participants working in a private facility. Participants worked in the acute inpatient setting (2/14), inpatient sub-acute setting (7/14) and outpatient rehabilitation (9/14), with some working across more than one setting. Participants were engaged primarily in working with the person with neurological communication disorder (assessment, counselling, individual and group therapy), however a significant part of their work was also spent working with family and carers (counselling, direct interventions as Supported Conversation for Adults with Aphasia (SCATM)-instructions), and in activities with various types of contact with multidisciplinary colleagues (e.g.

instructions in SCA™ [31] or other type training of multidisciplinary staff, goal-setting in multidisciplinary team, discharge meetings with staff from municipality). Furthermore, working with SLT colleagues, student supervision and recordkeeping comprised aspects of their role.

Data collection and analysis

Data was collected via an online questionnaire [32, see Appendix 1] using SurveyXact, and questionnaire content was informed by related research studies exploring psychosocial issues and QOL in clinical practice [2, 15, 21]. The original questionnaire [32] was in English, and it was decided not to translate the questions into Danish since participants were bilingual. Participants were asked to answer in English, as translation resources were not available for this study. The 48-item questionnaire included open-ended questions, multiple-choice questions, rating scales, and boxes permitting free text responses. Data was collected on demographic information (e.g. number of years of working with adults with aphasia, caseload information, setting(s) in which participants worked). The questionnaire contained questions intending to explore participants' knowledge, understanding and beliefs about QOL in general, and perceived barriers to applying QOL in clinical practice, including their beliefs about and use of QOL measures in clinical practice. The questionnaire also explored participants' views about how their education had prepared them for practice in relation to QOL and further training they might have undertaken.

Approval for the study was granted by City University London research ethics committee, and due to the nature of data collected (professionals) further ethical approval from The Danish Data Protection Agency was not required. No identifying information was collected, and participants consented to study participation by completing and submitting the online questionnaire. Answers were stored in the SurveyXact database, and subsequently downloaded and password-protected. Descriptive statistics were used to characterize the numerical data, and content analysis was used for free text responses [33]. Such approaches have been used successfully in similar studies, such as that of Collis

and Bloch [34]. Tallies were used alongside the qualitative analysis of free text responses as an additional measure of importance [33]. Rigour was established by three of the researchers (MC, JI, LRJ) coding independently, followed by discussions leading to consensus about the categories and subthemes.

Survey questions were analysed according to: (1) participant demographics including information about current work setting and tasks (Q1-17 summarised above); (2) Theme 1, Knowledge and Understanding (Q18-20, 27, 33, 36, 39, 42, 43a+b); (3) Theme 2, Education and Training (Q21-26, 33, 42, 47-48); and (4) Theme 3, Practice and Implementation (Q28-35, 37-42, 43c, 44-45).

Results

Theme 1. Knowledge and Understanding

Participation was a core theme for the clinicians in describing their understanding of the concept QOL (Q18; P2, 3, 13, 15). They referred to participation in relation to everyday life (P2), relationships (P2), and activities (P3, 13, 15). Participation was mentioned as a means of motivating clients by choosing personally meaningful activities (P3), or considering a range of activities (social, recreational, and work), as well as the opportunity to both give and receive in relation to other people (P13). *Living life as independently as possible* was also a core theme (P1, 3, 12, 15) with one clinician referring specifically to independence in activities (P3). *Being or having as much control over life as possible* was a clear theme (P4, 9, 11) comprising life in general, as well as “...that they can say what they want, when they want to, even though it is difficult” (P4), and “that you choose where you live and how. The right to decide how your daily life is arranged, and make your own decisions” (P9). One participant further mentioned: “find meaning and quality in choices and general terms of life” (P6). *Meaningfulness* appeared several times in clinicians’ responses: five referred explicitly to meaningful lives or work (P7, 11, 13, 14, 15): “Quality of life means ... having a meaningful position in

the private sphere as well as in the society..." (P11); one referred to using personally meaningful activities in rehabilitation (P3); and one referred to QOL as the ability to find meaning in life (P6). Clinicians P6, P8 and P12 also referred to being satisfied with life, and P5 also mentioned general wellbeing.

Some aspects were expressed by one or two participants (Q18). Two clinicians raised 'good, many and different' social relations (P12, 15); two clinicians raised QOL meant having a reason to live (P1, 13), including *"having something to look forward to.....looking forward to getting up in the morning"* (P1); and two mentioned values (P4, 8), with a particularly illustrative comment from P8: *"To me it expresses the values in a person's life. Quality of life is therefore affected by the persons, experiences, possibilities and things in a person's life. If there is a mismatch between the values that a person wants to have and the values the person actually does have, this can affect the quality of life in a negative way"*. Finally, expressing needs and communicating with others were mentioned only once each in the data (P11, 12 respectively), as was hope, and feeling respect for and from people around oneself (P1).

Clinicians described QOL as central, crucial, relevant, and very important to practice (Q18-19; P1, 3, 6). QOL was seen as relevant by the clinicians in almost every stage of SLT practice: *"I believe, the patient's quality of life is very important and a crucial part of the way we assess and treat our patients. An assessment or talk about the patient's quality of life gives our treatment direction as well as direct the SLT towards certain tools to gain the goals of the treatment"* (P3). QOL was important in terms of underpinning or influencing goal setting (Q19; P1, 3, 6, 13): *"It underpins our goal setting - we need to know what is important for a person to be able to do, so they can participate in a life that gives meaning to them"* (P13) and supporting and directing treatment (P1, 3, 7, 8): *"The treatment of any kind of deficit has to relate to the importance it has to the client and which context the client is a part of - or wish to be a part of"* (P7). For two clinicians, QOL was the aim or goal of SLT practice (P8, 14): *"I believe that quality of life should be the goal of SLT-practice"*

(P8), whereas for two other clinicians QOL was embraced throughout (P1, 3): *“It should be central in SLT-intervention, interviews and goal setting”* (P1). The majority of the clinicians (10/14) strongly believed that the psychosocial status was very important to the clients’ overall outcome of the intervention. QOL motivated clinicians to talk with patients and relatives to find out what was important and relevant to them, to underpin rehabilitation (P4, 6, 8, 13): *“To me it is important that the SLT works from the patients/relatives perspective on QOL”* (P8). Clinicians interpreted QOL to be relevant in clinical practice in terms of focusing on the communication environment (P8, 11, 12): *“The most important thing in our work is to facilitate communication between our clients and their surroundings”* (P12), including identifying alternative ways of communicating (P8, 11); working with others *“QOL should, in some cases, also include the patients’ close relatives”* (P3); and considering the aphasic person’s roles and tasks within family and society (P11).

Finally, all clinicians (except one) engaged in QOL issues because of their own philosophy, and additionally, half of them also reported their engagement resulting from the philosophy of their organisation (Q27). Nine of them believed QOL was very important to overall client management, and the remaining five considered it important (Q20). However, very few clinicians were aware of QOL measures they could use (n=2) and agreed they knew some QOL measures sufficiently to use them with aphasic clients (Q43a,b), and the majority (n=8) rated themselves with limited awareness. Clinicians themselves reported a lack of available relevant tools and tests (P5, 6) as well as lacking in their own personal knowledge of QOL tools, especially Danish tools, as barriers to considering QOL in clinical practice (Q33,42; P3, 5, 6, 13).

In summary, participation, independence, autonomy and meaningfulness were the prevailing interpretation and understanding of QOL for clients. There was universal support for the importance of QOL in practice, and QOL motivated discussions between SLTs and clients and families, as the basis for goal setting, and supporting and directing treatment. Importantly, clinicians held these

views in spite of a lack of relevant QOL tools, and limited awareness and knowledge of QOL tools generally.

Theme 2: Education and Training

Approximately one third of clinicians (Q26; P2, 4, 9, 14) believed that training about QOL should be at the pre-qualification level, and emphasized the importance of QOL and thinking about this from initial clinical interactions, e.g. *"it is very important that we meet the patients as adults who can decide their way of living for themselves"* (P9) and *"SLTs have to think this way the first time you meet the client and see QOL as "what is it all about"* (P2). Remaining clinicians believed QOL training was relevant at pre- and post-qualification levels (Q26). At the pre-qualification level, their responses indicated awareness raising about QOL issues was appropriate, emphasized the importance of QOL, and highlighted the desirable outcome, i.e. *"if the concept is implemented in initial clinical experiences it is more probable that the therapist develop and focus on QoL"* (P6). At post-qualification level, they commented on the value of experience, and more so the benefit of their current working context, and it was clear that post-qualification training suggested greater readiness and ability to engage and manage QOL issues: *"Perhaps one can make better use of methods and training after some time of practice with real patients"* (P12) and *"it is now possible to connect the theory to specific cases, and perhaps even have an on-going process, so that different methods can be tried out and evaluated"* (P3). Data from a later survey question (Q42 barriers to considering QOL in practice) is relevant to this theme, as four clinicians' responses suggested that at times, the way in which the SLT profession is realised, constrains one's understanding of what QOL is, or how to practise. This realisation is initially shaped by student education and further reinforced in subsequent training and daily clinical practice:

I think there is a (mis)understanding also in me of quality of life not being relevant to discuss for patients who cannot contribute with their perspectives on the subject. Maybe we are too

rigid in our conception of quality of life as something that should be measured and contain a lot of information from the patient. Maybe we should instead try to be open to how it could be adjusted to our setting. (P8)

Clinicians considered the value of their prior education and training (Q21, 22), and only three of them (P8, 9, 12) felt their pre-qualification training adequately prepared them to manage QOL issues. Critical perspectives on prior training suggested that content was too focused on impairment and neurology (P3, 4, 11, 15), e.g. *“When I was educated to become a SPL, my focus was on ... training and gaining the best possible speech-results for the patient. It still is, but I have learned that the patient often is filled with anxiety, confusion and questions about the future”* (P3). Clinicians identified that pre-qualification training could have been improved with more training on (1) theoretical underpinnings of QOL issues (P2, 4, 6, 11, 13); (2) knowledge of relevant assessment and intervention tools (P3, 6, 7, 13, 14); and (3) more practice and supervision (P1, 2, 7, 12). Specifically, this included: (1) a stronger theoretical understanding of the concept of QOL, knowledge of psychological theories such as coping theory, knowledge of the influence of aphasia on the person with aphasia (PWA) and his or her identity, and the consequences of aphasia for the family; (2) knowledge about *how to* actually interview and evaluate QOL in a patient with aphasia, how to discuss QOL issues with the client, and how to set goals in relation to QOL; and (3) more practice and supervision to manage QOL issues, especially in a multidisciplinary setting, where QOL was the overall focus of rehabilitation. For some clinicians, it seemed that practice and experience with real people with aphasia was seen as catalytic of a personal and professional development, which needed to take place before the SLT was able to fully appreciate the significance of including QOL perspectives in their approach to the PWA: *“I think that it is hard for an undergraduate to grapple all of the factors to consider in an assessment and training, and keep in mind the wider issues faced by clients”* (P13). Later survey questions (Q47, 48 inviting clinicians to identify learning needs to be addressed in workshop) reiterated the areas outlined above including gaining knowledge of, or understanding theory about, QOL *“hope to get a more conceptualized understanding of Quality of*

Life, that tends to be a rather fluffy thing in the way in the way it's being spoken about and handled (... by myself and others)" P14; talking about and exploring QOL with clients; specific and systematic ways of integrating QOL in SLT and interdisciplinary practice; and specific issues (assessing in early time post onset or sub-acute phase; how often to assess clients; long-term QOL; QOL for severely impaired clients; factors influencing QOL recovery).

Subsequently, clinicians had sought out additional training in QOL (Q23-25) with the majority (P1, 2, 6, 8, 9, 11, 13, 14, 15) attending conferences, talks, and courses in their own country, neighbouring Nordic countries, or overseas. Training included QOL, participation/ life participation approach, psychology, coaching, coping strategies, SCA™ [31], narrative documentation, and motivational interviewing. Four clinicians (P1, 3, 4, 7) referred to learning as derived through their own practices (self or peer reflection and feedback, reading articles) and 2 reported no further training. Clinicians (n=9) had benefited in various ways, including gaining knowledge and understanding, both of the topic itself and the importance in general (P2, 6), and confidence because it affirmed current practice (P14). Training drew clinicians' attention to QOL (P6, 11) and reminded them of the purpose behind treatment *"helps to refocus your attention on it, when the daily requirements of a clinic are to measure how many pictures a person can name, how many words they can spell etc"* (P13). Clinicians mentioned the value of working on QOL with clients as relevant to current cases, and the need for focusing on functional aspects in intervention (P3, 7), as well as benefit gained through years of experience (P1, 2). Concrete and practical aspects were valued, such as learning questions that invite PWA and relatives to contribute more to intervention planning, as well as gaining tools to assist clients to make decisions (P9, 11). These influenced choice of treatment stimuli and resulted in more personally meaningful treatment (P11). Tools and methods also assisted clinicians to explain aphasia: *"it was very beneficial for the PWA and the relative to understand that the purpose of rehab also was to learn to live with aphasia, instead of thinking aphasia as barrier of life"* (P11). Responses also indicated training needed to be active and use clinical case examples relevant to clinicians' caseloads (P4, 8).

In summary, clinicians judged their existing pre-qualification education to be inadequate in preparation for managing QOL in practice, although they recognised the value of raising awareness of importance of QOL at this level. Post-qualification further education was preferable and beneficial. A current working context provides immediate clinical opportunities to translate practical learning, and greater understanding of the complexity of living with aphasia for people and families. Clinicians' self-assessed need for more knowledge and experience is reflected in the breadth of the areas for additional education, which they identified, including theoretical knowledge, practical knowledge, and experiential knowledge of QOL. Of note, clinicians were motivated to learn techniques of coaching, motivational interviewing and narrative documentation that are complimentary in exploring QOL with clients with aphasia.

Theme 3. Practice and Implementation

As identified in theme 1, the clinicians' knowledge about tools relating to the measurement of QOL was lacking and often not adequate to permit their use. The practice they reported about their use of tools is in accordance with this, wherein more than half (n=8) did not feel confident at all in using QOL measures with their client, and the remaining six also rating themselves low in confidence (Q43c). The majority of clinicians (n=13) reported gathering information by asking and talking directly with the client, and with significant others (n=12). Two clinicians (P1, 8) additionally reported *what* they discussed with clients, including barriers to living life, what clients liked to do and considered important, what they were able to do/not do and how this felt, and what was desired. Three clinicians reported a lack of structure, systematization or formality in their interviewing and information gathering (P3, 6, 8). A small number enquired with the multidisciplinary team (MDT) (P5, 6, 7, 11), consulted medical notes (P6, 7) and observed clients to learn about their QOL (P4, 15). A third of the sample (n=5) reported never using tools to gather information about QOL (Q40); this result suggests that the majority of clinicians did use tools,

however only three clinicians (P2, 8, 15) reported using actual questionnaires, visual analogue scales, and self-evaluation forms (Q37) to assess QOL. These included the Danish Head Trauma Database Visual Analogue Scale (VAS) [35], the Communicative Effectiveness Index (CETI) [36], and the European Brain Injury Questionnaire (EBIQ) [37] (Q38). Instead, clinicians valued conversation; some favoured dialogue as more meaningful than questionnaires, and two participants (P3, 4) used questionnaires essentially as a springboard for discussion. Clinicians perceived barriers to using QOL tools (Q39, 42) as the tool itself (P1, 3, 4, 5, 7, 11, 12, 14, 15), as well as raising concerns regarding validity and sensitivity: *"It is difficult to measure QOL"* (P1); *"It can be a challenge to document QOL advances"* (P12).

Whilst only four clinicians enquired with the MDT (see above), the majority (n=12) perceived QOL as a multidisciplinary concern to some degree, and only two clinicians considered QOL as domain-specific (Q44). Clinicians (n=12) reported advantages and disadvantages of QOL being a shared multidisciplinary responsibility (Q45). Half of the sample (P1, 3, 7, 11, 14, 15) described only advantages, 4 clinicians (P4, 6, 8, 13) described both, and 2 clinicians (P5, 12) suggested only negative perspectives of multidisciplinary working. Advantages included overall better intervention that was more adapted to the whole person (P6, 7, 8, 11); provided a more cohesive approach to rehabilitation (P8); and an approach that was not too exclusively focused on communication problems (P3). One participant also suggested that rehabilitation would be maximised, if *all* professionals were familiar with and supported QOL goals in their sessions with the patient (P1). Disadvantages included that QOL may result in being no one's responsibility in the MDT (P4, 8 and 6) and that it is hard in practice to establish collaboration across the different disciplines (P12, 13).

A number of survey questions related to time spent on QOL during contact with clients. The majority of clinicians (n=9) reported spending about half of their clinical time with clients on QOL issues, with some spending more and less than this (Q30). Half the sample was satisfied with this time, and half was dissatisfied spending only about half of their time on QOL issues. Time was also reported as a

barrier in implementing QOL issues (Q33, Q42). Seven clinicians (P1, 2, 3, 4, 5, 12, 13) raised issues around lack of time either in relation to assessment or general lack of time for therapy: *“Because of cut downs, the client comes here for a shorter period of time. In my perspective you can’t hurry rehabilitation when it comes to life quality. You have to take the time, and have the talks with the client and their family”* (P4).

Barriers to implementing QOL in SLT practice were a general theme throughout the survey. There was an almost normal distribution in the data regarding the extent to which clinicians perceived barriers affecting their practice, from stopping them from applying QOL entirely, to not stopped at all (Q34). Barriers were experienced in relation to the organization and/or societal influence by almost half of the sample (P2, 3, 8, 12, 14, 15), and funding was the general issue raised here together with priorities other than QOL: *“In general I think that the municipalities (who pay for the rehabilitation) often regard the question of quality of life as a less important issue in terms of rehabilitation focus. There’s a tendency to focus on the issues that are most profitable e.g. getting back to work and be as independent in living as possible. It is very rarely seen that the municipalities will pay for rehabilitation which primarily focus on improving quality of life”* (P8). There is a possible contradiction in the data, wherein clinicians reported engaging in QOL due to their organization (Q27); in a later question, some consider their funding provider as constraining their practices (see immediate above); and then further, some (n=5) consider themselves actively encouraged by their organization to apply QOL in practice (Q28). We hypothesize that the municipality (funder) is seen as separate from their direct employing institution, however this requires further exploration in future research. Finally, five clinicians (P1, 4, 7, 9, 13) identified client-related aspects as barriers in implementing QOL issues in therapy (e.g. stroke and aphasia-related factors affecting questionnaire completion, educational background, and general reflection on life): *“in the beginning the client is much focussed on language rehabilitation, so often they are not ready to talk about how they feel before after some months”* (P4), and client factors of aphasia type or severity.

Most of the clinicians made suggestions that would enable them to apply QOL more in their practice, whilst two felt their current practice already adequately considered QOL issues (Q35). A recurring theme in eight of the 12 clinicians was their need of more support from their own professional context, e.g. having a shared understanding of the importance of QOL issues with SLT colleagues, with their workplace leaders, with interdisciplinary teams, and/or with stakeholders who fund rehabilitation: *“More support from my working place”* (P4); *“That the social system will recognize and acknowledge more the importance of quality of life when the patient is unable to work because of e.g. language disabilities”* (P15). Clinicians reported that better skills and more knowledge might improve integration of QOL in their practice (P1, 3, 5, 6, 12, 13), specifically finding out what evaluation tools were available and becoming familiar with these (P1, 3, 5, 6, 12). Finally, two clinicians (P7, 13) also mentioned that a change in their own focus, to involve the family more, might improve their approach.

In summary, many clinicians addressed QOL issues with their clients and significant others. Dialogue or informal questioning was preferred over the use of specific measures or tools. Barriers to implementing QOL in SLT practice were a general theme throughout the survey and were not only specific to the application of QOL measures or tools, but also pertained to the clinician (lack of knowledge and lack of routine practice of considering QOL with all clients) and to the client. Time and organisational system of rehabilitation were also mentioned, albeit by fewer clinicians.

Discussion

The following discussion is written with acknowledgement of the small sample size of self-selecting individuals, and with recognition that respondents completed a written survey (rather than interview) and in their non-native language, both of which are likely to have impacted on clinicians' their capacity to express their views fully when answering.

Defining quality of life

Danish clinicians were united in their views of the importance of QOL for clients and relatives, held firm views within themselves of this importance, and approximately half of them were affirmed further in these views by their workplaces. Clinicians varied greatly in how they defined and interpreted QOL, with responses ranging from hope, respect, and having a reason to live, to good social relationships and communicating with others. Amongst this variation, there was some agreement that QOL comprised participation, independence, autonomy, and meaningfulness for clients with aphasia. Participation in everyday life, relationships and activities was raised, as was meaningfulness in relation to life and work. Activities were common to these themes, including rehabilitation activities and life activities. Additionally, individual clinicians referred to life satisfaction, wellbeing, values and self-worth. These findings comprise the first published data on SLTs' views of QOL, the closest appropriate literature comparison being McKeivitt et al (2003) study. There is overlap between the areas raised by Danish SLTs and the physicians, occupational therapists and physiotherapists in McKeivitt et al's study wherein the majority of health professionals' responses were coded as happiness that included: "enjoyment of life, life satisfaction, feeling that life is worth living, having life choices, personal dignity, a sense of achievement, well-being (including spiritual well-being), living a life free of worry" [2]. Social aspects (the ability to engage in/enjoy social interaction, family and friends, communication, leisure activities) and independence were raised by a minority in McKeivitt and colleagues' study [2] and the current study's findings accord with this lesser emphasis. Interestingly, physical health was not raised by the Danish clinicians, but was raised by health professionals in McKeivitt et al. and may be attributed to the disciplinary backgrounds of those interviewed [2]. The findings regarding activities and relationships (interlinked with control, independence and meaning), also resonate with the views of individuals with aphasia themselves in the early stages post stroke [38] and chronic stages [39, 40] regarding living successfully with aphasia and achieving quality in life. Finally, on a conceptual level, SLTs' views of QOL align more with subjective wellbeing than with health-related QOL (HRQOL) [5, 41] – there is a

notable absence of *health* in their definitions, and only one clinician mentioned optimising communication *functioning* – although some aspects can be interpreted as psychological health and social health (which are two of the four agreed domains of QOL for people with stroke [42]). Interestingly, clinicians emphasized *Participation* in their definitions of QOL; participation is not a construct in HRQOL or wellbeing, and may be mentioned by clinicians for other reasons. It is likely that clinicians are influenced by the WHO ICF [12], which is the frame of reference guiding Danish clinicians in their goal setting and funding applications to their local government (see Introduction). It is also likely that the clinicians were mindful of the importance of participation (and choice, control, and meaningfulness) to their clients with aphasia, as participation is universally important to people with disabilities [43], as well as independence (including living in one's home for as long as possible) being a national political high priority in Denmark.

Evaluating quality of life

Danish clinicians revealed a clear preference for exploring QOL through dialogue and informal questioning, and a clear dual focus on the PWA and their relatives as integrally involved, eliciting what is important, relevant, and meaningful to them for directing treatment. This 'working in partnership with the person with aphasia' is likely related to the emphasis on client self-actualisation that Danish clinicians gain during their SLT training. Whilst other studies [e.g. 15] similarly utilise discussion with clients to evaluate QOL, the emphasis on partnership is unique to the practices of Danish clinicians as reported here. Furthermore, there are no published studies that identify the emphasis that Danish clinicians placed on discussing QOL with family members; in most other studies the focus is overwhelmingly on the client with aphasia [13-15, 21]. This may arise because Danish legislation explicitly mentions including family and/or directing intervention at family. Equally, it is possible to attribute this finding to the ICF being well established in thinking about aphasia in Denmark, both at an institutional level and at an individual professional level, wherein

family and relatives are identified in environmental contextual factors, as a means of modifying disability.

Despite these positive findings, there is reliance though on informal methods of evaluating QOL that is similar to studies of health professionals generally [2], and specifically to SLTs working in aphasia [13, 15, 21, 28]. Whilst this is understandable in the Danish context with the lack of translated formal assessments [28-30], there remains a core concern around the informality of information gathering in the QOL field, making any measurement of client outcome or intervention effectiveness impossible to achieve. Some of the clinicians themselves noted the lack of structure and systematization in their interviewing, potentially implying that areas could be overlooked in discussion. Very few clinicians in sample reported using observational means to gather information on QOL, a finding that conflicts with McKeivitt et al [2]. The World Health Organization in their World Report on Disability recommend more standardized and comparable data collection methods on disability and consequences, suggesting that more rigorous and robust methods for enquiring about and evaluating QOL are desirable [22].

Danish clinicians viewed QOL as influencing most aspects of their case management (information gathering, assessment, goal setting, treatment), with an apparent driving focus of QOL in directing the treatment plan for the client with aphasia. It is interesting to note that using QOL to identify a patient's priorities and preferences is uncommon in the field of QOL, as most published literature emphasizes application of QOL instruments. The Scientific Advisory Committee of the Medical Outcomes Trust (SACOMOT) identified 11 uses of QOL instruments, with a notable focus on (1) assessing and monitoring general and specific populations; (2) screening and diagnosing; and (3) assessing impact, efficacy, effectiveness, and economic value of health care interventions; and only their 11th application addressed QOL for the individual patient [44]. For the individual practitioner, the patient/client-specific application of QOL is the most relevant to daily clinical practice. Health

professionals in McKeivitt and colleagues' study [2] similarly reported using QOL to assess patients' needs and determine goals, however interestingly, the most frequently reported use of QOL measures in that study was in measuring outcome and/or effectiveness of intervention. Again, the lack of Danish formal assessment tools in general likely gives rise to the 'personal tailoring of treatment planning' application of QOL in Danish aphasia rehabilitation [28].

It is clear that Danish clinicians interpreted QOL subjectively (meaningfulness, autonomy, independence, values), however due to the written data collection method and lack of specific questioning, it is not known how they operationalized QOL, that is, what they actually asked clients and relatives about when considering their QOL. Two clinicians' responses provide some insight, noting they asked about barriers to living life, what client likes to do and considers important, what able to do/not do and how this feels, and what is desired. This approach is in some way similar to the structure of the World Health Organization Quality of Life (WHOQOL) assessment [45], wherein perceived ability, importance and satisfaction are rated by the individual [46]. Two named measures were reported as being used – the EBIQ [37] and the CETI [36]. The former enquires about the degree of difficulty or problem that the individual experiences in cognitive, social and emotional areas; the latter gauges the significant other's perspective of the aphasic person's current communication in the context of premorbid level of ability. Neither the EBIQ nor the CETI is a QOL instrument, however their mention suggests that clinicians perceive the measures to have some merit in enquiring about difficulties or abilities, from either the person or family members' perspective; alternatively they may be used as these measures represent the only translated client- or relative-reported measures available in Danish. Substantially more research is needed into the actual areas and questions that clinicians and clients discuss when reflecting on QOL in treatment planning, and how this is translated into specific rehabilitation goals. There is a clear indication in the data that clinicians perceive their funders as unprepared to pay for QOL-focused rehabilitation,

however it is not known what this would actually constitute and how they are currently restrained in their SLT provision. It is possible that clinicians are experiencing some of the tensions related to the conflicting purposes of goal setting in rehabilitation, namely the purpose of enhancing patient autonomy (involving the patient in goal setting typically leading to meaningful yet un-measurable goals [47]) with the purposes of evaluating patient outcomes and meeting contractual requirements [48]. Finally, specifically associated with tools, Danish clinicians had valid concerns beyond the availability of QOL measures, including concerns about the challenge in measuring QOL per se, as well as measuring change. Health professionals in McKeivitt et al. were similarly concerned about relevance of QOL measures for patients with stroke, and additionally reporting concerns of psychometrics (reliability and validity) and time taken to assess and analyse patients' responses [2]. Whilst Danish clinicians did not raise these concerns, they had other insightful comments reflecting a considered understanding of the issues associated with evaluating QOL such as how early and how often to assess QOL post-stroke.

Practising quality of life

There was clear recognition from SLTs in this study of the importance and centrality of QOL in practice, and this accords with the high value generally placed on QOL and psychosocial issues by aphasia clinicians worldwide [14, 15, 20]. Clinicians dedicated time to exploring it with clients and relatives to direct treatment, but remained concerned about the measurement of it, whose responsibility it is within the stroke team, time and timing issues, and the perceived lack of value placed on QOL by rehabilitation funders, and in some instances also from the clients themselves.

Practitioners felt unprepared by their initial education for practising in QOL in aphasia and had limited confidence in using QOL measures, similar to other studies in this field [13, 20]. Clinicians appreciated some exploration of QOL during their qualifying education, however the majority viewed QOL as the remit of post-qualification training and further clinical experience. Learning whilst

working permits a deeper appreciation and understanding of the issues, as well as immediate opportunities to translate knowledge into practice and apply skills and techniques. More clinical experience translates to a greater readiness to engage in QOL from the practitioner's point of view. Clinicians were motivated to know more about the theoretical underpinnings of QOL in stroke, and even more so about practical techniques and methods they could use with clients and relatives. There was a clear focus on process and method amongst clinicians' responses. Whilst participants placed great value in practicing and knowing more about QOL issues in aphasia therapy, these findings may not reflect the majority of the population of Danish clinicians as participants were self-selecting.

Implications for practice and research

Danish clinicians could advance their practices further by specifying how their patients' communication rehabilitation is connected to participation, autonomy, independence and meaningfulness. Clinicians may consider systematizing their existing QOL approach by drawing on a range of sources. These may include: (1) using existing qualitative interview-based studies of QOL [40] and translating the interview questions; (2) using literature for early stages post-stroke [38] and deriving interview questions to be used systematically with all clients; or (3) using literature from the ICF Core and Extended Sets for Stroke field, and deriving interview questions specifically for Participation [49]. It would be useful to consider evaluating intervention and outcomes from a QOL perspective, thus clinicians may consider applying rating scales at the end of intervention cycles to capture this. As well as systematizing their clinical approach, clinicians could afford to broaden their conceptualization of QOL in post-stroke aphasia and acknowledge aspects reported by individuals in other studies [40] that they are currently not considering, such as physical functioning and general health, which may influence QOL in their own right, as well as interact with communication difficulties to influence participation. Further education and training needs to address the

application of the concept in stroke rehabilitation generally, and the boundaries specific to SLT; as well as generate an agreed understanding of what QOL is amongst the SLT profession and the multidisciplinary stroke team, with acknowledgement and recognition from the health care system and funding agencies. Considering both the client and the family member, in their own right or relative as caregiver, is core in this process of developing an agreed understanding.

This preliminary study raises many questions for future research. There is a clear need for in-depth interviewing with clinicians to interrogate what QOL actually means in stroke rehabilitation, and in communication treatment, for individuals with aphasia. This issue is also raised by other practice surveys, suggesting a broader need to discuss QOL in relation to aphasia treatment approaches i.e. to functional, social and biopsychosocial [13, 14]. Interviews will enable a deeper understanding to be gained beyond written surveys. This line of enquiry needs to be complimented by similar in-depth interviews with patients with aphasia and their relatives regarding their QOL during rehabilitation; to date this has only been explored in SLT in the post-rehabilitation [40] or from the perspective of living successfully with aphasia [38], and not from the broad perspective of QOL with stroke. Indeed investigation with other client groups would enable a deeper understanding of exploring QOL in adult clinical practice, examining fundamental aspects of knowledge and skills generally as a SLT. The opportunities to translate formal QOL instruments are clear.

Conclusion

Danish clinicians interpret QOL as subjective wellbeing and participation, exploring it with most clients and relatives through dialogue in order to identify goals and direct speech and language therapy treatment. Pre-qualification education and training has value in raising awareness of the importance of QOL for patients with aphasia, however the clinicians' experiences post-qualification, as well as their own personal and professional development, make post-qualification education and training key in developing the workforce in this field. Clinicians perceived the need for greater

theoretical, practical and experiential knowledge regarding QOL, and the need for translated QOL instruments, in order to feel confident in applying QOL measures in practice. A unified understanding is needed that incorporates SLTs, the MDT and the general healthcare system, including the funder, so that clinicians and clients can pursue the goal of improving quality of life with aphasia.

Conflict of interest

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Appendix 1

Background Questions

1. What is your age?

- (1) 21-25
- (2) 26-30
- (3) 31-35
- (4) 36-40
- (5) 41-45
- (6) 46-50
- (7) 51-55
- (8) 56-60
- (9) 61-65
- (10) 65-

2. What is your gender?

- (1) Female
- (2) Male

3. Length of time qualified as an SLT

(please write years, months - e.g. 3,4 = 3 years and 4 months)

4. Length of time working as an SLT

(please deduct any years away from the profession)

(please write years, months - e.g. 3,4 = 3 years and 4 months)

5. Number of positions held since graduating

(please provide number)

6. Number of positions held in adult neurological clinical areas

(please provide number)

7. Time worked in adult neurological areas in total

(please write years, months - e.g. 3,4 = 3 years and 4 months)

8. Setting or stages of service provision worked in during employment history

(please tick all that are relevant)

- (1) Acute (inpatient)
- (2) Sub-acute (inpatient)
- (3) Outpatient rehabilitation
- (4) Other - please specify

9. Current work setting

(please tick all that are relevant)

- (1) Acute (inpatient)
- (2) Sub-acute (inpatient)
- (3) Outpatient rehabilitation
- (4) Other - please specify

10. Time in your current position

(please write years, months - e.g. 3,4 = 3 years and 4 months)

11. Is your current position full-time or part-time?

- (1) Full-time
- (2) Part-time

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

13. What setting description best fits your current position?

(please tick all that are relevant)

- (1) Municipality institution/clinic
- (2) Regional institution/clinic
- (3) Hospital
- (4) Private institution/clinic
- (5) Other - please specify

14. What geographic region of Denmark do you work in?

- (1) Region Hovedstaden
- (2) Region Sjælland
- (3) Region Syddanmark
- (4) Region Midt
- (5) Region Nordjylland

15. Number of patients/client on current caseload?

16. Typical number of patients/clients on caseload

(take average over last 3 months or thereabouts)

17. Please list the range of clinical activities you undertake in your current job

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?

(1) 1 (not important)

(2) 2

(3) 3

(4) 4

(5) 5 (very important)

21. Did you feel adequately prepared by your pre-qualification training to manage quality of life issues?

(1) Yes

(2) No

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?

(1) More

(2) 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 level?

(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?

(1) Own philosophy

(2) Organisation's philosophy

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

(1) 1 (actively discouraged)

(2) 2

(3) 3

(4) 4

(5) 5 (actively encouraged)

Question 29 not included in Danish version.

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

- (1) None of my time
- (2) Only a small part
- (3) About half of my time
- (4) Most of my time
- (5) All of my time

31. Roughly, how did you gauge this amount?

(please outline)

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

- (1) Yes
- (2) No

33. 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)

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

- (1) 1 (stop me from applying it entirely)
- (2) 2
- (3) 3
- (4) 4
- (5) 5 (don't stop me at all)

35. What would enable you to apply quality of life more in your practice?

(please give details)

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

- (1) 1 (not important)
- (2) 2
- (3) 3
- (4) 4
- (5) 5 (very important)

Tools/Measures

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

38. If any, specifically what tools and assessment do you use to do this?

39. What informs your choice of assessment tools?

40. With whom do you use them?

- (1) With all clients
- (2) With most clients
- (3) With some clients
- (4) Never
- (5) With family members

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

- (1) Yes
- (2) No

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

43. Please rate yourself on the following statements, where 1=disagree and 5=agree

	1 (disagree)	2	3	4	5 (agree)
a. I am aware of a range of quality of life measures I could use with clients with aphasia	(1) <input type="checkbox"/>	(2) <input type="checkbox"/>	(3) <input type="checkbox"/>	(4) <input type="checkbox"/>	(5) <input type="checkbox"/>
b. I know some quality of life measures sufficiently to use them in my practice	(1) <input type="checkbox"/>	(2) <input type="checkbox"/>	(3) <input type="checkbox"/>	(4) <input type="checkbox"/>	(5) <input type="checkbox"/>
c. I am confident in using quality of life measures with clients with aphasia	(1) <input type="checkbox"/>	(2) <input type="checkbox"/>	(3) <input type="checkbox"/>	(4) <input type="checkbox"/>	(5) <input type="checkbox"/>

44. To what extent do you think that a consideration of quality of life issues is a multi-disciplinary concern?

- (1) 1 (entirely multi-disciplinary)
- (2) 2
- (3) 3
- (4) 4

(5) 5 (therapy domain-specific)

45. If you believe that it is a multi-disciplinary concern, do you believe this shared responsibility has any advantages or disadvantages?

(please give details)

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

47. What do you hope to gain from this workshop on quality of life and wellbeing?

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