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Conceptualizing quality of life for older people with aphasia

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ABSTRACT

Background There is an increasing need in speech and language therapy for clinicians to provide intervention in the context of the broader life quality issues for people with aphasia. However, there is no descriptive research that is explicitly focused on quality of life (QoL) from the perspectives of older people with aphasia.

Aims The current study explores how older people with chronic aphasia who are living in the community describe their QoL in terms of what contributes to and detracts from the quality in their current and future lives. The study is descriptive in nature, and the purpose is to conceptualize the factors that influence QoL.

Methods & Procedures Thirty older participants (16 women, 14 men) with mild to moderate aphasic impairment took part. All participants had adequate communication skills to participate: demonstrating reliable yes/no response and moderate auditory comprehension ability. Participants were interviewed in their own homes using six brief unprompted open questions about QoL, in a structured interview. The first five questions were drawn from previous gerontological research (Farquhar, 1995), and a sixth question specifically targeting communication was added. Content analysis was used, identifying discrete units of data and then coding these into concepts and factors. Additional demographic information was collected, and participants' mood on day of interviewing was assessed using the Geriatric Depression Scale (Sheikh & Yesavage, 1986).

Outcomes & Results Activities, verbal communication, people, and body functioning were the core factors in QoL for these participants, and they described how these factors both contributed quality in life as well as detracted from life quality. Other factors that influenced QoL included stroke, mobility, positive personal outlook, in/dependence, home and health. Whilst the findings are limited by the lack of probing of participants' responses, the study does present preliminary evidence for what is important in QoL to older people with aphasia.

Conclusions Quality of life for older people with predominantly mild to moderate chronic aphasia who are living in the community is multifactorial in nature. Some factors lie within the remit of speech and language therapy, some lie beyond the professional role, but all are relevant for consideration in rehabilitation and community practice. Further qualitative research is implicated to better understand QoL with aphasia, using in-depth interviewing with a broader range of people with aphasia.

INTRODUCTION

The evidence base around quality of life (QoL) of people with aphasia has grown steadily over the last 10 to 15 years. For the most part, this evidence base is quantitative, and derived through the use of standardised and non-standardised questionnaires. A range of questionnaires has been used in aphasiology to investigate (1) overall QoL (Ross & Wertz, 2003), (2) health-related quality of life (HRQOL: Cruice, Worrall, Hickson, & Murison, 2003; Engell, Huber, & Hütter, 1998; Hilari, Wiggins, Roy, Byng & Smith, 2003), (3) subjective and psychological well-being (Cruice et al., 2003; Hilari & Byng, 2001; Hoen, Thelander, & Worsley, 1997), (4) life satisfaction (Hinckley, 1998), and (5) positive and negative affect (Lyon, Cariski, Keisler, Rosenbek, Levine, Kumpula, Ryff, Coyne, & Blanc, 1997). Each questionnaire has a specific conceptual base, and QoL is conceptualised as a number of separate domains. Questionnaires can cover several domains within one instrument, or be specific to one domain. Based on the content of the questionnaires used in the afore-mentioned research studies, the following domains have been explored in aphasiology: physical health, general/overall health, psychological health, mental health, emotional health, affect, daily activities, social activities, social support, social relationships, psychosocial issues, communication, energy, vitality, pain, the environment, and life satisfaction. Additional domains of QoL for aphasia have been suggested as body image, interpersonal, spiritual, and financial (LaPointe, 1999).

This evidence base suggests that QoL with aphasia is multifactorial, covering a substantial number of domains or factors. However, there is no evidence from the perspectives of older people with aphasia that confirms or refutes that the above-mentioned domains within QoL questionnaires are relevant to their life quality. To date, researchers and clinicians choosing QoL questionnaires have had to assume this for the individuals in question, informed by their reading in related literature in stroke and aphasia, and clinical intuition and experience. Health professionals however may be unconsciously biased in their selection of questionnaires, as research illustrates that health professions emphasize different aspects of QoL. For example, physiotherapists and occupational therapists refer to social aspects and physical function more when defining QoL for patients than do physicians (McKevitt, Redfern, La-Placa & Wolfe, 2003). It is thought that their different emphases may reflect the different nature of care and experiences they have with patients, or the different exposure to and use of QoL questionnaires in practice (McKevitt et al., 2003). To eliminate assumptions and bias, research is needed that explores what is important in QoL from the perspectives of the individuals in question.

Descriptive studies of QoL from the perspectives of non-neurological (healthy) older individuals are popular in the literature, and reveal the following are important in QoL: health and physical functioning, activities, family, relationships and companionship, social and leisure activities, social contacts, social roles, attitudes, psychological outlook and well-being, home and neighbourhood, the community and society, independence, and finances (Bowling, 1995; Bowling, Fleissig, Gabriel, Banister, Dykes, Dowding, Sutton, & Evans, 2003; Browne, O'Boyle, McGee, Joyce, McDonald, O'Malley, & Hiltbrunner, 1994; Farquhar, 1995; Fry, 2000; Nilsson, Ekman, Ericsson, & Winblad, 1996; Wolkenstein & Butler, 1992). Some of these studies investigate QoL by asking the participant to decide their top five important life areas (see Browne et al., 1994), however the majority employ open-ended questioning methods to elicit individual responses. One such example is Farquhar’s study (1995) of 204 older people in South East England, who were asked a set of five unprompted questions about their QoL. Responses were open coded by Farquhar into components such as activities, material circumstances, and ill health, for each of the questions. Similar methodologies have been used effectively with substantial numbers of respondents, such as 999 older people in Britain (see Bowling et al., 2003).

Large-scale descriptive studies of QoL with stroke and aphasia have not been conducted, however small-scale studies do provide insight. Bendz (2000) found that bodily dysfunction, fatigue in activities of daily living, fear of another stroke, desire to re-establish former identity, and concentration and memory problems were important to 10 stroke survivors, who were interviewed 3 months after their stroke. More recently, Tariah and colleagues (2006) found that nine stroke survivors considered “doing what you enjoy doing, lost roles and occupations, liv[ing] with what you have to live with, and hope for the future” as important in QoL (p33). In aphasiology, there is no publicly available research that has explicitly focused on descriptive studies of QoL, however, two studies provide a relatively comprehensive picture of the *consequences of aphasia* on people’s lives (Le Dorze & Brassard, 1995; Zemva, 1999). Based on interviews and focus groups conducted with 29 people with aphasia and their significant others, both studies reported similar consequences: changes in communication situations and interpersonal relationships, fewer social contacts and changed social life, loss of autonomy, restricted activities, stigmatisation, difficulty controlling emotions, and physical dependency, as well as negative feelings such as anxiety, loneliness, irritation, stress, annoyance, and frustration. These descriptive and qualitative research findings provide an excellent foundation for considering the impact of aphasia on life, but cannot be assumed to represent the holistic picture of an individual’s life nor can they be assumed to be important in overall QoL. Thus, the current study seeks to address the knowledge gap in the evidence base, using a descriptive methodology to explore what is important in QoL from the perspectives of older people with aphasia, using open-ended questions that enable participants to think about all aspects of their lives.

METHOD

Participants

Participants described in this paper were recruited into a larger study exploring the relationship between communication and quality of life (see Cruice et al., 2003) that was conducted in Brisbane and South-East Queensland in Australia. Participants were recruited primarily from university aphasia clinics and three metropolitan hospital speech pathology departments (discharged patients) via referral, and some were recruited from community stroke groups and the state stroke association via advertising. Forty-four older people with aphasia were contacted, of whom 40 expressed interest in the research. Five were subsequently unable to keep appointments or withdrew from the study on or before the first interview; four were unsuitable due to concomitant neurological disease or were not aphasic; and one was excluded for severe physical mobility restrictions. Therefore, a total of 30 people with aphasia (16 women, 14 men) were recruited according to these inclusion criteria: spoke English as their first language; demonstrated aphasia at time of stroke and self-reported ongoing aphasic difficulties; had a reliable yes/no response (no less than 16/20 on *Western Aphasia Battery* (WAB) Yes/No Questions, Kertesz, 1982); had moderate comprehension ability at time of interviewing (no less than 5/10 on WAB Comprehension subtest); had no concomitant neurological disease; were greater than 10 months post-stroke; and lived independently in the community (participants 2, 13 and 18 lived in small independent units/rooms within retirement village complexes). Participants also had normal to moderate mobility and those requiring a wheelchair were excluded from the study, as the larger study (Cruice et al., 2003) sought to minimise the impact of confounding variables, such as mobility limitations on QoL.

Participants' individual demographic information and language ability scores (WAB Aphasia quotient and subtests) are reported in Table 1, and means, standard deviations, and ranges for the sample are reported in Table 2. The range of WAB Aphasia Quotient scores indicates participants had mild to moderate-severe aphasia, with the majority of scores falling between 60 and 89 (primarily mild to moderate). A range of profiles was found: anomic (n=15), conduction (n=8), Broca's (n=3), Wernicke's (n=3), and transcortical sensory (n=1). These reflect a sample that was largely fluent with good auditory comprehension, and average naming and repetition skills.

Insert Tables 1 & 2 about here

Participants' mood on the day of interview was recorded using a self-report measure, the 15-item version of the *Geriatric Depression Scale* (GDS: Sheikh & Yesavage, 1986). Participants answered 'yes' or 'no' to 15 questions depending on how they had felt over the past week. Questions are counterbalanced, alternating positive and negative responses, and one point is counted for each depressive answer. A score of 0-4 indicates normal mood or emotional health status, 5-9 indicates mild depression, and 10-15 moderate to severe depression. Average mood for the sample is reported in Table 2. The majority (21) had normal mood or emotional health, six participants had mild depressive problems (5 women; 1 man), and the remaining three scored as moderately to severely depressed (1 woman; 2 men). Depressed participants (n = 9) tended to be older (mean of 75 yrs) than the normal mood participants (n = 21, mean of 69 yrs) at t = -1.96,

$p = .06$, and had significantly fewer years of schooling (mean of 9 yrs) than normal mood participants (mean of 12 yrs) at $t = 2.45$, $p < .05$. Normal mood and depressed participants were similar in terms of time post onset. Because mood is considered to influence reporting about one's QoL, depressed participants' responses were tracked through the data coding and analysis process. There were no discernable differences between participants with normal mood and mild depressive symptoms. A few points of difference were noted for participants more severe depressive symptoms, however the sample size ($n = 3$) was too small to be conclusive.

Interview Questions and Analysis

Participants were interviewed in their own homes using six open-ended questions, in a structured interview with the first author. The first five questions were drawn from existing gerontological research (Farquhar, 1995), and a sixth question specifically targeting communication was added. Farquhar's questions have been successfully used in large scale QoL research in ageing, cover important temporal elements (current and future), and encourage reflection of both the positive and negative in life. This final question exploring whether participants considered communication in their QoL was included for three reasons: firstly because communication is routinely ignored in most QoL conceptual theories, definitions, models, and questionnaires (Cruice, Worrall, & Hickson, 2000), it is theoretically relevant to address; secondly because the primary remit of speech pathology is communication ability, opportunity and effectiveness, it is central to scope of practice and professionally relevant to address; and thirdly, because these participants had an acquired communication disorder, it clinically relevant to address. It is important to note that this question is *neutral* referring to the impact of communication and not aphasia, and does not assume there is an impact.

A structured interview (asking the same open-ended unprompted questions in the same sequence of a number of participants) was considered the best method for comparability of the data. This interview procedure assumes that having questions consistently structured and ordered will reduce the influence that different interactions and levels of rapport can have on the quality of the data (Grbich, 1999). Questions were presented individually to the participant in written format, and also read aloud. Questions were rephrased for some participants who had difficulty understanding "give/take" (see below questions 2 and 3), and "what makes your life good/bad?" were used instead. Responses to the questions were not timed and participants were instructed to provide as little or as much information as they wanted. The interviewer did not probe responses, using a similar method as Farquhar (1995). It is important to note that the questions were *not designed* to guide an in-depth interview that aims to gain the insider's perspective like the phenomenological approaches that are currently popular in aphasiology and other neurogenic communication disorders (e.g. Baylor, Yorkston & Eadie, 2005; Parr, Byng, Gilpin & Ireland, 1997). The questions were as follows:

(1) (a) How would you describe the quality of your life? (b) And why do you say that?
(2) What things give your life quality?
(3) What things take quality away from your life?
(4) What would make the quality of your life better?
(5) What would make the quality of your life worse?
(6) Does communication have an impact on the quality of your life? If yes, then how?

Participant responses were audiotaped or transcribed verbatim online (if recording equipment malfunctioned or the participant requested not to be taped), and transcribed by the first author.

There were several stages in coding and analysing the data, and these are described below with illustrations of participants' responses to question two: What things give your life quality? Using content analysis (Patton, 1990), a research assistant read each participant's response to question two and categorised a word or a group of words as a *unit of data*. Example units of data included "growing orchids", "seeing my daughter and grandchildren", "movies", and "the horses play a big part in my life". Units of data from question two that were semantically similar were then coded as *concepts* and each concept was defined. For example, the units of "movies", "I go to the pictures", "so many things I can watch", and "going to the play" were coded as Entertainment, which was defined as "the activities which involve mainstream entertainment mediums and are the primary foci of interest for the individual (with the view that any additional/ potential interactions with people are secondary to the activity itself)". Concepts that were also semantically similar, for example, Occupational interests, Entertainment, Social activities, Personal interests, and Outdoor activities, were grouped together into a category (which in this case was Activities), and each of these was also defined. Categories are referred to as *factors* throughout this paper for ease of reading (this should not be interpreted as *statistical factor analysis*, which is not used in this study).

The process of identifying units of data, coding these into concepts and factors, and writing definitions, was conducted for each interview question, giving rise to 92 definitions of concepts and factors across all the data. Coding and analysis was undertaken by the second author, and regularly peer-checked with the first author. Consensus on unclear units of data was reached through discussion between first and second authors. Content analysis proved to be an effective method for analysing the current data, and has been the preferred method for analysis in previous large-scale QoL studies with normal older people in Canada (Fry, 2000) and England (Farquhar, 1995). Descriptive statistics (i.e. tallies of units of data and tallies of participants) were also used alongside the content analysis to identify and prioritise concepts in the data (Krippendorff, 1988), in a similar manner to Farquhar (1995). Results are presented according to the main factors that are important to participants' QoL, but do not include every small concept and category that emerged from the analysis. The study was approved by the Behavioural and Social Sciences Ethics Research Committee at the University of Queensland, Australia, and by the participating hospitals' ethics committees.

RESULTS

Results are presented in terms of 10 main factors that influenced current and future life quality of these older men and women with chronic aphasia, and are illustrated using units of analysis from participants' responses. The first four factors, Activities, Verbal communication, People, and Body Functioning, are considered *core* to QoL with chronic aphasia, as the factors appeared consistently throughout the responses and were mentioned by a substantial number of the sample (see Table 3). The remaining six factors *extend* what is important to QoL for these participants, and comprise Stroke, Mobility, Positive personal outlook, In/dependence, Home, and Health. These factors were mentioned less frequently and by fewer participants in the sample. The factors are pictorially represented as Figure 1, and the multiple concepts and categories that give rise to them are detailed in Appendix 1. Core factors are described first in the Results section.

Insert Figure 1 about here

Insert Table 3 about here

Activities

Activities was the most influential factor in the data affecting current and future life quality, in both positive and detrimental ways. Participants referred to activities using non-specific language, for example, “I can’t do what I used to be able before the stroke” but more typically mentioned specific activities. The variety of these activities suggested further categorisation, which gave rise to nine types of activity encompassing work-related interests (activities relating to previous occupation), personal interests (such as learning a foreign language, growing orchids, or fishing), entertainment (such as movies), social activities (such as dining or going out with friends), outdoor activities (such as walking around one’s garden), domestic activities (such as cooking, sewing, washing, ironing; “I do the cooking …I like to cook”), sports (such as swimming; “[I] used to play golf weekly”), literacy activities (reading, writing), and getting out or going away (such as going on trips). The meaningfulness of these activities was dependent on the individual participant. For example, not being able to learn Indonesian substantially impacted on participant 19’s life quality, as she enjoyed developing herself and her interests in her later years. Furthermore, some activities that were undertaken by several participants did not have the same meaning for all. For example, for participant 17, domestic activities were *essential* to her life quality and sense of self in her relationship with her adult daughter with whom she now lived:

> “I’d like to get up and ah…get out some. breakfast ..and then..give to P [daughter] .um wash up she goes to school or goes out and I could um do any washing or ironing..if I could do it” (response to question 4).

As well as the range of activities that appeared in the sample, participants qualified their level of involvement activities. Doing activities, having activities to do, and having the ability to do activities contributed to current or future life quality. Losing activities, being unable to do activities, and being limited in the way one does activities compromised life quality. Finally, some participants described how they had achieved QoL by changing the way they did their activities, accepting doing activities differently, experiencing success in doing activities differently, and trying new activities.

Verbal communication

Communication was understandably important in this study, and two thirds of participants referred to *words, talking* or *speaking* in generic terms when answering the first five interview questions. A few responses included specifically speaking (or not being able to speak) to another person (son, daughter, the family, or other people). This factor was intentionally defined as *verbal* communication, because of participants' emphasis on talking. This factor encompassed recognising one's own communication strengths, acknowledging the positive aspects of communicating with others (such as "speaking to my son", "[going to] discussion groups"), difficulties communicating verbally ("I know what I want to tell them but I can't in the words", "I can't speak anything, words you thinking, what can I say"), wanting better verbal communication ("I like to speech clearly", "oh just give me some better words! No no we don't want them all, because I I know what it is, it's just how to do that"), and concerns over losing their speech completely in the future. Participants were foremost preoccupied by their lack of current ability to talk or speak, and access words.

Participants also expressed concern about how they spoke ("I'm a bit slow on the talking", "I can't talk or say the right things", "I spose not as speak fluently as I used", and "Yes, I can't say what I want to say adequately, precisely and concise, without making a mess of it"), and compared themselves with past communication ability:

> "Before I had a stroke I used to go and have a talk good talk with someone – now I it's not alright, well it is and it isn't"

> "Yeah I was a good talker but not so good now. Sometimes particularly if I'm tired you know I can't say anything, I can't get anything out. But it's a lots better than it was. I guess I I don't talk too much like I used to, maybe it's a good thing…I even made speeches for ah against land mines and things like that".

Communication influenced participants' volunteering through formal ("see I used to go to Red Cross and I can't do that") and informal channels ("well I used to lot of painting.. to help other people.. can't do it now"); affected one man's movements in his community ("C [wife] and I go to town often but I don't go by myself..[aphasia] stops me going out..[it] depends on how people know you"); and severely comprised one woman's religious ministry to others:

> "You see and I'd go to these er. people and I'd tell you about something or what what the Lord would like to have, and all this sort of thing, and um..now I couldn't tell you how to to do of that. Yes I I can know I know what I want to tell them, but I can't in the words, you see, that's the words thing".

People

People were core to participants' QoL, and this factor encompassed having partners, family and other people in one's life ("[I] got good friends and got good family"), having partners for support ("I don't know what I'd do without my husband"), concerns over losing partners and family members (“I wouldn’t like to lose my husband”), and appreciating the social company of others (“good to be in contact with people”). There was a particular emphasis on family members in the data, with respondents especially naming their spouses or partners, children and grandchildren (“K and the baby”, “J plays a big part”). Name retrieval, which is typically difficult for people with aphasia, was often aided by using family photographs in the participant’s home. Whilst references to friends did appear in the data, only four participants mentioned them, and the non-specific category of ‘other people’ was more common.

Body functioning

Body functioning emerged as important to QoL across the interview questions, and thus is considered a core factor. However, it is important to note that less than half of the sample (8 men, 6 women) referred to body functioning, suggesting slightly less importance overall than three core factors already explained. This factor comprised the difficulties and changes in participants’ physical functioning (the use of named body parts which were arm, hand, knee and leg; e.g. “not being able to move the hand”, “having to write with my left hand”, “get your arm back”), cognitive functioning (“some things I can’t always remember”, “not being able to think properly”, “[I’d like to] being able to think more clearly”), and sensory functioning (“I don’t taste [things] as well [as I used to]”). Most participants were concerned about their body functioning in general, that is, they expressed concern about their current limitations and difficulties, and they desired improved functioning in the future. A few participants only expressed concern about losing their existing functioning in the future.

Stroke

As anticipated, there were many references in the data to the stroke as detracting from current life quality. Furthermore, nearly one third of participants were concerned about having a *second* stroke in the future.

Mobility

Participants valued their current mobility (e.g. “being able to walk around the house and garden”), and also desired to “be able to walk around as usual” or “walk better”. Restricted mobility detracted from life quality (e.g. “I can’t walk so good yet”, “It’s hard to physically move…we have a restraint imposed upon us”), and participants were concerned about potential loss of all mobility on future life quality (e.g. “if you were confined to a wheelchair”, “not being able to walk, move along”). This factor also included two participants’ responses that described using their scooters to move about their local environment. Mobility is an important consideration as it enables access to the local community, which in turn provides opportunities to communicate with others.

Positive personal outlook

This factor emerged from participants reflecting an attitude of acceptance or defiance over their situation (such as “it’s not what it used to be but you got to accept it”, “it doesn’t worry me, I’ll just say bugger ya, I don’t care”) or indicating a positive outlook overall (“life’s worth living”). A few participants (all female) described how they felt about being able to manage (“if I take me time, I succeed. I feel capable”). This positive attitude was noted particularly in relation to activities that were difficult for the person, who then followed up with comments such as “but I’m still getting better. [I’m] very stubborn”, “but other than that I’m good”, and “but I think on this I can cope”. Encouraging a positive outlook on life and adjustment to current abilities and the post-stroke life situation may not be possible for all clients, but for those who can, it is likely to improve their life quality after their stroke and aphasia.

In/dependence, Home, and Health

Participants sometimes mentioned their dependence on others compromising their QoL, for example, “you’ve always got to have something [sic: some*one*] else there” and “the feelings of helplessness, the little things you can’t do for yourself”). This factor was typically mentioned with reference to a specific desire, for example, one woman wanted more independence from her daughter and family (“[I] would like to move into a little house maybe I’ll cope by myself”), and two men wanted to be able to drive in order to independently get to places. It is likely that altered physical functioning and general stroke consequences have contributed to these participants’ experiences, however it is reasonable to suggest that altered communication functioning may also contribute to a person’s sense of independence.

As seen above, being in one’s own home contributed quality to life (“[I] have my house”, “house is important”), while the loss of home (“you had your own place and everything gone”) and the possibility of changing home circumstances (“if I had to go into a nursing home, I wouldn’t like that very much”) detracted from life quality. Finally, health problems were mentioned on a few occasions as affecting the quality of participants’ lives (e.g. “the diabetes pulls me down”).

DISCUSSION

Main findings

The findings of this study suggest that many of the factors that influence QoL with aphasia are shared with their peers. Relationships, social activities, psychological well-being (specifically positive disposition), mobility, home, health, helplessness, and independence have previously been identified in normal ageing research (Bowling et al., 2003; Farquhar, 1995). However, influential factors such as ill health, financial circumstances, old age, and being unhappy or miserable (Bowling et al., 2003; Farquhar, 1995) were not raised in the current study, and need further consideration for their relevance for older people with chronic aphasia.

The current study demonstrates that activities are fundamental to QoL with aphasia, just as they are crucial for non-aphasic stroke survivors (Bays, 2001) and normal older people (Bowling et al., 2003; Farquhar, 1995; Gabriel & Bowling, 2004; Nilsson, Ekman, & Sarvimäki, 1998). The variety of activities described by participants, and qualifiers associated with them, suggest that comprehensive information about life activities is needed to contextualise a client’s intervention. Although not demonstrated in this study, activities can be a vehicle for contributing to others’ lives and society in general. Previous research has found that helping others and having purpose in life is important for QoL in ageing (Cruice et al., 2003; Guse & Masesar, 1999; Trombetti, 2006), and that volunteering is linked to high levels of happiness (Oishi, Diener, & Lucas, 2007). Thus, the meaning or reason for engaging in activities needs probing in future research.

The restrictions in people’s activities have been noted in previous aphasia research (Le Dorze & Brassard, 1995; Zemva, 1999). Reduced involvement in activities is associated with poorer HRQoL (Hilari et al., 2003) and is predictive of both HRQoL and psychological well-being in people with aphasia (Cruice et al., 2003). In non-disability fields, social and daily activities are generally considered to be very important to personal development, as they are seen as “the primary means by which broader life goals are pursued and attained" (Horgas, Wilms, & Baltes, 1998, p. 556). They are associated with the notion of successful ageing, as well as social approval, ego involvement, self-actualisation, self-esteem, adjustment and happiness (Lemon, Bengston, & Peterson, 1972; Reitzes, Mutran, & Verrill, 1995). Thus engaging in activities will be essential for successful living or quality living with aphasia, noting too that it is often the meaning and significance of an activity, rather than the activity itself, which is important (Lundh & Nolan, 1996).

Because people's responses were not probed, it is difficult to state what the causes of individuals' difficulties with their activities were. There is however an inferred impact of altered expressive speech, altered body functioning of right arm, hand and leg, and altered mobility on activity engagement. Future research could better delineate the relative contribution of these factors in activity engagement, as well as identify the influence of environmental barriers, facilitators, and personal choice. The relationships between physical functioning, communication functioning, and general stroke consequences with independence and living situation also need to be explored for each individual. Similarly, the home was infrequently mentioned by respondents in this study, but deserves exploration in future research as it is especially important for older people's QoL (Gabriel & Bowling, 2004). Speech and language therapists may have a role in advocating for the person with aphasia if their voice cannot be heard in decision making around living arrangements after hospital.

Difficulties speaking or talking and finding the right words to express oneself was the dominant interpretation of the impact of communication on QoL in this research. This is similar to other findings wherein participants have focused greatly on expressive speech difficulties (e.g. Le

Dorze & Brassard, 1995) and reinforces the link between language functioning and well-being as noted by Cruice et al. (2003). What was somewhat unexpected was the lack of specific references. In the entire data, there are only nine references to talking to *people* (three are talking to family, son and daughter) and there are two references to talking *on the phone*. Participants did not report the variety of difficulties found in previous research (Le Dorze & Brassard, 1995), such as difficulties speaking in a group because of number of speakers, and pace of conversation. “Not being able to talk’ was a core factor in this research and is unique to this study’s population. It is likely that the general nature of the questions used in the current research resulted in less specific descriptions regarding communication. For example, participants in Le Dorze and Brassard’s study were asked to comment on difficult communication situations, and also describe what they did in order to avoid such difficulties. In future research, using more specific questions, combined with probing people’s responses, will uncover a more comprehensive picture of communication in QoL. Finally, participants did not comment on any difficulties with auditory comprehension or understanding, and this needs probing. Professionals assume that auditory comprehension ability influences QoL, for example by impacting on intimate and group conversations and relationships and creating frustration through misunderstanding, however this may not be the case.

Social contact is highly important to healthy older people, being ranked at the same level as their health (Farquhar, 1995), and this research confirms the importance of having people in one’s life and socialising with others as central to QoL in older people (Nilsson et al., 1998). There is little description however of the *quality* of aphasic people’s relationships. For example, *good* social relationships were the most mentioned factor in giving quality in life (Bowling et al., 2003), and changed interpersonal relationships is a significant and recognized consequence of aphasia, for example, “friction with spouse, loss of friends, loss of means for making social contacts, [and] efforts required to create new friendships” (Le Dorze & Brassard, 1995, p246). It is difficult to ascertain how much impact aphasic language difficulties had on people’s ability to express their thoughts, that is whether their difficulties limited them in fully discussing their relationships. It is equally possible that the lack of specific questioning and probing meant the interviews did not reveal this feature. Similarly, few friends were mentioned in the data, and the respondents did not comment on any loss of friends as having any impact on their life quality. This may disadvantage people with aphasia in attaining good QoL, as the presence and support of friends, as well as relatives, has been linked to positive well-being in healthy older people (Bowling, Farquhar, Grundy, & Formby, 1993).

The data also shows that functioning of one’s right arm, leg and hand, memory, taste, and mobility are important influences on QoL of people with aphasia after a stroke. This finding was anticipated because functional status, particularly in the upper extremities, is important to the QoL of stroke survivors (Bays, 2001) and healthy older people (Bowling & Gabriel, 2004). Whilst body functioning is clearly the remit of physiotherapy and occupational therapy, physical and cognitive limitations can impact on communicative activities and opportunities, and thus are relevant for consideration in speech and language therapy. Future inclusion of participants using wheelchairs for mobility will also implicate the need for physical therapies involvement. There was however very low representation of general health issues within the sample. There are only six references in the data, which focus on diabetes, lymphoma, and throat and respiratory infections, and there is no mention of pain. By contrast, in healthy older people, health is a major determinant of life quality (Bowling et al., 2003; Bowling & Gabriel, 2004; Farquhar, 1995; Gabriel & Bowling, 2004; Nilsson et al., 1998). One infers then that either the majority of respondents in this sample had no health problems, or, that health problems did exist in greater numbers of respondents, but they were of less priority in determining life quality now after stroke and aphasia, than for non-disabled older people.

Although a minor theme, there is evidence in the data that respondents' personal outlook influenced their perceptions of their lives and thus their life quality. This finding is similar to that of a study of 999 British elderly, wherein positive psychological outlook and acceptance of circumstances that cannot be altered, emerged as central to QoL (Bowling & Gabriel, 2004; Gabriel & Bowling, 2004). In the current study, personal outlook included positive attitude, adjustment to and acceptance of current state and new ways of doing things, and a sense of coping and managing. There is evidence in this study that the aphasic respondents were making adjustments to their lives similar to older people who adjust to changes brought about by ageing. These adjustments are considered compensation and accommodation processes, and involve replacing current activities with other ones, and using different means to achieve the same goal (Baltes & Carstensen, 1996; Lundh & Nolan, 1996).

A final point for discussion is the methodology. The current study used unprompted and structured interviewing with set questions and applied content analysis to the data, which is different from in-depth interviewing and framework method analysis (Parr et al., 1997) that we are familiar with in aphasia research. The strengths of the interviewing approach include being able to gather the perspectives of large numbers of participants (N = 179 in Cruice, 2001) in a time efficient manner, meaning the technique is attractive for inclusion in an otherwise large assessment battery (see Cruice et al., 2003). The strengths of the approach to analysis include a bottom up or data driven approach to identifying findings, with clearly defined concepts meaning that data can be traced and coded by persons unfamiliar with the original analysis. However, there are also weaknesses arising from the lack of probing or prompting of participant responses, meaning it is inappropriate to infer relationships or causation in the data. This also means that participants' responses may not reflect their full appreciation of QoL. Further research is also needed to reflect on how participants respond to different questions when considering their QoL, and which questions are appropriate for the individuals in question. For example, some participants did *not* mention communication in any of their responses to the first five questions; and not all participants found the final question helpful, with some having particular difficulty answering it (e.g. being unable to elaborate on one word responses or giving contradictory responses). Both these observations suggest further attention to the methodology of exploring QoL with people with aphasia is needed in future research.

Several directions for future research have already been suggested above, however three further points are made here. Firstly, in-depth interviews and/or focus groups are needed to explore the breadth and depth of the concept of QoL of older people with aphasia. More specific questions about barriers, facilitators and personal choice in activities and participation in life are needed to determine the relative impact of aphasia on QoL amongst other factors, such as functioning and mobility. Probing is also needed to fully explore participants' responses, especially to raise points such as how meaningful activities are to the individual, whether comprehension difficulties impact on QoL, and how important friends are to QoL. Secondly, future studies need to include different people with aphasia: – individuals without any physical difficulties; individuals with severe physical difficulties (i.e. wheelchair users); individuals with greater comprehension difficulty; individuals with more severe language impairment (of either form); and younger participants who may be more likely to report the impact of employment and finances on life quality. Thirdly, identifying the factors that create quality living with aphasia would be worthwhile, that is, what participants specifically identify as improving their life quality.

Clinical implications

Maximising a patient's sense of well-being and QoL is an important element of intervention for aphasia. For example, this goal constitutes one of the three core aims in stroke rehabilitation within the United Kingdom, according to the Royal College of Physicians' (RCP) *National clinical guidelines for stroke* (RCP, 2004). Subsequently, activities, communication, people, and functioning should be carefully explored with each aphasic stroke client from the outset of their rehabilitation. This is clearly best undertaken with the rehabilitation team as a whole as the client's perceptions of their QoL are equally important to all team members. The findings suggest there is a *continuum of ability* associated with activities, from having the ability to do them through to losing an activity completely from one's life. This implies that professionals need to explore each activity separately with each client, and not assume a similar level of ability across activities. Furthermore, there would be value in exploring how clients individually adjust their activities in order to maintain life quality in the face of their altered functioning and ability. Speech and language therapy (SLT) intervention would ideally target the improvement of clients' QoL (RCSLT, 2005), with a focus on expressive speech in SLT rehabilitation (potentially through conversation therapies), but also with a focus on developing and highlighting people's communication strengths. There is a clear role for clinicians to support the maintenance of relationships with family and wider social contacts, but also consider facilitating older people with aphasia to re-establish relationships with their friends (or develop new friendships) through meaningful activities. As indicated earlier in this paper, some factors such as health, home, stroke, and mobility lie beyond the direct scope of the speech and language professional, however, they are relevant for consideration in the overall context of intervention and knowing what is important to the individual client. For example, although the speech and language therapist is not responsible for managing someone's health, the clinician does have a role in contributing to further stroke prevention, by making client education materials (stroke prevention strategies, exercise, diet, etc) communicatively accessible for the client with aphasia.

CONCLUSION

This study provides preliminary evidence for the broader life quality issues of older people with a chronic mild to moderate aphasic impairment. Ten factors were identified as influencing current and future life quality, and encompass what people do (activities), who they share their life with (people), how they express themselves (verbal communication), their physical status (body functioning, stroke, mobility, and health), mental attitude (positive personal outlook), and independence. The findings highlight the need for further QoL research, using in-depth interviewing and different qualitative analysis techniques, to explore a broader range of QoL perspectives of different subgroups of people with aphasia.

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Table 1. Individual demographic information and functioning of aphasic participants, N = 30.

Participant Number	*Gender*	*Age*	*Years of Schooling*	*Previous Occupation*	*Months Post Stroke*	*GDS Score*	*WAB AQ*	*Physical Functioning**
1	M	64	19	marine engineer	42	2	91.9	2
2	F	68	7	receptionist	33	11	71.7	5
3	M	66	16	engineer	31	3	70.3	5
4	M	66	15	yachtsman	73	3	85.1	4
5	M	60	12	radio station manager	84	3	66.0	5
6	F	75	11	teacher	66	8	61.0	5
7	M	67	11	bank manager	79	0	80.5	4
8	F	65	9	secretary	83	4	30.0	4
9	F	78	11	clerk telephonist	27	5	82.1	5
10	M	76	20	clinical pharmacologist	10	2	91.4	5
11	M	69	14	clerk	21	2	63.8	3
12	M	72	6	ferry boat driver	63	1	93.7	1
13	F	64	7	betting agency supervisor	65	1	78.0	3
14	M	72	6	public servant	46	12	64.2	5
15	F	80	9	housewife	27	1	85.9	4
16	M	81	8	foreman/ supervisor	23	5	72.9	2
17	F	88	8	housewife	27	5	66.0	5
18	F	81	7	shoe sales assistant	42	2	61.2	4
19	F	68	11	nursing assistant	13	6	95.2	5
20	M	57	8	harness maker	21	2	95.7	4
21	F	79	8	unable to describe	24	1	49.3	4

22	M	63	14	boilermaker	108	2	21.9	3
23	F	77	10	book keeper	15	2	59.1	3
24	F	72	7	corner store owner	23	0	87.8	4
25	F	88	9	teacher	11	0	78.1	4
26	M	77	10	police officer	48	12	64.4	5
27	F	69	7	betting agency worker	19	5	94.8	4
28	M	60	9	caravan park operator	23	3	87.1	1
29	F	59	15	art worker	38	2	85.2	4
30	F	61	19	radiographer	49	3	95.8	3

* Using the Physical Fitness Dartmouth COOP Chart, participants reported what hardest level of physical activity they could do for at least 2 minutes, during the last 4 weeks. Increasing numbers indicate poorer levels of physical fitness. Legend is as follows: 1 = very heavy (run at fast pace, carry a heavy load upstairs or uphill); 2 = heavy (jog at slow pace, climb stairs or hill at moderate pace), 3 = moderate (walk at a medium pace, carry a heavy load on level ground), 4 = light (walk at a medium pace, carry a light load on level ground), and 5 = very light (walk at a slow pace, wash dishes).

Table 2. Average demographic information, language ability and mood scores of aphasic participants, N = 30.

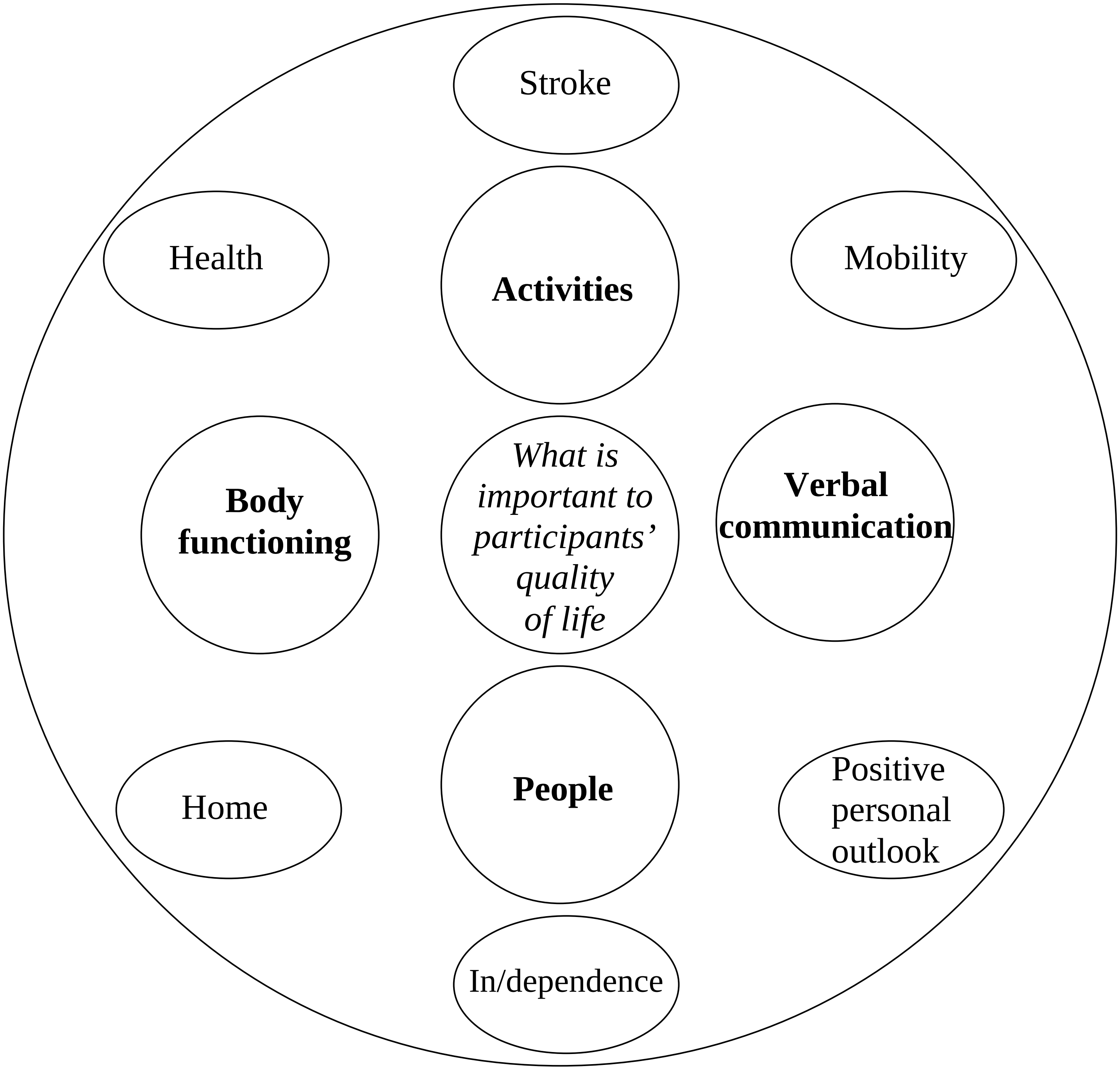
	Mean	**Standard deviation**	**Range**
Age	70.7 yrs	8.4	57-88
Years of Schooling	10.7	3.9	6-20
Time post onset (months)	41	25.6	10-108
WAB AQ	74.4	18.6	21.9 – 95.8*
Fluency	15	4.2	4 – 20
Comprehension	8.5	1.3	6 – 10
Repetition	6.9	2.9	0 – 10
Naming	6.7	2.4	0 – 9.5
GDS Score	3.6	3.31	0 – 12

* Four participants were above the standard WAB cutoff of 93.8 but still displayed aphasic language impairments.

Table 3. Number of participants referring to each factor during their interview (maximum possible is 30).

Factor	***Number of participants***
Activities	28
Verbal communication	24
People	27
Body functioning	14
Stroke	16
Mobility	11
Positive personal outlook	10
Independence	4
Home	6
Health	3

Figure 1. Pictorial representation of factors in quality of life.



Appendix 1.

This appendix is an illustration of how the 10 factors were generated from the categories and concepts in the data. The first factor, Activities, is completely worked through, that is, the categories and their definitions, and concepts and their definitions, are included. For the remaining 9 factors, definitions for both categories and concepts *have not been included* because it would exceed an appropriate length.

Factor: Activities

Question	***Category***	***Definition of category***	***Concepts within the category***	***Definition of concept***
1b	Things people can still do	Participants must refer to something that they do either inside the house, outside the immediate environment, or extended area (e.g. scooter) but which does not include references to other people/socialising.	N/A	N/A
1b	Limited/ loss of ability to do things	Participants must refer to things that they either can no longer do, have difficulty doing, do in a different way, or to what they'd like to be able to do. Excludes reference to verbal communication/ cognitive functions/ body parts.	N/A	N/A
2	Activities	Things that people said that they enjoy doing/ and or participating in and consists of five concepts:	Occupational Interests	Activities must be related to an individual's previous/present occupation *(as checked by self-reported participants' occupations).*
			Entertainment	These activities must involve mainstream entertainment mediums and be the primary foci of interest for the individual (with the view that any additional/potential

				interactions with people are secondary to the activity itself).
			Social activities	Activities that involve meeting up with/doing things with other people and are in some way organised e.g. between the interviewee and a specific group of people or through a specific place (i.e. University/Day respite centre).
			Outdoor activities	Activities that must take place outside and that do not include other people (e.g. the participants do not directly refer to a specific person or group of people when speaking about these activities).
			Personal interests	Activities that only relate to personal/individual interests (are only mentioned by one participant) and which are not related to previous/present occupations or people.
3	Activities	Things that people can either no longer do, have difficulty doing, would like to be able to do, or that they do differently to how they used to do them (excludes references to verbal communication/impairments) and can be	Sports activities	Participants must name a sport or a venue for a sport

		separated into four concepts:		
			Personal interests	Participants must name an activity that is not shared (repeated) by any of the other participants who answer this question.
			Domestic activities	Responses within this category must relate to the home/day to day living i.e. sewing and cooking. These activities are not perceived to be related to personal interests.
			Literacy	Participants must refer either to reading or writing difficulties but not a body part (i.e. hand).
4	Ability to engage in activities	Activities that people would either like to be able to do/ or be better at and can be separated into four concepts:	Literacy	Participants must refer to reading and/or writing and may also refer to computers. This sub-category excludes verbal communication with others, and is not place specific.
			Getting out/going away	Participants must refer to ‘going out’ as an activity in itself and which is not (directly) related to another activity/person but which may involve going to a specific place (e.g. town), or the idea of going away for an extended period of time e.g.

				so as to get away/ go on a trip/ have a holiday.
			Domestic activities	Participants must refer to activities take place in their own home
			Personal interests	Responses within this category must focus on the participant’s personal interests (which are not mentioned by more than one participant) and which involve being in a place specific to the activity in order to carry it out (e.g. University/outdoors).
5	An inability to do things	Participants must make a general reference to an inability to do things and may also provide examples, but which exclude references to: mobility, body- parts, people, another stroke, or their speech. Participants may also refer to the amount they might not be able to do, or the worth of these things.		
6	Things that participants no longer do	Participants must refer to specific things that they used to do which either involved helping/ speaking to a group of people or going to a specific place.		

Remaining 9 factors

Factor	***Question***	***Category***	***Concepts within the category*** *(when applicable)*
Verbal communication	1b	Impairments	Communication
	2	Communication	
	3	Verbal communication difficulties	
	4	Better verbal communication	
	5	Poor/ loss of speech	
	6	Communication strengths	Speaking
	6	Communication difficulties	Verbal communication
People	1b	People	
	2	People	Partners Family Other people
	5	Losing people	
	6	Other people (positive examples)	
Body functioning	1b	Impairments	Cognitive Physical
	3	Impairments	Cognitive Sensory Physical
	4	Full use of body parts/ functioning	Body Parts Cognitive
	5	Loss of/ impaired body parts	
Stroke	1b	The stroke	
	3	The stroke	
	4	No stroke	
	5	Another stroke	
Mobility	2	Mobility	
	3	Impairments	Restricted mobility
	4	Full use of body parts/ functioning	Impact on mobility
	5	Loss of mobility	

Positive personal outlook	1b	Positive personal outlook	Abilities Attitude to difficulties
	2	Positive outlook	
In/dependence	3	Dependence on others/ loss of independence	
	4	More independence	
Home	1b	Other (positive) Other (negative)	Place Home
	2	Home	
	5	Other (moving from home)	
Health	1b	Other (negative)	Health
	3	Poor health	
	4	Other	
	5	Poor health	