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**Health-related quality of life and aphasia severity: a  
pilot study for the New Zealand population.**

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## **Background**

In previous studies that have investigated quality of life (QOL) of stroke survivors, stroke survivors with aphasia have often been excluded. The Stroke and Aphasia Quality of Life scale (SAQOL-39) is a new reliable measure, which has recently been used with British stroke survivors with aphasia to investigate health-related quality of life (HRQL). This measure is beneficial for clinical decisions and rehabilitation outcomes for stroke survivors with aphasia.

## **Aims**

This study aims to describe the characteristics of a New Zealand group of stroke survivors with aphasia. The study also aims to explore the relationships between: an impairment-level measure and functional-level measure; HRQL and time post-stroke and; HRQL of British stroke survivors with aphasia compared to a New Zealand group of stroke survivors with aphasia.

## **Methods**

Ten participants were recruited by speech-language therapists from two health-care providers. Demographic information of the participants was obtained through informal discussion with participants and/or speech-language therapists.

Administration of the Western Aphasia Battery (WAB) and the SAQOL-39 took place in either the participants' home or speech-language therapy clinic.

Pearson correlations, repeated measures analysis of variance (ANOVA), z-tests, and descriptive statistics of the New Zealand stroke survivor aphasia group were the main statistical procedures conducted for this study.

## **Results**

The ten participants ranged in age from thirty years to seventy-two years of age. There was an even number of males and females, slightly more participants with fluent aphasia than nonfluent aphasia, slightly more participants older than sixty-five years of age than participants younger than sixty-five years of age, and 70% of the participants had a communication partner. All participants lived independently in the community.

A significant negative correlation was found between time post-stroke and the physical quality of life (QOL) domain ( $r = -0.719$ ). The homogeneity of variance assumption was met for the New Zealand stroke survivor aphasia group. Descriptive statistics of the New Zealand group for the variables - type of aphasia, sex, communication partner, and age were calculated. Results suggested that there were no significant differences between the different levels within these variables in determining QOL and overall HRQL. The only exception was for sex in the energy QOL domain, in which there was a notable discrepancy between males and females in their perceived energy QOL scores. A general description of the distribution of the New Zealand aphasia group is also provided.

### **Conclusions**

Aphasia severity and HRQL are not significantly related to each other, as time post-stroke increased – perceived physical QOL decreased, there are differences between New Zealand stroke survivors with aphasia and their British counterparts, several demographic variables played an insignificant role in determining HRQL, and energy QOL is the poorest perceived QOL domain.

Speech-language therapists should use the SAQOL-39 to acknowledge the significance of HRQL in making clinical decisions and speech-language therapy services should seek to address the HRQL areas that have the lowest perceived QOL.

### **Keywords**

Health-related quality of life (HRQL), quality of life (QOL), aphasia, Western Aphasia Battery (WAB), Stroke and Aphasia Quality of Life scale 39-item version (SAQOL-39)

## Introduction

There is currently a wealth of research looking at the health-related quality of life (HRQL) of people who have had a stroke (Tengs, Yu & Luistro 2001). However, the vast majority of this research looks at stroke as one entity, not breaking it down into the very different symptomatology that can result (Gresham, Kelly-Hayes, Wolf, Baiser, Kase, & D'Agostino 1998). Research needs to ascertain the HRQL of those whose strokes have resulted in aphasia, an acquired neurogenic language disorder, as in the past most stroke QOL scales have excluded those with aphasia - "Although a number of stroke-specific quality-of-life scales have been developed most exclude stroke survivors with aphasia and/or cognitive decline who are in fact those most prone to social isolation and exclusion." (Hilari, Byng, Lamping, & Smith 2003a: 1944). Exclusion of individuals with aphasia has been acknowledged in the literature as early as the year of 1988 when Niemi, Laaksonen, Kotila & Waltimo (1988: 1106) stated that "speech disturbances had no effect on the quality of life. However, three of the nine patients with severe aphasia could not deal with the questionnaire and, thus, our results probably underestimate the importance of aphasia".

The definitions of HRQL and aphasia are as follows: Quality of Life (QOL) is defined as "individual's perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. Health-related quality of life refers to those aspects of life affected by disease" (Sturm *et al.* 2004b: 2340).

Aphasia is defined as: "an impairment, due to acquired...damage of the central nervous system, of the ability to comprehend and formulate language. It is a multimodality disorder represented by a variety of impairments in auditory comprehension, reading, oral-expressive language, and writing. The disrupted language may be influenced by physiological inefficiency or impaired recognition, but it cannot be explained by dementia, sensory loss, or motor dysfunction" (Ross & Wertz 2003: 357).

Chapey (2001) discussed what she termed 'aphasia chronicity' which is when one considers the permanent consequences of a stroke, associated with aphasia and how to maximise the effectiveness of rehabilitation and treatment outcomes. "... focus on remediation of the consequences of aphasia's chronicity, that is, how we might establish effective methods and procedures for restoring meaning, purpose, comfort, and pleasure to daily life,..." (Chapey 2001: 299). Chapey (2001) also discussed the importance of looking beyond traditional aphasia therapy that focuses on improving linguistic areas of difficulty only. By adopting more of a social model, this allows for other difficulties to be addressed such as psychosocial issues, and acknowledging the potential impact aphasia post-stroke has on social participation and engaging in daily living activities.

Pound, Parr, Lindsay & Woolf (2000) discussed models of disability and contrasted the medical model with the social model (which arose from British disability theory). The social model challenged the traditional medical model approach to rehabilitation by saying that aphasia therapy should go beyond the impairments of an individual and include the disabling social barriers that can perpetuate a disability or handicap. "According to the social model, people are disabled, not by their own inabilities but by the socially constructed barriers which spring up around them" (Pound *et al.* 2000: 7).

By understanding the impact that aphasia has on HRQL, this will provide information about how to provide appropriate rehabilitation to stroke survivors with aphasia. "Measures of HRQL are particularly relevant in stroke when the key aims of rehabilitation are to facilitate adaptation to disability, to promote social and community integration, and to maximize well-being and quality of life." (Hilari *et al.* 2003a: 1944).

Until the publication of the 'Stroke and Aphasia Quality of Life scale 39-item version' (SAQOL-39), there was no reliable measure of HQRL for stroke survivors with aphasia –with the publication of this tool, the intention of this study is to ascertain the relationship between aphasia severity and

HRQL for stroke survivors with aphasia and this would be done by comparing an impairment-level assessment - the WAB to a functional-level assessment - the SAQOL-39.

It would be envisaged that HRQL would increase, as language functioning ability increased. This hypothesis is supported by the research of Bakheit, Carrington, Griffiths & Searle (2005) which found a significant correlation ( $r = 0.71$ ) between the WAB and the Communicative Effectiveness Index (CETI) where the greater the language functioning (WAB score), the greater the patient's functional communicative competence (CETI score).

The value of this data may allow patients to be highlighted on the case loads of speech-language therapists who may be at risk of low HRQL and which subsequently may have a negative impact on therapeutic outcomes. This is the first study that has investigated this relatively new tool in a New Zealand population. It will be of interest to compare HRQL of New Zealand stroke survivors with aphasia to previously published British data. This is important, as representativeness of the New Zealand sample can be considered and comparisons can be made with British data (Hilari *et al.* 2003a: 1949).

### **Clinical decisions for speech-language therapists**

Speech-language therapists sometimes make clinical decisions that can impact on individuals with aphasia (Robey 1998). Such decisions are guided by clinical experience and scientific evidence in health care (Robey 1998).

Kaplan (1994) discusses what he calls the 'Ziggy Theorem' which is a model that helps refine and focus clinical decisions in healthcare. The model has two key components which direct the purpose of healthcare: "to make people live longer and to enhance quality of life in the years before death" (Kaplan 1994: 451). The goal that arises from such principles is the goal that stresses "doing stuff" which means being alive and having the necessary capacity to participate in the desired activities for an individual (Kaplan 1994).

Assuming the Ziggy Theorem, speech-language therapists would need to emphasise not only rehabilitating the linguistic areas of speech and language most affected, but ensuring those areas worked on are having a positive functional impact on all the daily living activities for an individual. QOL scales are scales that should be considered as assessing only psychosocial and psychobehavioural aspects of an individual's life (McHorney 2002). The necessity of such scales for clinicians is that they help to assess the impact that the disease, treatment and natural history has on the QOL of an individual (McHorney 2002). These QOL aspects cannot be assessed by other assessments such as physiological assessments and such QOL scales could identify any aspects of an individual's life that are seen as poor and impacting on function (McHorney 2002).

### **Health-related quality of life (HRQL) for stroke survivors**

Tengs, Yu & Luistro (2001) reviewed 67 articles that appeared in peer-reviewed journals between the years of 1985 and 2000. What they found was there is an increasing number of people surviving their stroke and having to live with and adjust to the consequences of having a stroke. "The number of people who survive stroke and live with its consequences is increasing. The case fatality rate for stroke has declined over the past few decades, and 85% of people who experience a stroke now survive." (Tengs *et al.* 2001: 964).

The obvious implications of this figure are that there are many people who would require after-stroke care and treatment. Because of this it would be necessary for clinicians to view a client not just as a "survivor" but as an individual who requires adequate post-stroke assessment of therapeutic and treatment progress.

"This increase in survival has necessitated a new approach to measuring the health outcomes associated with stroke prevention, treatment and rehabilitation. Survival rates, once a helpful measure of preventive or therapeutic success, are no longer adequate for the task." (Tengs *et al.* 2001: 964).



## **Health-related quality of life (HRQL) for stroke survivors with aphasia**

Ross and Wertz (2003) conducted a study which aimed to assess if psychosocial symptoms experienced by stroke survivors with aphasia differed from their “normally-ageing” peers which were referred to as “non-brain-injured (NBI)” controls.

For the participants with aphasia they had to meet the criteria of at least one stroke (of which 6 months must have elapsed post-onset of stroke), brain damage restricted to the left hemisphere only, no other disorders that would have a significant impact on communicative abilities, and a diagnosis of aphasia.

The two scales that were used to assess QOL in the Ross & Wertz (2003) study were the ‘World Health Organisation’s Quality Of Life Instrument’ (WHOQOL-100) which addressed six areas- physical, psychological, independence, social, environment and spiritual. There was not a ‘communication’ domain. The other scale was the ‘Psychosocial Well-being Index’ (PWI) which aimed at assessing key constructs of QOL with aphasia (Ross & Wertz 2003).

Results indicated that components of three of the domains of the WHOQOL-100 best differentiated aspects of QOL between those stroke survivors with aphasia and those stroke survivors without aphasia. Within the area of independence – they were the participant’s ability to perform daily activities, to work and easily move about during the day in different environments (Ross & Wertz 2003: 361). Within the area of social relationships, they were the participant’s satisfaction with support received from friends and the satisfaction from their sex lives (Ross & Wertz 2003: 361); and lastly within the environment area – how well the participants could obtain information, access health services and use transport (Ross & Wertz 2003: 361).

Ross & Wertz (2003) highlight the point that by adopting a more social approach to disability post-stroke that speech language therapy will be better guided to take into account pertinent psychosocial factors for a stroke survivor with aphasia.

However, the limitation of this study was that it used QOL scales that had psychosocial areas which had not been deemed as relevant to the aphasia population. Because of this, the psychosocial areas

(and factors within the areas) may have not been significantly important to assess for individuals with aphasia and hence not an accurate representation of those health-related areas of life most affected post-stroke.

### **Scales that measure quality of life post-stroke**

Haan, Horn, Limburg, Van Der Meulen & Bossuyt (1992) compared several stroke scales – the ‘Orgogozo Scale’, the ‘National Institutes of Health Scale’, the ‘Canadian Neurological Scale’, the ‘Mathew Scale’, and the ‘Scandinavian Stroke Scale’.

The objectives of this study were to examine at 6 months post-stroke any relationships between neurological impairments and functional health; to ascertain which aspects of the stroke scales were the most crucial to explain functional outcomes, but most importantly, the extent to which the impact of the impairments were reflected in the appropriate stroke scales (Haan *et al.* 1992: 1178). 5 stroke scales were highly related to each other ( $r = -.85$  to  $.92$ ) (Haan *et al.* 1992) but Haan *et al.* (1992) found that the stroke scales only partly explained all of the 87 participants’ level of disability (now called ‘functioning’ Threats & Worrall 2004; Ross & Wertz 2005), handicap, and QOL. The stroke scales correlated poorly with psychosocial conditions  $r$ -squared value = 11.5. The stroke scales failed to account for psychosocial aspects which needed to be addressed if a person was to be viewed holistically.

Anderson, Laubscher & Burns (1996) used a scale for assessing individuals who have had a stroke, called the ‘Short Form 36 health survey questionnaire’ (SF-36). This scale is comprised of eight scales: physical functioning, role-limitations (physical, bodily pain, general health, vitality and social functioning) and role limitations (emotional and mental health) (Anderson *et al.* 1996).

A pitfall of this scale is that it does not assess everyday activities and social functioning (nor does it have a specific communication section). Therefore, the SF-36 had to be supplemented with the ‘Adelaide activities profile’ (AAP) which assesses an individual’s capacity to do a vast array of

everyday tasks such as domestic chores, and social activities like outdoor sport (Anderson *et al.* 1996).

Ferucci, Baldasseroni, Bandeinelli, Alferi, Cartei, Calvani, Baldini, Masotti & Marchionni (2000) took their research one step further and investigated if there was a relationship between HRQL and the severity of the ischaemic stroke and two other chronic conditions, Parkinson's disease and coronary heart disease.

Ferucci *et al.* (2000) used the 'Fugl-Meyer' scale (FMS) to assess the neurological damage of hemiplegia and the Sickness Impact Profile (SIP) to look at self-perceived limitations in roles and activities. They found that there was a significant relationship between severity and SIP score ( $p < 0.001$ ) whereby the SIP score was significantly poorer as disease severity of ischaemic stroke increased.

Although this study had ascertained a significant association between stroke severity and HRQL, the characteristics of the total 162 participants did not reflect the general stroke population. Potential participants who scored at a severe level on the 'Boston Diagnostic Aphasia Evaluation' (Goodglass & Kaplan 1972) were excluded so that indicated in this study that the HRQL was not assessed for some stroke survivors with aphasia.

Anderson, Carter, Brownlee, Hackett, Broad & Bonita (2004) is another key study which may highlight how those individuals with communication difficulties may have been excluded. This study administered the SF-36 through a telephone interview and this would have automatically eliminated those stroke survivors with aphasia who had difficulty communicating over the telephone. This posed a risk that some stroke survivors with aphasia would not have had their HRQL acknowledged and addressed through any treatment or therapy.

If stroke survivors with aphasia are to be included in a study, it is important to consider how data will be collected from these individuals.

The use of proxy respondents is a contentious issue in the stroke literature. This is when assessments are answered by the "significant other" such as a carer or partner and is often when the

stroke patient is deemed to have communication difficulties. It is expected that this would impact on the accuracy of responses in the data collected (Knapp & Hewison 1999).

Hackett, Duncan, Anderson, Broad & Bonita (2000) report on past research which claims that proxy respondents should be used when a participant has severe impairments in cognition, speech and language or all three. Hackett *et al.* (2000) explain that if these individuals with speech, language and/or cognition difficulties are to be included - the use of proxy respondents is necessary to gain a complete picture of stroke outcomes.

However, Snneuw, Aaronson, De Haan & Limburg (1997) found that there is typically a significant difference in self-reporting and proxy-reporting of functional status and QOL occurring post-stroke. Furthermore, Knapp & Hewison (1999) examined how patients and carers assess the functional abilities of a patient post-stroke. They too found a discrepancy in self-reporting and proxy-reporting and they suggested that the discrepancy in scores not only posed a problem in data collection but difficulty in rehabilitation and therapy outcomes. “Different perceptions might result from a misunderstanding of the nature and consequences of stroke or, alternatively, from unrealistic expectations about recovery...both these problems should be responsive to clinical intervention” (Knapp & Hewison 1999: 7).

### **Western Aphasia Battery (WAB), Stroke Specific Quality of Life Scale (SS-QOL) and Stroke and Aphasia Quality of Life scale 39 item version (SAQOL-39)**

Traditionally, there have been two types of assessments used when wanting to examine the abilities of an individual who has had a stroke and is seen as having aphasia to some degree (Aftonomos, Steele, Appelbaum & Harris 2001). They are what are referred to as ‘impairment’ level assessments such as the WAB (which assesses language functioning) and the other type of assessments which are referred to as ‘functional’ assessments such as the SAQOL-39.

Salter *et al.* (2005) discuss the importance of ensuring outcome measures in stroke rehabilitation are reflected appropriately in the ICF framework. “To be effective, outcomes research requires a

systematic approach to describing outcomes and classifying them meaningfully” (Salter *et al.* 2005: 507-528).

It must be ascertained whether the assessment is looking at the body function/structure, the activity level or whether the assessment is looking at the participation level (Salter *et al.* 1999). It would be appropriate then to consider an impairment-level assessment such as the WAB as assessing the body function/structure and activity level whereas a functional-level assessment like the SS-QOL (or SAQOL-39) would sit on the other end of the continuum towards the participation level (Salter *et al.* 2005: 509).

Hilari and Byng (2001) worked on adapting the existing HRQL scale which was the Stroke Specific Quality of Life Scale (SS-QOL) to make it more accessible to those with aphasia. The pre-testing of this adapted version indicated that the modified SS-QOL was highly accessible and acceptable to those with aphasia (18 participants). Hilari *et al.* (2003a) administered the new and improved SS-QOL which was named SAQOL-39 (the Stroke and Aphasia Quality of Life scale 39-item) to those with long-term aphasia who met criteria which included having at least one year elapse since their stroke and having no known pre-stroke history of severe cognitive difficulties or mental health issues.

By modifying the SSQOL, they found that 87% of the 95 respondents were able to self-report which then suggested that stroke survivors with aphasia could be included in HRQL research and not require the use of proxy respondents.

There seems to be the need to investigate ways in which time, resources and the efficacy of therapy can be effectively used. “Currently, aphasiologists are required to achieve maximum functional outcomes with minimum investment of time and material resources” (Ross & Wertz 1999). This can be done by examining the relationship between the impairment-level assessment (the WAB and the AQ score) and the functional-level assessment (SAQOL-39).

Ross & Wertz (1999) examined the relationship between the WAB and the ‘Porch Index of Communicative Ability’ (PICA). Using 22 participants they examined the association between

these two measures and found that they had a significant correlation between them ( $r = 0.886$ ,  $p = 0.01$ ). Ross & Wertz (1999) suggest that because of this strong correlation there may not be a need to administer both assessments, as one assessment may predict the performance in the other assessment.

More recently Bakheit *et al.* (2005) conducted a study where they compared the WAB and the 'Communicative Effectiveness Index' (CETI) – an impairment-level assessment with a functional-level assessment. They recruited 67 patients of whom had a stroke and were about to receive speech language therapy (SLT). The patients were assessed initially and at 4, 8, 12 and 24 weeks after SLT had commenced. What was found was a significant correlation between the two assessments in all assessment periods which was ( $r = 0.71$ ,  $p < 0.01$ ). The implication from this statistical finding is that the scores from the WAB or CETI can be inferred from each other and that even though therapy was given to the patients after the initial assessments of the WAB and CETI, it appeared that the significant correlation between the two assessments was stable over time even with intervention. However, Hilari, Wiggins, Roy, Byng & Smith (2003b) conducted a study that looked at predictors of HRQL. They found that some variables predicted lower HRQL in stroke survivors with aphasia. Examples of these variables were - reduced involvement in activities, increased distress and increased communication disability. However, they found that some variables did not significantly predict HRQL post-stroke such as: gender, ethnicity and marital status. This may suggest that one assessment/scale score may not be enough on its own to predict another score on another assessment/scale as there may be other confounding variables involved.

### **Time post-stroke**

Sturm *et al.* (2004b) examined the HRQL in stroke survivors 2 years post-stroke and what was found was that the mean HRQL score for the total 225 participants assessed was 0.47 (1.00 indicates the best HRQL). The weakness of this study was that the HRQL data was proxy-reported and may not be an accurate representation of HRQL for the stroke survivors.

Hackett, Duncan, Anderson, Broad & Bonita (2000) set out to “compare health-related quality of life (HRQL, as determined by the Short Form 36 (SF-36) questionnaire), among long-term survivors of stroke (cases) with age and sex-matched control subjects (controls) and with national population norms.” (Hackett *et al.* 2000: 440).

They reported that “this large, population-based study with complete follow-up has demonstrated that HRQL was generally good for those who survived to 6 years after stroke. Although the majority of cases were living at home and approximately half had not recovered completely from their stroke, their perceived mental health was as positive as that for the general population.” (Hackett *et al.* 2000: 443). Given that Williams *et al.* (1999) reported that 39% of mild to moderate stroke survivors were depressed 1 month post-stroke and Sturm *et al.* (2004a) found that disability and depression were also independent determinants of handicap. It may be that a stroke survivor’s mental health could have been poor immediately post-stroke, but may have improved as time elapsed.

Tuomilehto, Nuottimaki, Salmi, Aho, Kotila, Sarti & Rasenyte (1995) looked at the psychosocial status of stroke survivors after 14 years post-stroke. All stroke survivors were sent a questionnaire to familiarise themselves with the questions that were going to be asked by telephone, and then were interviewed by telephone. For the stroke survivors that were deemed to have what they referred to as “language disturbances” they were assisted by a proxy respondent.

Tuomilehto *et al.* (1995: 7) state that “85% of the respondents reported good or satisfying health”. This would imply that after a considerable amount of time the stroke survivor is reasonably satisfied with their life. Gresham *et al.* (1998) looked at the functional level of stroke survivors 20 years post-stroke. They took 148 stroke survivors and 148 age and sex-matched controls and looked at aspects of cognitive function, depressive symptomology and physical functioning. What they found was the stroke survivors had higher blood pressure, greater use of medications, less use of alcohol, and less indications of depression (Gresham *et al.* 1998: 795). However, there was no documentation of how the two groups compared with their communication abilities.

Lastly, Anderson *et al.* (2004) conducted a longitudinal study in New Zealand which saw 680 stroke survivors assessed initially in 1981 and assessed 21 years later in 2002. By 2002, only 50 of the original 680 stroke survivors were able to be assessed in 2002. What they found was that although the stroke cohort had nearly twice the mortality rate of the New Zealand population, the administration of the SF-36 saw those remaining 50 stroke survivors as having HRQL profiles similar to that of the general population.

This finding may suggest that the more time to adjust to the consequences of stroke the more likely it is that HRQL will improve.

### **Social support**

Lubinski (1995) discussed that successful communication provides a sense of satisfaction in being able to get a message across to someone else and understand what they communicate in return. According to Lubinski (1995), some stroke survivors with aphasia have difficulty doing this because of several reasons including lack of a communication partner.

Hilari & Northcott (2006) conducted a study that examined social support and HRQL. Social companionship and informational support which are two types of social support were found to have significant correlations with HRQL. This may suggest that for some individuals with aphasia - having a close person who acts as a 'communication partner' to help with communication barriers and providing general support may help with better HRQL. Ross & Wertz (2005: 860) suggest that the incorporation of the World Health Organisation (WHO) classification system into aphasia treatment would make aphasia treatment more socially relevant, as the WHO addresses functioning, disability and QOL.



## Research Objectives

The study seeks to answer the following questions;

- a) Does health-related quality of life increase as severity of aphasia decreases?
- b) Does health-related quality of life increase as time post-stroke increases?
- c) How does health-related quality of life of New Zealand stroke survivors with aphasia compare with British stroke survivors with aphasia?

## Methodology

### **Design**

This project was a group study looking at those stroke survivors with aphasia. Demographic variables (age, sex), health variables (time post-stroke) and other-related variables (communication partner, living arrangement) were collected through informal discussion with participants and/or speech-language therapists, and/or through access to participant clinical files.

### **Participants**

Ten participants were recruited for this study with the assistance of speech-language therapists from two health care providers within Auckland, New Zealand. Nine of the participants were receiving active intervention and one had recently been discharged from the speech-language therapy caseload (but was well known to the service). The criteria to be included in this study were: a single left hemisphere stroke resulting in aphasia; at least two months post-onset of aphasia; living within the Auckland region; able to communicate in English; within normal limits for hearing and vision.

### **Procedure**

Speech-language therapists from both the public health care provider and community speech-language therapy clinic made initial contact with the participants. During this initial contact, the nature of the study was explained and where possible the participants signed the consent forms. On

the occasions that the consent form was not signed at this initial contact, the researcher ensured this was done when first meeting with the participant and before administering any assessment/scale.

Administration of the two measures outlined below took place either in a quiet area within the participants' home or speech-language therapy clinic over one visit. The decision about where the assessment and scale would be administered was made by the participant.

## **Measures**

### ***The Western Aphasia Battery (WAB)***

Severity of aphasia was measured using the Western Aphasia Battery (Kertesz 1982). The WAB is designed to assess language functioning which is both oral and non-verbal. For the purposes of this study only the oral portion was administered which included spontaneous speech, comprehension, repetition and naming. This was for several reasons. Firstly because the oral portion can be administered to patients in an hour (Kertesz 1982) which was beneficial given that another measure (a HRQL scale) had to be administered. Secondly the second portion which is non-verbal and consists mainly of reading and writing tasks is not entirely necessary given that impairments in oral language often parallel difficulties in visual and verbal areas (Kertesz 1982).

Spontaneous speech (information content and fluency) was assessed, by asking six general conversational questions such as "How are you today", and also required the participants to describe a picture using sentences (if they could) of a family having a picnic. Comprehension was assessed by asking yes/no questions, asking the participants to point to 60 named items (including objects, furniture and body parts) and following sequential commands. Repetition was assessed by asking the participant to repeat utterances which ranged from one word to ten words. Naming was assessed by asking the participant to name 20 objects, to name as many animals in one minute, and to complete sentences and provide answers to simple questions.

Using the raw scores from each of these components of the oral portion of the WAB, the overall language score is calculated. This produces what is known as the 'aphasia quotient' (Kertesz 1982;

Shewan & Kertesz 1980). An aphasia quotient can range from 0 to 100 and, the lower the aphasia quotient (towards 0), the more severe the language impairment (Kertesz 1982). If a participant achieved a score of 93.8 or below, this meant aphasia was present (Kertesz 1982).

### ***The Stroke and Aphasia Quality Of Life scale 39-item version (SAQOL-39)***

The SAQOL-39 is a scale which has been specifically devised to assess the HRQL of individuals with aphasia following a stroke. This scale is designed to enable the participant to self-report and not require a proxy respondent such as a partner, family member or significant other. The layout of this scale adopts some ‘aphasia-friendly principles’ (Rose, Worrall & McKenna 2003) such as key words in bold, a large font, and only a few items per page.

There are thirty-nine items which investigate four QOL domains: physical, psychosocial, communication, and energy. The participant is required to answer each item based on the previous week only. This scale appears to be divided into two distinct sections with the first section requiring the participant to rate themselves on a scale from “Couldn’t do it at all” to “No trouble at all”. While the second section requires the participant to rate themselves on a scale from “Definitely yes” to “Definitely no”.

The score for each item ranges from 0 to 5. These scores are averaged over the 39 items giving a mean HRQL score between 0 and 5. Separately, the mean scores for each of the four domains (physical, communication, psychosocial and energy) can be calculated. The closer the overall score, and individual domain score is to 5, the higher the participant’s perceived HRQL/QOL.

## **Data Analysis**

Pearson correlations were calculated for comparing the variables (aphasia quotient with HRQL) and (time post-stroke with HRQL) to ascertain how the variables relate to each other.

A repeated measures ANOVA was conducted to ascertain sphericity, homogeneity of variance, and whether the scores were independent of each other. Repeated measures ANOVA allows for fewer

participants to be used in a sample, can account for most of the participant variation, and investigates if each participant is sampled independently from each other participant (Wright 1997). Therefore, this statistical procedure was useful for a sample size of  $N = 10$  and was able to explore the independence of the SAQOL-39 scores for each participant.

Means and standard errors of means were calculated for all four QOL domains and overall HRQL subsequently, z-tests were performed. Standard error looks at the sampling distribution of the data based upon the standard deviations, and standard error allows for sample size (Wright 1997). This was particularly important as the New Zealand sample was  $N = 10$  and the British sample was  $N = 83$ . Z-tests aimed to investigate whether the New Zealand and British samples were drawn from two different aphasia populations (Wright 1997).

Mean and standard deviations for variables – type of aphasia, sex, communication partner and age were calculated using SPSS Inc. (2005).

Descriptive statistics of means and standard deviations were calculated for the QOL scores for the New Zealand sample. A histogram was done to show the distribution of the New Zealand data visually. Additionally, relevant calculations of skewness and kurtosis were conducted to describe the symmetry (whether it looks the same either side of the mean of the histogram) of the data and the height of the data (based on a normal distribution, does the data have a high peak around the mean (high kurtosis) or a low peak around the mean (low kurtosis)), respectively (Howell 1999).

## Results

### **Participants**

Ten participants took part in this study. Table 1 below provides a description of all the participants. Participants ranged in age from thirty years through to seventy-two years of age. There was an equal number of males and females that took part in the study (50% male and 50% female). The

majority of participants had a communication partner (70%). All participants lived independently within the community.

The time post-stroke for the participants ranged from seven (7) months through to three-hundred and eighty one (381) months. There were slightly more individuals with fluent aphasia than nonfluent aphasia (60% fluent and 40% nonfluent).

**Table 1: Characteristics of participants**

<i>Client</i>	<i>Age</i>	<i>Sex</i>	<i>Communication partner</i>	<i>Living arrangement</i>	<i>Time post-stroke</i>	<i>Type of Aphasia (as per WAB classification)</i>
1	49	Male	Yes	Independent	39	Fluent
2	57	Male	Yes	Independent	27	Fluent
3	66	Female	Yes	Independent	19	Fluent
4	30	Male	Yes	Independent	42	Fluent
5	59	Female	No	Independent	21	Nonfluent
6	56	Male	Yes	Independent	7	Nonfluent
7	72	Female	Yes	Independent	42	Fluent
8	69	Female	No	Independent	381	Nonfluent
9	77	Male	Yes	Independent	8	Fluent
10	56	Female	No	Independent	97	Nonfluent

### **Relationship between time post-stroke, aphasia quotient and QOL domains**

Pearson correlations were performed to determine if there were any significant relationships between the variables: the four QOL domains/overall HRQL and time post-stroke; and the four

QOL domains/overall HRQL and aphasia quotient (see Table 2 and Table 3 below). The only significant correlational relationship that was found was between the physical QOL domain and time post-stroke ( $r = -0.719$ ,  $p = 0.019$ ) at the .05 level of significance (2-tailed) (see Figure 1 below). There was some correlational relationship between the overall HRQL domain and time post-stroke ( $r = -0.516$ ,  $p = 0.091$ ), but this was not significant at the .05 level of significance (2-tailed) (see Figure 2 below). Both correlations were negative correlations.

**Table 2: Correlations of SAQOL-39 domains with aphasia quotient**

<i>Aphasia Quotient</i>	<i>Correlation Coefficient</i>	<i>Significance (two-tailed)</i>
Overall HRQL	0.181	ns
Physical QOL	0.150	ns
Communication QOL	0.153	ns
Psychosocial QOL	-0.529	ns
Energy QOL	-0.448	ns

ns = Correlation not significant at the .05 level (2-tailed)

**Table 3: Correlations of SAQOL-39 domains with time post-stroke**

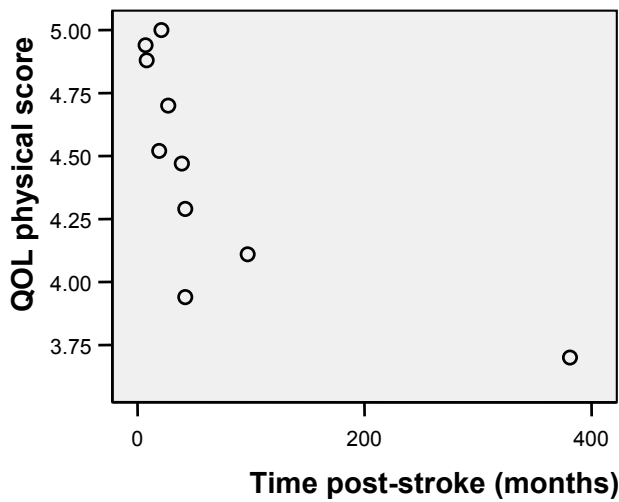
<i>Time post-stroke</i>	<i>Correlation Coefficient</i>	<i>Significance (two-tailed)</i>
Overall HRQL	-0.516	$p = 0.091^*$
Physical QOL	-0.719	$p = 0.019^{**}$
Communication QOL	-0.117	ns
Psychosocial QOL	0.434	ns
Energy QOL	0.434	ns

\* Correlation not significant at the .05 level (2-tailed), however some sort of relationship suggested.

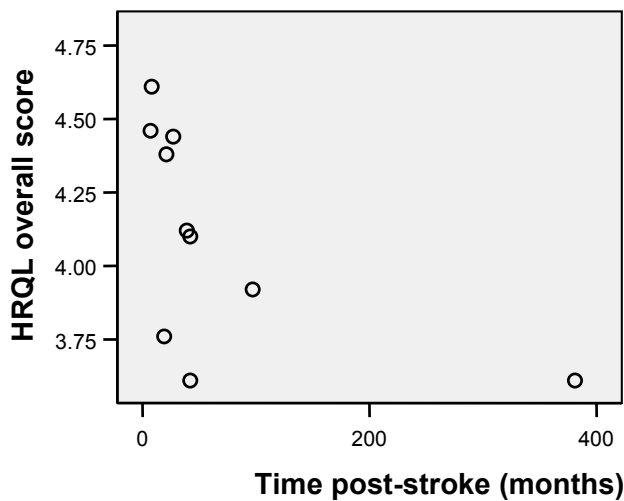
\*\* Correlation significant at the .05 level (2-tailed)

ns = Correlation not significant at the .05 level (2-tailed)

**Figure 1: Physical quality of life score as a function of time post-stroke**



**Figure 2: Overall health-related quality of life score as a function of time post-stroke**



### **Homogeneity of variance for New Zealand sample**

A repeated measures analysis of variance (ANOVA) was administered on the New Zealand data to ascertain if the assumption of homogeneity of variance was met.

The Mauchly's test of sphericity produced a result of  $p = 0.124$  which was not significant (see Table 4 below). This indicated that the assumption of homogeneity of variance was met. If the p-value was significant at the .05 level, the homogeneity of variance assumption would have been violated. Therefore, sphericity was assumed and a test of within-subjects effects was done (see

Table 5 below). This was done to ascertain if there were significant differences between each of the four QOL domains (physical, communication, psychosocial and energy) and overall HRQL. Results indicated that there were differences between the HRQL/QOL domain scores ( $F(3,27) = 7.59, p = 0.001$ ) and this meant that for each participant their HRQL/QOL scores were independent from each other.

**Table 4: Repeated measures ANOVA-homogeneity of variance**

**Mauchly's Test of Sphericity**

<i>Within Subjects Effect</i>	<i>Mauchly's W</i>	<i>Approx. Chi-Square</i>	<i>df</i>	<i>Sig.</i>	<i>Epsilon(a)</i>	<i>Greenhouse-Geisser</i>	<i>Huynh-Feldt</i>	<i>Lower-bound</i>
QOLfactor	.323	8.716	5	.124	.590	.724	.333	

**Table 5: Test of Within-Subjects Effects**

<i>Source</i>		<i>Type III Sum of Squares</i>	<i>df</i>	<i>Mean Square</i>	<i>F</i>	<i>Sig.</i>
QOLfactor	Sphericity Assumed	9.770	3	3.257	7.586	.001
	Greenhouse-Geisser	9.770	1.770	5.519	7.586	.006
	Huynh-Feldt	9.770	2.172	4.498	7.586	.003
	Lower-bound	9.770	1.000	9.770	7.586	.022
Error (QOLfactor)	Sphericity Assumed	11.591	27	.429		
	Greenhouse-Geisser	11.591	15.933	.728		
	Huynh-Feldt	11.591	19.548	.593		
	Lower-bound	11.591	9.000	1.288		

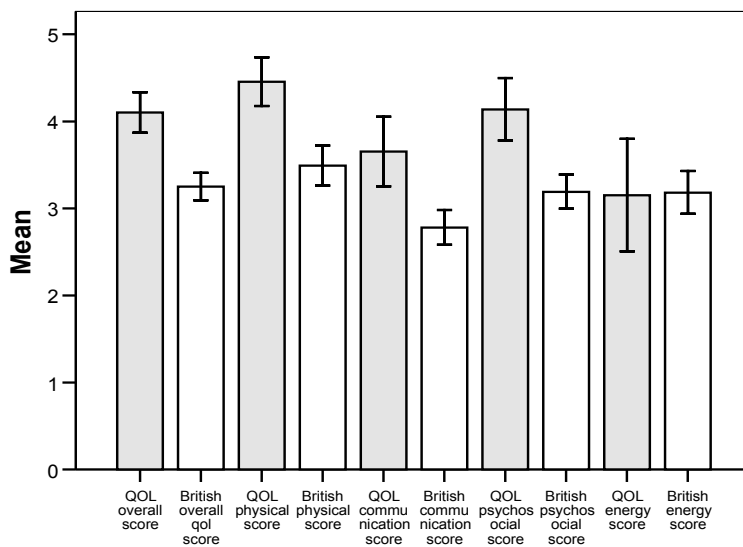


### Comparison of New Zealand and British QOL scores

Means and standard error of means (SE) were calculated for all four QOL domains and overall HRQL for both New Zealand and British samples and are displayed in Figure 3. Error Bars are also displayed in Figure 3 and each error bar represents +/- 2 SE.

From these scores, z-tests were conducted to compare HRQL/QOL domain scores for the New Zealand (N = 10) and British (N = 83) samples. The z-tests showed significant differences for the overall HRQL domain (p = 0.004); physical QOL domain (p = 0.004); communication QOL domain (p = 0.003); psychosocial QOL domain (p = 0.001) quality of life scores. There was not a significant difference for the energy QOL domain score (p = 0.865).

**Figure 3: NZ (N = 10) compared to British (N = 83) for means and standard errors**



### Descriptive statistics for variables – type of aphasia, sex, communication partner and age

Means and standard deviations were calculated for demographic variables that had two levels (type of aphasia, sex, communication partner and age, see Table 6 below).

#### **Overall HRQL**

There was not a large difference between means for type of aphasia (Nonfluent  $\bar{x} = 4.092$ ,  $s = 0.400$ ; Fluent  $\bar{x} = 4.106$ ,  $s = 0.382$ ).

There was not a large difference between means of sex (Male  $\bar{x}$  = 4.248, s = 0.398; Female  $\bar{x}$  = 3.954, s = 0.299).

There was not a large difference between means of communication partner (Yes  $\bar{x}$  = 4.157, s = 0.373; No  $\bar{x}$  = 3.970, s = 0.387).

There was not a large difference between means of age (<65  $\bar{x}$  = 4.155, s = 0.340; >65  $\bar{x}$  = 4.020, s = 0.443).

***For the four QOL subdomains (physical, communication, psychosocial and energy):***

The only notable difference between levels of any of the four variables for any of the four subdomains was between the means of sex under the energy QOL domain (Male  $\bar{x}$  = 3.600 s = 0.575; Female  $\bar{x}$  = 2.700, s = 1.229). (See Table 6 below, figures are in bold)

**Table 6: Descriptive Statistics including mean (and standard deviation)**

<i>Variable</i>	<i>Level</i>	<i>Number</i>	<i>Overall HRQL</i>	<i>Physical QOL</i>	<i>Communication QOL</i>	<i>Psychosocial QOL</i>	<i>Energy QOL</i>
Type of Aphasia	Nonfluent	4	4.092 (0.400)	4.437 (0.637)	3.637 (0.554)	4.630 (0.232)	3.125 (1.108)
	Fluent	6	4.106 (0.382)	4.466 (0.327)	3.661 (0.730)	3.806 (0.469)	3.166 (1.068)
Sex	Male	5	4.248 (0.398)	4.586 (0.404)	3.910 (0.751)	4.096 (0.487)	<b>3.600</b> <b>(0.575)</b>
	Female	5	3.954 (0.299)	4.324 (0.482)	3.394 (0.408)	4.176 (0.693)	<b>2.700</b> <b>(1.229)</b>
Communication Partner	Yes	7	4.157 (0.373)	4.534 (0.348)	3.730 (0.691)	3.911 (0.510)	3.107 (0.988)
	No	3	3.970 (0.387)	4.270 (0.664)	3.470 (0.541)	4.660 (0.274)	3.250 (1.322)
Age	<65 (younger)	6	4.155 (0.340)	4.526 (0.434)	3.566 (0.599)	4.215 (0.508)	3.250 (0.880)
	>65 (older)	4	4.020 (0.443)	4.347 (0.495)	3.780 (0.750)	4.017 (0.707)	3.000 (1.338)

**New Zealand data – means, standard deviations and distribution**

Mean and standard deviations (SD) were calculated for the New Zealand HRQL/QOL data (see Figure 4 below). Error bars are also displayed in Figure 4 and each error bar represents +/- 2 SD.

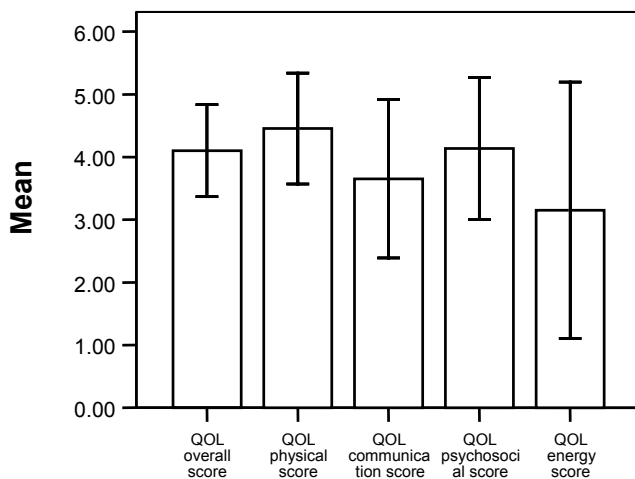
The means and standard deviations for the four QOL domains and overall HRQL were as follows (lowest to highest):

Energy  $\bar{x} = 3.150$ ,  $s = 1.021$ ; Communication  $\bar{x} = 3.652$ ,  $s = 0.631$ ; Overall  $\bar{x} = 4.101$ ,  $s = 0.367$ ; Psychosocial  $\bar{x} = 4.136$ ,  $s = 0.566$  and Physical  $\bar{x} = 4.455$ ,  $s = 0.442$ .

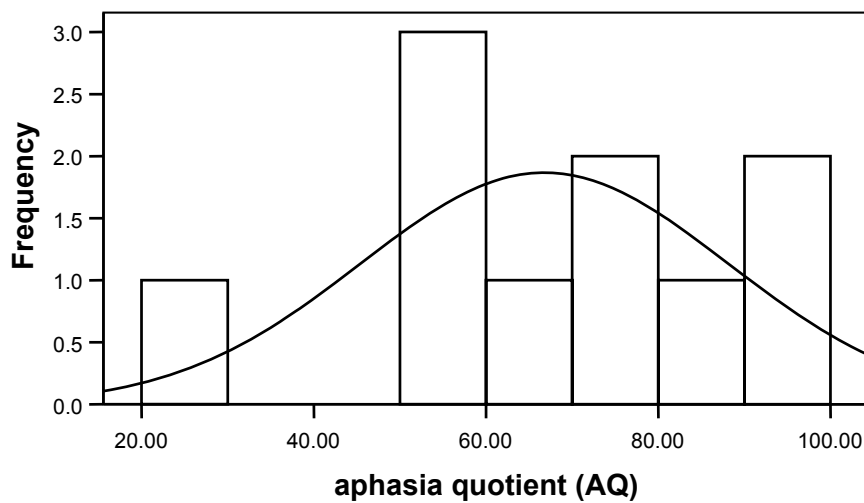
A histogram was made to investigate the distribution of the WAB aphasia quotients ( $\bar{x} = 66.77$ ,  $s = 21.377$ ) (see Figure 5). Skewness was calculated at  $-0.594$  and this indicated negative skewness. This means the distribution of the New Zealand data for aphasia quotients trailed off to the left and that there are more high scores than low scores (Howell 1999).

Kurtosis was also calculated which produced a value of  $-0.431$ . This value indicates that some of the variance within the New Zealand group of aphasia quotients can be explained by some extreme deviations (Howell 1999).

**Figure 4: Mean and standard deviations for quality of life domains and overall HRQL for the New Zealand group (N = 10)**



**Figure 5: Histogram showing distribution of the New Zealand WAB aphasia quotients (N = 10)**



## Discussion

### Main findings

This pilot study sought to look at HRQL and aphasia severity in the New Zealand stroke survivor with aphasia population using the WAB and the SAQOL-39.

To our knowledge, this is the first study that has investigated this relatively new HRQL tool on a New Zealand population.

An aim of this study was to investigate what relationships existed between HRQL and severity of aphasia. Based on previous literature, it was hypothesised that HRQL would increase as severity of aphasia decreased. No significant positive or negative correlational relationships were found between any of the four QOL domains/overall HRQL and aphasia severity. Therefore, this finding refutes previous literature and may suggest one cannot predict functional ability based upon impairment ability. Ferucci *et al.* (2000) found a negative correlational relationship with a score on the Sickness Impact Profile (SIP) decreasing as severity of stroke increased. Ross & Wertz (1999) found a positive correlational relationship between the WAB and the Porch Index of Communicative Ability (PICA). Which indicated that the higher the PICA score (communicative ability), the higher the WAB score (language functioning) (NB: the higher the WAB score, the lower the aphasia severity). This suggested one measure score could predict a score on another

measure. Furthermore, a recent study by Bakheit *et al.* (2005) compared the relationship of an impairment level measure (WAB) to a functional-level measure (CETI) and found a significant positive correlation between the two measures.

Another aim of this study was to investigate what relationships existed between time post-stroke and HRQL. Based on previous literature, it was hypothesised that HRQL would increase as time post-stroke increased, like that of a positive correlational relationship. What this study found was a significant negative correlational relationship between time post-stroke and the physical QOL domain which suggested that as time post-stroke increased, the perceived physical QOL decreased. Some sort of negative correlational relationship was also found between time post-stroke and the overall HRQL domain which suggested as time post-stroke increased, the perceived overall HRQL decreased. Therefore, these findings refuted previous literature and may suggest insight into physical QOL and overall HRQL improves as time elapses. By two years post-stroke, stroke survivors had an average perceived HRQL score (Sturm *et al.* 2004b). By six years post-stroke, Hackett *et al.* (2000) reported that stroke survivors had perceived mental health to the same level as that of the general population. Tuomilehto *et al.* (1995) found that after fourteen years post-stroke, 85% of the participants in their study reported excellent health. Anderson *et al.* (2004) conducted a longitudinal study in New Zealand and found that fifty of the remaining six hundred and eighty stroke survivors post-stroke had HRQL similar to that of the general New Zealand population.

Another aim of this study was to compare the HRQL of New Zealand stroke survivors with aphasia with their British counterparts. What was found was the two groups had significant differences between their overall HRQL scores and significant differences between their physical, communication and psychosocial QOL domain scores. However, there was not a significant difference between the energy QOL domain scores for the New Zealand and British groups.

These findings suggest that because the overall HRQL and the majority of QOL domains are different for the New Zealand and British aphasia groups that what may be applicable to one group may not be applicable to the other. This is most likely due to the sample data being drawn from two

different aphasia populations and therefore heterogeneity of variance may have existed. The finding that there was not a significant difference between the energy QOL domain scores may reflect that the SAQOL-39 does not have an equal number of questions per QOL domain to fully assess the impact aphasia has on energy (the proportions for 39 questions in total are as follows: 17 questions explore the physical QOL, 7 questions explore the communication QOL, 11 questions explore the psychosocial QOL and only 4 questions explore the energy QOL).

The demographic variables (type of aphasia, sex, communication partner and age) of the New Zealand stroke survivor aphasia group were explored. What was found was there were no large differences between the different levels within these variables in determining QOL and overall HRQL (except for sex in energy QOL). Depending on the variable, this finding can be supported by previous literature, can refute previous literature or simply stated that it has not specifically been explored.

The finding that there was not a large difference in HRQL/QOL for those with fluent or nonfluent aphasia suggests that there was the same perceived HRQL/QOL outcome regardless of type of aphasia. Type of aphasia, has not been specifically explored in previous HRQL literature, such as the study by Hilari *et al.* (2003a) where they looked at stroke type and aphasia severity, but not type of aphasia.

The finding that there was not a large difference in HRQL/QOL for males and females (except for energy QOL) suggests that there was the same perceived HRQL/QOL outcome regardless of sex (except for energy QOL). This finding is supported by the study of Hilari *et al.* (2003b) where they found sex to not be significantly associated with HRQL.

The finding that there was not a large difference in HRQL/QOL for whether a communication partner was present or not suggests that there was the same perceived HRQL/QOL outcome regardless of whether a stroke survivor with aphasia has a communication partner or not. This finding refuted previous research such as the study by Hilari & Northcott (2006) who looked at

perceived social support and found some types of support namely, social companionship and informational support to be significantly correlated with HRQL.

The finding that there was not a large difference in HRQL/QOL for the two age groups (<65 years and >65 years of age) suggests that there was the same perceived HRQL/QOL outcome regardless of age group. This finding refuted previous research such as the study by Hilari *et al.* (2003b) where they found that age was significantly correlated with HRQL.

An overall description of HRQL/QOL for the New Zealand aphasia group was as follows: this group perceived their best QOL area to be their physical ( $\bar{x} = 4.445$ ) and their poorest perceived QOL area to be their energy ( $\bar{x} = 3.150$ ). Their overall HRQL mean score was 4.101. The most relevant statistic for the nature of this study was the communication QOL mean score which of 3.652.

There appears to be a relationship between the number of items per QOL domain and the average perceived QOL score for that domain. For example: the SAQOL-39 allocated the most items to physical QOL and physical QOL obtained the highest perceived QOL mean score. Conversely the SAQOL-39 allocated the least number of items to energy QOL and energy QOL obtained the lowest perceived QOL mean score. With Rust and Golombok (2000) suggesting that areas within a measure should have more weighting if they are deemed to have greater importance, this may suggest that Hilari (2003a) deemed physical QOL as having had the most importance in order to investigate HRQL.

Although Hilari *et al.* (2003a) reported that the SAQOL-39 had good internal consistency (reliability), reliability does not always mean validity will be achieved (Miller 1997). With an unequal number of items for the four QOL domains (communication and energy being the lowest two QOL domains), the content validity of the scale could be questioned. The content validity is whether or not a measure is comprehensive enough and covered all areas of a measure adequately (Pring 2005). Given that physical deficits do not usually prevent a stroke survivor with aphasia

from having adequate social participation (Chapey 2001), the number of items allocated for the physical QOL in the SAQOL-39 may be unnecessary.

The New Zealand scores for HRQL/QOL may have important implications for clinical decisions that New Zealand speech-language therapists could make for those with aphasia. If one was to adopt the Ziggy Theorem (Kaplan 1994), New Zealand speech-language therapists should bear in mind the poorer QOL areas for those with aphasia such as energy when identifying rehabilitation goals for a stroke survivor with aphasia. With the model emphasising making sure one is occupied with what one is most interested in doing (Kaplan 1994). It is important not only to ensure communication is considered in rehabilitation but, to also consider those QOL areas that are perceived the poorest, and secondly may most impact on the efficacy of therapy, daily living activities and social participation for a stroke survivor with aphasia.

### **Future Research**

It is recommended that future studies use a much larger sample of the New Zealand stroke survivor with aphasia population. With Wild & Seber (2000) advocating for samples to be “as large as they can be”, a larger sample of stroke survivors with aphasia would enable stronger conclusions and generalisations to be made about the New Zealand population from which the sample was drawn. This would lead to better external validity, where the results would be more applicable to the New Zealand stroke survivor with aphasia population. Ideally, one would want to compare approximately equal sample sizes between two different populations so homogeneity of variance can be assumed for both groups. Therefore a New Zealand sample of approximately  $N = 83$  would be useful in order to directly compare to the British sample of  $N = 83$  (Hilari 2003c).

Future studies should aim to include as many of the demographic variables that Hilari *et al.* (2003a) investigated in their study. These include: stroke type, ethnic group, marital status, socioeconomic status and employment status. There are two advantages to doing this. Firstly, further comparisons could be made with the British aphasia group. Secondly, one could investigate if there are any confounding variables which may mediate HRQL with an independent variable such as aphasia



severity. Alternatively one could investigate the factors which directly influence HRQL (e.g. stroke type). Any variations or confounding variables could have specific clinical implications for clinical practice and rehabilitation outcomes for a stroke survivor with aphasia population.

Some of the results from this study have not been investigated or found in previous research. Replications of this study (using a larger sample size) would be necessary in order to ascertain if the same results could be found again.

## Summary and Conclusions

The results obtained from this study suggest the following for the New Zealand stroke survivor with aphasia group. One cannot predict HRQL based upon aphasia severity; as time post-stroke increases a greater insight into physical QOL and overall HRQL develops; what may apply to one British stroke survivor with aphasia may not apply to a New Zealand stroke survivor with aphasia; some demographic variables do not play a major role in influencing HRQL/QOL and may be unnecessary to be considered within speech-language therapy and rehabilitation management; the physical QOL domain is the least affected and the energy QOL domain is the most affected post-stroke; and lastly the second most poorly perceived post-stroke is the communication QOL domain. Based on these findings, this study refuted previous literature on the relationship between aphasia severity and HRQL, and the relationship between time post-stroke and HRQL.

This study has explored aphasia chronicity not only at an impairment-level but at a functional-level using the SAQOL-39 measure. This approach has enabled the study to look beyond those principles of traditional aphasia therapy. This approach has allowed a more holistic view to be adopted. The areas of linguistic influence and HRQL which acknowledge the social significance of communication (Chapey 2001), such as daily living activities and social exchanges with family, friends and other members of the community have been investigated.

The use of the SAQOL-39 measure can allow New Zealand speech-language therapists to determine which speech-language therapy services are needed. This study has helped to highlight those areas of service that may be of more significance for New Zealand stroke survivors with aphasia. For instance, although communication QOL would typically be the domain of most interest to speech-language therapists it appears energy QOL is the most poorly perceived post-stroke. Therefore, it is recommended that speech-language therapy services focus on the HRQL domain(s) that a stroke survivor with aphasia perceives as being the poorest, even if clinically, deficits are greater in another HRQL domain.

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