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Running head for publication

Predictors of HRQL in chronic aphasia

Title

Predictors of health-related quality of life (HRQL) in people with chronic aphasia

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Abstract

Background: In recent years, quality of life measures have been used increasingly to evaluate the effectiveness of services or interventions. For people with chronic disabilities, research has focused on identifying the main predictors of their HRQL, in order to address the issue of how to meet their needs in rehabilitation in a more holistic way.

Aims: This study assessed the main predictors of HRQL in people with chronic aphasia following stroke. We investigated the relationship between HRQL and various demographic and stroke-related variables and other variables that have been associated with HRQL in stroke survivors (e.g., emotional distress, daily activities, social support).

Methods: A cross sectional design was adopted. A cluster sampling framework was used to recruit participants with chronic aphasia (> 1 year) from 3 different sites. Questionnaires and assessments on the different variables were administered to all participants by a Speech and Language Therapist, in an interview format. Multiple regression analysis was used to assess what were the main predictors of HRQL in people with aphasia.

Results: Eighty-three out of ninety-five participants (87%) were able to self-report on all the assessments. Emotional distress, involvement in home and outdoors activities, extent of communication disability and number of comorbid conditions explained 52% of the variance in HRQL (adjusted $R^2=.52$). Stroke type (infarct vs haemorrhage), time post onset and demographic variables (gender, ethnicity, marital status, employment status and socioeconomic status) were not significantly associated with HRQL in these participants.

Conclusions: Increased distress, reduced involvement in activities, increased communication disability and comorbidity predict poorer HRQL in people with chronic aphasia after stroke. Service providers need to take these factors into account when designing intervention programmes.

Predictors of health-related quality of life (HRQL) in people with chronic aphasia

INTRODUCTION

Evaluating health care provision: patient-based outcomes

In recent decades there has been a paradigm shift in the way health and health care provision are conceptualised and evaluated. In 1948, the WHO indicated that health is no longer merely the absence of disease, but rather 'a state of complete physical, mental and social well-being'. This is a broad conceptualisation and although there is no consensus on an exact definition of health it is generally accepted that it incorporates physical, mental and social components (Berzon, Hays & Shumaker, 1993).

This broader conceptualisation of health is reflected in the way health care interventions are evaluated. Evaluation has moved beyond the measurement of traditional clinical outcomes such as morbidity and mortality to establishing the effectiveness of interventions based on critical and rigorous scientific evidence using a wide range of outcome measures (NHS Executive, 1996). Another change in recent years is that patients have become increasingly involved in treatment decisions (NHS Executive, 1999) and there is general consensus that patients and carers are 'experts' in their own conditions. Patient-based measures of outcome are, therefore, increasingly used in the evaluation of health care interventions.

Health related quality of life (HRQL) and chronic disability

HRQL measures represent one form of patient-based measures. HRQL reflects the impact of a health state on a person's ability to lead a fulfilling life (Bullinger, Anderson, Cella & Aaronson, 1993). It incorporates the individual's perception of and satisfaction with his/her physical, mental/emotional, family and social functioning (Berzon et al., 1993; Hays, Anderson, & Revicki, 1993; de Haan, Horn, Limburg, Van Der Meulen & Bossuyt, 1993).

HRQL measures are particularly useful in the evaluation of health care interventions for people with chronic diseases and disabilities. Rehabilitation of people with chronic disabilities has traditionally focused on compensatory programmes (Frey, 1984) but in recent years it has begun to concentrate more on facilitating adaptation to disability and social and community integration (RCP, 2000; Turner, 1990; Wood-Dauphinee & Williams, 1987). Patient-based HRQL measures are particularly suited for the evaluation of health care provision in people with chronic disabilities as they allow us to better understand and measure the impact of disease on the patient's life as a whole (Patrick & Erickson, 1993). They also allow us to incorporate the patient's perspective in clinical decision making (Wenger, Mattson, Furberg, Elinson, 1984; Mayou & Bryant, 1993).

Stroke and aphasia

Stroke is the most common cause of long-term adult disability in the world. A number of studies have looked at patient outcomes and quality of life¹ following stroke. In most of these studies quality of life is affected by depression (Ahlsio, Britton & Murray, 1984; Niemi, Laaksonen, Kotila & Waltimo, 1988; King, 1996; Duncan et al., 1997; Jonkman, deWeerd & Vrijens, 1998; Neau et al., 1998; Clarke, Black, Badley, Lawrence & Williams, 1999; Lofgren, Gustafson & Nyberg, 1999); and physical disabilities/ reduced activities (Ahlsio et al., 1984; Ebrahim, Barer & Nouri, 1986; Niemi et al., 1988; Viitanen, Fugl-Meyer, Bernspaang & Fugl-Meyer, 1988; Astrom, Adolfsson, Asplund & Astrom, 1992; Astrom, Asplund & Astrom, 1992; Angeleri, Angeleri, Foschi, Giaquinto & Nolfi, 1993; Kwa, Limburg & de Haan, 1996; King, 1996; Wilkinson et al., 1997; Duncan et al., 1997; Jonkman et al., 1998; Neau et al., 1998; Clarke et al., 1999; Lofgren et al., 1999).

Other predictors of poor quality of life have included reduced social support (Osberg et al., 1988; Viitanen et al., 1988; Astrom et al., 1992; Astrom, Asplund & Astrom 1992; King, 1996; Wyller, Holmen, Laake & Laake, 1998); and cognitive decline in some studies (Niemi et al., 1988; Jonkman et al., 1998; Clarke et al., 1999) but not in others (Kwa et al., 1996). Out of 14

studies reviewed that included people with aphasia, only two found aphasia to be significantly associated with poorer quality of life (Neau et al., 1998, in univariate but not multivariate analysis; Kwa et al., 1996).

Other factors that have been associated with poorer quality of life after stroke are older age in some studies (Astrom et al., 1992; Astrom, Asplund & Astrom, 1992; deHaan, Limburg, Van der Meulen, Jacobs & Aaronson, 1995) but not in others (Ahlsio et al., 1984; Ebrahim et al., 1986; Wyller et al., 1998); increased comorbidity (de Haan et al., 1995; Duncan et al., 1997; Clarke et al., 1999); lower socioeconomic or educational/professional status (King et al., 1996; Neau et al., 1998); and some stroke related variables [e.g., ischaemic and hemispheric stroke in Niemi et al. (1988); supratentorial strokes in de Haan et al (1995); and larger infarct volume in Kwa et al. (1996)].

It is not easy, however, to draw meaningful conclusions from this literature due to a number of methodological and conceptual challenges. In particular, a key methodological challenge in the area of stroke HRQL is that people with aphasia may have difficulty completing self-report assessments. As a result, in some of the studies, people with aphasia were excluded (e.g., Duncan et al., 1997; Jonkman et al., 1998; Clarke et al., 1999). In some it is unclear whether they were included or not. In the studies that did include people with aphasia, aphasia often resulted in missed assessments (Ebrahim et al., 1986; Kwa et al., 1996; Wilkinson et al., 1997). Alternatively, proxy respondents were used (e.g., Astrom et al., 1992; de Haan et al., 1995). Analysing proxy-reported HRQL findings alongside self-reported findings is questionable as quality of life is regarded as a highly subjective concept. The use of proxies is always less preferable than self-reports and the nature of HRQL may mean that the validity of proxy reports is further compromised. In some studies, no information is provided on how people with aphasia coped with the whole procedure (Foster & Young, 1996; King, 1996; Lofgren et al., 1999; Bethoux et al., 1999). This is problematic as it is anticipated that they would require at least some modification of the testing materials and special skills on behalf of

the interviewer in order to give their experience of stroke. The validity of these assessments is therefore in doubt.

Another methodological challenge is that methods of assessing HRQL vary. Researchers have used a single Visual Analogue Scale (e.g., Kwa et al., 1996) to measure HRQL; an interview (e.g., Lawrence & Christie, 1979); generic scales like the Nottingham Health Profile (e.g., Wilkinson et al., 1997), the Sickness Impact Profile (de Haan et al., 1995; Hochstenbach, Donders, Mulder, vanLimbeek & Schoonderwaldt, 1996; Neau et al., 1998; Jonkman et al., 1998) and the Short Form-36 (Wilkinson et al., 1997; Dorman et al., 1999; Hackett et al., 2000); or a battery of different tests (e.g., Angeleri et al., 1993). This methodological variation results in confusion as to what the concept of HRQL is supposed to reflect and what is the best way of measuring it.

A key conceptual challenge is that often the concept of quality of life is loosely defined or not defined at all (e.g., in Angeleri et al., 1993; Kwa et al., 1996; Duncan et al., 1997; Bethoux F., Calmels P., & Gautheron V., 1999). In other studies HRQL/quality of life is not distinguished from related concepts, for example, it is expressed as life satisfaction (Ahlsio et al., 1984; Viitanen et al., 1988; Astrom et al., 1992; Astrom, Asplund & Astrom, 1992) or subjective well-being (Niemi et al., 1988). A few of the studies mentioned above did not set out to assess quality of life or HRQL per se but related concepts such as subjective well-being (Wyller et al., 1998; Lofgren et al., 1999), life satisfaction (Osberg et al., 1988), handicap (Clarke et al., 1999) and social and psychological effects of stroke (Ebrahim et al., 1986).

In the field of aphasiology, a number of studies have explored the *impact* of aphasia (e.g., more recently, LeDorze & Brassard, 1995; Hemsley & Code, 1996; Sarno, 1997; Hoen, Thelander & Worsley, 1997; Lyon et al., 1997; Parr, Byng & Gilpin, 1997; Cruice, Worrall & Hickson, 2000b), rather than specifically the HRQL of people living with aphasia. Some of these studies have used measures such as the Ryff Psychological Well-being Scales (see Hoen et al., 1997) or the Psychological Well-being Index (see Lyon et al., 1997), which have not been tested extensively for their psychometric properties. Others have used semi-

structured or in-depth interviewing techniques (LeDorze & Brassard, 1995; Parr et al., 1997). These studies give us useful information on issues related to the impact of aphasia. However, their methodology makes them hard to replicate in clinical practice and to draw comparisons between people with aphasia and other people living with stroke.

In summary, in recent years we have witnessed a proliferation of studies exploring the HRQL and related outcomes of people with stroke and aphasia. It remains a challenge to get a clear picture of the HRQL of people living with aphasia and the factors affecting it due to a number of conceptual and methodological issues (see also Cruice M., Worrall L. & Hickson L., 2000a).

The current study's approach

The main aim of this study was to identify the main predictors of HRQL in people with chronic aphasia following stroke. Some of the challenges identified above were addressed in the current study in the following ways:

- **Conceptual clarity**

In this study HRQL is conceptualised as reflecting the impact of a health state on a person's ability to lead a fulfilling life (Bullinger et al., 1993). It incorporates the individual's subjective evaluation of his/her physical, mental/emotional, family and social functioning (Berzon et al., 1993; Hays et al., 1993; de Haan et al., 1993).

- **Measurement approach: potential for replication in clinical practice**

A viable way of investigating HRQL in people with aphasia in clinical practice is by use of a single HRQL measure. There is currently no single measure for the assessment of HRQL in people with aphasia. We have, therefore, modified the Stroke-specific quality of life scale (SS-QOL, Williams, Weinberger, Harris, Clark & Biller, 1999), which is a patient-derived stroke specific scale. The purpose of the modification was to make the measure communicatively accessible to people with aphasia and increase its content validity and acceptability with this population group (Hilari, 2000; Hilari & Byng, 2001). The resulting instrument is the Stroke

and aphasia quality of life scale, 39-item version (SAQOL-39). SAQOL-39 has high acceptability, internal consistency, test-retest reliability and construct validity with people with chronic aphasia following stroke.²

- Accessibility: Assessments used should be accessible to the population under study

A Speech and Language Therapist (SLT) experienced in working with people with aphasia carried out all the assessments in an interview format, in order to facilitate the understanding and communication of people with aphasia. All materials were shown to participants in an accessible format so that they could read the items while the interviewer said them. To facilitate participants' response, they had only to point to their responses. Materials used had been previously reviewed for their level of linguistic complexity. Although their content (in terms of meaning) remained unchanged to avoid invalidation, their presentation was modified to make them more communicatively accessible. In particular, few items were presented per page. Practice items were introduced at the beginning of each questionnaire to make sure the respondent understood the response format and what s/he had to do. Larger font was used (14-16) and key words were presented in bold (Hilari & Byng, 2001).

METHODS

Design

A cross sectional design was adopted. A questionnaire-based interview was administered and data were collected on HRQL and potential predictors. The latter were demographic variables (age, sex, ethnic background, socioeconomic status, marital status, employment status); stroke and other health variables (type of stroke, time post onset and comorbidity); and other factors that have been associated with HRQL in people with stroke in other studies (emotional distress/depression, reduced activities, cognitive decline, aphasia, social support).

Participants

Participants were recruited as a clustered sample from 2 SLT Service Providers (NHS Trusts), one inner city and one semi-rural, and a not-for-profit organisation for people with aphasia. All recruiting sites were in Southeast England. The inclusion criteria were: aphasia due to a stroke, at least 1 year post onset, no known pre-stroke history of severe cognitive decline or mental health problems and living at home prior to the stroke.

Procedure

In the participating sites, review of SLT records was undertaken to identify eligible participants. Consent was obtained from eligible participants in writing at least 2 days after the main information on the project was given. All the participants were interviewed twice at home or in their SLT site by the main investigator, who administered all the questionnaires and assessments. Participants' aphasia was screened with the Frenchay Aphasia Screening Test (FAST) (Enderby, Wood & Wade, 1987). If people scored less than 7/15 on the receptive domains of the FAST it was assumed, based on our previous research (Hilari & Byng, 2001), that they could not reliably understand the questionnaires that were used. On these occasions, with the participant's consent a proxy respondent was used (usually the spouse/partner or the main carer of the person with aphasia). These cases were excluded from the current analysis.

Measures

HRQL was assessed with the SAQOL-39, the aphasia adapted version of the SS-QOL. The SAQOL-39 asks questions about the effects of stroke and aphasia on people's lives that group into 4 domains: physical, psychosocial (including family and social issues), communication and energy. Its response format is a 5-point scale ranging in the first part from 'couldn't do it at all' to 'no trouble at all' and in the second part from 'definitely yes' to 'definitely no'.

Information on demographic, stroke related and comorbidity variables were collected from the participants' SLT notes. They were confirmed and supplemented through a short interview with the participants.

For emotional distress the General Health Questionnaire – 12 item version (GHQ-12) (Goldberg, 1972) was used. The GHQ is a measure of distress that has been extensively used as a screening tool for psychiatric disorders. Its psychometric properties have been extensively tested (for reviews see Goldberg & Williams, 1988; Vieweg & Hedlund, 1983). It has also been used in stroke studies (e.g., Ebrahim et al., 1986; Dennis, O'Rourke, Slattery, Staniforth & Warlow, 1997; Dennis, O' Rourke, Lewis, Sharpe & Wolfe, 2000).

To assess cognition, the Raven Coloured Progressive Matrices (RCPM) (Raven, 1962) was used. The RCPM uses non-verbal symbols to assess cognition, it does not require verbal responses from the respondents and only minimal verbal instruction is necessary. As such it is, to the best of our knowledge, the most valid instrument for the assessment of cognition in people with language impairments. It has been used to explore cognitive decline in brain damage and aphasia (e.g., Villardita, 1985). The coloured rather than the standard matrices were preferred as they are considerably shorter, reducing respondent burden. Smits et al. (1997) highlight two extra advantages of the RCPM. The matrices themselves are coloured large-print drawings, which are visible for older subjects with modestly impaired eyesight. Each part of the test starts with easy items, which is encouraging for the respondents as they can answer at least some of the items correctly.

Communication disability was assessed with the American Speech and Hearing Association Functional Assessment of Communication Skills for Adults (ASHA-FACS) (Frattali, Thompson, Holland, Wohl & Ferketic, 1995). The ASHA-FACS asks about communicative activities that people with aphasia perform and whether they perform them independently or with assistance. Examples of items include requesting information of others, explaining how to do something, expressing feelings and writing messages. It is rated by the SLT of the

person with aphasia based on observations of this person or observations by others who are familiar with the person.

Participation in activities was explored with Frenchay Activities Index (FAI) (Wade, Legh-Smith & Langton Hewer, 1985). The FAI is a measure of general (i.e., other than personal care) activities of stroke patients, which has been standardised on a sample of 976 stroke patients (seen just after the stroke, and at 3- 6- and 12-months post onset). It includes in and outside the home activities, social and leisure activities and an item on work.

Social support was assessed with the Social Support Survey (SSS) (Sherbourne & Stewart, 1991). The SSS assesses the perceived availability of four types of support (tangible, emotional/informational, social companionship and affectionate support). It has a sound theoretical basis and good psychometric properties, which were tested on a group of chronically ill outpatients.

Data analysis

Multiple regression analysis (standard regression method, Tabachnik & Fidell, 2001) was used to assess the relative impact of a selected set of independent variables (IVs) on HRQL. We had a large number of potential predictors and a relatively modest sample size. This could challenge the viability of the regression analysis by reducing the cases to variables ratio. Tabachnick & Fidell (2001) suggest that for testing multiple correlation the simplest rule of thumb is $n \geq 50 + 8m$ (where m is the number of IVs). To reduce the number of variables that would enter the regression model, univariate analyses were initially undertaken between each IV and HRQL. One-way ANOVA, independent t -tests and Pearson's product correlation coefficients were calculated depending on the nature of the IVs. The demographic, stroke and health variables that were not significantly associated with HRQL in univariate analyses were not entered in the regression model. All other variables, i.e., emotional distress/depression, reduced activities, cognitive decline, aphasia and social support were included in the regression model. These variables are of theoretical interest as they have been implicated in

previous research and their contribution to HRQL for people with aphasia needs to be assessed and better understood. They are also of greater interest to care providers as they may be addressed in rehabilitation and be subject to intervention. All analyses were performed with SPSS 10.0 for Windows (SPSS Inc., 1999).

RESULTS

Participants

One hundred and sixteen eligible participants were identified and were asked to take part in the study. Ninety-five people (82%) agreed to take part. No further information is available on the 21 people who did not take part as we did not have their consent for their records to be reviewed. Of the ninety-five people who took part in the study, 12 had such severe language problems (FAST receptive score < 7/15) that they were unable to self-report on the questionnaires that were used. For those participants proxy respondents were used and their results will be analysed separately in another study.

Table 1 details the characteristics of the remaining 83 participants. The majority were male (62.7%) and they ranged in age from 21 to 92 (mean 61.67 ± 15.47). About 43% were over 66 years old and 15.7% were between 21 and 45. The majority of the sample were white (78.3%) and married/had a partner (62.6%). Although almost 56% of the sample were of working age (≤ 65) only 6% were involved in some type of work (part-time or voluntary work and students). No participants were in full-time work. Participants' socioeconomic class was determined according to the new social classification system proposed by the Office of National Statistics (Rose & O' Reilly, 1997), which is based on occupation. Participants were classified according to their last occupation before the stroke, using the collapsed version of the socioeconomic classification (SEC). According to this criterion, approximately 35% were professionals and managers, 35% were other administrative and clerical workers, or own account non-professional and supervisors, or technicians and related workers, 25% were intermediate or other workers and 5% had never worked.

[Table 1 about here]

Univariate analyses

HRQL as measured by the SAQOL-39 was normally distributed (Kolmogorov-Smirnov test ns at $p \leq .2$) with a mean(SD) of 3.27(.7) and a median of 3.26 and scores ranging from 1.72 to 4.46. Univariate analyses were used to assess the relations between HRQL and demographic, stroke-related, comorbidity and other variables.

Demographic variables

The only demographic variable that was significantly correlated with HRQL was age ($r = -.27$, $p < .05$), with increased age associated with poorer HRQL. Gender, ethnic background, marital/relationship status, socioeconomic status and employment status were not significantly associated with HRQL in this group of people with aphasia. These variables were not included in further analyses.

Stroke-related and other health variables

The stroke variables explored in this study (type of stroke and time post onset) were not significantly associated with the participants' HRQL. Comorbidity was significantly and negatively correlated with HRQL ($r = -.25$, $p < .05$), with more comorbid conditions resulting in poorer HRQL. This variable was included in the subsequent multiple regression analysis.

Other variables

Descriptive statistics on the measures of depression/emotional distress (GHQ-12), level of activities (FAI), communication disability (ASHA-FACS), cognitive level (RCPM) and social support (SSS) are presented in table 2.

[Table 2 about here]

Participants' scores on these measures were correlated with their HRQL (SAQOL-39) scores. All correlations were positive (wherever necessary scores were re-coded so that in all instruments high scores were indicative of good outcomes/function and low scores were indicative of poor outcome/function). The total scores were used for the FAI. There was one item in the FAI that asked about gardening and was not applicable to 30% of the respondents who did not have a garden. Missing data were imputed for each case, using the case's mean. The average of the ASHA-FACS and the SSS were used as recommended by the authors. The RCPM scores were converted to Standard Progressive Matrices (SPM) grades (Raven, Raven & Court, 2000). The SPM grades range from 1-5 and they represent percentile ranks. SPM grades were also re-coded so that 5 was 'intellectually superior', at or above the 95th percentile and 1 was 'intellectually impaired', at or below the 5th percentile. Table 2 presents the results of these correlations.

[Table 3 about here]

The results suggest that HRQL was significantly poorer in people with high emotional distress ($p < .01$), high communication disability ($p < .01$), low activity level ($p < .01$) and low cognitive level ($p < .05$). High levels of social support were somewhat associated with better HRQL (the results approached significance with $p \leq .08$). All these variables were entered in the subsequent multiple regression analysis.

Multiple regression analysis

Multiple regression analysis was performed to assess the relationship between the dependent variable (DV) HRQL as expressed by the SAQOL-39 mean scores and correlated IVs. The standard method was used, where all IVs are entered in the regression equation at once. This way, each IV is evaluated in terms of what it adds to the prediction of the DV that is different from the predictability afforded by all other IVs. IVs were age, number of comorbid conditions, the GHQ-12, the FAI, the ASHA-FACS, the SPM grade and the SSS.

Evaluation of the regression assumptions indicated that no transformation of variables was necessary. The residuals (differences between obtained and predicted DV scores) were normally distributed and the assumptions of homoscedasticity and linearity were met. The errors of prediction (residuals) were independent of one another (*Durbin-Watson* test of independence of errors = 2.09). Multicollinearity among IVs was not a problem: all tolerance values were $>.2$ (Menard, 1995). There were no outliers among IVs and on the DV: there were no particularly influential cases (maximum *Cook's distance* = .16, i.e., there were no values >1); the average leverage $((m+1)/n)$ (where m is the number of IVs) was 0.09 and the maximum *centered leverage* was .275 which is below $(3(m+1)/n)$ as recommended by Stevens (1992); using a $p<.001$ criterion for *Mahalanobis distance*, there were no multivariate outliers among the cases ($\max=22.304<\text{critical } \chi^2 \text{ for 7df at } 24.322$).

Table 3 displays a summary of the regression model. The overall model accounted for 51% of the variance (adjusted) in the SAQOL-39 scores. R for regression was significantly different from zero, with $F(7,74) = 13.260, p < .001$.

Inspection of the B coefficients showed that emotional distress (GHQ-12) ($t(74) = 3.81, p<.001$), activity level (FAI) ($t(74) = 3.52, p\leq .001$), communication disability (ASHA-FACS) ($t(74) = 2.15, p<.05$) and comorbidity ($t(74) = -2.48, p<.05$) were significant predictors of HRQL (SAQOL-39). Three variables - cognition (SPM grade), social support (SSS) and age - were not significant predictors. Inspection of the 95% confidence intervals for the IVs showed that for these 3 variables the confidence intervals included zero. This is further evidence that these 3 variables may weaken the overall model, as in some samples they have a negative relationship with HRQL and in others they have a positive relationship. For example, low cognitive level (as measured by the RCPM) was associated with good HRQL in some cases and poor HRQL in others.

[Table 4 about here]

A second regression analysis was run including only the significant predictors (i.e., emotional distress, activity level, communication disability and comorbidity). In this model all the assumptions were met including the recommended cases-to-variables ratio where $n \geq 50 + 8m$, $n \geq 50 + (8 \cdot 4)$, $n \geq 82$ and here $n = 83$. This model accounted for 52% of the variance (adjusted) in the SAQOL-39 scores. R for regression was significantly different from zero, with $F(4,78) = 23.37$, $p < .001$. B coefficients showed that emotional distress (GHQ-12) ($t(78) = 4.62$, $p < .001$), activity level (FAI) ($t(78) = 3.40$, $p = .001$), communication disability (ASHA-FACS) ($t(78) = 2.29$, $p < .05$) and comorbidity ($t(78) = -2.18$, $p < .05$) were all significant predictors of HRQL (SAQOL-39).

In summary, high emotional distress, low activity level, high communication disability and high comorbidity were significant predictors of poorer HRQL. These variables accounted for 52% of the variance of the SAQOL-39.

DISCUSSION

This study explored the main predictors of HRQL in people with chronic aphasia after stroke. One of the main strengths of this study lies in its design, which allowed 83 people with aphasia to self-report on the impact of stroke and aphasia on their lives. It highlights that careful selection of materials and mode of administration can ensure inclusion of people with communication disability in stroke studies. To the best of our knowledge this is the largest study of HRQL in people with aphasia in Britain.

Main findings

Eighty two per cent of all eligible participants identified took part in the study. This high response rate indicates that our sample was representative of the population targeted. Physical disabilities and reduced level of activities have been repeatedly identified as among the main predictors of quality of life after stroke. High emotional distress and depression

have also been repeatedly associated with reduced HRQL in people with stroke and aphasia. Our findings show a similar pattern with the subgroup of people living with aphasia after stroke and emphasise the potential importance of these aspects for effective service provision. In particular, our results highlight the importance of both identifying and then providing services to people experiencing emotional distress as it continues to be a problem impacting on quality of life even in the long-term after the stroke. However, a caveat here is that identifying that emotional distress is a significant predictor for quality of life does not necessarily mean that service providers should add assessing emotional distress to the battery of measures they implement. Asking people to reveal these kinds of problems is probably unethical unless something is going to be done with the information obtained, such as offering appropriate services or timely onward referral.

Services addressing the emotional distress that people with aphasia are dealing with are often not available routinely. The clear link with HRQL demonstrated here suggests that it should have a higher priority in service provision. Evidence suggests, however, that this need not necessarily be through implementing full-blown psychological therapies, for example, but could also be addressed through incorporation of work on self-esteem and confidence building alongside other therapies (e.g. Pound, Parr, Lindsay & Wolfe, 2000), or modification of attitude and behaviour by health care staff and carers, which can affect patients' motivation for and response to rehabilitation (Maclean, Pound, Wolfe & Rudd, 2000; Parr et al 1997).

The majority of stroke studies that included people with aphasia concluded that the HRQL of people with aphasia was not significantly different from that of people living with the effects of stroke without aphasia. In the present study the impact of severity of communication disability on HRQL was assessed. We measured communication disability with the ASHA-FACS. The ASHA-FACS correlate highly with measures of aphasia language impairment, such as the Western Aphasia Battery (Kertesz, 1982) ($r = .76, p < .05$) (Frattali et al., 1995) and the FAST ($r = .79, p < .01$) (Hilari, 2002). Severity of communication disability (as measured by the ASHA-FACS) was a significant predictor of HRQL with higher communication disability

resulting in poorer quality of life. This was despite the fact that the majority of our participants had high scores on the ASHA-FACS, i.e., indicative of mild communication disability (67.5% scored at or above 6, with scores ranging from 1 to 7). These findings are similar to the Kwa et al. (1996) study where 38% of the subjects had aphasia [measured with the Boston Diagnostic Aphasia Examination (Goodglass & Kaplan, 1983)]. Severity of aphasia was a significant predictor of quality of life despite the fact that data from the people with most severe aphasia were not included in the analysis (25% of their subjects could not complete the quality of life assessment due to communication problems).

A number of methodological issues may explain why aphasia was not a significant predictor of HRQL in other stroke studies. In some studies aphasia resulted in missed assessments (Ebrahim et al., 1986; Angeleri et al., 1993; Wilkinson et al., 1997). In other studies proxy respondents were used instead of the person with aphasia (Astrom et al., 1992; Astrom, Asplund & Astrom 1992; de Haan et al., 1995; Tuomilehto et al., 1995; Neau et al., 1998). Studies on agreement between self-report and proxy respondents have found that there is considerable disagreement in rating functional abilities (Knapp & Hewison, 1999) and quality of life (Sneeuw, Aaronson, de Haan & Limburg, 1997) after stroke. Hence, we believe it is advisable to analyse proxy data separately from self-report data. Lastly, in the remaining reviewed studies that included people with aphasia quite complex instruments were used to measure quality of life. These included the Ferrans and Powers quality of life index (Ferrans & Powers, 1985) in King (1996), the Philadelphia Geriatric Center Morale Scale (PGCMS, Lawton, 1975) in Lofgren et al. (1999), the Reintegration to Normal Living Index (RNLI, Wood-Dauphinee, Opzoomer, Williams, Marchand & Spitzer, 1988) in Bethoux et al. (1999) and a 45 item questionnaire in Niemi et al. (1988). None of these studies give any information on how people with aphasia managed these complex instruments. The validity of these assessments is questioned as people with aphasia may have not understood at least some of the items or may have not been able to express their responses with precision.

Cognitive level was not a significant predictor of HRQL in our sample. Our findings agree with those of one study that specifically investigated the role of cognitive decline on quality of life after stroke (Kwa et al., 1996). These authors used the CAMCOG to measure cognition, which is part of the Cambridge Examination for Mental Disorders of the Elderly (CAMDEX, Roth et al., 1986). They indicated that people with aphasia were helped if needed with gestures and pointing. They concluded that cognitive decline was not a significant predictor of quality of life after stroke.

A few studies have associated cognitive decline with reduced quality of life after stroke (Niemi et al., 1988; Jonkman et al., 1998; and Clarke et al., 1999). In the first two of these studies cognition was assessed with the Wechsler Adult Intelligence Scale (WAIS) and the Wechsler Memory Scale (WMS), which rely heavily on language. For people with aphasia, it is unclear whether such instruments measure language or cognitive skills. The third study (Clarke et al., 1999) did not attempt to differentiate between aphasia and cognitive decline. Rather the authors measured “cognitive disability” with the communication and cognition sub-scales of the Functional Independence Measure (FIM, Keith, Granger, Hamilton & Sherwin, 1987). Such assessments will tend to identify people with aphasia as also having cognitive decline. The conclusion, therefore, that cognitive decline affects quality of life may well mask the effect of aphasia on quality of life. The results of the current study did not find a significant effect of cognitive decline on HRQL and may reflect the adaptation of measures to make them as accessible as possible to people with aphasia.

A number of studies have found that aspects of social support seem to affect quality of life after stroke (Osberg et al., 1988; Viitanen et al., 1988; Astrom et al., 1992; Astrom, Asplund & Astrom 1992; King, 1996; Wyller et al., 1998). The absence of association between social support and HRQL in this sample of people with chronic aphasia may be related to the distribution of the social support scores. The SSS scores range from 1 to 5 with high scores indicating high social support and in our sample the median was 3.9 and the mean 3.7. Only 12% of the participants scored 1 or 2 in this scale compared to 66.3% who scored 4 or 5. The

fact that our sample had high levels of support may account, at least partly, for the lack of a significant association between social support and HRQL. Still, this lack of association may indeed be a true finding. In a related area, Robinson et al. (1999) found that during the first few weeks after stroke perceived social support was highly associated with depression whereas during the chronic period (12- or 24-month follow up) this association was not significant and other factors like financial security, living arrangements and work experience were more pertinent.

The number of comorbid conditions was a significant predictor of HRQL in the regression analysis whereas age was not. There was a tendency for older people to have more comorbid conditions ($r = .37, p < .001$), which seems to indicate that it is not age itself that leads to reduced quality of life but rather the increased health problems that it may bring with it.

Future research

Future studies could use the SAQOL-39 with stroke survivors with and without aphasia. This would allow for direct comparisons between different stroke groups. It would enable us to understand better the impact of aphasia as opposed to the impact of stroke and aphasia that was measured in this study.

More research is needed in the area of HRQL outcomes in severe aphasia using a range of methodologies. We will explore our findings on HRQL in people with severe aphasia using proxy respondents. Alternative methodologies may include qualitative techniques like participant and non-participant observation. All of these approaches however are methodologically challenging. HRQL is generally defined as a subjective phenomenon. This makes it hard to observe without making value judgements that link the observed behaviour to the assumed subjective perception. This is problematic for measurement.

Further work is also needed to investigate the inter-relationship between communication disability, emotional distress and activity level and how they interact to affect HRQL. Longitudinal cohort studies could be used to unravel cause and effect relationships.

Future studies could also investigate the influence of social support on quality of life in aphasia. Using a combination of different support indicators such as social network (e.g., number of friends and relatives, contact with friends and relatives, group membership) and perceived support (e.g., the SSS) may help explore whether there are any effects that were not identified in the current investigation.

Summary and conclusion

The HRQL of people living with long term aphasia after stroke is significantly affected by their emotional distress, their activity level, the severity of their communication disability and their overall health. Service providers need to take these factors into account when planning and implementing interventions aimed at improving people's quality of life. Long-term services to people with aphasia can address emotional health, enable participation in someone's immediate social context and in the community and society more generally (Byng et al 2000, Pound et al 2000), and engage with the factors which contribute to communication disability.

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Footnotes

¹ Quality of life is a related but broader term than HRQL, often related to a person's culture and value systems (WHO, 1993) and incorporating factors like a safe environment and material well-being. The health care system and its providers usually do not assume responsibility for these more global human concerns although they may be adversely affected by disease (Patrick & Erickson, 1993). Most of the literature reviewed here has actually assessed what is commonly viewed now as HRQL, but have used the term quality of life. In reporting other people's work we have used the terms they used.

² The development and psychometric properties of the SAQOL-39 are fully described in Hilari (2002). Their publication in a peer-reviewed journal is planned for 2003. Further information and copies of the instrument can be requested of the first author.

Table 1: Characteristics of the participants

Characteristics	N=83	Percent
Gender		
Female	31	37.3%
Male	52	62.7%
Age		
Mean (SD)	61.67 (15.47)	
Range	21-92	
21-45	13	15.7%
46-65	34	41%
66+	36	43.4%
Stroke type		
Ischaemic	36	43.4%
Haemorrhagic	16	19.3%
Unknown	31	37.3%
Time post onset		
Mean in years (SD)	3.5 (3.09)	
Range	1y 1m-20y 10m	
1-2 years post onset	26	31.3%
2-4 years post onset	31	37.3%
4+ years post onset	26	31.3%
Comorbidity		
None or one comorbid condition	34	41%
Two or more comorbid conditions	49	59%
Ethnic group		
Asian	7	8.4%
Black	11	13.3%
White	65	78.3%
Marital status		
Married	42	50.6%
Has partner	10	12%

Characteristics	N=83	Percent
Single	14	16.9%
Divorced or spouse died	17	20.5%
Socioeconomic status (revised collapsed SEC)		
Professionals/senior managers	23	27.7%
Associate professional/ junior managers	6	7.2%
Other admin. and clerical workers	13	15.7%
Own account non-professional	5	6%
Supervisors, technicians and related workers	11	13.3%
Intermediate workers	9	10.8%
Other workers	12	14.5%
Never worked/other inactive	4	4.8%
Employment status		
Retired before the stroke	31	37.3%
Inactive because of the stroke	47	56.6%
Some p/t or voluntary work	3	3.6%
Students	2	2.4%

Table 2: Descriptive statistics for ASHA-FACS, FAI, GHQ-12, SPM grade and SSS.

		ASHA-FACS	FAI	GHQ-12	SPM grade	SSS
N	Valid	83	83	83	82	83
	Missing	0	0	0	1	0
Mean		5.7783	21.34	8.86	2.61	3.6893
Median		5.9470	22.00	10.00	2.00	3.8947
Std. Deviation		.8900	9.88	3.17	.91	.9547
Range		3.96	38	12	4	3.89
Minimum		2.99	3	0	1	1.11
Maximum		6.95	41	12	5	5.00

Table 3: Correlations of SAQOL-39 with GHQ-12, FAI, ASHA-FACS, SPM grade and SSS.

		GHQ-12	FAI	ASHA-FACS	SPM grade	SSS
SAQOL-39	Pearson's correlation (<i>r</i>)	.53**	.58**	.46**	.27*	.19
	Sig. (two-tailed)	.000	.000	.000	.014	.080
	N	83	83	83	82	83

** Correlation significant at the .01 level (2-tailed)

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

Table 4: Summary of standard multiple regression analysis of the relation of HRQL with correlated predictors.

Predictors	Adjusted R^2	R^2 Change	B	β	t
(Constant)			.63		1.09
ASHA			.18	.22	2.15*
FAI			2.531E-02	.36	3.52**
GHQ-12			7.823E-02	.35	3.81**
SPM grade	.51***	.56***	3.430E-02	.04	.51
SSS			4.563E-02	.06	.71
Comorbidity			-.30	-.21	-2.48*
Age			4.869E-03	.11	1.17

Dependent Variable: SAQOL-39 mean

*** $p < .001$; ** $p < .01$; * $p < .05$