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Does mode of administration affect health-related quality of life outcomes after stroke?

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Running head: Effects of mode of administration on SAQOL-39g

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Abstract

Telephone interviews and postal surveys may be a resource-efficient way of assessing health-related quality of life post-stroke, if they produce data equivalent to face-to-face interviews. We explored whether telephone interviews and postal surveys of the *Stroke and Aphasia Quality of Life Scale (SAQOL-39g)* yielded similar results to face-to-face interviews. Participants included people with aphasia and comprised two groups: group one (n=22) were 3-6 months post-stroke; group two (n= 26) were \geq one year post-stroke. They completed either a face-to-face and a telephone interview or a face-to-face interview and a postal survey of the SAQOL-39g. Response rates were higher for group two (87%) than for group one (72%-77%). There were no significant differences between respondents and non-respondents on demographics, co-morbidities, stroke severity or communication impairment. Concordance between face-to-face and telephone administrations (0.90–0.98) was excellent; and very good-excellent between face-to-face and postal administrations (0.84–0.96), though scores in postal administrations were lower (significant for psychosocial domain and overall SAQOL-39g in group two). These findings suggest that the SAQOL-39g yields similar results in different modes of administration. Researchers and clinicians may employ alternative modes, particularly in the longer term post-stroke, in order to reduce costs or facilitate clients with access difficulties.

Stroke is the single most common cause of long-term disability across the Western world (Leonardi-Bee, Steiner & Bath-Hextall, 2007). Compared to other chronic conditions, it can be especially detrimental to a person's health-related quality of life (HRQL) (Sprangers, de Regt, Andries, van Agt, Bijl, de Boer, et al., 2000). Maximising the HRQL of people surviving strokes with chronic disability is a key aim of stroke rehabilitation programmes (Royal College of Physicians, 2008). Yet common stroke outcome measures do not capture subjective data about a client's sense of well-being and how this changes in the months after a stroke (e.g., *Functional Independence Measure*, Keith et al., 1987; *Functional Assessment Measure*, Hall et al., 1993; *Barthel Index*, Shah et al., 1989).

Stroke-specific quality of life scales, designed to evaluate the impact of stroke on a person's life and to measure change across time include the *Stroke Specific Quality of Life Scale (SS-QOL)* (Williams, Weinberger, Harris, Clark & Biller, 1999), the *Stroke Impact Scale (SIS)* (Duncan, Wallace, Lai, Johnson, Embretson & Laster, 1999) and the *Burden of Stroke Scale (BOSS)* (Doyle, McNeil, Hula & Mikolic, 2003). Although communication difficulties are a common result of a stroke, the only measure which has been specifically adapted for and tested with people with aphasia is the *Stroke and Aphasia Quality of Life Scale (SAQOL-39 and SAQOL-39g)*, Hilari, Byng, Lamping & Smith, 2003; Hilari & Byng, 2009; Hilari, Lamping, Smith, Northcott, Lamb & Marshall, 2009). The SAQOL-39 was tested with people with chronic aphasia. The SAQOL-39g is a version of the SAQOL-39 developed for a generic stroke population. It includes the same items as the SAQOL-39 but items are grouped into three (physical, psychosocial and communication) rather than four (physical, psychosocial, communication and energy) domains.

These stroke specific HRQL measures were psychometrically tested through face-to-face administration. However, HRQL measures can not only be administered as a face-to-face interview but also over the phone or sent to people to complete and return by post. A number of research studies have investigated whether the mode of administration affects the results of HRQL assessments. The question is an important one. Telephone and postal administrations are cheaper and less time-consuming than face-to-face interviews (Smeeth, Fletcher, Stirling, Nunes, Breeze, Ng, et al., 2001; Weinberger, Nagle, Hanlon, Samsa, Schmader, Landsman, et al., 1994). Once stroke survivors have left the rehabilitation setting and returned home, a telephone or postal interview obviates the need for them to attend an outpatient appointment or for a member of the stroke rehabilitation team to visit the participant at home. They can therefore be more convenient for participants and less time-consuming for clinicians, representing a more efficient use of resources.

In stroke, face-to-face interviewing is the standard way of assessing HRQL in clinical practice, particularly in the early stages post-stroke when participants may still be in hospital. A telephone or postal administration will be a viable, resource-efficient option for assessing HRQL only if there is high concordance between face-to-face and telephone or postal modes of administration. However, among a stroke population the telephone and postal modes can pose particular challenges for people who have communication difficulties, such as aphasia. Many people with aphasia have difficulties understanding and using spoken language (Damasio, 1991), which are essential skills for using the telephone, while a disruption to a person's reading and writing skills would make it difficult for them to understand and complete a postal questionnaire. Strategies typically recommended for supporting the communication of people with aphasia are only possible in a face-to-face scenario. For example, to help a person with aphasia understand questions it might be

necessary to write down key words and use gesture to support comprehension (Kagan & Gailey, 1993). A person who has difficulty responding to questions verbally might employ non-verbal means such as facial expression, gesture or drawing to get their message across (Lawson & Fawcus, 1999), none of which could be used over the telephone or when completing a postal survey. A face-to-face interview therefore offers maximal opportunities for the interviewer to support the understanding and expression of a person with communication impairment.

A number of studies have compared different modes of administering HRQL measures. These have varied from disease-specific studies to those investigating more generic groups (e.g., Hanmer et al., 2007, who investigated non-institutionalised adults in the US). Before considering the stroke-specific studies we will discuss those investigating more generic groups.

These studies have examined differences between participants' HRQL scores across two or three modalities and a clear trend emerges for interviewer-administered modes (i.e. face-to-face and telephone interviews) to produce more positive scores than self-administered modes (such as postal interviews) for HRQL (e.g., Hanmer, Hays & Fryback, 2007). Several studies reported that interviewer-administered modes elicited more positive scores only for certain aspects of HRQL, particularly those relating to mental health (e.g., Erhart, Wetzel, Krügel & Ravens-Sieberer, 2009; McHorney, Kosinski & Ware, 1994; Weinberger, Oddone, Samsa & Landsman, 1996).

The sample sizes of these studies vary considerably from 30,000+ (Hanmer, Hays & Fryback, 2007; Smeeth et al., 2001) to 31 (Weinberger et al., 1994). The larger studies typically administered a single interview to each participant. For example, Smeeth et al (2001)

randomly allocated participants to either a postal survey, an interview by a nurse or an interview by a lay person. In the smaller studies participants tended to carry out interviews in more than one mode of administration, enabling the authors to evaluate the concordance between modes of administration (e.g., Weinberger et al., 1994; Weinberger et al., 1996), which was found to be high. One of the larger studies (McHorney et al., 1994) carried out sensitivity tests to evaluate the validity of the different modes of administration and reported no evidence of differential discriminant validity between telephone and postal surveys.

Several studies also compared response rates and missing data between different modes of administration. Postal interviews were found to have higher completion rates than telephone interviews (Erhart et al., 2009; McHorney et al., 1994) and face-to-face interviews (Smeeth et al., 2001). However, postal interviews were also characterised by higher percentages of missing data (McHorney et al., 1994; Smeeth et al., 2001), although Hawthorne et al (2003) reported no significant differences between the rate of missing data for telephone and postal interviews. McHorney et al (1994) also examined costs and found that telephone interviews (\$47.86) were considerably more expensive than postal interviews (\$27.07). Weinberger et al (1996) reported that 70% of their participants preferred face-to-face interviews to telephone or postal modes.

Studies examining mode effects when administering HRQL measures among a stroke population have been rare. One study compared the administration of the Stroke Impact Scale (SIS) on the telephone and as a postal survey in 458 veterans with stroke, randomly assigned to the two groups (Duncan, Reker, Kwon, Lai, Studenski, Perera, et al., 2005). They

examined the costs, response rates and reliability of the measure under the different modes of administration and mode effects.

They found that the telephone interviews were twice as expensive as the postal surveys but produced better quality data. There was a higher response rate (69% for telephone, 45% for postal) and there were no significant differences between respondents and non-respondents for the telephone group. In contrast, participants were more likely to respond to the postal survey if they were married, living in the community before their stroke and had a more favourable disability status at discharge. Non-respondents were more likely to be widowed or divorced and to have a prior history of stroke. There was also missing data in the postal survey but not in the telephone interviews and test-retest reliability was better in the telephone interviews (ICCs ranged from 0.75-0.95 for postal retest and from 0.68-0.98 for telephone retest). The distribution of scores did not indicate the presence of mode effects. The authors point out that since their sample consisted entirely of veterans and was 98% male, it may not be possible to generalise the results to the stroke population at large.

Duncan et al's study did not compare the results of the same respondents across different modes of administration and so did not evaluate the concordance between telephone and postal modes of administration or with face-to-face administration. Although people with aphasia were included in the study (18.8% of the postal group and 22.6% of the telephone group had aphasia), no mention is made of the difficulties of carrying out a HRQL measure in different modes of administration with people with communication impairments following stroke.

Some of these issues were addressed in a more recent study which investigated whether face-to-face and telephone interviews produced significantly different results on a range of

stroke measures in stroke survivors (n=11) and their carers (n=8) (Hoffmann, Worrall, Eames & Ryan, 2010). The measures included the SAQOL-39, the *Caregiver Strain Index* (Robinson, 1983) and the *Hospital Anxiety and Depression Scale* (Zigmond & Snaith, 1983). There were no significant differences between face-to-face and telephone interviews on any of the outcome measures used. These results are promising. Yet people with communication impairments were not included in this study.

Moreover, it is possible that people's response to different modes of administration may vary with time post-stroke. For example, people may become more willing/ able to complete a HRQL scale as a postal survey in the longer term after their stroke, after they have had more time to adjust to their disabilities. In Hoffmann et al (2010) above, a number of outcome measures could be used at approximately three months post-onset of stroke without showing any significant differences between telephone and face-to-face administration. In Duncan et al (2005), postal and telephone interviews were carried out at 12 weeks post-stroke and response rates were markedly lower for postal administration (45%) than telephone (69%) suggesting that postal administration may be less accessible in the early stages post-stroke. However, no previous research studies have compared concordance or response rates at different stages of recovery post-stroke.

The main aim of the current study was to examine the concordance between participants' scores on the SAQOL-39g in different modes of administration among a general stroke population. We compared a) face-to-face to telephone interviews and b) face-to-face interviews to postal surveys in people with stroke, including those with communication impairments. We also examined response rates and factors that may have deterred people from responding to the questionnaire in different modes. In addition we investigated

concordance and response rates for the different modes of administration at different stages of recovery post-stroke.

Method

This study received ethics approval from a UK National Health Service (NHS) Local Research Ethics Committee (LREC) and from City University London Senate Research Ethics Committee (REC).

Participants

Participants were recruited from two different settings. Group one was recruited through an NHS Hospital from a sample of people with stroke taking part in a larger study (Hilari et al., 2009; Hilari, Northcott, Roy, Marshall, Wiggins, Chataway, et al., 2010). Those from the larger sample that were three or six months post-stroke during a set six month period were invited to take part. Group two was recruited through central London stroke self-help groups and were ≥ 1 year post-stroke. Participants had to have suffered a stroke; have no known history of mental health problems or cognitive decline prior to the stroke; have no severe or potentially terminal co-morbidity; be able and well enough to give informed consent; and speak adequate English.

Information about participants' medical and mental health history and their cognitive status was available from medical notes and discussions with the clinical team for group one and through case history interviews and general practitioner (GP) reports for group two. Potential participants' English proficiency was informally evaluated through the clinical team and (where appropriate) family reports and the researcher's own judgement. Participants with severe receptive aphasia were excluded as they would have been unable to self-report

on the questionnaire used (Hilari et al., 2003). The inclusion criteria was a score of >7/15 on the verbal and written receptive subtests of the *Frenchay Aphasia Screening Test* (FAST, Enderby, Wood & Wade, 1987). However, participants with any level of expressive aphasia were included.

For group one, participants' ability to give informed consent was initially discussed with the clinical team. If the clinical team felt that it was appropriate, the researcher then discussed the project with potential participants. For group two, the researcher gave presentations about the project at central London stroke self-help groups and asked members if they would be interested in receiving further information about taking part. Potential participants were provided with a written information sheet and consent form in a format accessible to people with aphasia. This explained what the project entailed for participants and the purpose of the research. The information was discussed with potential participants and left with them for at least 24 hours. They were given an opportunity to ask questions and raise concerns before deciding whether to take part.

Procedure

Due to the logistics of their participation in a larger study, participants in group one completed the SAQOL-39g in a face-to-face interview first and then, those who were three months post-stroke completed the SAQOL-39g in a telephone interview and those who were six months post-stroke by post. Telephone interviews took place 3-10 days after the face-to-face interview. The postal version of the questionnaire was sent to participants within three days of the face-to-face interview; it was followed-up by a telephone call on day five to check participants had received it and to prompt them to fill it in; and if necessary a second call on day 14. Postal questionnaires were returned to the research team within 2-3 weeks.

We aimed to recruit 30 participants for group two (≥ 1 year post-stroke). Participants were randomly assigned to get one of these four possible administration permutations: face-to-face followed by telephone; telephone followed by face-to-face; face-to-face followed by postal; postal followed by face-to-face (<http://www.randomization.com>, seed 10363). The time intervals between the two administrations were within those of group one.

Measures

Information on gender, age, stroke type and severity, number of co-morbidities, ethnic group and marital status was available from medical notes in group one and was collated through GP letters and a case history interview in group two (see Table 1). Stroke severity and the presence of dysarthria were determined using the *National Institute for Health Stroke Scale* (NIHSS, Brott, Adams, Olinger, Marler, Barsan, Biller et al., 1989). Scores on the NIHSS range from 0-31; higher scores reflect more severe strokes. Aphasia was assessed with the FAST, as indicated above, and presence of aphasia was determined using its cut-off scores. Health-related quality of life was measured with the SAQOL-39g. The SAQOL-39g consists of 39 items that cover three domains: physical, psychosocial and communication. Scores on the SAQOL-39g range from 1-5. There are two response formats: 1= *could not do it at all* to 5= *no trouble at all* and 1= *definitely yes* to 5= *definitely no*. Higher scores indicate better quality of life.

When administering the SAQOL-39g in the telephone mode, the researcher began by reading out the introduction to the assessment. She then explained the different response options. She read each question aloud and facilitated participants' comprehension when necessary by stressing key words, using pauses, repeating questions, checking understanding

and reminding the participant of the response options. The researcher also asked questions to clarify the participants' meaning when necessary.

A postal version of the SAQOL-39g was developed. Each section was presented on a different A4 sheet, with the response options clearly presented at the top of the page. Key words were highlighted using bold and underlined text. Respondents were asked to mark one response option for each question. The postal questionnaire was sent to participants with a covering letter and a stamped addressed envelope in which to return it.

Data analysis

Descriptive statistics were used to present respondent characteristics and summarise data. Differences between respondents and non-respondents were examined for group one only. Chi-Square tests were used to compare respondents and non-respondents on age group, gender, ethnicity, number of co-morbidities, communication impairment and stroke severity. ANOVA tests were used to compare scores on the initial face-to-face administration for respondents and non-respondents to the telephone/postal survey. When Mauchly's test (Mauchly, 1940) indicated that the sphericity assumption had been violated a Greenhouse Geisser correction (Greenhouse & Geisser, 1959) was applied. Concordance between face-to-face and telephone/postal administration of the SAQOL-39g was examined by calculating intraclass correlation coefficients (ICC). Paired sample t-tests were used to compare mean scores across different administrations.

Results

Response rates

Group one: we asked 52 of the participants of the larger study to take part in this study: 21 were invited to take part in the telephone interview, 11 agreed to take part (52%), and eight actually completed the telephone retest (38% of those asked; 72% of those who agreed). Thirty-one were asked to participate in the postal survey, 18 agreed to take part (58%), and 14 completed the questionnaire (45% of those asked; 77% of those who agreed). Reasons for declining to take part were recorded; some participants gave more than one reason. For the telephone administration reasons comprised being still on rehabilitation ward (difficulty accessing the phone or unwell, n=3), having no phone (n=2), hearing difficulties (n=2) and unwilling to take part (n=3). For the postal administration, reasons for declining participation were aphasia (n=3), physical difficulties [visual (n=3), writing (n=3) and picking up post/posting letters (n=1)] and unwilling (n=2). Of those agreeing to but not completing the second administration, two out of three refused the telephone interview and one was inaccessible; three out of four did not return their questionnaires for the postal administration and one returned it too late.

Group two: 30 participants were recruited and 15 were asked to do a face-to-face and a telephone completion of the SAQOL-39g and 15 a face-to-face and a postal completion. They all agreed to take part and in each group 13 out of 15 (87%) completed both modes of administration. Two refused the telephone completion, because of their difficulties communicating by telephone. Two participants did not return their postal questionnaires (no reasons given).

We statistically compared response rates between the two groups. In group one, of 52 people that were asked to take part in this study, 22 completed the study (42%); in group

two this was 87% and this difference was significant $\chi^2(1) = 15.42, p < .001$. However, if we look at those who agreed to take part, 29 agreed from group one and 22 completed the study (76%) vs. 87% in group two. This difference was not significant.

Respondent characteristics

Table one details the respondent characteristics for group one (n = 22) and group two (n = 26). The two groups were similar in age, gender and marital status. Group two came from more varied ethnic backgrounds (31% non-white versus 18% in group one) and they included a higher percentage of people who were more severely affected by their stroke (65% versus 46%), who had aphasia or dysarthria (73% versus 23%); and three or more other health problems (77% versus 46%).

[table one about here]

Comparison between respondents and non-respondents

For group one, we drew comparisons between respondents (n=22) and non-respondents (n=30). Of the 30 non-respondents, 7 agreed to take part but failed to complete the telephone or postal administration, while 23 declined to take part. We were unable to do this for group two given the small number of non-respondents (two in the telephone and two in the postal administration). Chi-Square tests were used to compare respondents and non-respondents on age, gender, ethnicity, number of co-morbidities, communication impairment and stroke severity. None of these factors were found to have a significant effect on whether participants responded or not to postal and telephone administrations. The data from the initial face-to-face administration of the SAQOL-39g in group one was also analysed using a three-factor mixed ANOVA with variables respondent/non-respondent

(between subject variable), telephone/postal administration (between subject variable) and domain of the SAQOL-39 (within subject variable). Mauchly's test indicated that the sphericity assumption was violated and a Greenhouse Geisser correction was applied. The results were not significant, though there was a tendency for non-respondents to have lower scores on face-to face administration of SAQOL-39g than respondents (overall mean 3.71 versus 4.14 respectively, $p=0.06$).

SAQOL-39g scores in different modes of administration

There were no missing mean scores and extremely low percentages of missing data (0% - 1.8%). Table two details means (SD) for the SAQOL-39g domains and overall mean in a) face-to-face and telephone administration and b) face-to-face and postal administration, in the two groups. For both groups SAQOL-39g scores in face-to-face and telephone administrations were very similar. There were no significant differences between them in paired samples t-tests. Scores in the postal administration tended to be lower than those in the face-to-face administration, and in group two the difference was significant for the psychosocial domain [$t(12) = 3.23, p < 0.01$] and the overall mean [$t(12) = 2.49, p < 0.05$].

[table two about here]

Table three presents the ICCs between face-to-face and telephone administration, and face-to-face and postal administration, in the two groups. Correlations were very high between face-to-face and telephone scores in both groups (ICC = 0.90-0.98). Correlations between face-to-face and postal scores tended to be lower in both groups, yet they remained high (ICC = 0.84 – 0.96).

[table three about here]

Discussion

We asked people at different stages post-stroke (< 6 months or ≥ 1 year) to complete the SAQOL-39g in a face to face interview and either a telephone interview or a postal survey. We explored whether any factors affected completion of the questionnaire in the different modes of administration and whether the different modes of administration yielded similar results. All participants successfully completed the face-to-face interviews. In group one (3-6 months post-stroke), 21 were invited to take part in the telephone interviews, 11 agreed and eight completed them; and 31 were asked to take part in the postal surveys, 18 agreed and 14 completed them. In group two (≥ 1 year post-stroke), 15 were asked to take part in the telephone interviews and 15 in the postal surveys; they all agreed and 13 completed each mode. There were no significant differences between respondents and non-respondents. In all modes of administration, there was very little missing data (highest: 1.78% in the postal administration of group two). There was excellent concordance between face-to-face and telephone administrations (0.90 – 0.98); and very good-excellent concordance between face-to-face and postal administrations (0.84 – 0.96), though there was a tendency for mean scores to be lower in postal administrations (reached significance for psychosocial domain and overall mean SAQOL-39g scores in group two).

An important feature of this study is the inclusion of people with communication impairments, with the exception of those with severe comprehension impairments who were unable to self-report on the measure. In group one, five of the 22 participants (23%) had aphasia (n=3) or dysarthria (n=2) and in group two, 18 (aphasia n=12, dysarthria n=6) out of 26 (69%) had a communication impairment. Several other studies examining different modes of administration of quality of life measures among stroke-specific and general

elderly populations do not provide any information about whether participants were aphasic (e.g., Segal, Gillard & Schall, 1996, Weinberger et al., 1994; Weinberger, Oddone, Samsa & Landsman, 1996) or exclude people with aphasia (e.g., Hoffman et al., 2010).

Although the number of people with aphasia in group one is too small to draw any meaningful conclusions and a small number of people gave aphasia as a reason for not completing the telephone/postal questionnaire, the substantial proportion of people with chronic aphasia in group two demonstrated that they were able to complete a HRQL measure in telephone interviews or postal surveys with a high level of concordance between modes. Admittedly some of them were familiar with the measure used as about half first had the SAQOL-39 administered in a face-to-face interview. Yet, this does not diminish the clinical implications of this finding. Clinicians will typically first assess clients face-to-face but they may then incorporate alternative administration methods in follow-up assessments (Harris, Weinberger & Tierny, 1997).

We compared two groups of participants at different stages in their recovery post-stroke. Completion rates for the telephone and postal interviews were higher for group two (87%), whose participants were more than one year post-stroke, than for group one (76% of those who agreed to take part and 42% of those asked). This may suggest that, for the majority of people who have had a stroke, postal surveys and telephone interviews may not be a suitable option in the earlier stages of their recovery. However, in the chronic stage of recovery, the majority of participants may be willing and able to complete a HRQL measure in these modes. This was the case in this study, despite the fact that those in the chronic stage (group two) included more people who had aphasia, more severe strokes and higher levels of co-morbidity. Though this finding warrants further investigation in larger studies, it

seems to suggest that time post-onset may be an important factor when considering the suitability of using telephone or postal administrations of HRQL assessments.

For group one, where response rates were lower, we were able to compare respondents versus non-respondents. None of the variables examined were found to differ significantly between them, including age, gender, ethnicity, number of co-morbidities, communication impairment and stroke severity. Although there was a tendency for non-respondents to have lower scores on face-to face administration of SAQOL-39g than respondents, this too was not significant. Looking at the reasons people offered for declining to take part, a variety of issues emerged, such as logistics (having/ accessing a phone), physical difficulties (hearing for telephone administration, visual and writing problems for postal administration), communication impairment and unwillingness; but no single reason stood out as more important than others.

Despite the high level of concordance, a tendency emerged in the data for postal results to be slightly lower than those from face-to-face interviews, particularly in group two. This could be due to people having more difficulties completing the HRQL measure by themselves, especially as group two included more people who had aphasia, more severe strokes and higher levels of co-morbidity. Yet, this does not explain the direction of the effect (postal: lower) and the fact that this difference reached significance for the psychosocial domain and the overall score in group two. Studies examining participant responses to HRQL measures in different modes have reported a similar pattern, whereby respondents give more positive responses to an interviewer (face-to-face or telephone) than they do when they carry out the same questionnaire with no interviewer present (e.g., Hanmer, Hays & Fryback, 2007; Weinberger et al., 1996). Moreover, this effect seems to be

more marked for certain types of questions, e.g. mental health (Erhart et al., 2009). This may reflect a social desirability effect, i.e. a tendency for people to present themselves in a positive light to an interviewer and therefore being more reluctant to report what they perceive as undesirable behaviours (Tomlin, Pinney, Buncher, McKay & Brown, 1998) or sensitive health problems (Rhodes, Girman, Jacobsen, Guess, Hanson, Oesterling, et al., 1995). It may be that the psychosocial questions in the SAQOL-39 provoke a similar tendency for respondents given their more personal and sensitive nature.

Limitations of this study include the relatively small sample size (n=48), the exclusion of people with severe comprehension impairments and the use of randomisation for order of administration in group two only. A larger sample would have allowed us to explore more systematically the relative importance of reasons for non-responding in the telephone and postal modes; and to compare effects of order of administration (Harris et al., 1997; Hays, Kim, Spritzer, Kaplan, Tally, Feeny, et al., 2009; Weinberger et al., 1996). A larger study would also include more people with aphasia and other stroke-related disabilities (e.g. cognitive decline) and could provide more information about the specific difficulties they encounter in carrying out the SAQOL-39 in the telephone and postal modes. Strategies that can act as facilitators could also be investigated, e.g. providing a written copy of the tool for telephone interviews or using internet video conferencing technology (such as Skype or Aboobe Connect) to allow the clinician to facilitate (Hoffmann et al., 2010). This would provide guidance for clinicians when deciding which mode of administration and facilitation strategies would be most suitable for particular clients.

Future research could also explore other aspects that can affect the usefulness of an assessment, such as the relative costs and time demands of the different modes of

administration. Previous research has shown that postal surveys cost on average \$37.91, which is roughly half the cost of telephone surveys (\$80.58) (Duncan et al., 2005). However, these data apply in the US, and relative costs could be different in other countries. On the other hand, Weinberger et al (1996) compared the time required to complete the SF-36 and found that live interviews were considerably shorter than self-administered ones (9.6 ± 5.6 minutes v. 12.7 ± 8.3 minutes). Lastly, participant preferences concerning the different modes of administration could be further explored (Weinberger et al., 1996).

Conclusion

Our findings suggest that the majority of people with stroke, including those with aphasia who do not have severely impaired comprehension, are able to complete telephone and postal administrations of HRQL assessments in the longer term post stroke. In the earlier stages (3-6 months), a range of factors, including logistics (still in rehabilitation, no access to a phone), and stroke related impairments (visual, communication, and difficulty with writing and picking up post or posting letters) may prevent them from doing so. Yet, for those who are able to complete the SAQOL-39 in alternative modes of administration, concordance with a face-to-face interview is excellent for the telephone interview and very good-excellent for the postal survey. These findings have important clinical and research implications. Therapists may consider conducting follow-up or review assessments in alternative modes in order to facilitate clients with difficulties accessing clinics or in order to reduce costs. Researchers can also employ telephone interviews or postal surveys in order to reduce research costs or to recruit larger samples in their studies.

References

- Brott, T., Adams, H. P., Olinger, C. P., Marler, J. R., Barsan, W. G., Biller, J., et al. (1989). Measurements of acute cerebral infarction: A clinical examination scale. *Stroke*, *20*, 964-970.
- Damasio, A. R. (1991). Signs of aphasia. In M. T. Sarno (Ed.), *Acquired aphasia* (2nd ed.). San Diego, CA: Academic Press.
- Doyle, P., McNeil, M., Hula, W., Mikolic, J. (2003). The burden of stroke scale (BOSS) *Aphasiology*, *17*(3), 291-304.
- Duncan, P. W., Wallace, D., Lai, S. M., Johnson, D., Embretson, S., Laster, L. J. (1999). The stroke impact scale version 2.0. evaluation of reliability, validity, and sensitivity to change. *Stroke*, *30*, 2131-2140.
- Duncan, P. W., Reker, D., Kwon, S., Lai, S. M., Studenski, S., Perera, S., et al. (2005). Measuring stroke impact with the stroke impact scale: Telephone versus mail administration in veterans with stroke. *MedCare*, *43*(5), 507-515.
- Enderby, P., Wood, V., Wade, D. (1987). *Frenchay Aphasia Screening Test*. Windsor: NFER-Nelson.
- Erhart, M., Wetzel, R. M., Krügel, A., Ravens-Sieberer, U. (2009). Effects of phone versus mail survey methods on the measurement of health-related quality of life and emotional and behavioural problems in adolescents. *BMC Public Health*, *30*, 491-502.
- Greenhouse, S.W. & Geisser, S. (1959). On methods in the analysis of profile data. *Psychometrika*, *24*, 95-112.
- Hall, K. M., Hamilton, B. B., Gordon, W. A., Zasler, N. D. (1993). Characteristics and comparisons of functional assessment indices: Disability rating scale, functional independence measure and functional assessment measure. *Journal of Head Trauma Rehabilitation*, *8*, 60-75.
- Hanmer, J., Hays, R., Fryback, D. G. (2007). Mode of administration is important in U.S. national estimates of health-related quality of life. *Medical Care*, *45*(12), 1171-1179.
- Harris, L. E., Weinberger, M., Tierney, W. M. (1997.) Assessing inner-city patients' hospital experiences: A controlled trial of telephone interviews versus mailed surveys. *Medical Care*, *35*(1), 70-76.

- Hays, R. D., Kim, S., Spritzer, K. L., Kaplan, R. M., Tally, S., Feeny, D., et al. (2009). Effects of mode and order of administration on generic health-related quality of life scores. *Value Health, 12*(6), 1035-1039.
- Hilari, K., Byng, S., Lamping, D. L., Smith, S. C. (2003). Stroke and aphasia quality of life scale-39 (SAQOL-39): Evaluation of acceptability, reliability and validity. *Stroke, 34*, 1944-1950.
- Hilari, K., & Byng, S. (2009). Health-related quality of life in people with severe aphasia. *International Journal of Language and Communication Disorders, 44*(2), 193-205.
- Hilari, K., Lamping, D. L., Smith, S. C., Northcott, S., Lamb, A., Marshall J. (2009). Psychometric properties of the Stroke and Aphasia Quality of Life scale (SAQOL-39) in a generic stroke population. *Clinical Rehabilitation, 23*(6), 544-557.
- Hilari, K., Northcott, S., Roy, P., Marshall, J., Wiggins, R. D., Chataway, J., Ames D. (2010). Psychological distress after stroke and aphasia: The first six months. *Clinical Rehabilitation, 24*(2), 181-190.
- Hoffmann, T., Worrall, L., Eames, S., Ryan, A. (2010). Measuring outcomes in people who have had a stroke and their carers: Can the telephone be used? *Topics in Stroke Rehabilitation, 17*(2), 119-127.
- Kagan, A. & Gailey, G. (1993). Functional is not enough: Training conversation partners for aphasic adults. In A. L. Holland, & M. M. Forbes (Eds.), *Aphasia treatment: World perspectives*. London: Chapman & Hall.
- Keith, R. A., Granger, C. V., Hamilton, B. B., Sherwin, F. S. (1987). The functional independence measure: A new tool for rehabilitation. In M.G. Eisenberg, R.C. Grzesiak (Eds.), *Advances in clinical rehabilitation* (pp.6-18). New York: Springer Publishing., 1.
- Lawson, R., & Fawcus, M. (1999). Increasing effective communication using a total communication approach. In S. Byng, K. Swinburn, & C. Pound (Eds.), *The aphasia therapy file*. Hove: Psychology Press.

- Leonardi-Bee, J., Steiner, T., Bath-Hextall, F. J. (2007). Naftidrofuryl for acute stroke. *Cochrane Database of Systematic Reviews*, Issue 2.
- Mauchly, J. (1940). Significance test for sphericity for a normal n-variate distribution. *Annals of Mathematical Statistics*, 11 (2), 204-209.
- Rhodes, T., Girman, C. J., Jacobsen, S. J., Guess, H. A., Hanson, K. A., Oesterling, J. E., & Lieber, M. M. (1995). Does the mode of administration affect the reporting of urinary problems? *American Journal of Epidemiology*, 141(11), S49-S49.
- Robinson, B. (1983). Validation of a caregiver strain index. *Journal of Gerontology*, 38(3), 344-348.
- Royal College of Physicians (2008). National clinical guideline for stroke (3rd ed.). *Report prepared by the intercollegiate working party for stroke*. London: Royal College of Physicians.
- Segal, M. E., Gillard, M., Schall, R. R. (1996). Telephone and in-person proxy agreement between stroke patients and caregivers for the functional independence measure. *American Journal of Physical Medicine and Rehabilitation*, 75(3), 208-212.
- Shah, S., Vanclay, F., Cooper, B. (1989). Improving the sensitivity of the Barthel Index for stroke rehabilitation. *Journal of Clinical Epidemiology*, 42(8), 703–709.
- Smeeth, L., Fletcher, A. E., Stirling, S., Nunes, M., Breeze, E., Ng, E. et al. (2001). Randomised comparison of three methods of administering a screening questionnaire to elderly people: Findings from the MRC trial of the assessment and management of older people in the community. *British Medical Journal*, 323, 1-7.
- Sprangers, M. A. G., de Regt, E. B., Andries, F., van Agt, H. M. E., Bijl, R. V., de Boer, J. B., et al. (2000). Which chronic conditions are associated with a better or poorer quality of life? *Journal of Clinical Epidemiology*, 53(9), 895-907.
- Tomlin, M. E., Pinney, S., Buncher, C. R., McKay, R., Brown, M. K. (1998). The effect of the mode of questionnaire administration on workers' responses to cigarette smoking questions. *American Journal of Epidemiology*, 147(11), S85-S85.

- Weinberger, M., Nagle, B., Hanlon, J. T., Samsa, G. P., Schmader, K., Landsman, P. B. et al. (1994). Assessing health-related quality of life in elderly outpatients: Telephone versus face-to-face administration. *Journal of the American Geriatrics Society*, 42(12), 1295-1299.
- Weinberger, M., Oddone, E. Z., Samsa, G. P., Landsman, P. B. (1996). Are health-related quality-of-life measures affected by the mode of administration? *Journal of Clinical Epidemiology*, 49(2), 135-140.
- Williams, L. S., Weinberger, M., Harris, E., Clark, D. O., Biller, J. (1999). Development of a stroke-specific quality of life scale. *Stroke*, 30, 1362-1369.
- Zigmond, A. & Snaith, R. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica*, 67(1), 61-70.

Table 1: Respondent characteristics

Characteristics	Group 1 (3-6m post stroke) n=22	Group 2 (1+ year post stroke) n=26
Gender		
Female	11 (50%)	11 (42%)
Male	11 (50%)	15 (58%)
Age		
Mean (SD)	70.68 (10.72)	72.69 (11.01)
Range	51-90	51-87
Stroke type		
Ischaemic	17 (77%)	14 (54%)
Haemorrhagic	5 (23%)	
Unknown	N/A	12 (46%)
Stroke severity (<i>National Institute for Health Stroke Scale scores</i>)		
Minor (0-4)	12 (54%)	9 (35%)
Moderate (5-15)	10 (46%)	16 (61%)
Moderate-severe (16+)	0	1 (4%)
Number of co-morbidities		
0-2	12 (54%)	6 (23%)
3+	10 (46%)	20 (77%)
Ethnic group		
White	18 (82%)	18 (69%)
Asian	1 (4.5%)	3 (12%)
Black	1 (4.5%)	5 (19%)
Other	2 (9%)	0
Marital status		
Single	4 (18%)	5 (19%)
Has partner/ Married	13 (59%)	12 (46%)

Divorced/ widowed	5 (23%)	9 (35%)
Communication impairment		
Aphasia	3 (14%)	13 (50%)
Dysarthria	2 (9%)	6 (23%)
No communication impairment	17 (77%)	7 (27%)

Table 2 : Distribution of *Stoke and Aphasia Quality of Life Scale (SAQOL-39g)* scores [mean(SD)] across different modes of administration

Group 1				
SAQOL-39g domain and total	Face-to-face (n=8)	Telephone (n=8)	Face-to-face (n=14)	Postal (n=14)
Physical	4.43 (0.66)	4.33 (0.69)	4.20 (0.99)	3.89 (1.15)
Psychosocial	4.12 (0.65)	4.16 (0.56)	3.75 (0.95)	3.55 (1.12)
Communication	4.54 (0.90)	4.59 (0.94)	4.44 (0.94)	4.37 (0.97)
Total	4.32 (0.55)	4.31 (0.62)	4.06 (0.78)	3.84 (0.94)
Group 2				
SAQOL-39g domain and total	Face-to-face (n=13)	Telephone (n=13)	Face-to-face (n=13)	Postal (n=13)
Physical	3.53 (0.97)	3.54 (0.95)	3.21 (0.86)	3.11 (1.10)
Psychosocial	3.63 (0.97)	3.73 (0.81)	3.03 (0.76)**	2.58 (0.58)**
Communication	4.53 (0.60)	4.60 (0.53)	3.69 (1.08)	3.52 (0.90)
Total	3.75 (0.74)	3.81 (0.63)	3.22 (0.64)*	2.96 (0.66)*

*: p<0.05

** : p<0.01

Table 3: Correlations between scores from face-to-face and telephone or postal modes of administration of the *Stoke and Aphasia Quality of Life Scale (SAQOL-39g)*

	Group 1		Group 2	
	Postal (n=13)	Telephone (n=8)	Postal (n=13)	Telephone (n=13)
SAQOL-39g				
Physical	0.89	0.98	0.96	0.97
Psychosocial	0.90	0.90	0.84	0.98
Communication	0.95	0.98	0.86	0.97
Total	0.91	0.96	0.91	0.98