Measuring Outcomes in People Who Have Had a Stroke and Their Carers: Can the Telephone Be Used?

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Purpose: Telephone interviews may be a cost-effective alternative to administering stroke outcome measures for people who are living in the community following a stroke, but there is a lack of research that has compared the different modes of administering outcome measures. The aim of this study was to determine whether telephone administration of selected stroke outcome measures resulted in significantly different results to face-to-face administration of the same outcome measures. Method: Nineteen participants who were taking part in a randomised controlled trial (RCT) evaluating the effectiveness of a postdischarge education and support package for stroke patients and their carers were recruited for this study. Participants had the RCT follow-up outcome measures, at 3 months post discharge, administered by both telephone and face-to-face. Participants were randomised to receive either the telephone or face-to-face administration first and a period of 2 weeks separated the two administrations. Outcome measures were the Knowledge of Stroke Questionnaire, a stroke self-efficacy questionnaire, Hospital Anxiety and Depression Scale, Stroke and Aphasia Quality of Life Scale, and the Caregiver Strain Index. Results: There were no significant differences between scores obtained on any of the outcome measures that were administered by telephone and face-to-face (P > .05). Conclusion: The telephone can be used to administer the outcome measures that were evaluated in this study to stroke patients and carers. These findings may be of benefit to stroke researchers and clinicians who wish to incorporate the use of telephone measures into the follow-up care of stroke patients and their carers. Key words: carers, cerebrovascular accident, outcome measures, patients, stroke, telephone

Stroke is a common cause of disability and can have a profound impact on a person’s physical, emotional, and social functioning and well-being and that of their carers and family.1–4 The transition from a hospital to home environment can be a challenging time; following a stroke, individuals can experience a loss in functional ability, barriers to community integration, increases in idle time, social isolation, depression, anxiety, financial and vocational changes, and lower feelings of personal autonomy.5,6

The importance of patient and carer education post stroke is widely acknowledged.7,8 A systematic review about the effects of information provision following stroke examined 17 randomised controlled trials (RCTs) and found that providing information about stroke can improve patients’ stroke knowledge and satisfaction with aspects of the care received.7 Despite the benefits of stroke education, studies from a number of countries have reported that a large proportion of stroke patients feel unprepared for discharge and that there continue to be inadequacies in either the quantity and/or quality of information that patients and carers receive about stroke prior to discharge.9–13

In an attempt to better meet the educational needs of stroke patients and their carers, a new intervention has been developed. This intervention provides stroke patients and carers with a computer-generated written education package14 on hospital discharge tailored to the individuals’ informational needs and supplements this information with extensive verbal reinforcement both at discharge and on a number of occasions, via the telephone, up until 3 months post discharge. The intervention is currently being evaluated in a RCT that has used a number of patient and carer outcome measures. Telephone administration of
Some studies have found that telephone administration of outcome measures can be equally suitable or even more suitable than other modes.\textsuperscript{17,19} In an RCT that compared telephone versus in-person interviews on reports of alcohol use, it was found that participants’ drinking status was the same regardless of whether the interview was conducted face-to-face or by telephone.\textsuperscript{17} A study by Revicki and colleagues\textsuperscript{19} evaluated the correlation between data (symptoms, health-related quality of life, and medication compliance) collected from telephone and face-to-face interviews with patients with bipolar disorder. They reported excellent agreement (intraclass correlation coefficients [ICC] 0.66–0.92) between interviews conducted by the different modes of administration and concluded that telephone interviews are a feasible and reliable method of collecting data from health-related outcome measures.\textsuperscript{19}

Conversely, a number of studies have found that interviews produce significantly different results depending on the mode of administration.\textsuperscript{15,20,25} A study involving patients with chronic medical diseases who had attended a general medical clinic investigated the administration of a health-related quality of life outcome measure (SF-36) by randomly assigning patients to receive either telephone, face-to-face, or self-administration, followed by the other modes.\textsuperscript{20} Although the outcome measure demonstrated internal consistency regardless of the mode of administration, absolute difference scores between modes were large, with telephone administration producing the least favourable results. In this study, a high percentage (40%) of the participants who were invited to participate refused, which could have potentially resulted in response bias.\textsuperscript{20,26}

The lack of opportunity to observe and respond to participant’s nonverbal cues during telephone administration of outcomes may affect the accuracy of responses as well as result in the participant experiencing uncertainty or decreased motivation.\textsuperscript{16,27} Participants might also be more likely to honestly answer questions that are sensitive or confronting when filling out a questionnaire in private.\textsuperscript{15,27} Cook and colleagues\textsuperscript{19} conducted an RCT that compared self-administration with interviewer administration

the outcome measures would enable the inclusion of patients from a wider geographical area and consequently increase the sample size of the RCT. However, the literature is unclear as to which method of outcome administration produces the most accurate results.\textsuperscript{15–21}

One common method of data collection in stroke research is face-to-face interviews, however this method requires the investment of a large amount of resources, both in terms of the time of research personnel and financial outlay.\textsuperscript{21} Self-administration of outcome measures is less resource-intensive, yet it can be affected by a poor response rate. There is the potential for nonresponse bias in results, because data may be returned by only the most motivated and compliant participants.\textsuperscript{18,22} An alternative method of data collection is telephone administration of outcome measures. This method allows participants to be recruited from more diverse geographic areas, is typically less expensive than face-to-face interviews, and has a quick turnaround time.\textsuperscript{19}

It appears that the ideal method of administration is dependent on factors such as characteristics of the outcome measures that are being used, the type of data that are being collected, and characteristics of the target population that is being assessed.\textsuperscript{15,21} It has been found that in situations where participants have an impairment, such as that following stroke, self-administration may be less appropriate than other methods as it requires a greater degree of energy, motivation, and literary and communication skills.\textsuperscript{21–23} Physical difficulties that can affect an individual following stroke, such as upper limb hemiparesis, may also limit an individual’s ability to complete a written questionnaire.\textsuperscript{23} The cognitive and perceptual impairments that some individuals experience post stroke can result in individuals being unable to complete a questionnaire independently due to a lack of understanding, poor memory, reduced concentration, or difficulty identifying the correct response option. Additionally, communication impairments such as aphasia and dysarthria may result in difficulty during both face-to-face and telephone interviews due to a reduced understanding of verbal instruction and an inability of the individual being interviewed to formulate an appropriate or intelligible response.\textsuperscript{24}
for a health-related quality of life measure for people with asthma. Higher scores were reported for the self-administered questionnaires, which were also more consistent with other measures of dysfunction and sickness that were administered. As the questionnaire was very long (152 items), the authors suggested that participants may have been unable to sustain their attention throughout the entire interview.15

Very few studies have specifically compared different modes of administration of stroke-related outcome measures. Korner-Bitensky and colleagues28 conducted a study in which 366 stroke and orthopaedic patients, up to 5 years post discharge from hospital, were randomly assigned to receive face-to-face or telephone administration of outcome measures such as the Barthel Index, Zung Self-Rating Depression Scale, Reintegration to Normal Living Index, and the Pfeiffer Short Portable Mental Status Questionnaire. They found that telephone-administered outcome measures showed good comparability to face-to-face administration of the same outcome measures, however less frequent reporting of disability over the telephone was observed, particularly in participants with severe impairments.28 A study by Mackintosh and colleagues29 found satisfactory agreement (P<.05; 75% agreement) between face-to-face and telephone interviews when collecting falls information using standardised questions from nine community-dwelling people with stroke. Goldstein and colleagues24 assessed the feasibility and psychometric properties of the telephone-administered version of the Health Utilities Index Mark 2 and 3 (HUI2/3) with 76 stroke patients and 109 carers. Telephone interviews were found to produce a high amount of missing data, which was attributed to stroke-related impairments, such as aphasia and impaired cognitive abilities. However as Goldstein et al’s study did not compare telephone administration with another mode of administration, it is not possible to conclude whether similar results would have occurred if another mode of administration was used. Duncan and colleagues30 conducted a study investigating the administration of a stroke-specific measure (Stroke Impact Scale) to 458 participants who were 12 weeks post stroke. Participants were randomly assigned to receive the outcome measures via telephone or mail administration. The researchers reported that telephone administration produced a higher response rate, less bias in responder selection, and higher test-retest reliability.30 Smith and colleagues18 conducted an RCT that compared telephone and face-to-face administration of the FIM™ in 40 community-dwelling people who were between 3 and 10 months after discharge from rehabilitation following a stroke. Telephone administration of the FIM™ demonstrated good intermodal agreement, and there was good agreement across items and good stability for both methods of administration. The authors suggested that telephone administration of the FIM™ can be a reliable, cost-effective, and convenient mode of collecting data from stroke patients.18 To further investigate the effect of mode on the administration of outcome measures in a sample of people with stroke and their carers, this study aimed to determine whether telephone administration of selected stroke outcome measures produces significantly different results to face-to-face administration of the same outcome measures.

Methods

Participants

Participants were recruited from the acute stroke units of two major metropolitan hospitals in Brisbane, Australia, between November 2008 and March 2009. Stroke patients and their carers who were participating in the previously described RCT were invited, on a consecutive basis, to also participate in the current study. Eligibility criteria included medical stability; not living in residential care prior to admission or having residential care as a planned discharge destination; having adequate spoken and written English, cognition, communication, and corrected vision and hearing to complete the consent process and outcome measures; contactable via the telephone; and living within 50 km of the hospital after discharge.

*FIM™ is a trademark of Uniform Data System for Medical Rehabilitation, a division of UB Foundation Activities, Inc.
Procedure

Ethical clearance for the study was obtained from university and hospital ethics committees. After providing consent, participants were randomised using a random numbers table into one of two groups (Group 1 and Group 2) by an independent researcher who was not involved in the data collection for the study. As part of the main RCT, participants were scheduled to have the RCT outcome measures administered at a 3-month postdischarge follow-up assessment. Participants in the current study who were randomised into Group 1 received telephone administration of the outcome measures followed by face-to-face administration. Participants who were randomised into Group 2 received face-to-face administration of the outcome measures, followed by telephone administration. A period of 2 weeks separated the two methods of administration. Previous studies have shown that after returning home following a stroke, a stroke patient’s clinical status may not vary greatly within 2 weeks, however it is long enough to eliminate some test-retest bias. One research assistant completed the telephone interviews for participants in Group 1 and the face-to-face interviews for participants in Group 2. Another research assistant completed the telephone interviews for participants in Group 2 and the face-to-face interviews for participants in Group 1. This reduced examiner bias in the results. Demographic and relevant clinical variables were collected from either participants’ medical charts or from interviews with each participant. These included age; gender; living situation; relationship of carer to patient; years of formal education completed; type, side, and date of stroke; presence of selected impairments (visuo-perceptual, cognitive, or aphasia); and health literacy. Health literacy was measured using the Rapid Estimate of Adult Literacy in Medicine (REALM), a reading recognition test that measures the ability of the reader to pronounce 66 commonly used medical and lay terms for body parts and illnesses. Raw scores range from 0 to 66 and were converted into four grade range estimates of literacy.

Outcome measures

Some of the outcome measures that were evaluated in this study were existing published assessments, whereas others were developed or adapted for use in the main RCT as no suitable assessments existed to assess the domains of interest. The Knowledge of Stroke Questionnaire was used to assess both patients’ and carers’ knowledge about stroke. It is a 30-item questionnaire that has been used as a 25-item questionnaire in previous stroke research; it was modified, by the addition of five questions, for use in the main RCT. Evaluation of the original version found that this test has good content validity and test-retest reliability (ICC 0.66) when it was administered face-to-face.

Patient and carer self-efficacy was examined using a 9-item self-efficacy questionnaire that was designed specifically for use in the main RCT. Each item is scored on a 10-point Likert Scale, where 1 = not at all confident and 10 = extremely confident. It includes questions regarding an individual’s confidence in his or her ability to access practical and emotional help, access and understand information, cope with the impact of stroke, manage stress, take action to prevent secondary stroke, and communicate with health professionals.

The Hospital Anxiety and Depression Scale (HADS) was used to measure the presence and severity of anxiety and depression in both stroke patients and carers. Each item is answered on a 4-point response category, with a total possible score of 0–21 for the anxiety subscale and 0–21 for the depression subscale. Lower scores indicate lower levels of the emotion that is being measured. The use of the HADS with people who have had a stroke has been validated, and a review of studies that have examined the HADS found that the mean Cronbach’s alpha was 0.83 for the anxiety subscale (HADS-A) and 0.82 for the depression subscale (HADS-D).

The Stroke and Aphasia Quality of Life Scale (SAQOL-39) is a measure of the quality of life of people who have had a stroke. It has 39 items and is scored on a 5-point scale (two response formats: 1 = could not do it at all to 5 = no trouble at all, and 1 = definitely yes to 5 = definitely no). The SAQOL-39 consists of four subdomains (physical tasks, communication, energy levels, and psychosocial), with a higher score indicating a better quality of life. Although originally tested with people with aphasia, the SAQOL-39 has demonstrated good reliability, validity, and responsiveness to change when used with stroke patients, both those with and those without aphasia.
The Caregiver Strain Index is a 13-item questionnaire that assesses the degree to which carers of patients experienced difficulties that are common to informal carers. The tool has been found to have good internal reliability, construct validity, and internal consistency, with a Cronbach's alpha of 0.86.\(^{39,40}\)

**Data analysis**

Data were analysed using the Statistical Package for Social Sciences, version 17 (SPSS, Inc., Chicago, Illinois, USA). The Wilcoxon matched-pairs signed-ranks test was used to test the hypothesis that there would be no significant differences between scores obtained from the face-to-face and telephone interviews. A \(P\) value \(\leq 0.05\) was considered to be statistically significant.

**Results**

Between November 2008 and March 2009, 26 patients and 22 carers were recruited into the main RCT. Of these, 35 (20 patients and 15 carers) met the eligibility criteria for the study and were invited to participate. Twenty-eight participants (16 patients and 12 carers) also provided consent to participate in this substudy and were randomised into Group 1 or Group 2. Nine participants (6 from Group 1 and 3 from Group 2) were unable to be contacted to complete the second interview. Therefore, complete data were obtained from 11 patients (7 were in Group 1 and 4 in Group 2) and 8 carers (4 were in Group 1 and 4 in Group 2). Table 1 shows the demographic and clinical characteristics of the participants.

**Discussion**

This study found that there were no statistically significant differences between the telephone and face-to-face administration of the outcome measures for stroke patients and carers. There were no significant differences between scores obtained on any of the outcome measures.

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**Table 1.** Demographic and clinical characteristics of participants

<table>
<thead>
<tr>
<th>Demographic and clinical characteristics</th>
<th>Patients (n=11)</th>
<th>Carers (n=8)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Female, n (%)</strong></td>
<td>7 (64%)</td>
<td>5 (63%)</td>
</tr>
<tr>
<td><strong>Age, mean (SD, range)</strong></td>
<td>69 (12.5, 48–85)</td>
<td>56 (11.6, 41–75)</td>
</tr>
<tr>
<td><strong>Years of formal education, mean (SD, range)</strong></td>
<td>10 (3.2, 6–16)</td>
<td>13 (11.6, 10–17)</td>
</tr>
<tr>
<td><strong>Days since stroke at time of first interview, mean (SD, range)</strong></td>
<td>101.8 (14.3, 75–125)</td>
<td>111.9 (21.8, 90–143)</td>
</tr>
<tr>
<td><strong>Living situation, n (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alone</td>
<td>4 (36%)</td>
<td>0</td>
</tr>
<tr>
<td>Partner/spouse</td>
<td>4 (36%)</td>
<td>7 (88%)</td>
</tr>
<tr>
<td>Family/friend</td>
<td>3 (27%)</td>
<td>1 (13%)</td>
</tr>
<tr>
<td><strong>Relationship to patient, n (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child</td>
<td>NA</td>
<td>5 (63%)</td>
</tr>
<tr>
<td>Partner/spouse</td>
<td>NA</td>
<td>3 (28%)</td>
</tr>
<tr>
<td><strong>Presence of stroke related impairments, n (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visuo-perceptual</td>
<td>1 (9%)</td>
<td>NA</td>
</tr>
<tr>
<td>Cognition</td>
<td>2 (18%)</td>
<td>NA</td>
</tr>
<tr>
<td>Aphasia</td>
<td>1 (9%)</td>
<td>NA</td>
</tr>
<tr>
<td>Type of stroke, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ischaemic</td>
<td>9 (82%)</td>
<td>NA</td>
</tr>
<tr>
<td>Haemorrhagic</td>
<td>2 (18%)</td>
<td>NA</td>
</tr>
<tr>
<td><strong>Side of stroke, n (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Left</td>
<td>4 (36%)</td>
<td>NA</td>
</tr>
<tr>
<td>Right</td>
<td>7 (64%)</td>
<td>NA</td>
</tr>
<tr>
<td><strong>REALM score (range)</strong></td>
<td>54 (34–66)</td>
<td>62 (59–65)</td>
</tr>
<tr>
<td><strong>Reading grade estimate</strong></td>
<td>7–8th grade</td>
<td>9th grade and above</td>
</tr>
</tbody>
</table>

*Note: NA=not applicable; REALM=Rapid Estimate of Adult Literacy in Medicine.*
As some of the outcome measures that were evaluated in this study are measures that are often used in stroke research (eg, the HADS, Caregiver Strain Index, and SAQOL-39), researchers may be able to plan to administer these outcome measures by telephone in research studies. Depending on the purpose and nature of the study, telephone administration of outcome measures in research studies may enable recruitment of patients from a more geographically dispersed region and thus help to increase the sample size. A sufficient sample size in research studies is important to ensure that statistical power is obtained and the risk of type II error is reduced. Also, telephone administration eliminates the need for participants and/or researchers to travel to a face-to-face assessment, which saves both time and resources, is more convenient for those involved, and may potentially contribute to increased response rates and/or lower attrition rates.

Other studies have concluded that telephone administration of outcome measures in research has the potential to produce less missing data and reduce costs, when compared to other modes of administration. Harris and colleagues compared telephone and mail-administered outcome measures for patients who were discharged from an inpatient medical service. It was found that mail surveys resulted in 31% missing data, whereas telephone surveys only had 20% of data missing (P<.001), and that the cost

Table 2. Mean scores and results of Wilcoxon matched-pairs signed rank test for analysis of differences between face-to-face and telephone administration of outcome measures for stroke patients

<table>
<thead>
<tr>
<th>Item</th>
<th>Face-to-face mean score (SD, range)</th>
<th>Telephone mean score (SD, range)</th>
<th>z value</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge of Stroke</td>
<td>20.0 (3.6, 11–23)</td>
<td>20.1 (3.7, 15–27)</td>
<td>-0.10</td>
<td>.92</td>
</tr>
<tr>
<td>Self-efficacy (total score)</td>
<td>76.6 (8.5, 64–88)</td>
<td>73.4 (10.9, 55–87)</td>
<td>-1.51</td>
<td>.13</td>
</tr>
<tr>
<td>HADS - anxiety</td>
<td>5.8 (4.7, 0–14)</td>
<td>6.5 (4.3, 1–13)</td>
<td>-0.51</td>
<td>.61</td>
</tr>
<tr>
<td>HADS - depression</td>
<td>4.6 (5.3, 0–19)</td>
<td>5.1 (3.8, 1–12)</td>
<td>-0.78</td>
<td>.44</td>
</tr>
<tr>
<td>SAQOL - total</td>
<td>3.6 (0.9, 2–5)</td>
<td>3.7 (0.7, 3–5)</td>
<td>-0.80</td>
<td>.42</td>
</tr>
<tr>
<td>SAQOL - physical</td>
<td>3.9 (1.0, 2–5)</td>
<td>4.1 (0.7, 2–5)</td>
<td>-0.98</td>
<td>.33</td>
</tr>
<tr>
<td>SAQOL - psychosocial</td>
<td>3.4 (1.1, 2–5)</td>
<td>3.5 (1.1, 2–5)</td>
<td>-0.58</td>
<td>.56</td>
</tr>
<tr>
<td>SAQOL - communication</td>
<td>4.5 (0.7, 3–5)</td>
<td>4.4 (0.5, 4–5)</td>
<td>-0.53</td>
<td>.59</td>
</tr>
<tr>
<td>SAQOL - energy</td>
<td>2.8 (1.4, 1–5)</td>
<td>2.9 (1.0, 2–5)</td>
<td>-0.92</td>
<td>.36</td>
</tr>
</tbody>
</table>

Note: HADS = Hospital Anxiety and Depression Scale; SAQOL = Stroke and Aphasia Quality of Life Scale.

Table 3. Mean scores and results of Wilcoxon matched-pairs signed rank test for analysis of differences between face-to-face and telephone administration of outcome measures for carers of stroke patients

<table>
<thead>
<tr>
<th>Item</th>
<th>Face-to-face mean score (SD, range)</th>
<th>Telephone mean score (SD, range)</th>
<th>z value</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge of Stroke</td>
<td>24.1 (2.4, 20–27)</td>
<td>23.5 (4.0, 19–28)</td>
<td>-0.54</td>
<td>.59</td>
</tr>
<tr>
<td>Self-efficacy (total score)</td>
<td>81.7 (4.1, 74–86)</td>
<td>79.9 (5.8, 71–87)</td>
<td>-0.70</td>
<td>.48</td>
</tr>
<tr>
<td>HADS - anxiety</td>
<td>3.5 (2.7, 1–8)</td>
<td>5.6 (4.9, 1–15)</td>
<td>-1.08</td>
<td>.28</td>
</tr>
<tr>
<td>HADS - depression</td>
<td>1.9 (2.0, 0–5)</td>
<td>1.6 (1.2, 0–3)</td>
<td>-0.43</td>
<td>.67</td>
</tr>
<tr>
<td>Caregiver Strain Index</td>
<td>4.3 (2.8, 0–8)</td>
<td>3.9 (3.0, 0–8)</td>
<td>-0.53</td>
<td>.60</td>
</tr>
</tbody>
</table>

Note: HADS = Hospital Anxiety and Depression Scale.
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Replicating this study with a more diverse and larger sample of stroke patients and their carers is warranted, as is further research into the feasibility and accuracy of using the telephone to administer outcome measures for stroke patients who have moderate and severe aphasia and/or cognitive difficulties. It may be beneficial to investigate a modified telephone interview, for example, providing written supporting material to the participants to enhance their comprehension of the interview material and facilitate the expression of their responses. Research into the use of video teleconferencing, such as Skype, may also prove to be a useful method of interviewing patients with more severe speech, language, and/or cognitive impairments. For stroke patients who do not have communication and/or cognitive disability, research that compares the accuracy of self-administration of various stroke outcomes with telephone and face-to-face administration would provide useful information. In studies that evaluate the health outcomes of stroke patients and their carers, a wide range of outcome measures are used, many of which are amenable to telephone administration. Research that investigates the feasibility and accuracy of telephone administration of additional stroke outcome measures would be valuable.

The results from this study suggest that the telephone is a feasible option for the administration of the outcome measures that were specifically investigated. These findings can benefit researchers who wish to use the telephone to increase the size or representativeness of their study sample and clinicians who wish to use these outcome measures via telephone to conduct follow-up evaluations of their patients.

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