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MEASURING QUALITY OF LIFE IN PEOPLE WITH APHASIA: THE STROKE SPECIFIC QUALITY OF LIFE SCALE

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Assessing health related quality of life (HRQOL) in people with communication disabilities is a challenge in health related research. Materials used to assess HRQOL are often linguistically complex and their mode of administration usually does not facilitate people with communication disabilities to give their experiences. We are currently running a medium scale study (80 participants) which aims to explore the HRQOL of people with long-term aphasia and to assess the psychometric properties and the acceptability of the Stroke Specific Quality of Life Scale (SS-QOL) (Williams *et al.* 1999) as a single measure for the assessment of HRQOL in this population. Here the initial stages of modifying the SS-QOL for use with people with aphasia will be presented. We will concentrate on the process of making the scale communicatively accessible to people with aphasia and increasing its content validity with this population group.

Introduction

In recent years there has been a trend towards incorporating HRQOL measures in patient outcome research. The purpose of this is to better understand the impact of disease on the patient's life as a whole (Patrick and Erickson 1993), to evaluate the efficacy of different therapeutic interventions and service provisions (de Haan *et al.* 1993); and to incorporate the patient's perspective in clinical decision making (Wenger *et al.* 1984, Mayou and Bryant 1993).

In the field of stroke, however, assessing HRQOL is a challenge as some people after stroke suffer from speech and language and/or cognitive difficulties. They have difficulty completing self-report assessments and questionnaires. As a result, although there is a considerable amount of research investigating emotional outcomes and HRQOL in stroke survivors we still have limited information for the vulnerable group of people with aphasia. Sometimes they are excluded from the studies (e.g. Duncan *et al.* 1997, Jonkman *et al.* 1998, Clarke *et al.* 1999). In the studies that do include people with aphasia (e.g. Foster and Young 1996, King 1996, Bethoux *et al.* 1999, Lofgren *et al.* 1999) often the validity of the assessments is doubtful. People with aphasia would have had difficulty understanding some of the items of the questionnaires used and expressing their responses. 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.

To overcome some of these difficulties we are developing an interview-administered version of the Stroke Specific Quality of Life Scale (SS-QOL) (Williams *et al.* 1999) for

people with mild to moderate receptive aphasia. We chose the SS-QOL for the following reasons. First, it is a patient derived measure: to establish domain and item content validity the developers held focused interviews with stroke survivors to identify the domains most affected by their stroke (Williams *et al.* 1999). Second, it is designed specifically for use in clinical trials: this makes it a relatively easy and quick to administer measure.

Developing an aphasia-adapted version of the SS-QOL is a long process, which includes modifying the original instrument and testing the reliability, validity and responsiveness to change of the modified version in large cohorts of people. The first steps of this process are described here, i.e. making the SS-QOL communicatively accessible to people with mild to moderate receptive aphasia and increasing its content validity with this group of people.

The SS-QOL

The SS-QOL is divided in two parts, which cover 12 domains. Part 1 is a list of questions that ask how much trouble the respondent has with activities in the areas of self-care, vision, language, mobility, work and upper-extremity function. The response format is a five-point scale ranging from ‘couldn’t do it at all’ to ‘no trouble at all’. Part 2 is a list of statements with which the respondent has to agree or disagree. They cover the areas of thinking, personality, mood, family roles, social roles and energy. See figure 1 for two examples.

	Couldn’t do it at all	A lot of trouble	Some trouble	A little trouble	No trouble at all
SC1. Did you have trouble preparing food?	1	2	3	4	5

	Strongly agree	Moderately agree	Neither agree nor disagree	Moderately disagree	Strongly disagree
P2. I was impatient with others	1	2	3	4	5

Figure 1. Examples from SS-QOL (part 1 and part 2 respectively)

The stages of the modification process presented were: initial modifications; pilot testing with 12 people with aphasia; further modifications; field pre-test with 18 people with aphasia.

Initial modifications

To identify what aspects of the SS-QOL needed to be modified and how to modify them we ran two focus groups with speech and language therapists specialising in aphasia. The instrument was also reviewed by a linguist and a questionnaire expert from the National Centre for Social Research. The following issues were raised and the following modifications were made.

Use of the instrument

The ability of a person with aphasia to complete a self-report instrument is affected by his/her level of reading and writing difficulties. Thus, we aimed to develop an interview-administered version of the SS-QOL, where the respondent points to his responses while the

interviewer reads aloud the items and marks the given responses on a scoring sheet.

Layout

To make the items more accessible to people with communication difficulties the font was increased to 14 and few items were presented per page (between three and six).

Linguistic and reading complexity

The following aspects of the questionnaire were changed to make it easier for people with aphasia. Long items were shortened to reduce reading demands. This was done by giving examples orally (e.g. 'did you have trouble eating *e.g. cutting food or swallowing*') and by omitting redundant information (e.g. '...when bending over or reaching for things?' was changed to '...when bending over or reaching?'). Some items needed modification from American to British English. Key words were emboldened. As the interviewer reads aloud the whole item the respondent is not expected to miss any information. Lead-in questions were introduced as the questions in the individual domains tended to start in the same way.

Content validity

Content validity refers to whether a measure adequately covers all aspects of the concept to be measured. People with aphasia were not included in the process of developing the SS-QOL, and this has implications on its content validity with this group of people. For example, language minimally involves speaking and understanding what is said. As the language domain of the SS-QOL had no items on understanding other people we decided to include one. Moreover, research on differences in cognition between people with right hemisphere damage (RHD) and left hemisphere damage (LHD) indicates that LHD people have specific difficulties with decision-making (Tartaglione *et al.* 1991). We thus included an item on making decisions in the thinking domain. Similarly, two items were added in the family roles and social roles domains to reflect the effects of language problems in these domains.

Strongly agree-strongly disagree (SA-SD) format

The SA-SD response format is a popular yet controversial response format in social research. It is generally used to measure attitudes and beliefs and it seems to fit well attitudinal statements like 'Abortions should be illegal' where the respondents opinion is sought. The second part of the SS-QOL however is a list of problems or feelings that people may have after stroke and it's not their opinion that is sought but rather their experience or feelings. Moreover, the SA-SD response format is linguistically complex both in terms of word length and word meaning. Thus, people with aphasia may have considerable problems answering the second part items. It was felt essential to involve people with aphasia in the decision making process on whether to keep the SA-SD response format or whether to replace it with a potentially simpler response format. We generated five alternative response formats trying to keep them as close as possible in meaning to the original format. These were:

- *very true/true/neither true nor false/false/very false*
- *yes, a lot/yes, a little/neither yes nor no/ not really/no, not at all.* This response format was tried with the items as they were (statements) and
- with the statements turned into questions, as 'yes' and 'no' fit better with questions
- *that is so right/ I guess so/I don't know/I don't think so/certainly not*
- *xx/ x/ x✓/ ✓/ ✓✓* (which may be easier for people with reading difficulties).

Pilot testing with 12 people with aphasia

The main aim of the pilot was to determine whether indeed the SA–SD response format was the most challenging and to choose an easier format, if needed. A secondary aim was to see how the respondents would cope with difficult items (e.g. conceptually complex or negative). Five items were reproduced six times with the original and each of the alternative response formats. Twelve subjects from the people with mild/moderate aphasia attending groups at the City Dysphasic Group were randomly approached and agreed to take part. Each one answered the five items with the six different response sets presented in random order. They were then asked which one they found most difficult and which one they found easier and why. Table 1 below shows their responses (figures represent the number of people who gave this response).

Table 1. Opinions on response formats of people with aphasia

	Agree-disagree	Yes-no	Question yes-no	Comment	True-false	✗ - ✓
Easiest	1	0	4 'easy', 'natural', 'like normal conversation' 'straight' 'very clear'	0	2	5 'easy', 'you see it and you know', 'you don't have to read', 'it's quicker'
Most difficult	3 'confusing' 'hard with these (pointing to negative items)'	2	0	3	2	2 'you can't read it, you have to think what it means', 'it's terribly confusing'

These results are obviously drawn from a very small sample of people with aphasia. They are thus seen as just an indication of what some people may think. Clearly, there is some variability in their views. Some of them confirmed our suspicions and found the SA-SD format the hardest. It is interesting to note, however, that the 'yes-no' response format where the items were converted to questions was the only format that nobody found most difficult.

Further modifications

We interpreted these results in the light of our expert reviewers' opinions. Two more questionnaire development experts were involved at this stage and the following modifications were made. First, the second part statements were converted to questions. Converting the items into questions did not affect their meaning. This also resulted in uniformity with the first part. Second, the following response format was adopted for the second part: 'definitely yes/mostly yes/neither yes nor no/mostly no/definitely no'. The 'yes-no' response format was conceptually similar to the original and highly acceptable to people with aphasia. Third, the pilot testing indicated that some people with aphasia had difficulty choosing their response when the item was negative. Negation was thus removed from the

negative items, e.g. 'I didn't go out as often as I would like' was changed to 'Did you go out less often than you would like?' Fourth, transitional questions were introduced between the different domains, e.g. 'the next set of questions asks about your family and social life'. Fifth, practice items were introduced before the different response formats to ensure that the respondents could use them.

Field pre-test

The aim of the field pre-test was to test the modified SS-QOL for feasibility. People with aphasia of at least one year duration were recruited from the City Dysphasic Group. Eighteen people volunteered to participate. Participants had to complete the modified SS-QOL in an interview format and then give their opinion of the questionnaire.

In terms of accessibility, overall the questionnaire was accessible to people with mild to moderate receptive aphasia. Receptive aphasia severity was determined by participants' performance on the receptive sub-scales of the Frenchay Aphasia Screening Test (Enderby *et al.* 1987). All participants who scored 7/15 or more (i.e. 17 out of the 18) were able to complete the modified SS-QOL. One person scored 6/15 and he was unable to give reliable responses to the questionnaire. Seventeen out of 18 felt that the questionnaire was straightforward. Seven felt they had some or little difficulty understanding some of the items but were facilitated by the interviewer. Two felt they had slight difficulty choosing their responses from the 'yes-no' format. Positive comments included 'I like the way it's set out'. 'Quite clear'. '90% of it is brilliant'. Negative comments were: 'thinking about them (the items) was a bit hard' and 'it's hard to decide which answer to use from these ('yes-no' ones)'.

In terms of acceptability, all participants felt that the questionnaire overall covered the effects the stroke had on their lives. When the participants were asked whether there is anything that is important to them and was not covered, eight identified the following. There should be more on feelings, e.g. frustration, embarrassment and worrying. There was nothing on how the partner is affected: 'My husband gets fed up by not being able to have an intellectual conversation with me... I am terribly boring. He avoids talking to me.' There was nothing on how difficult it is to find out information about things or access services. Attitudes to life before and after the stroke change: 'Before I used to worry about money...I had enough money but I always worried about it. Now I have no money ... but I don't worry at all.' Other comments included: 'it's interesting to have to think about how you feel', 'very good', 'it's good that somebody is doing something about it', 'very interesting and helpful and it brought a lot of things to my head that I thought 'ahh...yes..'', 'if you had asked me these questions 4 years ago (just after the stroke) it would have been very difficult'.

Summary and further research

A communicatively accessible version of the SS-QOL is being developed to be used with people with mild to moderate receptive aphasia. The modification process so far has included focus group discussions and expert reviews of the instrument and a two-stage pre-testing of the modifications with people with aphasia. This pre-testing has indicated that the modified SS-QOL is highly accessible and acceptable to people with mild to moderate receptive aphasia. There are still a few items that the participants in our studies found rather difficult. There are also some aspects of the impact of aphasia on people's lives that the SS-QOL does not capture. In our continuing research with the SS-QOL we are addressing these issues and we are assessing the psychometric properties of the modified version.

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