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Measuring Well-being in Aphasia: The GHQ-28 versus the NHP

Katerina Hilari

City University, London, U.K.

Sally Byng

Connect - the Communication Disability Network, London, U.K.

Tim Pring

City University, London, U.K.

Address for correspondence: Katerina Hilari, Department of Language and Communication Science, City University, Northampton Square, London EC1V 0HB, U.K.
E-mail: k.hilari@city.ac.uk

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ABSTRACT

This study aimed to get the opinion of people with aphasia on two subjective well-being measures: the General Health Questionnaire 28-item version (GHQ-28) (Goldberg & Hillier, 1979) and the Nottingham Health Profile (NHP) (Hunt et al., 1981). Twelve persons with moderate to mild aphasia of at least two years duration completed the GHQ-28 and the NHP. In a semi-structured interview they gave their feedback on the two questionnaires. All participants were able to complete both the instruments. Nine out of twelve showed high psychological distress ($>5/28$) in the GHQ-28. The NHP (part 1 less the physical abilities section) had a correlation of 0.78 ($p<.01$) with the GHQ-28. The social dysfunction sub-scale of the NHP identified more problems in the people with aphasia than the social isolation sub-scale of the GHQ-28. The majority of the participants (ten out of twelve) preferred the NHP as they found it easier to understand and to respond to. This small-scale study indicated that both the GHQ-28 and the NHP can be administered to people with moderate to mild aphasia and provide useful information on their well-being. Participants reported that the NHP was easier to do and it asked more relevant questions to their situation.

Over the past decades, better living conditions and advances in medical treatments have resulted in more people having to live with the aftermath of a disease than immediately die from it. The increasing prevalence of chronic disability is reflected in health related research with an increase in studies exploring the quality of life and the well-being of users of health care services. In the field of stroke, during the last ten years, there has been a considerable amount of research investigating the long term outcome and/or psychosocial and emotional impact of stroke (e.g., Astrom, Asplund, & Astrom, 1992; deHaan, Limburg, Van der Meulen, Jacobs, & Aaronson, 1995; Foster & Young, 1996; Hochstenbach, Donders, Mulder, vanLimbeek, & Schoonderwaldt, 1996 [Dutch]; King, 1996; Wyller, Holmen, Laake, & Laake, 1998; Lofgren, Gustafson, & Nyberg, 1999; Bethoux, Calmels, & Gautheron, 1999; Clarke, Black, Badley, Lawrence, & Williams, 1999).

A challenge in this type of research, however, is that often after a stroke a person may not be able to complete self-report assessments. In particular, people with cognitive or speech and language difficulties 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. As a result, in some of these studies, people with aphasia were excluded (e.g., Duncan et al., 1997; Jonkman, deWeerd, & Vrijens, 1998; Clarke et al., 1999) or no information is provided on them (e.g., Wyller et al., 1998). In the studies that included people with aphasia (e.g., Astrom et al., 1992; deHaan et al., 1995; Foster & Young, 1996; King, 1996; Lofgren et al., 1999; Bethoux et al., 1999) commonly no information is provided on how they coped with the whole procedure. For example, were any of the research materials modified to be aphasia friendly? How did the investigators check the people with aphasia's understanding of the questions? Secondly, no specific information is given on the psychosocial profiles of the people with aphasia. For example, even when there was no significant difference in the overall quality of life or well-being between aphasic and non aphasic stroke survivors, did aphasic survivors tend to score lower on e.g., social health or role and relationships items?

In the field of aphasiology a number of studies have addressed issues related to the psychosocial aspects 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, & Ireland, 1997). Some of these studies have used semi-structured or in-depth interviewing techniques (LeDorze & Brassard, 1995; Parr et al., 1997). Others 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 extensively tested for their psychometric properties. Although these studies provide useful information on the psychosocial aspects of aphasia, their methodology makes them hard to compare with studies investigating the effects of stroke or other conditions. Thus, it is difficult to get a picture of the well-being of people with aphasia relative to that of other people or other groups.

In order to further the exploration of the psychosocial impact of aphasia, this study focuses on the opinions of people with aphasia about instruments, which are used to ascertain their well-being/quality of life. In order to address some of the shortcomings mentioned above, instruments which meet the following criteria would be best used:

- . they are subjective, i.e. they are completed by the person with aphasia;
- . they are linguistically straightforward so that with minor modifications they can be used with people with aphasia;
- . they are reported to be quick and easy to administer so that they can be used in clinical practice;
- . they have good psychometric properties;
- . they allow comparison of findings with those of other disease groups and the general population;
- . they allow easy communication and discussion of findings with other professionals.

Two measures that met the above criteria were decided upon for use in this study: the General Health Questionnaire [the 28-item version (GHQ-28) (Goldberg and Hillier, 1979)] and the Nottingham Health Profile (NHP) (Hunt, McKenna, McEwen, Williams, & Papp, 1981). Both instruments have good psychometric properties and have been extensively used with various patient groups including stroke and the general population. The GHQ-28 focuses on psychological distress and is very sensitive as a screening tool for psychiatric disorders. Still, its response format (see below) could be challenging for people with aphasia. The NHP covers a broader scope of functioning (physical, social, emotional), has a *yes/no* response format, but is lengthier than the GHQ-28 (45 compared to 28 items).

As these instruments have not been validated on people with language problems, it is possible that validity could be compromised if the participants had difficulty understanding the items and expressing their responses. For this reason, in this study every effort was made to make the instruments communicatively accessible to people with

mild to moderate receptive aphasia (see 'Presentation of the measures' below).

The present study

For the purposes of the study, participants were administered the two instruments and subsequently were asked to compare the two questionnaires and provide feedback on their experience in completing them. The paper will focus on the participants' feedback, as well as provide brief information on their results on the two instruments and possible implications of these scores.

METHOD

Subject selection

The participants were recruited from the City Dysphasic Group, London. The selection criteria were the following: aphasia due to a stroke; at least 2 years post onset; severity of receptive aphasia moderate or mild. To reduce respondent burden no aphasia assessments were carried out for the purposes of this research. Aphasia severity was determined by the participants' Speech and Language Therapists. Information on the project was given to the people with aphasia participating in a range of activities at the Centre. Fifteen people volunteered to participate but due to time constraints and transportation difficulties twelve finally decided to take part. The characteristics of the participants are shown in table 1.

Table 1 about here

Measures

The General Health Questionnaire 28-item version

The GHQ (main version: 60 items) is a self-administered screening instrument aimed at detecting those with diagnosable psychiatric disorders (Goldberg, 1972). The GHQ-28 or 'Scaled GHQ' provides four scores on somatic symptoms, anxiety and insomnia, social dysfunction and severe depression. It was chosen in the present investigation because it provides more information than the other versions (GHQ-60, GHQ-30, GHQ-20, GHQ-12), which give a single severity score.

The questions ask the subject to compare his/her current state to his/her usual situation (e.g., 'Have you recently been thinking of your self as a worthless person?'). S/he has to choose one out of four responses of the following format e.g., *not at all*, *no more than usual*, *rather more than usual*, *much more than usual*.

Items may be scored using 0-1-2-3 Likert scores, or they may be scored 0-0-1-1, which indicates whether a symptom is absent or present. The GHQ has been criticised as likely to miss long-standing problems as subjects will respond *no more than usual* to them and thus score 0 (e.g., Bowling, 1997). To overcome this problem, in the present investigation, we chose an alternative scoring system that has been suggested by Goodchild & Duncan Jones (1985). They divide the items as negative (e.g., "felt that life isn't worth living") and positive (e.g., "felt you were doing things well"). Positive items are scored normally as 0-0-1-1, whereas negative items are scored as 0-1-1-1, i.e., *same as usual* is seen as indicating a problem.

The Nottingham Health Profile

The NHP is a self-administered questionnaire designed to give an indication of perceived physical, social and emotional health problems (Hunt, McEwen, & McKenna, 1985). It has been described as showing how people feel when they are experiencing various states of ill health (Bowling, 1997).

The NHP consists of two parts. Part one has 38 items grouped into six sections: physical abilities, sleep, emotional reactions, social isolation, pain and energy level. It is a list of statements e.g., 'I'm feeling on edge' which the subject scores as *yes* or *no*. Part two has seven items and it provides an indication of handicap. It records whether the subject's present state of health is causing them problems with work (paid

employment), looking after the home, social life, home life (relationships with people at home), sex life, interests and hobbies, and holidays.

Supplement to the NHP

It was felt that the second part of the NHP could be explored further to provide more information on the extent of handicap of the people with aphasia. Knowing that there has been a change in a person's social life, for example, does not say much. In order to appreciate the meaning of this change, one would need to know how important social life is to the person and whether the change was for the better or the worse. A supplement was therefore added consisting of three questions for each area covered in the second part (work, social life, etc.). The questions were (e.g., for social life): How important is social life to you? How satisfied were you with your social life before the stroke? How satisfied are you with your social life after the stroke? The subject had to mark his/her response on a 100mm visual analogue scale (VAS) going from 'not important at all' to 'very important' for the first question and from 'not satisfied at all' to 'very satisfied' for the second and third questions.

Presentation of the measures

The presentation of both the NHP and the GHQ-28 were modified to make them more aphasia friendly. This was done without changing format or wording, which would have affected their psychometric properties. The following modifications were made on both the instruments:

- . large print was used
- . key words were emboldened
- . few items were presented per page
- . where necessary the interviewer read the items with the aphasic participant and marked the responses that the participants indicated.

Due to its complexity, the GHQ-28 response format required some explanation. In addition, the '*same as usual*' and '*no more than usual*' responses were marked throughout the instrument with an = sign underneath, to make scanning through the response line easier.

The semi-structured interview

The following questions formed an interview guide:

- . Which one of the two questionnaires gave more information about you?
- . Which one described your feelings better?
- . Which one asked more relevant questions?
- . Which one was easier?
- . Are there important things to you that were not covered at all?
- . Which one did you like better? Why?
- . Any other comments?

The interviewer had the freedom to change the order of the questions and also omit any questions that were not felt appropriate or useful to ask. The interviewees were also encouraged to make any comments they wanted regarding the instruments or the procedure.

Procedure

At the beginning of the session with each person the purpose of the research project and the tasks of the session were explained and written consent was obtained. Then the two instruments were administered one after the other. Half of the participants did the GHQ-28 first and the other half did the NHP first. Following completion of the instruments, the interviewer gave a short description of each and encouraged the participants to flip through them to remind themselves of their content. Then the interview questions were asked and participants were encouraged to make comments.

Table 2 shows how long each part of the session took. The shortest session was about 30 minutes and the longest about an hour.

table 2 about here

RESULTS

GHQ-28 and NHP scores

As indicated earlier, it is beyond the scope of this presentation to go into detail on the results of the two instruments. The raw scores are given in the Appendix. Here, only brief information will be given, in order to highlight how the two instruments compare with one- another and how they worked for the people with aphasia.

Looking at psychological distress, 9 out of the 12 participants scored 5 items or more in the GHQ-28, which is the cut off point for identifying probable psychiatric cases. Eight of these people scored positively for presence of emotional reactions in the equivalent section of the NHP. The total NHP (part 1) score (less the physical mobility section) had a correlation of 0.78 (Spearman rho, $p < .01$) with the GHQ-28 score. With regard to social functioning, the NHP picked up more problems. Seven participants scored in the Social Isolation sub-scale of the NHP, of whom only four scored in the Social Dysfunction sub-scale of the GHQ-28.

The supplement to the NHP indicated that, excluding work, the most affected area of functioning for people with aphasia was social life. Ten out of 12 participants reported a decrease in their satisfaction with their social life after the stroke (average decrease: 65%). Table 3 shows how many subjects reported a decrease in satisfaction after the stroke in each area of functioning covered, and the extent of the average decrease.

table 3 about here

In terms of work, the 2nd part of the NHP indicated that all the participants who worked before their stroke (8/12) had to retire because of the stroke. Five of the 8 viewed work as important or very important in their life and were very dissatisfied that they could no longer work.

Interview

A summary of the responses to the main interview questions is presented in table 4.

table 4 about here

Overall, the participants showed a clear preference for the NHP. Ten out of the 12 people reported liking it better with four finding it easier, five reporting that it asked a broader range of questions and gave more information about them and one describing it as “clear, simple and direct”. Two persons were unable to say why they liked it better. Only 1 person found the GHQ-28 easier because it was shorter. Despite the emphasis of the GHQ-28 on feelings, inner thoughts and psychological distress, again the majority felt that the NHP described their feelings better.

Some people made negative comments about the GHQ-28. One found it “intrusive”; another felt that by doing the GHQ-28 only “you didn’t know enough about me”; another one found there was “no point” in some of the items (pointing mostly to severe depression items); finally one person found the GHQ-28 “confusing”, “difficult to understand” and she felt it made her “irritable”. With regard to the NHP, two subjects felt that the first part was not particularly useful.

Five participants were asked, in addition, whether each one of the instruments was a useful questionnaire to do with people with aphasia. All of them found the NHP useful and 3 out of 5 found the GHQ-28 useful. One participant who presented with mild receptive and moderate expressive aphasia felt that the GHQ-28 would probably be too hard for people with more severe aphasia than herself. She also suggested that it would not be good to do the GHQ-28 early post onset (e.g., before 6 months post onset), as it would upset people.

DISCUSSION

This study compared the GHQ-28 and the NHP in terms of their applicability and acceptability with people with aphasia. The selection criteria for these two instruments have been covered above. It should be pointed out, however, that, as their description has indicated, they do not actually measure the same thing and they do not come from the same conceptual basis. One should therefore consider carefully what is it that is to be measured before selecting one or the other.

In the present investigation, the NHP was selected (from a conceptual point of view) as it was judged to be a good measure of overall subjective health. The main advantages were its simplicity and broad range (physical, social, and emotional health, energy level, sleep and pain, and an indication of handicap). Overall, the results of this study and the aphasic participants’ feedback supported the selection of the NHP.

The supplement to the second part of the NHP was well received by the people with aphasia. Even the two people who criticised the first part of the NHP found the whole questionnaire a useful test to do. The supplement may

have played an effective role in that, as it gave participants a chance to reflect more on the effects of stroke and aphasia on their lives and make comparisons with their pre-stroke situation. Despite the increased time required for the supplement (average = 9 min), it was reported to be worthwhile by the participants.

The GHQ-28 was selected as it is a well-regarded measure of psychological distress, which may pick up more signs of anxiety and/or depression. This appeared to be important given previous studies which report a high prevalence of anxiety and/or depression in the post stroke populations (e.g., Feibel & Springer, 1982; Robinson, Book Starr, & Price, 1984; Astrom, 1996; King, 1996; Fukunishi, Aoki, & Hosaka, 1997). Our findings confirm this as nine out of the twelve participants showed high emotional distress. All the participants were able to complete the GHQ-28, which indicates that it could be used as a screening tool for psychological distress with people with moderate to mild aphasia. However, 10 out of our 12 participants had mild or very mild receptive aphasia, and some of them still found it hard despite the modifications that were made to make it more aphasia friendly.

In the presentation of the results of the participants on the two instruments we concentrated on social functioning and emotional distress. The NHP picked up more social functioning problems than the GHQ-28. This could be related to the fact that 6 out of the 7 items of the Social Dysfunction sub-scale of the GHQ-28 are positive items (e.g., “being satisfied with the way you’ve carried out your task”, “being keeping yourself busy and occupied”). It is possible that there were not enough negative items (e.g., “I’m finding it hard to get on with people”, “ I feel I’m a burden to people”, of the NHP) that people with aphasia could identify with. With regard to emotional distress, in this study, the total NHP (part 1) score (less the physical mobility section) had a correlation of 0.78 (Spearman rho, $p < .01$) with the GHQ-28 score. However, the number of participants in this study is relatively small and therefore no meaningful conclusions can be drawn on the sensitivity of the NHP in picking up levels of emotional distress that may be of clinical significance.

In the present study people with severe aphasia were excluded because of the assumed complexity of the two questionnaires and the whole procedure. We are of the opinion however that most of the NHP items could be supplemented with pictures to make it accessible to more severely affected people with aphasia. This would be harder for the GHQ-28 and still its response format would probably cause considerable difficulty to a person with severe aphasia.

SUMMARY AND CONCLUSIONS

The present study showed that commonly used measures of well-being can be made communicatively accessible to people with moderate to mild receptive aphasia. The NHP and the GHQ-28 were modified by using large print, presenting key words in bold and presenting few items per page. They were administered in an interview format in order to facilitate people with aphasia give their responses and for the GHQ-28 we explained its response format and used an example as a practice item. Thus all the participants in this study were able to complete the two instruments.

The main aim of the study was to obtain feedback from people with aphasia on these two measures of well-being. The great majority of the participants preferred the NHP as they found it easier, they felt it asked more relevant questions to somebody who has had a stroke and aphasia, and it gave more information about them. The supplement to the NHP may have contributed to this effect. For each area covered in the NHP 2nd part the supplement asked how important it is to the participant, how satisfied s/he was with it before the stroke and how satisfied s/he is now after the stroke. It thus gave the participants the opportunity to reflect a little more on their experience of stroke and give more information on the extent of the stroke and aphasia related handicap.

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APPENDICES

A) Participants' scores on the GHQ-28

Subjects	Anxiety and Insomnia	Depression	Social Dysfunction	Somatic Symptoms	Total
1	2/7	4/7	0/7	6/7	12/28
2	2/7	0/7	1/7	1/7	4/28
3	4/7	1/7	3/7	3/7	11/28
4	1/7	0/7	0/7	1/7	2/28
5	3/7	0/7	0/7	5/7	8/28
6	2/7	1/7	2/7	2/7	7/28
7	5/7	0/7	0/7	0/7	5/28
8	6/7	4/7	0/7	2/7	12/28
9	0/7	0/7	0/7	1/7	1/28
10	4/7	0/7	5/7	4/7	13/28
11	1/7	1/7	0/7	4/7	6/28
12	3/7	1/7	4/7	3/7	11/28

B) Participants' scores on the NHP (Part 1)

Subjects	Pain	Energy Level	Physical Abilities	Social Isolation	Sleep	Emotional Reactions	Total
1	1/8	1/3	3/8	3/5	0/5	4/9	12/38
2	0/8	0/3	0/8	0/5	0/5	2/9	2/38
3	0/8	3/3	4/8	3/5	0/5	1/9	11/38
4	2/8	1/3	2/8	0/5	2/5	0/9	7/38
5	8/8	3/3	1/8	0/5	0/5	2/9	14/38
6	0/8	1/3	1/8	1/5	2/5	1/9	6/38
7	0/8	0/3	0/8	0/5	1/5	2/9	3/38
8	0/8	0/3	0/8	4/5	3/5	5/9	12/38
9	0/8	0/3	0/8	3/5	1/5	0/9	4/38
10	5/8	3/3	4/8	2/5	1/5	6/9	21/38
11	0/8	1/3	2/8	0/5	0/5	0/9	3/38
12	0/8	2/3	1/8	2/5	1/5	2/9	8/38

C) Participants' responses on the NHP (Part 2). 'Yes' indicates problems in that area.

Subjects	Work	Looking after the home	Social Life	Home Life	Sex Life	Interest s and Hobbies	Holidays
1	Yes	Yes	Yes	Yes	Yes	Yes	Yes
2	N/A	No	Yes	No	No	Yes	Yes
3	Yes	Yes	Yes	Yes	Yes	Yes	No
4	Yes	No	No	No	No	No	No
5	Yes	Yes	Yes	No	No	Yes	Yes
6	Yes	No	Yes	No	No	Yes	No
7	N/A	No	Yes	No	No	No	No
8	Yes	No	Yes	N/A	Yes	No	Yes
9	Yes	No	No	No	No	Yes	No
10	N/A	Yes	Yes	Yes	Yes	Yes	Yes
11	Yes	Yes	No	No	No	No	No
12	N/A	No	Yes	No	No	Yes	No

Table 1: Participants' characteristics.

Subject s	Sex	Age	Time post onset	CVA type	Receptiv e Aphasia Severity	Expressive Aphasia Severity	Right Hemiparesis
1	F	37	13y	?Haemorrhage	V. Mild	Moderate	Yes
2	F	70	2y 3m	?Haemorrhage	V. Mild	Mild	No
3	M	51	10y 6m	Infarct	V. Mild	Mod-Mild	Yes
4	M	67	5y	Infarct	V. Mild	V. Mild	No
5	F	47	11y 1m	Infarct	V. Mild	V. Mild	No
6	M	44	3y 4m	?	Mild	Moderate	Yes
7	F	59	10y	Haemorrhage	Mild	Mild-Mod	No
8	M	37	19y	?	Mild	Mild-Mod	No
9	M	69	2y 8m	Haemorrhage	Mild	Mild-Mod	No
10	F	60	3y 7m	Infarct	Mild	Mild-Mod	Yes
11	M	46	2y	Infarct	Moderate	Moderate	Yes
12	M	74	2y 1m	Haemorrhage	Moderate	Severe	No

Table 2: Administration times of the GHQ-28, the NHP, the NHP supplement, and the interview.

Duration in minutes	GHQ-28	NHP	NHP Supplement	Interview	Total
Range	5 - 20 min	7 - 22 min	5 - 19 min	5 - 15 min	27 - 59 min
Average	12.08 min	12.75 min	9 min	8.42 min	42.25 min

Table 3: Number of subjects reporting a decrease in satisfaction in different areas of functioning, and extent of that decrease.

N=12	Number of subjects	Average decrease
Looking after the home	5	46%
Social life	10	65%
Home life	7	54%
Sex life	8	60%
Interests and Hobbies	7	59%
Holidays	6	53%

Table 4: Number of participants and their responses to some of the interview questions.

N=12	Gave more informatio n	Described feelings better	Asked more relevant questions	Was easier	Subject liked it better
GHQ-28	2 /12	3 /12	0 /12	1 /12	0 /12
NHP	7 /12	7 /12	10 /12	10 /12	10 /12
Same or 'I don't know'	3 /12	2 /12	2 /12	1 /12	2 /12