PAPERS AND ORIGINALS

Comparative trial of volunteer and professional treatments of dysphasia after stroke

MARGARET MEIKLE, ENID WECHSLER, ANNEMARIE TUPPER, MADELEINE BENENSON, JOSEPHINE BUTLER, DAVID MULHALL, GERALD STERN

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Summary and conclusions

A study of the treatment of dysphasia after stroke compared the progress of two groups of disabled patients. One received conventional treatment from qualified speech therapists and the other from non-professional volunteers. Methods of assessing communication difficulties were also compared and the impact of aphasic illness on families examined. No important differences in the results of treatment were seen between the two groups. The volunteers, however, often had to assume some of the responsibilities of social workers, and transport to hospital created practical and economic problems.

It is concluded that the two forms of treatment provide essentially the same benefit, although doubt must still remain because relatively few patients were studied.

Introduction

About one-third of patients who survive a major stroke have serious communication difficulties; the problems facing an afflicted patient and his family are considerable and the resources of speech-therapy departments limited. Valerie Eaton Griffiths¹

pioneered the use of volunteer helpers to alleviate these difficulties, and many schemes now exist in the United Kingdom using non-professional helpers.² The comparative efficacy of such schemes has not been determined, and little is known about the most effective ways of deploying the skills of a professional speech therapist. The primary aim of this study was to compare the progress of two groups of dysphasic patients, one receiving formal, conventional treatment from qualified speech therapists in outpatient clinics and the other treatment from non-professional volunteers working in the patient's home under the guidance of an experienced speech therapist. Ancillary aims of the project were to study family interactions and to compare methods of assessing communication difficulties.

Patients and methods

We considered for entry to the trial all patients with dysphasia after a stroke that had occurred at least three weeks previously who had passed through the acute phase of their illnesses to be left with disabling dysphasia. Hospital consultants and general practitioners near University College Hospital were informed of the nature and purpose of the trial and were invited to refer patients for assessment and possible inclusion. Informed consent was obtained from near relatives and, when possible, the patients. Assessment included a detailed history, physical examination, relevant investigations and assessments on the Porch Index of Communicative Ability (PICA),³ and an unpublished test developed at the Wolfson Rehabilitation Centre. This last is a fairly simple test, taking about half an hour to administer, that assesses comprehension, verbal expression, writing, and spelling.

Of the 87 patients referred, 56 were excluded for the following reasons: 15 declined when the nature of the trial was explained; 17 had severe intercurrent physical illness precluding regular hospital attendance for speech therapy; 12 were rejected because formal assessment of their speech capacity showed too small a treatable deficit (the treatment gap being less than the fourth percentile on the PICA); five patients had dysphasia that was not due to a stroke; five were too demented to participate; one lived too far from the hospital to permit regular visits; and one was not proficient in English before his illness. When all assessments were completed patients were randomly allocated to one of two treatment groups. Serial assessments of each patient were made at about six-weekly intervals using the PICA; the Wolfson test was performed initially, after three months,

Departments of Neurology and Speech Therapy, University College Hospital, London WC1E 6AU

MARGARET MEIKLE, LCST, (now senior speech therapist, Northwick Park Hospital, Harrow, Middlesex)

ENID WECHSLER, MSC, LCST, senior speech therapist

ANNEMARIE TUPPER, MB, DPHYSMEDENG, consultant physician in rehabilitation

MADELEINE BENENSON, volunteers' organiser

JOSEPHINE BUTLER, administrator

GERALD STERN, MD, FRCP, consultant neurologist

Middlesex Hospital Medical School, London

DAVID MULHALL, PHD, lecturer in psychology

and at the end of treatment. Patients remained in the trial until two successive estimations on the PICA showed no appreciable improvement, until they requested to be withdrawn from the trial, or until the trial was completed in December 1978. Patients receiving conventional treatment attended hospital for a minimum of three and a maximum of five sessions per week lasting about 45 minutes, including when possible a group session.

We recruited volunteers initially through an article in a local newspaper but also by word of mouth. An enthusiastic and energetic team was soon established. Most were housewives, but the remainder included students, secretaries, a retired nursing sister, and a postman (the patients came from more diverse social and occupational backgrounds than the helpers). After being interviewed for suitability volunteers were given a short introductory course that included both explanations about the nature of stroke and dysphasia and an explanatory film. A patient assigned to volunteer treatment was first visited by the volunteer supervisor, who selected a team of four appropriate helpers, so that each patient could receive four home visits a week and also attend a separate group session at the Camden Medical Rehabilitation Centre run by the helpers. Therapists and

attitudes, and behaviour of both patient and self since the stroke. These psychological states are recorded and used to construct a questionnaire unique to that relationship, from which a graphic representation of the relationship is extracted and discussed with the informants. Details of the method and results have been described elsewhere.⁵

Results

During the period July 1976 to August 1978 we admitted 31 patients to the trial: 16 attended departments of speech therapy as outpatients and 15 were treated in their homes by volunteers. Five of those receiving conventional treatment missed up to half of their possible treatment sessions mainly because of illness, but also because of holidays and transport difficulties. The helpers occasionally lost or did not complete their registers, so that accurate information was not available. Two patients had not completed treatment when the trial closed, thereby reducing the number for inclusion in the results to 29 (16 receiving conventional and 13 volunteer treatment). The table

Details of patients and results according to PICA score

Case No	Sex	Age	Occupation	No of weeks after onset of entry to trial	No of weeks in trial	Overall percentile PICA score		Treatment
						Initial	Final	
1	M	58	Company secretary	120	32	58	90	Conventional
2	M	65	Insurance broker	16	65	70	90	"
3	M	82	Window cleaner	26	18	54	75	Volunteer
4	M	53	Accountant	96	63	43	78	Conventional
5	F	79	Housewife	52	20	65	77	Volunteer
6	F	52	Housewife	268	46	60	64	Conventional
7	M	71	Carpenter	18	7	22	20	Volunteer
8	M	76	University professor	52	12	36	34	"
9	F	70	Retired	15	32	43	49	Conventional
10	M	59	Ophthalmic polisher	5	23	38	66	Volunteer
11	M	57	News vendor	4	12	92	97	"
12	M	57	Doctor	115	49	52	52	"
13	F	75	Housewife	10	84	56	74	Conventional
14	M	63	Civil servant	52	24	49	40	Volunteer
15	M	74	Lorry driver	20	66	26	38	Conventional
16	M	57	Publisher	18	22	55	95	"
17	M	59	Decorator	46	42	33	41	Volunteer
18	F	66	Housewife	16	35	64	53	Conventional
19	M	70	Shop owner	31	46	86	93	Volunteer
20	M	71	Labourer	5	22	49	75	Conventional
21	M	64	Surveyor	12	20	86	94	"
22	M	71	Commissionaire	17	5	15	*	Volunteer
23	M	68	Retired furrier	4	40	89	94	Conventional
24	M	74	Lawyer	10	42	73	86	Volunteer
25	M	69	Civil servant	4	2	83	†	"
26	M	74	Coalman	4	23	70	92	Conventional
27	F	66	Retired seamstress	24	24	44	62	Volunteer
28	F	55	Housewife	8	20	70	92	Conventional
29	F	59	Waitress	18	21	67	73	"
30	F	74	Housewife	8	16	13	16	"
31	M	57	University professor	7	7	44	77	"

PICA = Porch index of communicative ability.

*Patient moved from area.

†Patient withdrew from trial.

helpers were asked to keep records of treatment sessions including cancellations due to illness, holidays, or transport difficulties.

The speech therapist responsible for the assessments explained to each team the nature of the patient's disabilities on the basis of the PICA scores. As well as evaluating communicative ability this test gives clear indications of treatment, with certain verbal, gestural, and graphic tasks in which a patient is just able to achieve a successful response determining the strategy of treatment. Although the average time for administering and scoring the PICA is two hours, we found that a further hour was required to explain and discuss the results and prospective treatments with volunteers. When required, advice and guidance were given, often by telephone, by the volunteer supervisor between serial assessments. Standard items of equipment used by speech therapists were demonstrated and were available to volunteers, who were encouraged, however, to use their ingenuity and initiative in providing their own materials and developing their own techniques. These ranged from identifying familiar objects in the patient's home and items brought in by helpers and in newspapers and magazines or using letters for word and sentence building, to reading stories and following them with comprehension tests.

To assess the impact of dysphasia on a family we used the Personal Relations Index.⁴ This constructs a dynamic representation of the relationship between patient and spouse and is a method of structuring information received in a clinical interview. The patient's spouse or close relative is interviewed and asked to describe the typical feelings,

shows the overall results in the two groups. Patients whose PICA scores formed a plateau exited from the trial and were counted as successes; patients exiting from the trial for other reasons were not regarded as successes.

Survival analysis—The time in trial was analysed using actuarial survival techniques with exit from the trial as a criterion because PICA scores formed the plateau as the "event" of interest. Patients who had left the trial for other reasons were regarded as having censored trial times. The figure shows the actuarial percentage in trial for the two treatment groups, and comparison of the two curves shows no important difference between the two treatments (log-rank test: $\chi^2 = 1.57$, $DF = 1$, $P = 0.21$). In trials of this type the sensitivity of the log-rank test depends on the number of observed events rather than the total number of patients entered in the trial. Here, 21 patients recorded an event—that is, exited from the trial because their PICA scores had formed a plateau—giving the log-rank test powers of 32%, 61%, 76%, and 85% to detect treatment differences in the ratios of 2, 3, 4, and 5 to 1 respectively; thus, while one treatment was unlikely to be more than four times as effective as the other, insufficient events were recorded in the trial to detect differences less extreme than 2:1.

Analysis of covariance—The survival analysis detailed above is the only unbiased analysis of the data because it includes results from all the randomised patients. Other analyses can use only data from patients who have been in the trial for a reasonable time. Using the data actually recorded, analyses were made of the change in PICA

scores from initial to final assessment and of the percentage change in the PICA scores from the initial value. In both analyses the time between the initial and final assessments and the initial PICA scores were used as covariants. The covariants were not important in the analysis of either variant, and no important treatment differences were apparent.

A two-factor analysis of variants (patients $\times$ PICA overall percentiles) with repeated measures on the PICA overall percentiles confirmed that there was no significant difference between the two forms of treatment and established that an appreciable improvement between initial and final assessments occurred in both patient groups. Analysis of the Wolfson test supported these conclusions. The parallel overall findings of the Wolfson test, which takes less time and is simpler to use, is most encouraging. Although detailed analysis of the subtest scores suggests the need for standardisation, this method of assessment may prove helpful to clinicians.

Ten of the 16 patients allocated to hospital treatment required transport by ambulance, which necessitated an average of 156 return ambulance journeys for each patient during the course of treatment. Patients treated in their own homes by volunteers needed transport only for the weekly club; few helpers could use their own cars, and so mini-cabs were provided.

The results of the Personal Relations Index interview emphasised the problems that may arise within a family as a result of a stroke and the difficulties of empathising with an inability to communicate. Analysing and explaining this predicament sympathetically to the family can often facilitate their understanding and ability to cope.

Discussion

This study would have been greatly enhanced by including a comparable but untreated group of dysphasic patients to act as controls, particularly with respect to spontaneous improvement, but this would have been ethically unacceptable and, from the point of view of patient referral, impracticable. Because of the complexity of individual dysphasic disabilities and the numerous factors that might influence the rate and degree of spontaneous improvement as well as responses to specific treatment, we are reluctant to draw unequivocal conclusions from the relatively few patients in this trial. Nevertheless, several important findings emerge. Patients were referred after letters, discussion, and circulars had been directed to local hospital consultants, general practitioners, and speech therapists at other hospitals. Initially we were disappointed at the small number of referrals and the even smaller number suitable for entry to the trial. Experience gained from starting up clubs for patients with stroke in different parts of the United Kingdom using similar

recruitment methods, however, shows that in an area with a population of about 250 000 the usual number of patients referred in the first year is 20 to 25⁶; this figure is less than the two per thousand estimated by epidemiologists.^{7 8} As stroke is age-related, demographic details about catchment areas are clearly necessary in evaluating referral rates.

The particular relationships of volunteer helpers and professionals in this trial exposed many problems that proved to be soluble and may be of practical value to others concerned in similar experiments. For example, dysphasia presents in diverse forms, and the classification is not universally accepted by all professionals: a predominantly expressive disorder might be termed Broca's aphasia, motor aphasia, or non-fluent or effluent aphasia, and there might be similar divergences of opinion concerning the optimum treatment strategies. Yet we had to convey the elements of diagnosis and management to helpers who might be newly recruited, and it was hardly surprising that we encountered difficulty: a decision to stop intensive treatment in a patient whose test results had plateaued according to the design of the trial could cause distress and misapprehension when hopes of further improvement were entertained. These problems required careful explanation and discussion with the helpers. Much was learned by everyone about the most satisfactory method of conveying technical data and clinical decisions.

Understandably, patients tended to ask volunteers to help them with personal and social problems and to assume some of the responsibilities of social workers. This might entail asking why meals on wheels were not delivered, arranging a visit to a chiropodist, or collecting a pension. These are problems that commonly arise with any disabled patients, but particularly when a communication defect is present. We gained the firm impression that helpers as well as patients and their families gained considerable satisfaction from participation of this kind.

Finally, the practical and economic aspects of transport to and from hospital for dysphasic patients, often with hemiplegia, must be considered. This trial was conducted in a densely urban sector of a metropolitan area. The difficulties of traffic congestion, long journeys, shortages of ambulances and drivers, and long and often tiring absences from home for comparatively short periods of daily treatment were recurring problems. A similar trial in a rural area with longer journeys might present different problems, but transport expenses and difficulties might prove comparable.

In this trial we found no differences in outcome between the two types of treatment. While this result may possibly be intrinsically valid, doubt must remain because of the size of the trial. Nevertheless, by considering the numerous factors that may have influenced the result—that is, medical, social, professional, administrative, and financial factors—we may have raised important points relating to the management of other major health-care problems in the face of limited resources.

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References

- Eaton Griffiths, V, *British Medical Journal*, 1975, **3**, 633.
- Lesser, R, and Watt, M, *British Medical Journal*, 1978, **2**, 1045.
- Porch, B E, *Porch Index of Communicative Ability*. Palo Alto, California, Consulting Psychologists' Press, 1971.
- Mulhall, D J, *International Journal of Man-Machine Studies*, 1977, **9**, 315.
- Mulhall, D J, *British Journal of Disorders of Communication*, 1978, **13**, 127.
- Eaton Griffiths, V, personal communication, 1978.
- Hodgkin, K, *Towards Earlier Diagnosis*. Edinburgh, Livingstone, 1963.
- Fry, J, *Profiles of Disease*. Edinburgh, Livingstone, 1966.

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