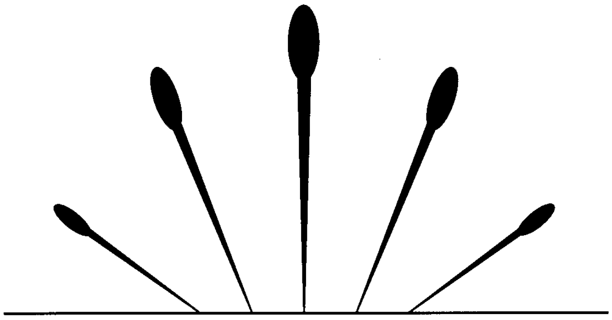
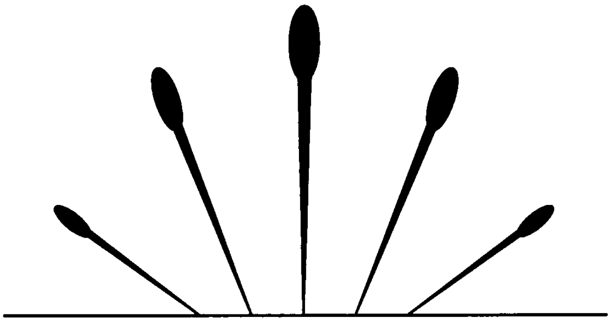


EVALUATION OF PHYSIOTHERAPY FOR PEOPLE WITH STROKE

KING's FUND CENTRE

REPORT OF A WORKSHOP ON APPROPRIATE OUTCOMES OF PHYSIOTHERAPY FOR PEOPLE WITH STROKE

CECILY PARTRIDGE



EVALUATION OF PHYSIOTHERAPY FOR PEOPLE WITH STROKE

The King's Fund Centre, London
3 November 1993

KING's
FUND
CENTRE

REPORT OF A WORKSHOP ON APPROPRIATE OUTCOMES
OF PHYSIOTHERAPY FOR PEOPLE WITH STROKE

CECILY PARTRIDGE

Published by the King's Fund Centre
126 Albert Street
London
NW1 7NF

Tel: 071-267 6111

ISBN 1 85717 074 1

A CIP catalogue record for this book is available from the British Library

Distributed by Bournemouth English Book Centre (BEBC)
PO Box 1496
Poole
Dorset
BH12 3YD

The King's Fund Centre is a service development agency which promotes improvements in health and social care. We do this by working with people in health and social services, in voluntary agencies, and with the users of these services. We encourage people to try out new ideas, provide financial or practical support to new developments, and enable experiences to be shared through workshops, conferences, information services and publications. Our aim is to ensure that good developments in health and social care are widely taken up. The King's Fund Centre is part of the King's Fund.

• CONTENTS •

• ACKNOWLEDGEMENTS •

I would like to thank all the people who have supported this work. The King's Fund financed the workshop and provided excellent facilities at 126 Albert Street. I am particularly grateful to Christine Farrell for her interest and help.

The successful completion of this project is due largely to the skill and enthusiasm of the group facilitators. They attended meetings in the early planning stage, led the groups on the day and prepared reports of the group work. They were Ann Ashburn, Lorraine de Souza, Sue Edwards, Anna Hamer and Heather Thornton.

The workshop could not have been undertaken without the enthusiastic collaboration of the physiotherapists who took part in the workshop. They brought their considerable specialist knowledge to the difficult task of trying to arrive at a consensus on appropriate end points of physiotherapy for people with stroke. They were Sally Ann Adams, Gill Baer, Julie Baldry, Moira Banks, Alan Bass, Linzie Bassett, Janice Champion, Fiona Collen, Julia Copping, Sally de la Fontaine, Willy de Weerdt, Brian Durward, Judy Eade, Catherine Elliot, Anne Forster, Jenny Freeman, Carol Marsden, Sue Mawson, Fiona McGrath, Rowena Mee, Carol Napper, Nia Owen, Phillipa Perkins, Pauline Pope, Catherine Sackley, Lesley Scurlock, Jackie Shanley, Lindsay Smith, Jayne Steadman, Judith Sweeny, Gilly Thomas, Jennifer Todd, Sarah Tyson and Lynda Wheeler.

The Stroke Association funded the focus groups and Dr Sylvia McLauchlan's interest and enthusiasm were crucial. Mary Oliver and Sue Williams, regional organisers of the Stroke Association, arranged for the groups to be held at their centres. The people disabled by stroke and their relatives gave generously of their time and spoke very openly about their treatment, which provided important insights into patients' perspectives. To all of these people I am most grateful.

• INTRODUCTION •

Stroke is one of the commonest causes of severe disablement[1] and the costs to patients, their families, and society must be huge, but have not been quantified.[2] Physiotherapists have been involved for decades in the treatment and management of stroke patients, and consider it a specialist area of practice.

Evaluation of physiotherapy for people with stroke is complex: not only are symptoms diverse but some natural resolution is expected in the early weeks. Therefore any effect claimed for physiotherapy, or indeed any aspect of rehabilitation, must be shown to be over and above this natural recovery. In addition, physiotherapy approaches to the treatment and management of people with neurological conditions have been developed empirically, and are based on assumptions about motor control and neurophysiological mechanisms rather than on scientific evidence of efficacy.[3]

Studies which have attempted to evaluate packages of rehabilitation,[4,5] of which physiotherapy was a part, have not provided clear and unequivocal evidence of effectiveness, or indeed the lack of it. Critical reviews of these and other studies of rehabilitation for people with stroke[6,7,8,9,10] have identified considerable methodological problems. Sample sizes were often small, little information was provided about the physiotherapy given or the characteristics of those who gave it; perhaps most important of all, the outcome measures used were not directly related to the aims of physiotherapy and were therefore inappropriate to evaluate its effects.

Though the evidence is not clear-cut, the general conclusion is that stroke patients do derive benefit from rehabilitation with physiotherapy, but details of optimal physiotherapy are lacking. Despite the limitations of these studies, Ashburn,[11] on the basis of evidence accumulated so far, suggests that 'stroke rehabilitation has value for selected groups of patients, early active intervention encourages functional independence and mobility, and more intense rehabilitation for physically resilient patients achieves better results than less intensive treatment'. However, the lack of clarity in the situation is evident in the conclusion of the *Bulletin on Stroke Rehabilitation* in the series on Effective Health Care[12] which stated there was 'a lack of good evidence on which to base clear purchasing decisions'.

There are a number of reasons why it is now imperative to evaluate the outcome of physiotherapy practice for this patient group. First and foremost, unless clear information is available about the likely results of different interventions, patients will not receive optimum treatment. Second, practice based solely on clinical experience is no longer acceptable; decisions about selection of patients for treatment, its type and duration should be based on clear evidence of effectiveness. Third, given the current financial stringency in the health service, and the number of people with stroke, managers are reluctant to purchase services without clear evidence of what they can achieve. This may well mean that patients with stroke are deprived of services they need to enable them to achieve their potential.

The concept of outcome can be considered in different ways: one is to consider the extent to which stated aims of treatment are actually achieved, another is to consider what adverse events occur if the treatment is not given. Much of the research into physiotherapy for stroke has not been undertaken by physiotherapists and this may be why the measures used have not been appropriate. What is needed therefore is for physiotherapists to come to a professional consensus about appropriate and expected outcomes of physiotherapy treatment.

To this end, physiotherapists experienced in the treatment of neurological conditions were asked to come together to try to reach agreement on appropriate outcomes of physiotherapy for people with stroke. Alongside this work, it was considered essential to incorporate the opinions of the people who were disabled by stroke and those who cared for them. Focus groups were held to explore their views and material from them is included in Part 2.

This report represents the first stage in work seeking to evaluate the contribution of physiotherapy to reducing physical disability in people with stroke. The report is being circulated for comment.

The task of the second stage is to examine the identified outcomes, together with the feedback from different sources, and to consider their measurement. This stage will include scrutiny of tools of measurement currently in use, to decide on their validity in relation to the outcomes identified in the workshop and to investigate the extent to which items could be derived from the workshop material and scored as pass/fail. This type of scoring provides binary outcome variables which can be seen as insensitive to small changes, but if items are carefully selected and criteria for passing or failing are clearly defined, they can provide discrete information about levels of ability or disability; they also provide data which are amenable to different forms of analysis.

The third stage will be a multicentre clinical trial which should provide clear evidence about the effectiveness of physiotherapy for people with stroke. A multidisciplinary committee has been set up and a protocol is being prepared for submission for funding.

PART 1

• CONSENSUS WORKSHOP •

PRELIMINARY WORK

The first task was to select a core group of workshop facilitators. Five senior physiotherapists, who, between them, had a record of clinical work with people with stroke, and also some experience of research into the treatment and management of neurological conditions, were invited to take part.

To select topics for the workshop, a brainstorming exercise was used to find items considered as outcomes of physiotherapy for people with stroke. In all, 93 items were produced. They covered a wide range from the physical – mobility, balance, posture and contractures – to the more psychological – satisfaction, mood and quality of life.

Categorisation of these items provided six broad groupings. The first four were related directly to gross body movement:

- In lying towards sitting
- In sitting towards standing
- In standing towards walking
- Walking and onwards.

These categories illustrate the dynamic nature of physiotherapy. It is never static, and always works towards functional goals. They cover the direct focus of most physiotherapy and follow the sequence of recovery of gross body movements from lying through sitting and standing to walking which have been demonstrated in over 700 patients with stroke.[13,14] The physical disability caused by stroke shows great variation, and may range from a transient one-sided weakness which resolves within a few days to profound paralysis.

Physiotherapy may involve treating patients of any level of disability. The last two groups might be seen as less obviously related to physiotherapy but nonetheless were considered important in terms of outcomes:

- Mood, quality of life and satisfaction with physiotherapy
- Avoidable complications.

It was agreed that satisfaction with treatment should be included because patients' opinions are important. However, it was felt that simple rating scales of satisfaction commonly used would be unlikely to provide useful information. Domains of importance to patients receiving physiotherapy must be identified so that questions can be targeted appropriately. Mood and quality of life are also concepts frequently used in evaluating treatment for conditions involving long-term disability.

The sixth group, avoidable complications, included unfortunate events which might occur if treatment was not given or was inadequate or inappropriate. It was agreed that these six categories would be used as group topics for the consensus workshop.

Recruitment

Experienced physiotherapists who had specialised in the treatment of neurological patients were recruited for the workshop. Those invited to take part were selected on the basis of their specialisation in neurological conditions, and to represent a wide geographical spread throughout Britain. To enable effective working of the groups, the size of each was limited to six. The response to invitations was extremely enthusiastic and requests to join the workshop well exceeded the 36 places available.

GROUP WORK

Each person was assigned to one of the six groups. Each of Groups 1 to 4 were asked to consider the following questions:

- What do we hope to change with physiotherapy?
- What are we looking for in terms of motor performance that could be expected to result from, or be assisted by, physiotherapy?

Measurement of outcome is clearly a central issue, but it was excluded from this workshop to allow participants to concentrate on outcome without being distracted by considerations of measurement. Measurement will be the focus of the second stage of this work.

With an intact neurological system, movement is fluid and largely automatic; it is also smoothly co-ordinated and requires minimum effort. When this is lost through a stroke, physiotherapists work with the patients to give them the ability to move from and to different positions and to achieve postures for function in the most easy and energy-efficient way.

All the groups agreed that there would be constraints to achieving aims of physiotherapy treatment which would have to be monitored, if outcomes of physiotherapy were to be assessed. They included cognitive and perceptual impairment and psychological state, which were seen as influencing the ability to respond to treatment and to re-learn skills. Shoulder pain, and pain of thalamic origin, pre-existing medical conditions and joint pathologies were all seen as likely to affect performance and exercise tolerance, and possibly, therefore, outcomes.

GROUP 1: IN LYING TOWARDS SITTING

This group considered it was essential that outcomes of physiotherapy should include qualitative aspects of function and that treatment goals should reflect this. Discussion was mainly related to patients in the early post-stroke stages.

Three areas of physiotherapy intervention were identified with the following aims:

- To maintain the potential for recovery by effective use of the environment and the prevention of secondary complications, such as the development of abnormal movement patterns, or chest infections.
- To maximise functional recovery by ensuring continuity of patients' management. The provision of information and communication with patients and other health professionals is crucial in the early stages of care.
- Re-education of movement and posture. Key components were identified and are listed below.

KEY COMPONENTS

(a) Acquisition of mid-line, i.e. appropriate alignment of each body part in relation to the others and also to the surface on which it is supported.

(b) Head and trunk righting reactions when the body is moved.[15]

(c) Selective trunk activity, i.e. the ability to move the bottom half of the body in relation to the top, and one side of the body in relation to the other.[16]

(d) Interplay of trunk and pelvis – the ability to stabilise the pelvis in order to move the trunk.

(e) Dynamic stability of the pelvis during movement.

In sitting towards standing – Position of feet and arms
Relationship of knees and feet
Weight transference forward and up into standing
Alignment of head, shoulders, pelvis and limbs.

(b) Freedom to move body parts

Head, trunk and limbs away from and back to mid-line.

(c) Reduction of unwanted activity

Overactivity of non-stroke side
Associated reactions, when one part of the body moves others also move involuntarily
Asymmetry in posture.

(d) Independence

In sitting and during sitting to standing – Ability to maintain positions without support
Ability to follow guidance and correct movement
Ability to move about.

(e) Achievement of sitting to standing in different situations and environments

GROUP 3: IN STANDING TOWARDS WALKING

The aim of this group was to identify factors directly related to physiotherapy interventions in standing and preparing to step.

Standing balance, a key component for this group, was defined as 'the ability to maintain upright posture independently and transfer weight from one leg to the other to achieve a functional goal'. For more specific analysis within the workshop, the working definition of 'standing' was to be with feet astride but within the pelvic circumference.

The task would be to heel off with the arms resting by the side of the body with the head in mid-line. Three factors emerged in discussion as the basic requirements for the performance of this task:

1 Cognitive preparation

2 Postural adjustments

3 Motor components.

The integration of sensory motor function was considered to be essential. The key motor components for successful attainment of the group's task were considered to be as follows.

KEY COMPONENTS

(a) Full range of movement of muscles and joints within normal range and appropriate to the patient's age.

(b) Normal eccentric and concentric muscle activity throughout, with particular emphasis on the legs and pelvis.

The following specific factors were agreed to be those that physiotherapy could influence, and therefore appropriate outcomes:

- Mobility of the foot and great toe, and the ability to respond to changes in the supporting surface

- Extensor/abductor activity of the hips with the release of the leg into flexion while maintaining alignment of the anterior superior iliac spines.
- Symmetrical alignment of the scapulae, and of the scapulae with the head and pelvis.
- The ability to move on an automatic and voluntary basis.
- The ability to move the arms freely for function.
- Endurance/task tolerance training.

GROUP 4: WALKING AND ONWARDS

The group first recognised the substantial volume of work that has been undertaken on analysis of gait using sophisticated equipment. Then by brainstorming and consideration of the two questions, they identified the following areas as important.

1 Quality

Walking is about dynamic movement, and the emphasis should be on the quality of the movement in terms of fluidity and automaticity of gait. Although components of walking were identified, it was considered important that they were assessed within the context of walking rather than in isolation.

It was considered essential to take account of the expressed wishes of the patient: some patients will want to achieve the maximum possible recovery of quality of movement, others may decide to use aids or rely on assistance because of the effort involved or for other personal reasons. Some patients may have abnormal movements but feel that their walking is adequate for their needs and do not wish to work for further improvement in quality.

2 Function

There can be a problem in defining what 'walking' comprises, as it is interpreted in different ways in relation to individual needs. The range can be from the patients who feel they have achieved a great deal though they are only able to walk a few steps to get them to the bathroom, to those who are able to walk well and be mobile for a few hours each day, but may remain dissatisfied as their job requires them to be on their feet throughout the day.

Considering common problems and goals of treatment enabled the group to move forward to identify agreed outcomes. The group decided that often the main aim of treatment initially was achieving stance phase and identified the following.

KEY MOTOR COMPONENTS

(a) Head in mid-line and free to move.

(b) Shoulder girdles level and free to move.

(c) Arms relaxed and free for function.

(d) Demonstrable arm swing walking at speed.

(e) Weight bearing in sequence through the foot.

(f) Knee yields into flexion in mid-stance maintaining dynamic stability.

(g) In stance phase, the hip moves from flexion to extension with absence of Trendelenburg sign.

(h) Trunk interplay – there are small movements occurring in the trunk to allow effective weight transference.

(i) Prior to toe off there is a release into knee flexion while the hip remains in a degree of extension.

(j) From early to late swing phase, the following interrelated components can be observed:

- during swing phase, the foot moves from plantar flexion at toe off into dorsiflexion at heel strike thus clearing the floor
- the knee moves from flexion at toe off towards a more extended position at heel strike
- the hip moves from extension at toe off towards flexion at heel strike.

On the basis of these components, the group then identified aspects which would relate to outcome in walking.

Temporal/distance measures can be used to assess overall ability:

- Velocity
- Step length
- Cadence.

Progression of function to include:

- Stairs/slopes/variable surfaces
- Carrying and picking up objects
- Walking and talking
- Mobility in leisure community activities, ability to walk through busy streets, manage kerbs, etc.
- Hopping/running/jumping.

Other factors to be taken into account include:

- Levels of verbal and physical assistance required.
- Use of aids and appliances. If the patient only has the use of one arm, the ability to walk without an aid has considerable implications for upper limb function.

GROUP 5: SATISFACTION WITH PHYSIOTHERAPY

The group agreed to use the following definition of the term 'satisfaction': 'satisfaction is a measure of the extent to which an individual feels his or her needs or aspirations are fulfilled'. Discussion about satisfaction centred on the opinions of the patients and their carers, and covered the following six areas, the first five of which had been identified in the focus groups.

1 The timing of the physiotherapy interventions

Both the start time of treatment and its ending gave rise to concern. Treatment could start too early, or be delayed too long. Its ending was seen as a major problem, often occurring long before patients felt ready to manage on their own. Some form of continuing access was very much appreciated, and felt to be important to avoid deterioration over time. Therapists agreed that constraints within the health service meant there was great variability in the availability of early treatment, and that patients and therapists often did not agree on the discharge date.

2 Intensity of treatment

Overall, patients often felt they were not getting enough of the physiotherapist's time. This could be because of infrequent sessions, or sessions in which patients felt that they had very little attention from the therapist.

Again therapists agreed that this might happen, but was less likely to do so in a specialised rehabilitation unit. Patients also felt this to be the case.

3 Communication

There were two dimensions within this category:

- Listening – therapists having the time and skill to listen to patients' concerns and worries. Therapists felt they did usually listen, but it could be a problem if time was limited.

- Explanation – therapists explaining about stroke and the purpose of any treatment or advice they are giving.

Participants agreed it was necessary to ensure that any advice had been understood, and that frequent repetition might be necessary. It was felt that more experienced therapists were usually more effective communicators, and that communication was an extremely important part of therapy.

4 Collaboration

Patients thought all staff should know what the physiotherapists were doing so that patients were not given conflicting advice; failure to do this often caused distress and frustration. Participants agreed that sharing information was desirable, but often this did not happen except in specialist rehabilitation units.

5 The physiotherapist

Patients thought the following qualities were important:

- Experience in the treatment of patients with stroke.
- Interest in neurological conditions.
- Ability to understand each patient as an individual.

Therapists agreed it was essential for those treating stroke patients to be skilled and experienced, and have an interest in neurology.

6 The treatment

Patients' opinion of their treatment was a further category added by the group participants who felt patients should be asked about different aspects of their treatment programme.

All group members agreed that these six categories represented appropriate domains which could be used to assess the patients' satisfaction with their treatment.

MOOD

Two possible sources of influence on mood were agreed:

1. How mood affects physiotherapy – this was thought to be an aspect which it was essential to consider.
2. How physiotherapy affects mood – this would be less easy to disentangle, but it was agreed that a secondary effect of physiotherapy could be elevation of mood with reduction in tension and anxiety.

The group agreed that many patients would have reactive depression[17] and this should be monitored during physiotherapy, as it might affect performance. If patients had a depressive illness and psychiatric morbidity, they should not be included in clinical trials of physiotherapy as it would be likely to distort results.

It was considered desirable to monitor pre-existing traits which might influence results, such as trait anxiety. It was also considered desirable by most but essential by some participants to monitor mood states such as anxiety and tension in patients receiving physiotherapy.

QUALITY OF LIFE

It was accepted that the concept of quality of life represented dimensions of human experience that ranged from those associated with the necessities of life, such as food and shelter, to a sense of fulfilment and personal happiness. The group agreed that physiotherapy could affect a patient's overall quality of life, but that it would be at a tertiary level: if treatment was successful at a primary level, for example enabling an immobile patient to walk independently, this should mean less dependence on others, and in some people this could result in a perception of an improved quality of life. Also, in the early post-stroke stages, having a competent physiotherapist helping to overcome disabilities and enable function again might enhance quality of life. It was recognised that it might be difficult to demonstrate these links directly as there would be so many other factors influencing anyone's life.

There was agreement that at a tertiary level physiotherapy may affect quality of life in both the short and the longer term, and two examples were identified:

1. Positive effect – by accelerating recovery from disability and facilitating the process of acceptance of the condition.
2. Negative effect – if there is conflict between goals of patients and goals of physiotherapists.

GROUP 6: AVOIDABLE COMPLICATIONS

This group started by agreeing that avoidable complications were to be considered as secondary disabilities in those who survived the initial neural insult. Seventeen complications were identified which the group was able to rank: three complications were prioritised in terms of their relevance to physiotherapy. The three priorities were:

1 Contractures

2 Pressure sores

3 Painful shoulder on the affected side.

The aims of physiotherapy in relation to each complication were similar:

- To prevent the complication from occurring.
- To reduce or control the complication.
- To correct complications which have already occurred.

These three aims relate to the epidemiological concepts of primary, secondary and tertiary prevention.

Priority 1 – Contractures which encompass two main physical phenomena, tissue tightness and tissue shortening

The two main causes of contracture were seen to be:

- Immobility leading to joint stiffness.
- Abnormal muscle tone leading to soft tissue stiffness.

It was agreed that the aims of physiotherapy in preventing contractures are achieved by promoting mobility through normal patterns of movement and function. It was also agreed that employing compensatory techniques, such as over-use of the unaffected side, would encourage the development of contractures.

The major aims of physiotherapy to prevent contractures would be:

1 Facilitation of movement out of fixed positions of the trunk and limbs.

2 Maintenance of joint range and soft tissue length.

3 Education of patient and carers to ensure the movement of joints through range by achieving function in daily living activities.

Priority 2 – Pressure sores

The group agreed that the physiotherapist could work with others to prevent sores. It was agreed that patients were at risk in the acute stage, especially if they were unconscious and, in the long term severely disabled.

Aims of treatment would be:

1 Education in pressure area care.

2 Position to equalise weight on loaded tissues and to increase area of loading.

3 Facilitation of movement out of fixed positions.

4 Avoidance of sustained pressure on any body area.

Priority 3 – Painful shoulder

It was agreed that where abnormal movement or positioning of the shoulder joint was the cause of pain, physiotherapy had a role but was unlikely to be able to relieve pain of thalamic origin.

Aims of treatment would be:

1 Education of the patient, and all members of the health care team, on the need for careful handling of the shoulder region of the affected arm.

2 Prevention of loss of shoulder movement.

3 Identification of predisposing factors for shoulder pain, such as abnormal tone, subluxation of the shoulder joint, perceptual and spatial neglect, and lack of movement.

4 Lifting and handling techniques to take account of vulnerability of shoulder region.

There was agreement that physiotherapy could help to avoid complications if there was collaboration with all team members. Their occurrence, however, could not necessarily be seen as failed physiotherapy or lack of it, as many other factors were involved. Once complications were present, the effect of physiotherapy could be assessed in terms of the extent of the reduction in the complication concerned.

Risk factors were identified which might increase the likelihood of avoidable complications:

- Perceptual and spatial neglect
- Cognitive dysfunction may lead to poor maintenance of good positioning
- Sensory impairment, not being aware if the arm is in a good position
- Hemianopia
- Severely abnormal tone
- Lack of voluntary movement and poor level of function
- Poor motivation and depressed mood.

CONCLUSIONS

The task set for the workshop was challenging. The aim was to reach a consensus within each group on the given topic. Because of the limited time available, there was not the opportunity for formal discussions between the groups, which means that opinions expressed may not reflect the views of all participants. Some groups managed to achieve more consensus than others and clearly there is more work to be done. For this workshop the topic of measurement was specifically excluded to allow participants to concentrate on the concept of outcome.

The key outcomes identified by each of the four groups working on movement show a number of similar themes: this is important as it shows that each group, though working on different stages of movement, independently identified similar features. It adds validity to the claim that a considerable degree of consensus was achieved in the workshop, and that outcomes relate to the aims of physiotherapy.

The common themes were: symmetry, selective activity, interaction with base of support and sequencing of movement. Symmetry was described as: alignment of body parts (Group 1), symmetry of weight distribution and mid-line orientation (Group 2), acquisition of mid-line and symmetrical alignment (Group 3), and head in mid-line (Group 4).

Selective activity was defined in terms of interplay of movement, and maintaining stability of one part of the body while others were free to move. The words used were: an ability to stabilise the pelvis in order to move the trunk (Group 1), freedom to move body parts (Group 2), ability to move arms freely for function (Group 3), and small movements in trunk allowing effective weight transference (Group 4).

In each position, facilitating the ability of the body to respond and adapt to supporting surfaces was considered an important aim. Terms used were: contact of body parts with supporting surface (Group 1), ability to accept body weight (Group 2), ability of foot and great toe to respond to changes in the supporting surface (Group 3), and weight bearing on variable surfaces (Group 4).

Finally, sequencing of movements which enable smooth movement was identified by all groups and described as: moving away from and towards affected side (Group 1), transference forward and up into standing (Group 2), extensor/abductor activity of hips with release of leg into flexion (Group 3), and the foot moves from planter flexion at toe off into dorsiflexion at heel strike (Group 4).

The results of the work of the groups on psychological aspects and avoidable complications stand separate from the four movement groups. The discussion of satisfaction was based on the patients' and carers' opinions. Therapists recognised timing of treatment and its intensity, communication, and collaboration between staff as common problem areas. It was agreed that it would be both appropriate and possible to monitor services in relation to these domains. Timing and intensity might reflect difficulties with staffing levels and local policies; others, such as communication and collaboration, might depend more on interpersonal skills, but all were crucial to good practice. The group members readily recognised that experience and interest in neurological conditions were central characteristics for their physiotherapist as was the ability to understand each patient as an individual. These areas identified by patients and carers, and supported by physiotherapists provide a basis for examining stroke patients' satisfaction with their treatment. In addition, the group also thought it might be useful to ask patients about different aspects of the treatment itself.

The effect of mood was agreed to be twofold: it might influence recovery from disability adversely, and negate effects of treatment or, alternatively, the therapy might have a beneficial effect on the patients' mood. For both of these reasons it was considered important to monitor mood in studies of physiotherapy for people with stroke.

Quality of life is closely related to both satisfaction and mood, and therapists agreed physiotherapy could have dual effects: a positive effect by accelerating recovery from disability, and a negative effect if there was conflict between patients' and therapists' expectations and goals.

Contractures, pressure sores, and pain in the affected shoulder were all seen as secondary disabilities which the patient might acquire, but which could be avoided by collaboration between all team members. Physiotherapists do use a number of methods of treatment specifically directed towards avoiding these disabilities. However, when they did occur, it did not necessarily mean a failure of physiotherapy, but could indicate a weakness in any part of the team.

The extent of the overall agreement both within and between the groups represents a valid advance in knowledge about outcomes of physiotherapy, and provides valuable information which helps to clarify the way forward for work to evaluate the treatment of physical disability of people with stroke.

Measurement of outcome is clearly the next imperative. Some of the outcomes identified and agreed relate to specific features of movement and function which could be assessed directly, but there were others that would be less easy to assess and some which might not be able to be assessed objectively. What is important is to ensure that in future studies of physiotherapy, key outcomes related to the aims of treatment are included. Some of them have been identified by this work.

PART 2

• FOCUS GROUPS •

BACKGROUND

There has been a move in health care towards considering the opinions of people receiving a service as legitimate information about the outcome of medical and other health care interventions. Recent government publications such as the *Patient's Charter*[18] outline patients' rights in terms of delivery of services, and the document *The Health of the Nation*[19] recognises that a key area in the health service is to enable people with physical disabilities to achieve their optimal level of function. Objective levels of functioning can be measured, but in order to investigate the quality of the service to the individual, in terms of the extent to which their needs are met, it is necessary to obtain information from those who have actually received that service.

The purpose of this work was to explore the opinions of people who had received physiotherapy for a stroke with the aim of incorporating these views into the workshop. The method used was focus groups with people who were disabled by a stroke and with their main carer.

A total of 16 people who had received or were receiving physiotherapy for physical disabilities following a stroke participated. There were three men and 13 women, whose stroke had occurred between two months and three years ago. Their ages ranged from 29 to 70 years. A further six people, currently caring for a spouse with stroke were involved. Two of the focus groups were held with Stroke Association members and one in a hospital rehabilitation department. Although the groups took place in southern England, the hospitals in which patients had received treatment, and on which their opinions were based, were in many different parts of the country, including the north and north-east of England and the Midlands.

The focus of the groups was the opinions of patients and carers about what they considered desirable and undesirable about physiotherapy so that key aspects of what they particularly appreciated and felt to be important were identified, as well as what had not been available to them.

PROCEDURE

The members of the group were seated in a circle. They were thanked for coming and the purpose of the group was explained to them. Their permission was sought to tape-record the session. They were assured of complete confidentiality and reassured that their names would not be mentioned. All readily agreed to the recording and many said they were glad to have the opportunity to express their opinions. Each session lasted about one hour.

Transcripts were made of the recordings and the content was analysed. The aim of the analysis was to identify themes occurring in the written material. The search was for themes which occurred frequently, indicating areas important to patients receiving physiotherapy and to their carers. Five broad categories were identified in the transcripts, and endorsed by two independent scrutineers. The first was to do with timing, when the physiotherapy started and finished; the second with the amount of time the physiotherapist spent with the patient; the third with all aspects of communication; the fourth with collaboration between members of staff; and the fifth with the characteristics of the physiotherapists and patients' interactions with them.

It was clear that for most of these people the stroke had been a devastating event: 'Stroke is so many things at once, you're never the same again'. This was true for the carers too and one with a severely disabled husband said: 'We struggled so much to keep him alive, sometimes I wonder why now', and: 'I wouldn't wish it on my worst enemy'.

Sessions became quite emotional, but at the end participants said it had been helpful to them to be able to talk. 'I hope this can help somebody else later not to feel the frustration, you feel so helpless.' The participants all said that physiotherapy could and often did play an important role in recovery from the disability of stroke: 'Without the intense physio my wife would have been a cabbage', 'Without the physiotherapy she wouldn't have made the progress she did', and: 'When the physio dropped off I was losing ground, the ability to walk was lessening, so we employed a mature private physiotherapist and I started to make progress again'. 'The GP isn't a lot of help, physiotherapy is a must and you need it.'

TIMING

The timing of the start of physiotherapy was considered important, some felt it should start as soon as possible: 'It was dreadful, I had to wait four weeks for a referral', 'Definitely as soon as possible'. Others felt that there should be a delay in the start of treatment, until the patients are 'more themselves': 'Not at first, nothing intensive to start till about two weeks or so', 'A fortnight of rest first', 'After about a month when you're laid out then comes the intensive time that's really crucial'. Very strong feelings were expressed about stopping physiotherapy before patients had achieved their potential: 'This two-month limit is absolute nonsense, everyone is different', 'You need to go on seeing the physiotherapist because otherwise you go backwards', and: 'In the hospital it's quick, quick, quick and out you go'. A carer said: 'After the initial fortnight or so of rest you must be moved around and do things, if you don't go through that stage then the later stages of treatment become less effective'. Examples were given of what happened when treatment was discontinued: 'I stopped treatment and after a few weeks my arm started stiffening up, I couldn't straighten it properly' and: 'I started to need a stick again and was not so steady walking'; both of these people said when they could no longer have NHS physiotherapy, they went to a private physiotherapist. 'Physiotherapy is a must and you need it.'

AMOUNT AND TYPE OF PHYSIOTHERAPY

Both timing and amount of physiotherapy depended to some extent on the availability of a physiotherapist. Many of the group participants said there was either no-one in post, or a succession of therapists who only stayed a short time. It was only in the specialised rehabilitation units that shortage of staff was not seen as a problem. The actual amount of time spent with the physiotherapist was seen as important, as was the one-to-one relationship. 'Just gentle physiotherapy at first for two weeks or so', but later on: 'Half an hour a day is really pretty useless', 'I used to go to the gym and do nothing, just sit in a chair', alternatively: 'I had three lots of physio a day, two in the gym and one in the day room, that was great'. 'She had intense physio twice a day and this got her onto her feet.' Another said: 'They do help in the gym but once you're back in the ward the support is not there, you are just left'. When the physiotherapy does not go on long enough: 'It's bad because you rely on memories of what the instructions were, how they *were* going to help you, instead of fresh instructions for what you have *become*. At the Y unit it's nine o'clock in the morning till four in the afternoon, that's very good'. 'After about four weeks, the next couple of months are really critical, and it must be the right sort of therapy.'

Five of the patients said that they paid to have private physiotherapy when they were told they could no longer have any more out-patient National Health physiotherapy and they thought they were deteriorating. They regained lost functions when they managed to find a 'good' physiotherapist.

COMMUNICATION

Under this broad heading the following subdivisions were considered: listening, giving information, and explanation.

Listening

Listening was considered extremely important. Examples given were mainly of its absence: 'Listening is so very important, some people are better than others', 'Listening means investing time in a person and it's so important'. 'Why isn't listening taught to people in their training?' Physiotherapists were not alone in not listening, it was considered the exception rather than the rule that anyone in hospital listened. 'It would be so good if someone had two minutes to sit down and say "What is troubling you today?" and then listen'.

Information

In general, people felt they were not given enough information: 'No, no, definitely not', 'There seems to be a secret society, you mustn't tell the patient anything', and: 'They should appreciate you are not just a number, the lump lying in the bed is a person with worries.' It was considered a good idea to write things down: 'You might get confused if they use a word; if it's written, in a quiet moment you can look at it and understand better what is needed'.

'If you've had a stroke they say it is two years and you don't get any better, but you do, it may only be a little bit but you are getting better.' 'They said to me, "After the first year you won't make a lot of improvement" and I've proven them wrong. I couldn't walk unaided after the first year, after two years I now can walk, progress is minuscule... but to me it's a new triumph every time.'

Explanation

Again, the examples here were mainly of poor practice, and there was general agreement on them by the group members. 'It seems a common failing – that with the stress of their job they won't give you that little bit of time to explain – and we've all been in different hospitals.' 'They don't explain, do they, you just have to guess what they are thinking.' 'It's very important to explain what and why and be told what the likely outcome is.'

Many instances were given where information was lacking: 'Nobody told me I'd had a stroke till I came here [to the rehabilitation unit]. No-one explains to you, "This is quite normal, you will get frustrated at times and you will get depressed".' 'There's definitely not enough explanation, when they come along you need to know why they want you to co-operate, if they don't give a reason why should you struggle with the weights ...' 'The physiotherapy was extremely good but there again I do wish they would say "Today we are going to do this, because it's going to ... " and then explain it, the purpose of it, I'm sure they would get more co-operation if they did.' 'I remember better if [it is] explained to me – there's more chance of my following advice if I know why I'm doing it.' 'Memory is very short, very poor in the beginning, so you need lots of repeating, you don't remember anything from day to day and they shouldn't expect it.'

One man who said he 'read up about it' because nobody told him what was going on, said: 'The problem was they didn't explain – they couldn't cope with me because I wanted to know what they were doing'. Another said the problem is that 'instructions are not patient-centred. You need a lot of repetition, you're not with it at first, so you need instructions fresh each time, later on as you get more together you can do more on your own, but not at first'. 'More should be explained not only to [the patient] but to the family.' One woman said: 'It's even more important for the husband/wife as they have to look after us'. 'They [medical staff] have the habit of using abbreviations and letters, which is very confusing.'

COLLABORATION

This was mainly about the extent to which all staff were consistent in what they said and did, the advice they gave, and the extent to which they understood what each other was doing. 'Each should know what the other is doing, nurses should do the same, that's why changing staff is awful.'

Talking of a specialist unit: 'Everyone there worked together, that's the best thing and everyone knew what was going on wherever you were'. Each person reinforced the work of the others in the rehabilitation units, a continuous day-long programme of involvement in activity. 'The patient should be part of everything that's going on.'

THE PHYSIOTHERAPIST

The groups found it easy to identify the therapists they considered to be good or bad, and there was usually agreement where people from the same area were seeing the same therapists. It was less easy to specify the exact qualities. 'There are therapists and therapists'. 'I had one, she seemed to care and spoke to me as if I was a normal person, the others treated me like an idiot'. Both patients and relatives felt they could tell very quickly whether or not the therapist was experienced: 'Definitely within the first week', and they felt it was not necessarily related to age.

Other aspects considered important were that therapists should 'understand each individual is different' and 'know how the patient thinks and feels and talk to the relatives'. But it was considered very unhelpful to say: 'I know how you feel'. 'How can they possibly know?' Therapists who were very positive and enthusiastic were appreciated, a strong sense of humour was also a great asset. Being interested in the condition of stroke was important: 'She said, "What we're really interested in here is respiratory care", that's not much help'. Treatment goals were 'something the physio tells you about, something they decide and then tell you.'

Some group members were reluctant at first to be critical but they soon lost their inhibitions: 'I'm not knocking the girl but I could do better after I was trained at Centre X.' 'They weren't very good, my wife found it a waste, a dead loss and she refused to go back to her.' 'She really hadn't any experience at all so I took her to the Y Centre so that they could show her, but it didn't really help.' 'She said, "Are you feeling well?" in a slightly raised voice like I'm an idiot.' 'The physio said to me, "Well we can't do any more for you, it's a year now and that's it." I went home and broke my heart, in fact I was so ill I had to get the doctor in.' 'The physio should treat you as a person.'

Other therapists were highly valued: 'She was absolutely wonderful, fantastic, you could see she knew her job, you felt really confident in her'. 'I had a very positive young woman, that was great.' 'M is really great, we all like her.' In general it was the therapists in rehabilitation centres and some private practitioners who were seen as having the qualities patients and carers valued.

RELATIVES

Many of the relatives' comments came under the previous categories, but they also talked about their own role. 'The X Centre had me there three times a week watching what they did, but just what they give you isn't enough, you need to be able to help yourself.' 'However good the carer, however loyal ... it really needs someone else, someone outside.' 'All the time I wouldn't give in, I mean if we give in they've got no chance.'

Some of the carers were more articulate than others and knew how to obtain information: 'I certainly didn't have a problem getting information'. Others spoke of physiotherapists, 'Especially the younger ones, who are prepared to give you prognoses which are totally wrong and demoralising. For example, you won't get your arm back, that's absolutely disastrous, they don't know and every patient is different, I can't stress this enough.'

Constant comparisons were made between the care in district general hospitals and specialist rehabilitation units. In the former, physiotherapy was said to be often unavailable or physiotherapists' time was severely rationed and the overall level of skill of the therapists, or indeed their interest in stroke, was limited. Relatives felt that not only was progress not made in most district hospitals, but patients often deteriorated while there, only making progress when they were able to get another period in a rehabilitation unit or a good private physiotherapist. 'At the good centres they laugh a lot and make light of things, that helps a lot.' 'They've got such patience, and they encourage you.' 'In these centres they have a different dedication, in the other [general hospital] they couldn't care less, and you get lots of conflicting advice, you go crazy.'

CONCLUSION

The extent of agreement within each group, and the similarity in the topics raised, suggest that these areas are of great importance to patients with stroke and to their carers.

Physiotherapists supported the opinions of the patients and their carers and recognised deficiencies commonly found in the provision of services for people with stroke. Two key factors identified by patients and carers, and agreed by therapists, were that the setting in which the treatment took place, either specialist unit or district general hospital, affected the availability and quality of treatment, the former offering the possibility of much better overall care. The other key factor was seen as the skill and experience of the therapist. Poor practice in terms of treatment and management, communication with the patient, liaison with other staff and relatives was considered to be the result of inexperience often compounded by shortage of staff. The best option was seen as a skilled and experienced therapist working in a rehabilitation setting.

The literature generally supports early intervention as appropriate, and physiotherapists reported finding that contractures could be acquired in the early weeks, which complicated and delayed recovery at a later stage. The opinion expressed by some patients and carers that intensive rehabilitation should start after four to six weeks was supported by some therapists who felt that people with a severe stroke were often more able and cognitively prepared for active collaboration at this stage.

The very strong feelings expressed about discharge from treatment were recognised by the therapists. One part of the problem was seen as some Trusts which favour the use of treatment packages, where there are set periods of in-patient care for given diagnostic conditions, with earlier discharge being an indicator of an efficient service. Another problem was seen as the prominence of the medical model of 'cure' which tends to dominate thinking and practice in most general hospitals. There can be impatience with patients who do not make quick progress.

Therapists thought patients' expectations could often be raised inappropriately, for example, if the doctor said: 'The therapist will get you better', without further explanation. Adequate and appropriate information about what the treatment is likely to achieve is needed. Explaining that there will periods of progression and plateaus over time may help. Encouraging the patients to take as much control as they can over their recovery from disability can be helpful; patients who believe in their own control over their recovery are likely to achieve better outcomes,[20] and to see withdrawal of professional help as success rather than failure.

Therapists felt that there were some patients with long-term disabilities who, without some form of continuing access to professional help, were likely to deteriorate. The comment was made that patients with other long-term conditions were able to receive treatment for life with medication, and some form of continuing therapy support would not only be humanitarian but also a cheaper option than long-term social support for the increasing disablement. Therapists generally felt that patients should not have to resort to the private sector to get adequate treatment.

Good communication was seen by the therapists as a central part of establishing a good therapeutic relationship. They also recognised that patients have a right to information about their condition and their treatment. Listening was seen as a crucial part of communication: a reason suggested for it happening so infrequently was that hospital days are usually structured for staff rather than patients. It was recognised that relatives needed help and support to take on and sustain the burden of care.

• REFERENCES •

1 Martin J, Meltzer H, Elliot D. The prevalence of disability among adults. OPCS surveys of disability in Great Britain. London: HMSO, 1980.

2 Dennis M, Warlow C. Strategy for stroke. BMJ 1991; 303:636–8.

3 Gordon J. Assumptions underlying physical therapy interventions: theoretical and historical perspectives. In: Carr J, Shepherd R, Gentile A, Held J, editors. Movement science foundation for physical therapy in rehabilitation. London: Heinemann, 1987: 1–30.

4 Brocklehurst J, Andrews K, Richards B, Laycock P. How much physical therapy for patients with stroke? Br Med J 1987; 1:1307–10.

5 Garroway W, Akhtar A, Prescott R, Hockey L. Management of acute stroke in the elderly: preliminary results of a controlled trial. Br Med J 1980; 280:1040–3.

6 Wade D, Wood V, Langton Hewer R. Recovery after stroke – the first three months. J Neurolog Neurosurg Psychiatry 1985;48:7–13.

7 Tinson D. How stroke patients spend their days. Int Disabil Studies 1989;11:45–9.

8 Ernst E. A review of stroke rehabilitation and physiotherapy. Stroke 1990; 25:1081–5.

9 Dombovy M, Sandock B, Basford J. Rehabilitation for stroke – a review. Stroke 1986; 17:363–9.

10 Ashburn A, Partridge C, De Souza L. Physiotherapy in the rehabilitation of stroke: a review. Clin Rehabil 1993; 4:337–6.

11 See 10.

12 Stroke Rehabilitation. Effective Health Care 1992; March, No.2, University of Leeds.

13 Partridge C J, Edwards M S, Johnston M. Recovery from physical disability after stroke: normal patterns as a basis for evaluation. The Lancet 1987; 14 February: 373–5.

14 Partridge C J, Edwards M S, Morris L. Recovery from physical disability after stroke: profiles for different levels of starting severity. Clinical Rehabilitation 1993; 7 210–17.

15 Bobath B. Adult hemiplegia: evaluation and treatment 3e. London: Heinemann, 1990.

16 Davies P M. Right in the middle. Berlin: Springer Verlag, 1990.

17 Price R D. Affective disorders after stroke. Stroke 1990; (suppl 11): 12–3.

18 Department of Health. The Patient's Charter. London: DoH, 1991.

19 Department of Health. Health of the Nation. London: HMSO, June 1991.

20 Partridge CJ, Johnston M. Perceived control and recovery from stroke. Br J Clinical Psychology 1987; 28:53–60.

EVALUATION OF PHYSIOTHERAPY FOR PEOPLE WITH STROKE

A workshop was held at the King's Fund Centre in November 1993 in which physiotherapists experienced in the treatment of neurological conditions took part to investigate the effectiveness of physiotherapy for people disabled by stroke.

This readable and comprehensive report provides details of the topics discussed, and reviews the key components related to aims of treatment which were identified during the workshop. It also contains appropriate dimensions for patient-centred service evaluation based on feedback from three focus groups exploring the opinions of people with stroke and their carers about the physiotherapy services they had received.

Both the methods used and the results obtained in each section will be of value to therapists, doctors and all health professionals with an interest in evaluating and improving services for people with stroke and their carers.

ISBN 1-85717-074-1

9 781857 170740 >