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WHO

REGIONAL OFFICE FOR EUROPE

MANAGEMENT AND REHABILITATION OF STROKE

Report on a WHO Consultation

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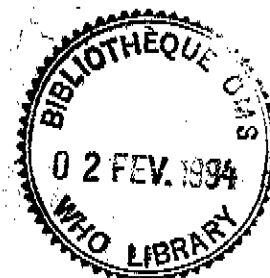

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1994

EUR/HFA target 9

TARGET 9
REDUCING CARDIOVASCULAR DISEASE

By the year 2000, mortality from diseases of the circulatory system should be reduced, in the case of people under 65 years by at least 15%, and there should be progress in improving the quality of life of all people suffering from cardiovascular disease

ABSTRACT

Stroke is a major burden of disease for health services, patients and families in all European countries. Reduction of this burden requires further strengthening of preventive activities and improvements in stroke management and rehabilitation. Standards of management and rehabilitation vary and it is likely that the best practice in centres of excellence has wider applications. Scientific evidence on effectiveness of best practice of acute care, early and late rehabilitation and secondary prevention provides clear support for the reorganization of stroke care. The key strategy is the establishment of local stroke services organized around inter-disciplinary teams and hospital stroke units. To make further progress in applying best practice more widely, it will be necessary to achieve a broad European consensus on the following: monitoring of quality of care; organization of stroke services; principles of acute stroke care; secondary prevention; and rehabilitation. A major conference to disseminate a European consensus statement on stroke management and rehabilitation is planned for 1995.

Keywords

CEREBROVASCULAR DISORDERS – prevent/control
CEREBOVASCULAR DISORDERS – rehabilitation
HEALTH STATUS INDICATORS
QUALITY ASSURANCE, HEALTH CARE
EUROPE

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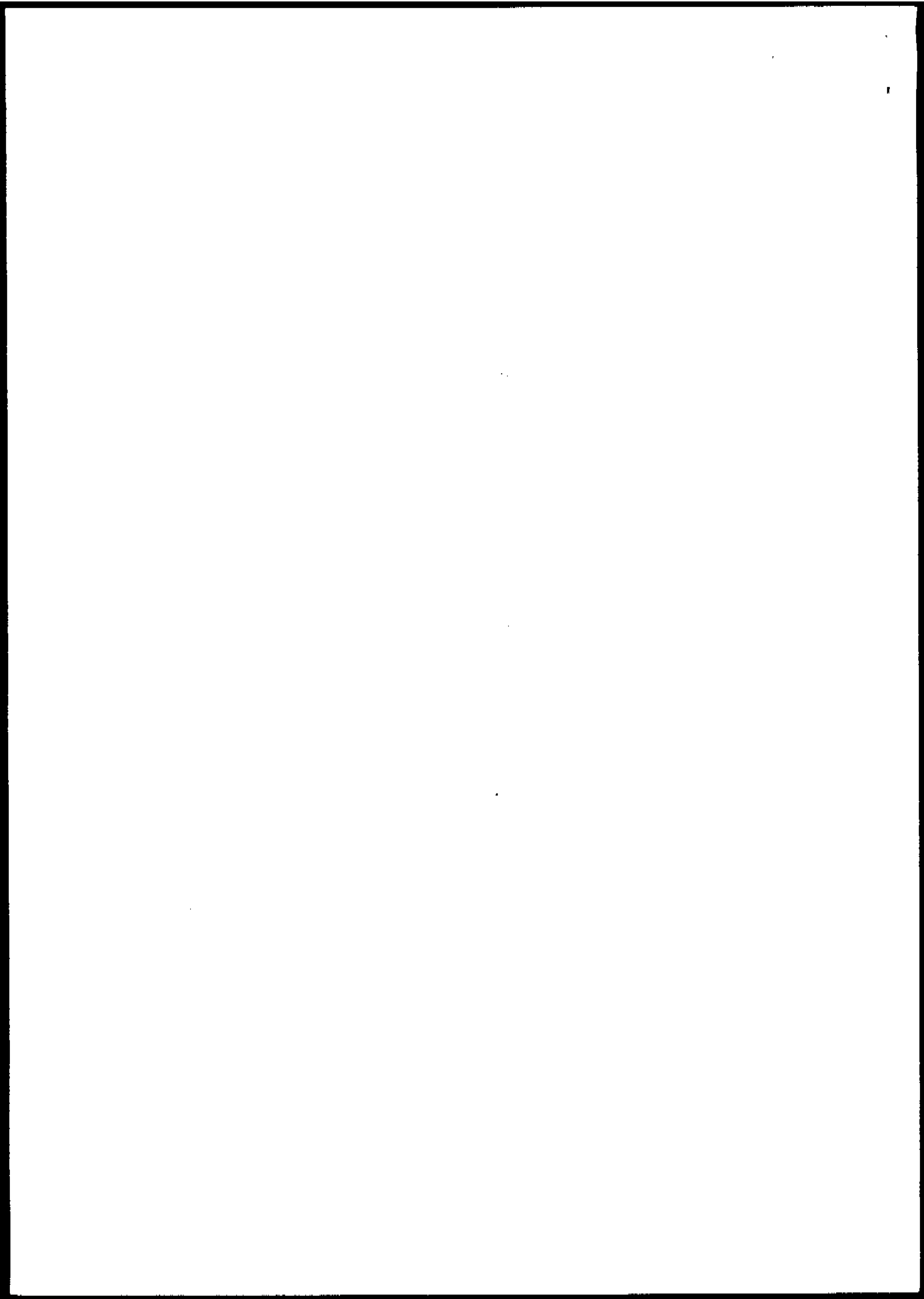

1. INTRODUCTION

Trends in stroke have shown a decline over the last few decades but stroke remains a very common and important cause of mortality and morbidity. The situation is in particular unfavourable in central and eastern European countries where mortality rates are about twice as high as in western European countries and these rates have increasing trends. There is no doubt that primary prevention has clear importance for reducing the burden of disease due to stroke. Therefore strengthening of preventive activities will remain a cornerstone in the further reduction of cerebrovascular mortality. However, there is compelling evidence that better stroke management and rehabilitation can reduce mortality and morbidity as well. In order to achieve better standards in stroke care in Europe a meeting on stroke management and rehabilitation was organized by the WHO Regional Office for Europe. The function of this meeting was to share knowledge about the best ways of managing acute care, secondary prevention and rehabilitation. Dr Asplund was elected as chairman of the meeting and Professor Ebrahim as rapporteur.

This consultation is one of a series aimed at developing a consensus about guidelines for stroke management and rehabilitation. The steps in this process include:

1.1 Description of current situation in countries of the European region.

1.2 Development of a short list of simple measures of structure, process and outcome of acute care, secondary prevention and rehabilitation services.

1.3 Production of a stroke database linking information on outcomes with structures and processes of care for comparative studies between and within countries.

1.4 Development of guidelines for stroke management based on scientific evidence of effectiveness, economic appraisal and experience gained from examination of the database.

1.5 Dissemination of consensus guidelines for local application.

1.6 Evaluation of impact of guidelines on structure, process and outcomes of stroke management.

2. STROKE: SOME BASIC FACTS

Stroke is a problem of elderly people. Demographic change in Europe will lead to a large increase in the very old who are at greatest risk of stroke. Older people are also more likely to suffer serious disability and have higher health care costs.

The age-specific stroke mortality is falling in western Europe. This may be explained by either a reduction in the severity of stroke (reduction in the ratio of cerebral haemorrhage to cerebral infarction) or improvements in medical care or by both factors. At the same time trends in most central and eastern European countries show substantial increases.

Case fatality varies dramatically between different countries and also within countries. Costs to society both direct and indirect are very large: e.g. stroke consumes more bed-days in

hospitals and nursing homes than any other somatic illness. However, there are very few cost-effectiveness analyses of options in stroke management to aid decision making.

Scientific evidence to support the effectiveness of organized stroke care provided in stroke units is well-established. There is also a reasonable consensus that rehabilitation is effective in the late phase of stroke although the evidence is weaker.

3. Stroke Management and Rehabilitation in Europe

There is major variation between eastern, central and western European countries in the organization and resources available for stroke care. This reflects current economic conditions, knowledge and belief about what can be done in stroke care.

Central and eastern European countries have major problems of access to neuroradiology and therefore cannot always make accurate diagnoses. The training of rehabilitation professions is deficient in many countries and there is a scarcity of well-trained staff. There are heavy demands on families in all countries, yet there are few attempts to support and train family carers.

There is a lack of comparable routine data on standards of care and stroke outcomes throughout Europe. This means that it is impossible to make comparisons between or within countries. Monitoring of changes in standards of care and outcomes is a basic requirement in achieving a consensus on the need for change. This data is also required for evaluating the impact of new strategies.

Improving stroke care cannot wait for economic change. It will be necessary to develop appropriate strategies that are locally applicable and will permit a long term plan of improvement to evolve.

4. Acute Management of Stroke

4.1 Goals

The goals of acute management are the reduction in mortality and morbidity from stroke complications (e.g. pressure sores, pulmonary embolus, infections) and the avoidance of institutional care.

4.2 Needs

A local stroke expert is required to lead the better management of stroke patients. The speciality background is of less importance than enthusiasm and a willingness to accept that something can be done for most patients. In many countries considerable investment in training and more resources for patient care will be required to attract and keep motivated staff.

There is no relationship between provision of high technology neuroradiology and clinical outcomes. However it is necessary to recognize the importance of managing patients to standards thought to be internationally appropriate.

The evaluation of the role of acute medical and surgical treatments has been conducted

mainly in western countries. However, findings from randomize controlled trials have not been widely disseminated in all central and eastern European countries. It will be necessary to make information on the lack of effectiveness of extracranial or intracranial vascular bypass surgery, acute phase carotid endarterectomy, craniotomy and medical treatments more widely available.

Further evaluation of the role of the hospital and early discharge schemes is required as it is possible that this will lead to cost savings and more effective rehabilitation.

4.3 Possibilities

Specific acute medical and surgical treatments should only be given as part of a randomized controlled trial. This would avoid inappropriate therapy and waste of scarce resources.

The use of standardized protocols and guidelines might help improve management by forcing more considered application of therapy and encouraging access to appropriate investigations. Diverting resources from other areas of health care (e.g. sports medicine in eastern Europe) might help in developing rehabilitation where little currently exists.

The discovery of an effective acute treatment for stroke will increase the demand for acute hospital care. Early discharge from hospital will become crucial if stroke services are to be provided within current resource limitations.

The primary health care doctor and nurse might be considered as a member of the multi-disciplinary team. It is highly unlikely that the management of complex disability due to stroke will ever be satisfactorily managed exclusively by primary health care teams.

4.4 Strategies

(a) Training of doctors, nurses and therapists in the principles of stroke care.

(b) Development of better access to facilities for acute stroke diagnosis and management, in particular stroke units.

(c) Encouragement of a team approach to care and better integration with early rehabilitation.

(d) Better communication and allocation of work between inpatient and outpatient sectors.

(e) Use of protocols or guidelines to aid appropriate investigation and management.

4.5 Assessment of the quality of acute care

Potentially useful indicators of quality of care:

Structure

(a) Number of Computer Tomography (CT) scanners
(b) Number of stroke specialist services
(c) Regular training courses in stroke

Process

(a) Proportion of patients randomized to acute treatment trials
(b) Proportion of patients managed according to protocol guidelines

Outcome

(a) Case-fatality at 28 days
(b) Number of avoidable complications (e.g. pressure sores, dehydration)
(c) Institutional care rate

5. EARLY REHABILITATION

Early rehabilitation for stroke is defined as the rehabilitation provided during the acute phase of the illness during the period of spontaneous recovery. This includes the first three to six months after the event. In European countries, the location of rehabilitation services varies, with some services being distant from acute hospitals. The concept of stroke units is also variable but can be taken to be a geographically defined in-patient unit that takes responsibility for all aspects of management from day one, is staffed by a multi-disciplinary team applying an eclectic and wide-ranging approach to therapies.

5.1 Goals

The purposes of rehabilitation include the improvement of quality of life and satisfaction, reduction in complications and achieving a patient's maximum capability for a normal life. Rehabilitation should be available to all stroke patients within acute care settings.

5.2 Needs

The major need is to apply existing knowledge on the effectiveness of organized stroke care in improving outcomes over the first year of a stroke. To ensure that routine stroke services achieve the potential gains it will be necessary for set up systems to monitor the processes and outcomes of care.

A standard, valid and reliable short list of outcome measures is needed. Outcome measures are useful for individual case management and in making aggregate comparisons of services to examine sources of variation. Comparisons might be between different types of service, between regions of a country or between countries.

The relationship between service inputs and outcomes in stroke is not well-understood. There is great concern that in observational studies, interpretation of variations in outcome will be confounded by aspects of case mix (i.e., severity of disease). A simple approach to this concern is to make routine assessment of stroke severity as well and to examine outcomes in strata of stroke severity. Simple methods of doing this include: conscious level, pre-stroke ability and admission Barthel Index score.

Problems associated with application of routine assessment of outcomes include the lack of understanding of the relationships between inputs and outcomes, the wide goals of rehabilitation that are not considered in summary simple indicators of outcome, differences between professionals in what is acceptable.

There is a need to describe the wide range of therapies currently provided for stroke patients. It is important to recognize that therapists have several characteristics: theoretical knowledge, skills (i.e. equivalent to handicraft), and talent. Any assessment of the effectiveness of therapies has to acknowledge these factors. This means that large multi-centre randomized controlled trials will be required to test effectiveness of techniques as this will reduce any bias produced by differences in the characteristics of therapists.

5.3 Possibilities

The possibility of achieving a consensus on outcomes is worth attempting to achieve. Consensus is aided by the new climate of openness, a willingness to make comparisons, and a desire to apply the best approaches to management more widely.

Total quality management for improving stroke care is popular in rehabilitation therapies. This approach assumes that the relationship between inputs and outcomes is well-understood. It is most relevant in improving those aspects of rehabilitation where evidence of effectiveness is strong and the major task is to apply what is known.

The shortage of rehabilitation therapists in most European countries is a major barrier to more widespread access to such services. Increases in training programmes of therapists only on rehabilitation skills may not be good value for money as this would inevitably increase health care costs without guarantee of better outcomes. It may be better to develop training packages which would target the work of therapists on education and training of nursing staff, informal carers and others rather than carrying out therapy independently.

5.4 Strategies

It is essential to attempt more widespread application of randomized controlled trials to evaluate specific contributions of different therapies. Continuing to use ineffective therapies is a waste of scarce resources.

Therapists tend to prefer qualitative methodologies and an emphasis on total quality management. Total quality management is particularly useful in achieving improvements in the application of effective treatments. Suitable areas for total quality management include the development of stroke units and the application of the general principles of stroke rehabilitation.

5.5 Assessment of the quality of care

This is a major challenge in stroke rehabilitation. The major determinant of poor outcomes is the severity of the stroke rather than the type of care given. Outcomes that are relatively independent of confounding by severity (i.e. case-mix) are needed to make simple comparisons between different services.

One way around this problem is to focus on aspects of the structure, process and outcome of care in areas where there is consensus. For example:

Structure:

(a) Number of stroke units
(b) Number of specialists in stroke medicine
(c) Number of therapists working in multi-disciplinary teams
(d) Number of training courses for stroke teams

Process:

(a) Proportion of patients managed in a stroke unit or by a multi- disciplinary team
(b) Proportion of patients with a statement of goals of therapy
(c) Proportion of patients with routine ADL assessments on admission and discharge
(d) Proportion having CT imaging
(e) Proportion autopsied
(f) Number of educational programmes for staff and relatives
(g) Proportion of patients randomized to treatment evaluation trials

Outcome:

(a) Proportion of patients with avoidable complications (e.g. pressure sores, sub-luxed shoulders, contractures)
(b) Mortality at 28-days and 3 months
(c) Place of discharge
(d) Functional ability at discharge
(e) Life satisfaction
(f) Costs of care per patient

6. LATE REHABILITATION

Late rehabilitation is not defined in terms of its content but in terms of its organization. In general, it is rehabilitation occurring after the spontaneous recovery phase (i.e. beyond three to six months) and is done in the community rather than the acute hospital.

6.1 Goals

The goals of late rehabilitation are concerned with reducing disability, avoiding complications, ensuring easy access to help and further therapy and with continuity of care.

6.2 Needs

The scientific evidence to support the effectiveness of late rehabilitation is limited. Clinical judgement suggests that any improvements occurring after the spontaneous recovery phase are more likely to be due to the effects of therapy than other factors. Further randomized controlled trials of the impact of specific types of late rehabilitation would be useful but are not the highest research priority. The need for rehabilitation late after stroke is apparent from long term follow up of survivors. At one year about 1 in 3 need help in the bathroom and lavatory, there is a reduction in the amount and range of social activity and families play a major role in providing direct support. More subtle types of impairment may go undetected (e.g. cognitive impairment, depression, co-morbidity) unless careful assessments are done. The health and quality of life of family careers is also of concern.

The selection of patients and determining how much and what type of therapy should be given are also areas where there is considerable uncertainty. It is possible that observational

study designs will give answers to these questions.

Assessment and monitoring tools are a major problem in the late stage of rehabilitation. Much of the concern is with reducing the disadvantage associated with stroke and this is influenced by many factors. The role of pre-stroke personality and adaptability to disability will have an influence on conventional measures of quality of life (e.g. Nottingham Health Profile) that is independent of any effects of therapy.

6.3 Possibilities

The basic principles of rehabilitation should be emphasized but application must be modified by local circumstances. These principles for individual patient management are assessment, setting goals, monitoring progress, re-setting goals. For services, the principles are easy access, comprehensiveness (i.e. acute, rehabilitation and prevention), and continuity.

In practice this may mean:

- first stage screening assessments (e.g. ADLs) conducted annually
- second stage professional assessments (e.g. balance, transfers)
- use of treatment contracts to permit clear targets and limits to treatment
- ensuring smooth transitions from acute rehabilitation to chronic care
- providing a single point of contact for advice and practical help
- more systematic research and development
- educational programmes for staff and families

6.4 Strategies

The first step is to establish effective early rehabilitation (see 5.4 above). Late rehabilitation can then evolve as part of a more comprehensive stroke service.

It will be necessary to organize some system of follow-up that will permit assessments to be conducted and target late rehabilitation where it will do most good.

6.5 Assessment of the quality of care

Potential indicators of the quality of care will include the following:

Structure

(a) Is there a system for follow-up?
(b) Do stroke patients have access to rehabilitation at home?

Process

(a) What proportion of patients are followed up each year?
(b) How much and what type of therapy is given?

Outcomes

(a) Proportion of patients in institutional care at one year
(b) Proportion of patients suffering from avoidable complications
(c) Patient and carer satisfaction

7. SECONDARY PREVENTION

Secondary prevention refers to the use of prophylactic methods of avoiding a recurrent stroke in those people with evidence of cardiovascular disease. The modalities involved include:

- accurate diagnosis of treatable causes of stroke (e.g. subacute bacterial endocarditis, hyperviscosity syndromes, vasculitis),
- modification of major cardiovascular risk factors,
- use of antiplatelet agents,
- anticoagulants and
- carotid artery surgery.

7.1 Goals

The goals of secondary prevention are to prevent recurrent stroke and thereby reduce the burden of disease.

7.2 Needs

There is considerable scientific evidence to guide action. The risk of recurrence of stroke is about 7% per year which is 15 times the expected stroke risk. After 3-4 years this excess recurrence rate falls to 3-4 times expected risks. This implies that stroke prevention must be timed relatively early if people at highest risk of recurrence are to be treated.

The major need is to apply existing knowledge more widely, increase the proportion of patients getting secondary prevention, and examine the reasons behind poor adherence to good practice amongst physicians.

A secondary need is to examine the cost-effectiveness of the various options to aid decision making and priorities for action. Cost-effectiveness will vary depending on the quality of and investment in existing services. For example, the marginal costs of a policy of anticoagulation for atrial fibrillation will be much lower in places where high quality services already exist.

7.3 Possibilities

Treatment of underlying diseases: this is done best in units where investigation of stroke is carried out systematically. While it has great benefit for individual patients, it has little population benefit because of the small numbers involved.

Modification of cardiovascular risk factors: the potential benefits of reducing high blood pressure, quitting smoking, and control of hypercholesterolaemia are potentially very large because of the substantial numbers of stroke survivors affected. Reduction of high blood pressure in the first few days after stroke is likely to be dangerous and should not be considered.

Use of anti-platelet agents: the evidence to support treatment with aspirin is very strong and it is estimated that in the UK the costs of preventing one stroke are around £900 which represents good value for money as treating a stroke costs between £3000-7000. This advantage is reduced dramatically by use of more expensive drugs such as ticlopidine.

Use of anticoagulants in patients with atrial fibrillation: this has limited applicability but will lead to a reduction in the total stroke burden of about 0.5% a year. However, poor

control will be associated with more complications and any advantage could be overwhelmed by costs of treating bleeding complications.

Carotid endarterectomy: this too has limited applicability and is highly depended on the quality of service. It takes about 12 operations to prevent one stroke and this represents a cost of about £30,000 per stroke prevented.

7.4 Strategies

There is good information on effectiveness for each of the possibilities listed above. However, an option appraisal based on cost-effectiveness in different countries would be very helpful.

At present in the majority of European countries it is essential to focus on the control of major cardiovascular risk factors and the use of anti-platelet agents as the major means of preventing recurrent stroke. These strategies appear to give good value for money and there is evidence that they are not well applied.

7.5 Assessment of the quality of care

Quality assessment in this area is straight forward because of the high quality of data on effectiveness of therapy.

Structure

(a) Availability of neuroradiology

Process

(a) Proportion of patients with a diagnosis
(b) Proportion of patients CT scanned
(c) Proportion of eligible patients treated with aspirin
(d) Proportion of inappropriate carotid artery investigations
(e) Proportion of inappropriate carotid endarterectomies

Outcome

(a) Stroke recurrence rate at one year
(b) Complications of prophylaxis

8. MAPPING STROKE MANAGEMENT IN EUROPE

Examining the current position in Europe would aid progress in achieving change . This is potentially a very labour intensive and expensive task so feasible methods will have to be adopted. The use of clinical scenarios sent to physicians in Europe was considered but problems of representativeness of respondents made this problematic.

8.1 Centres of excellence

An alternative strategy is to ask "centres of excellence" what they do in each participating country. In general these centres have established stroke databases and would be likely to respond to requests for information on the quality of their services. These centres of excellence will represent the best that can be achieved within the context of each country and will provide targets for other centres.

It may be possible to recruit centres through existing networks (e.g. International Stroke

Trial) and local knowledge. The dimensions determined by the working group on monitoring would be able to make up a short list of questions on structure, process and outcomes of care to apply to each centre together with a request for summary data. It was agreed that this should be attempted.

8.2 Quality initiatives

It was suggested that a network for the development of a shared database should be established and be coordinated by WHO because of their expertise in this work. Existing European collaborative database projects (e.g. EC Biomed funded work) will need to be contacted to suggest that they share their expertise and data with a wider European network. It was agreed that WHO would contact existing known database investigators to negotiate future collaboration.

9. SUMMARY OF PRIORITIES FOR IMPROVING STROKE MANAGEMENT

Although each country determines its own national and local priorities general principles listed below can be useful in aiding local improvements in standards of care.

It is necessary to consider priorities for both the long and short term. In the former case, the development of suitably trained professionals, the purchase of CT scanners and the allocation of more resources to stroke management are all desirable. However, in the current context of resource containment in health care it is necessary to focus on the improvements that can be achieved without increase in resources and changes that can be made in the short term.

The following principles can be recommended:

- Stroke services should be locally organized because needs, resources and organization are locally determined

- Priorities should be determined by evidence of effectiveness and value for money. Interventions of doubtful effectiveness should not be applied except in the context of randomized controlled trials.

- Organization of stroke services is the overriding priority and this implies the following:

  - coordinator and service leader
  - stroke service centered on a stroke unit
  - multidisciplinary team approach
  - use of aspirin for secondary prevention

- National and international networks, in particular support for the Cochrane Collaboration[a] which aims to disseminate information on effectiveness of treatment in a wide range of conditions, including stroke.

- Education programmes for staff (including exchange programmes as part of international

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[a] The Stroke Collaborative Review Group of the Cochrane Collaboration, Neurosciences Trials Unit, Department of Clinical Neurosciences, Western General Hospital, Edinburgh EH4 2XU, United Kingdom.

networks) and families of stroke patients.

10. THE NEXT STEPS

The aim of this collaboration is to develop a concerted European action on improving stroke management. This will require a series of actions:

10.1 Working groups

The improvement of stroke management requires consensus to be reached on the following topics:

- Monitoring of the quality of care
- Organization of stroke services
- Principles of acute stroke care
- Secondary prevention
- Rehabilitation

This will be done by the election of a working group leader from the participants of this meeting. The leaders will be responsible for bringing together collaborators from a range of disciplines and countries to write a short outline of the areas of consensus on policy that should be adopted in the above-mentioned five areas and highlighting any areas of major disagreement. Help will be provided by WHO Europe in identifying suitable collaborators. It is not intended that working groups will meet but that communication will be by circulation of drafts and telephone discussions.

10.2 Follow up meetings

A follow up meeting will be held in Spring 1994 to discuss the consensus documents produced by each of the working groups. The purpose of this meeting is to ensure that all key issues have been covered and to make final decisions about the inclusion of consensus topics. It is accepted that some working groups may find it impossible to reach a clear consensus at this stage.

A further task will be the detailed planning of the consensus conference.

10.3 Consensus conference

This will be held in summer 1995 and will comprise delegates from the Ministries of Health of European countries, stroke associations in European countries, experts in stroke. It is expected that around 200 people will attend. The major reason for holding a conference is to get relevant groups to put effort into improving stroke care, raise awareness of the issues involved and to demonstrate that it is possible to make improvements by defining a well-documented problem, applying well-documented solutions and achieving change through applying limited goals, undisputable evidence, clear and feasible targets and not exceeding existing resources.

It will be necessary to find sources of funding for this conference although WHO would undertake efforts to cover part of the costs.

10.4 Dissemination of the collaboration

The work currently underway requires dissemination to ensure that professionals and stroke groups throughout Europe are informed and can contribute to the collaboration. It was agreed that the report of this meeting would be submitted for publication in Cerebrovascular Diseases Journal and that a short note of the meeting would be submitted to the Lancet and other relevant journals.

Annex 1

LIST OF WORKING PAPERS

Dr K. Asplund	Pan of actions to improve stroke care in European countries
Dr M. Dennis	Secondary Prevention of Stroke - UK Perspective
Professor S. Ebrahim	How to monitor and assess stroke care and rehabilitation
Professor G. Enina	Proposal for a National Stroke Prevention and Control Programme for Latvia
Dr I. Henriques	Goals and priority actions to improve stroke care in Europe - examples from two countries, Switzerland and Portugal
Ms B. Ireland	Priority areas and actions to improve the quality of stroke care in Europe
Professor M. Kaste	Early and late rehabilitation. Current approaches. Assessment of the quality of the outcome
Dr J. Mosbech	Current trends in stroke in Europe
Professor P.Traubner	Practices of stroke care and rehabilitation in Slovakia. Indicators of quality of care
Ms E. Wahrens	Quality assurance development of occupational therapy treatment of CVA-patients
Professor D. Zemaitytė	Stroke care and rehabilitation practice in Lithuania

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