

COORDINATED STROKE STRATEGY

Stroke Rehabilitation Consensus Panel Report

Submitted to the
Heart and Stroke Foundation of Ontario
May 2000



STROKE REHABILITATION CONSENSUS PANEL REPORT

Submitted to the
Stroke Strategy Steering Committee
Heart and Stroke Foundation of Ontario

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The Panel acknowledges the valuable contribution made by Dr. Louise Lemieux-Charles of the Hospital Management Research Unit, University of Toronto. Dr. Lemieux-Charles provided expert assistance designing and facilitating a process to enable each member to participate collaboratively in reviewing the current system of stroke rehabilitation in Ontario.

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Joann Trypuc undertook the challenging task of preparing the final draft of the report. The Panel appreciates her contribution, and the expertise and skill she brought to the task.

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Canadian Association of Rehabilitation Professionals
Canadian Health Services Research Foundation
Canadian Paraplegic Association (Ontario)
Canadian Public Health Association
Cancer Care Ontario
Care Delivery Network Program
Centre for Addiction and Mental Health (Clarke Division)
Central West Health Planning Information Network
District Health Councils in Ontario
Health-South Rehabilitation Institute of San Antonio (RIOSAs)
Health Services Restructuring Commission
Institute for Work and Health

McGill University, School of Physical & Occupational Therapy
McMaster University, School of Rehabilitation Science
Ontario Association of Community Care Access Centres
Ontario Association of Non-Profit Homes and Services for Seniors
Ontario Association of Speech-Language Pathologists and Audiologists
Ontario Community Support Association
Ontario Council of University Programs in Rehabilitation Sciences
Ontario Gerontology Association
Ontario Home Health Care Providers Association
Ontario Hospital Association
Ontario March of Dimes
Ontario Medical Association
Ontario Nursing Home Association
Ontario Physiotherapy Association
Ontario Society of Occupational Therapists
Regional Geriatric Programs in Ontario
Registered Nurses' Association of Ontario
Registered Practical Nurses' Association of Ontario
ReliaStar Life Insurance Company
Saint Elizabeth Health Care
Stroke Recovery Association of Ontario
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Victorian Order of Nurses (Ontario)

EXECUTIVE SUMMARY

Stroke rehabilitation is one of the key components of the spectrum of stroke care. When a person survives a stroke, rehabilitation is a critical enabler that helps survivors maximize their quality of life physically, cognitively, emotionally and socially. The Heart and Stroke Foundation of Ontario estimates that there are 15,000 to 20,000 strokes a year in Ontario. Although it is reasonable to conclude that many people who suffer a stroke will require some rehabilitation, it is unclear how much is actually needed. The level of neurological impairment, disability and handicap of stroke survivors varies considerably, as does the length and intensity of rehabilitation that they require.

Although the economic and human costs of stroke are considerable, currently Ontario stroke survivors, their families and health professionals do not benefit from a well-organized, well-designed, high quality system that provides effective stroke rehabilitation to reduce disability and handicap. Such a system of stroke rehabilitation in Ontario is critically important to ensure that:

- The right intensity of stroke rehabilitation is given at the right time so that the abilities damaged by stroke are improved and maintained.
- The changing needs of stroke survivors are monitored and services adapted to meet these changing needs.
- Health care providers and other community agencies work as partners so that stroke rehabilitation is provided in an integrated fashion.
- Rehabilitation is based on the most up-to-date evidence and research, and uses the most effective techniques and approaches.

Consensus Panel on Stroke Rehabilitation

The Heart and Stroke Foundation of Ontario (HSFO), in consultation with the Ministry of Health and Long-Term Care (MOHLTC), established a consensus panel on stroke rehabilitation in 1999. In addition to defining stroke and stroke rehabilitation, describing the current system and the need for stroke rehabilitation, and identifying system barriers, the Panel was charged with summarizing what experts currently recommend in stroke rehabilitation based on best evidence, designing a system for stroke rehabilitation, and proposing ways to close gaps in the provision of stroke rehabilitation.

An extensive literature and data review, an evaluation of the research using a levels of evidence framework, and input from stroke survivors, their families and professional caregivers informed the Panel's discussions and conclusions. The Panel believes that its vision and recommendations for a system of stroke rehabilitation will position the province to meet the needs for stroke rehabilitation in the future.

Definitions

The Panel defined stroke as:

An acute neurologic dysfunction of vascular origin with sudden or at least rapid occurrence of symptoms and signs corresponding to the involvement of focal areas in the brain. Focal brain injury arising from vascular neck trauma is included but acquired traumatic injury to the brain is excluded. Also excluded from this definition are syncopes of cardiac or other origin, diffuse brain injury due to inflammation, infection, subarachnoid hemorrhage, anoxia, and cardiac arrest. This definition is reflected by CMG 13 (excluding 772.1 and 772.2).

Stroke rehabilitation was defined as:

A progressive, dynamic, goal-oriented process aimed at enabling a person with an impairment to reach his or her optimal physical, cognitive, emotional, communicative and/or social functional level.

It is multidimensional consisting of prevention and treatment of medical complications, restoration of maximal independent functioning, facilitation of psychosocial coping and adaptation by the patient and family, promotion of community reintegration and enhancement of quality of life for stroke survivors (adapted from Roth et al., 1998).

Stroke rehabilitation relies on both remedial interventions designed to reduce neurological deficits and teaching compensatory techniques to enhance functional independence in the presence of neurologic impairment (adapted from Roth et al., 1998).

Expert Advice Based On Research Evidence

Over 600 articles from the literature and rehabilitation data were reviewed, and their relative importance and contribution to the field of stroke rehabilitation were assessed using a levels of evidence framework. The Panel concluded that:

1. Clinicians experienced in stroke should carry out the initial assessment.
 2. There should be access to specialized, interdisciplinary stroke rehabilitation.
 3. Stroke survivors should have access to different levels of rehabilitation intensity.
 4. Caregivers should have stroke rehabilitation support.
 5. Long-term rehabilitation services should be widely available in nursing facilities, complex continuing care facilities, and in outpatient and community programs.
 6. Strategies should be developed to prevent the recurrence of stroke.
 7. Outcome data are required for stroke rehabilitation.
-

A System for Stroke Rehabilitation in Ontario

The Panel's vision for stroke rehabilitation is:

Individuals who experience a stroke will have timely access to the appropriate intensity and duration of rehabilitation services. These services will be provided in a comprehensive and coordinated way to patients and families, by agencies and health care providers who are expert in stroke care and practise rehabilitation principles.

Guiding Principles

The following principles guided the Panel's development of a stroke rehabilitation system for Ontario:

1. Stroke rehabilitation will be client-centred and will meet the diverse and changing needs of stroke survivors and their families.
 2. Stroke survivors will have their rehabilitation potential assessed by experts, and will have timely and appropriate access to stroke rehabilitation expertise throughout the care continuum. This access includes re-accessing stroke rehabilitation if and when the need arises.
 3. Stroke rehabilitation expertise will be demonstrated formally through certification or informally through recognized clinical leadership in the community. Expertise will be maintained and enhanced by using rehabilitation principles, continuously working with stroke survivors, and engaging in continuing education. Consolidating stroke patients in each setting along the continuum of recovery helps to strengthen the development of rehabilitation expertise.
 4. Stroke rehabilitation will incorporate high quality, accurate and timely information, and information management.
 5. New technologies such as telehealth will be used to support rehabilitation consultation, education, and service to rural, northern and remote communities.
 6. Stroke rehabilitation will be research and evidence-based.
 7. Stroke rehabilitation will be supported with a sufficient number of appropriately trained health care providers (e.g., physicians, nurses, therapists, and assistants).
-

Development of Regional Stroke Rehabilitation Systems

The Panel's vision for stroke rehabilitation emphasizes accessibility to quality care that is provided in a coordinated manner that puts the stroke survivor at the centre of service delivery. The Panel believes that this vision can only be achieved with the development of regional stroke rehabilitation systems that are linked to broader stroke networks and regional rehabilitation networks. This will ensure a collaborative approach that is consistent with the Panel's vision for stroke rehabilitation.

Regional stroke rehabilitation systems will be made up of three components:

- Regional centres that have patient care, education and research responsibilities in stroke rehabilitation.
- Local inpatient units that are sited in selected hospitals in each regional system and linked with a regional centre.
- Community-based rehabilitation that maintains and builds on the gains a stroke-survivor has made while receiving hospital-based rehabilitation.

Regional stroke rehabilitation systems have a number of important benefits. A regional system approach will help support a collaborative approach to stroke rehabilitation, where services are coordinated and integrated from the acute phase of stroke to all levels of stroke rehabilitation, as well as primary and secondary prevention programs. In addition, a regional system approach will help ensure equitable access to a broad range of stroke rehabilitation services throughout the province. It will also help consolidate stroke rehabilitation expertise and resources.

It is recognized that regional stroke rehabilitation systems will build on and improve current services. The development of these systems is a shared partnership between hospitals, community care access centres, other health care organizations, agencies and providers, the Heart and Stroke Foundation of Ontario, and the MOHLTC.

Components of the Continuum

Inpatient Beds

A regional stroke rehabilitation system must have sufficient inpatient resources to meet the needs of the population. These inpatient resources include:

- beds for low intensity-long duration rehabilitation;
- beds for high intensity-short duration rehabilitation; and
- beds for highly specialized and complex rehabilitation.

The Panel recommends that hospitals with rehabilitation beds establish dedicated stroke units that include both short and long-duration stroke rehabilitation beds. The regional stroke rehabilitation systems should monitor the demand for and use of these beds to determine appropriate benchmarks that will ensure access for stroke patients.

It is recognized that regional rehabilitation facilities provide highly specialized regional and long-term local services. They are important regional resources with a valuable role to play in clinical service, education, research and outreach that goes beyond their local community to the broader region. The Panel recommends that the MOHLTC recognize that stroke rehabilitation includes a broad range of conditions, some of which require highly specialized services, and that the specialized component of stroke rehabilitation be reflected in regional bed allocations in the regional rehabilitation facilities.

Ambulatory and Home-based Stroke Rehabilitation

Ambulatory and home-based rehabilitation plays an important role in the continuum of rehabilitation services. With an increasing emphasis on transferring stroke survivors from inpatient hospital care to ambulatory and home-based rehabilitation, the demand for these services must be assessed. The Panel recommends that the regional stroke systems monitor waiting lists and other indicators of need for ambulatory and home-based stroke rehabilitation, to determine the reinvestments required to meet regional needs, and to recommend to the MOHLTC the resources that should be allocated to meet these needs.

The Panel also believes that best practices for home-based stroke rehabilitation must be identified so that both patients and family members benefit. It is recommended that the MOHLTC fund pilot projects to identify best practices for home-based stroke rehabilitation. These pilot projects should examine best practices in a range of settings, including urban, rural, northern and remote locations.

Supporting Mechanisms

The Panel recommends a number of mechanisms to support the regional stroke rehabilitation system. These include:

Mechanisms to Coordinate Care Across the Continuum

Good transition management can make a big difference in what stroke survivors and their families experience as they move along the continuum of stroke rehabilitation. Integrating care across the continuum requires a coordinated effort by all partners as well as investments in time, staff and funding. It is recommended that hospitals, community care access centres and other health care providers work in partnership to improve the coordination of stroke rehabilitation, especially in the transition from hospital to community-based care. The MOHLTC should consider providing resources to support these initiatives. It is further recommended that these partners develop guidelines for stroke rehabilitation, including care pathways across organizations, paying special attention to hand-off points so that a seamless continuum of care is created. An important enabler of these activities is an objective assessment tool for stroke rehabilitation that is used throughout the province. It is recommended that the MOHLTC mandate the provincial use of an objective assessment tool(s) for stroke rehabilitation based on a modified Functional Independence Measure. This tool(s) should be used by stroke rehabilitation providers across the continuum to ensure reliable, standardized and comprehensive assessments.

Information

The importance of establishing a stroke rehabilitation information system to monitor the provision of stroke rehabilitation is recognized in the Panel's recommendation to the MOHLTC to support the development of a stroke rehabilitation information system to monitor the provision of stroke rehabilitation. This system should include a data set based on the conceptual framework of the International Classification of Impairments, Disabilities and Handicaps, and a modified Functional Independence Measure.

Professional Support

Professional caregivers that provide stroke rehabilitation must have the appropriate education to ensure that stroke survivors receive appropriate and effective care based on the most up-to-date knowledge and research. Professionals with specialized stroke rehabilitation expertise have a valuable role to play consulting with other providers in the regional stroke rehabilitation system. Recognizing the important role of outreach, the Panel recommends that regional centres and local units provide outreach services to support the education of professional caregivers and enhanced consultations throughout regional stroke rehabilitation systems. The MOHLTC should endeavour to support these outreach activities.

Research

Effective stroke rehabilitation is based on the most up-to-date applied research. The Panel recommends that the MOHLTC and HSFO fund stroke rehabilitation research, with Ontario's Academic Health Science Centres playing a role in coordinating the research agenda. In addition, the MOHLTC and the HSFO should jointly support an ongoing program to review and summarize the evidence of stroke rehabilitation research, with the purpose of maintaining timely and accurate information on effective stroke rehabilitation, identifying areas for further research, supporting continuous peer review, and encouraging improved evidence-based practice.

Human Resources

A comprehensive and effective system for stroke rehabilitation is only possible if there is a sufficient number of appropriate stroke rehabilitation caregivers (e.g., physicians, nurses, therapists and assistants). In addition to regional human resource plans, there must be an overarching provincial plan. The Panel recommends that the MOHLTC, in partnership with the health care field, develop a provincial human resources plan that will ensure the education of a sufficient number of appropriate stroke rehabilitation caregivers to support the vision and recommendations of this report.

Future Work

Over the course of its work on stroke rehabilitation, the Panel recognized the importance of community reintegration and the wide range of support services needed by stroke survivors and their families. The Panel concluded that a review of community reintegration needs to be conducted, and recommended that HSFO establish a Consensus Panel with the participation of the MOHLTC to: 1) develop models for addressing community integration, including the psychosocial and practical needs of stroke survivors and their families, and 2) identify the role of the HSFO, MOHLTC, and other key institutions and organizations in assisting communities to eliminate barriers, support community reintegration, and develop effective strategies to meet the needs of stroke survivors.

The Panel recognizes that although a great deal has been accomplished in stroke rehabilitation, a great deal remains to be done. It concludes with the recommendation that HSFO continue to play an advocacy role linked to other organizations and initiatives like the Canadian Stroke Network.



COORDINATED STROKE STRATEGY



1 INTRODUCTION



- Economic and human costs of stroke are considerable
 - Current system needs to be improved
 - Panel formed to summarize best advice and design a system
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BACKGROUND

Stroke rehabilitation is one of the key components of the spectrum of stroke care. When a person survives a stroke, rehabilitation is a critical enabler that helps survivors maximize their quality of life physically, cognitively, emotionally and socially.

The Heart and Stroke Foundation of Ontario estimates that there are 15,000 to 20,000 strokes a year in Ontario. The extent to which stroke rehabilitation is needed by these individuals is unclear. The National Population Health Survey indicated that 88,000 Ontarians reported living in the community with the effects of stroke (1996/97).¹ In addition, about 22% of institutionalized adults 65 years of age or older have had a stroke.² Although it is reasonable to conclude that many people who suffer a stroke will require some rehabilitation, it is unclear how much is actually needed. The level of neurological impairment, disability and handicap of stroke survivors varies considerably, as does the length and intensity of rehabilitation that they require.

The economic and human costs of stroke are considerable. Ontario spends over \$500 million annually on stroke rehabilitation. Persons with a primary diagnosis of stroke make up the largest category of patients in rehabilitation – both facility and home care – and have the third longest length of stay in rehabilitation after spinal cord and brain dysfunction (Canadian Institute for Health Information, 1999). The estimated direct and indirect costs of stroke to the Ontario economy range from \$718.5-\$964.0 million a year (Chan and Hayes, 1998).³ As for the human costs, many stroke survivors experience physical and cognitive impairments, they may face restrictions in their activities of everyday living, and they struggle with emotional, psychological and social issues as a result of being stroke survivors. Unpaid caregivers such as family members or friends may also experience psychological, emotional and economic consequences of providing care to stroke survivors.

Research evidence indicates that stroke rehabilitation benefits stroke survivors. In fact, basic neurosciences research suggests that the brain's capacity to respond to injury is greater than previously thought (Dombrov, 1991). The potential for stroke survivors to achieve optimal functioning is becoming more promising. The question is, however, does Ontario have a stroke rehabilitation system that will support stroke survivors to achieve their potential?

Currently in Ontario, stroke survivors, their families and health professionals do not benefit from a well-organized, well-designed, high quality system that provides effective stroke rehabilitation to reduce disability and handicap. There are a number of excellent regional efforts in stroke rehabilitation in Ontario, however, improvements need to be made to ensure the following:

- Equitable access to interdisciplinary stroke rehabilitation so that stroke survivors who need rehabilitation have access to it (this is of particular concern in rural, northern and remote areas of the province).
- Appropriate access to stroke rehabilitation where care is timely and of the appropriate intensity and/or duration.

1 Statistics Canada, 1999.

2 Statistics Canada, Oct. 27, 1995.

3 Direct costs were estimated to be approximately \$528.7 million, and included such things as acute care, emergency health services and drugs. Indirect costs were estimated to range from \$244.5-\$375.8 million, and included such things as lost productivity and pensions.

- Coordinated care where stroke survivors move smoothly through the continuum as their care needs change.
- Up-to-date, evidence-based statements that describe effective stroke rehabilitation.
- Routine information on the extent to which stroke rehabilitation is reducing functional disability and handicap.

A well designed, comprehensive, seamless and coordinated system of stroke rehabilitation in Ontario is critically important to ensure that:

- The right intensity of stroke rehabilitation is given at the right time so that the abilities damaged by stroke are improved and maintained.
- The changing needs of stroke survivors are monitored and services adapted to meet these changing needs.
- Health care providers and other community agencies work as partners so that stroke rehabilitation is provided in an integrated fashion.
- Rehabilitation is based on the most up-to-date evidence and research, and uses the most effective techniques and approaches.

CONSENSUS PANEL ON STROKE REHABILITATION⁴

Over the past five years, the Heart and Stroke Foundation of Ontario (HSFO) has helped develop an organized approach to the primary prevention of stroke and the emergency management of stroke. The HSFO determined that a similar systematic approach to rehabilitation was needed.⁵ The HSFO, in consultation with the Ministry of Health and Long-Term Care (MOHLTC), established a consensus panel on stroke rehabilitation in 1999. The Panel included representatives of the MOHLTC, the HSFO and key stakeholders from across the province representing consumers, providers of health care and health insurance, planners and researchers.

The terms of reference of the Panel were to:

- define stroke and stroke rehabilitation;
- describe the current system (public, private, regional, provincial, rural, northern, care provided by families) and identify system barriers;
- describe the need for stroke rehabilitation (individual/population);
- summarize what experts currently recommend in stroke rehabilitation based on best evidence;
- design a system for stroke rehabilitation (planning principles, system evaluation, performance outcomes and indicators); and
- propose ways to close gaps in the provision of stroke rehabilitation, including in rural and northern Ontario.

⁴ See Appendix 1 for the terms of reference of the Consensus Panel. The Panel met six times between October 1999 and March 31, 2000.

⁵ See Appendix 2.

OVERVIEW OF THE REPORT

This report presents the observations, conclusions and recommendations of the Consensus Panel on Stroke Rehabilitation. Chapter 2 presents the methods used to collect and assess background information. Chapter 3 presents the definitions of stroke, stroke rehabilitation and other terms. Chapter 4 presents expert advice based on a comprehensive review and assessment of stroke rehabilitation research and data. Chapter 5 presents an environmental scan of stroke rehabilitation in Ontario including data, research and reports, and observations of the current system. Chapter 6 presents the vision, guiding principles and key features of an Ontario system of stroke rehabilitation. The reader is encouraged to refer to the appendices of the report, which present a wide-range of background information developed for the Panel.



COORDINATED STROKE STRATEGY

2 METHODS



HEART
AND STROKE
FOUNDATION
OF ONTARIO

- Over 600 articles were reviewed for Panel's work
 - Input sought from stroke survivors and families
-

The Panel conducted a literature and data review, as well as an evaluation of the research using a levels of evidence framework. The results of these activities were used to inform the Panel's discussions and conclusions.

LITERATURE AND DATA REVIEW

Literature Review

International, national and provincial developments in stroke rehabilitation were reviewed by the Panel. General background literature was compiled through a search of stroke rehabilitation using PubMed, Citations to Nursing and Allied Health Literature (CINAHL), HealthSTAR, and the ACP Journal Club. Miscellaneous web sites were identified and reviewed for useful information. Where valuable information was supported by specific references, these articles were obtained and their references reviewed. *The Canadian Journal of Rehabilitation* was searched and organizations in Ontario were asked for references to relevant provincial background material and reports. A notable report was *Stroke Care in Ontario: Hospital Survey Results* (Tu and Porter, 1999)

Generally, the literature demonstrated that stroke rehabilitation has received a fair amount of attention internationally. For example, the World Health Organization, the European Community and Australia have published visions of a systematic approach to stroke rehabilitation. The United States Agency for Health Care Policy and Research completed a comprehensive review of the evidence on the benefits of stroke rehabilitation in 1995. New evidence of effective rehabilitation is coming from advanced techniques in comparing and summarizing the published research literature (Jadad, 1998). It is also evident that Ontario's skill in research transfer is developing (Sibbald and Kossuth, 1998). See Appendix 3 for a review of the international environment for stroke rehabilitation.

Data Review

St. Elizabeth Health Care, the Toronto Community Care Access Centre (CCAC), and the Lanark, Leeds and Grenville CCAC provided information on the number of stroke patients admitted to their services. In addition, the CCACs quantified the number of services provided over several years.

The Institute for Clinical Evaluative Sciences provided information on stroke hospital admissions and discharges, discharge destination, length of stay and mortality using data from the Canadian Institute for Health Information.

The Panel developed five stroke case descriptions - severe young stroke, severe older stroke, older moderate stroke, older small stroke, and mild stroke not requiring hospitalization. These cases were used in a workshop to identify the ideal rehabilitation scenario in each case. Members' experiences were then used to identify the gaps between the ideal rehabilitation scenario and the current system.

A brief survey for stroke survivors and caregivers was prepared to obtain views from the community. The Stroke Recovery Association of Ontario circulated the survey to its members. The York-Durham Aphasia Centre modified the survey and distributed it to its clients. The HSFO also circulated the survey to the local coordinators in its *Living with Stroke* program.

LEVELS OF EVIDENCE REVIEW

A review of the research literature and an assessment of the findings were conducted using a levels of evidence framework. The Panel established an Evidence Review Subgroup led by Dr. R. Teasell, which included Dr. Stephen Bagg, Dr. Sandra Black, Sharon Jankowski, Dr. Moira Kapral, Dr. Shawn Marshall and Anne Wells. The subgroup reviewed a detailed report on the evidence with references, the Panel reviewed a summary of the evidence, and Dr. Teasell formulated major system level recommendations for discussion by the Panel.

The Panel reviewed over 600 articles from the literature review as well as assessed the data that were collected. Although attempts were made to be as comprehensive as possible, due to the fact that the area is so broad the evidence review is incomplete in several areas.

The levels of evidence framework used by the Panel was taken from the Report by the Health Information Partnership, Eastern Ontario Region/Queen's University (Purdue et al., 1998). This report used the same levels of evidence as the United States Agency for Health Care Policy and Research in Post-Stroke Rehabilitation (Gresham et al., 1995).

The levels of evidence used by the Panel were:

- Level 1a or Strong: Supported by the results of two or more randomized controlled trials (RCT) or by a meta-analysis.
- Level 1b or Moderate: Supported by a single RCT or by two or more non-randomized analytic studies (case control or cohort studies).
- Level 2 or Limited: Supported by a single cohort or case-control study, by studies using quasi-experimental designs such as pre- and post-treatment comparisons.
- Level 3 or Consensus: Supported by a consensus statement from a panel of experts. This level implies no available evidence.

Where it was difficult to apply the levels of evidence, particularly for non-interventional research, the most applicable level was chosen.

The Panel selected definitions for stroke, stroke rehabilitation and other terms that were determined to be relevant to its work.



COORDINATED STROKE STRATEGY

3

DEFINITIONS



Stroke rehabilitation is a progressive, dynamic, goal-oriented process aimed at enabling a person with an impairment to reach his or her optimal physical, cognitive, emotional, communicative and/or social functional level.

STROKE

The Panel reviewed several definitions of stroke (Bamford, 1992; Malmgren et al., 1987; World Health Organization, 1989). A modified version of the WHO definition of stroke in adults and young adults was selected:

Stroke is an acute neurologic dysfunction of vascular origin with sudden or at least rapid occurrence of symptoms and signs corresponding to the involvement of focal areas in the brain. Focal brain injury arising from vascular neck trauma is included but acquired traumatic injury to the brain is excluded. Also excluded from this definition are syncopes of cardiac or other origin, diffuse brain injury due to inflammation, infection, subarachnoid hemorrhage, anoxia, and cardiac arrest. This definition is reflected by CMG 13 (excluding 772.1 and 772.2).

It was recognized that stroke in children is an important area that needed to be addressed. However, this subject could not be given the same attention as adult stroke due to the Panel's membership.

It was also recognized that the definition of stroke used by the Panel had to be relatively similar to other definitions in use so that comparisons could be made of management, performance and outcomes between different health care systems around the world (Malmgren et al., 1987). Variations in health systems have the potential to provide valuable insights into the relationship between stroke management and outcomes (Wolfe et al., 1999).

STROKE REHABILITATION

The Panel reviewed a number of definitions of rehabilitation, cardiac rehabilitation and stroke rehabilitation.⁶ The definitions used by the Peel District Health Council (1997), the Institute for Work and Health (Holyoke and Elkan, 1995), the OHA Rehabilitation Task Group (1999) and Roth et al. (1998) were adapted, and the final definition used by the Panel for stroke rehabilitation was:

Stroke rehabilitation is a progressive, dynamic, goal-oriented process aimed at enabling a person with an impairment to reach his or her optimal physical, cognitive, emotional, communicative and/or social functional level.

It is multidimensional consisting of prevention and treatment of medical complications, restoration of maximal independent functioning, facilitation of psychosocial coping and adaptation by the patient and family, promotion of community reintegration and enhancement of quality of life for stroke survivors (adapted from Roth et al., 1998).

⁶ Definitions of rehabilitation: Institute for Work and Health (IWH) Phase 1 Report on rehabilitation in Ontario (Holyoke and Elkan, 1995); Ontario Ministry of Health (1993); World Health Organization (1983); Canadian Paraplegic Association (1999); Ontario Council of University Programs in Rehabilitation Sciences (1999); Peel District Health Council (1997).

Definitions of cardiac rehabilitation: the Cardiac Care Network of Ontario (Consensus Panel, 1999); the section on "adult stroke" from the OHA Rehabilitation Program Definitions (Rehabilitation Program Definitions Task Group, 1999).

Definitions of stroke rehabilitation: Gresham et al. (1995); Roth et al. (1998); the Joint Committee for Stroke Facilities (1972); Reddy and Reddy (1997); WHO (1989).

Stroke rehabilitation relies on both remedial interventions designed to reduce neurological deficits and teaching compensatory techniques to enhance functional independence in the presence of neurologic impairment (adapted from Roth et al., 1998).

Stroke rehabilitation must be timed to respond to biological recovery as well as the inherent adaptive capacity of individuals and families. It requires a coordinated, skilled, and sensitive effort by many people over time. Given the basic mechanisms underlying later recovery (see Appendix 4), optimal recovery seems “to be dependent to a large degree on patient motivation, ability to learn, and the guidance of trained rehabilitation staff” (Heitzner and Teasell, 1998: 399).

Traditionally, rehabilitation has focused on inpatient care with the overall goal being to return the patient home. In this instance, the purpose of rehabilitation is to maximise recovery in the biological time available after stroke through intensive efforts to help the patient reach his or her highest level of function. From this traditional perspective, once recovery has plateaued, stroke rehabilitation has come to an end. Determining when this end point has been reached can be confounded by factors that are unrelated to the patient’s biological potential or personal choice (e.g., patient motivation, transportation and program barriers).

The traditional paradigm for all rehabilitation is in evolution (Kilgore, 1995). There is a need to investigate the intensity and setting of rehabilitation for stroke survivors who have varying types and severities of impairment. There is also a need to investigate the long-term benefits of stroke rehabilitation and the requirements for, and benefits of, “maintenance therapies” and “slow stream” or low intensity long-term rehabilitation.

OTHER TERMS

Impairment, Disability and Handicap

The World Health Organization (WHO) provides a separate classification system for the disability associated with health conditions listed in the International Classification of Diseases, Tenth Revision (WHO, 1980). The disease and disability classification systems complement each other and help to describe the impact of impairments on disabilities and handicaps.

The Panel adopted the WHO’s definitions of impairments, disabilities and handicaps:

Impairments are shortfalls in the working of various body systems or structures due to disease.

Disabilities are when impairments create shortfalls in a person’s ability to meet the demands of daily living.

Handicaps are when disabilities create shortfalls in fulfilling various social roles.

These three terms provide a useful framework to describe the level at which rehabilitation and treatment are targetted, and the primary rehabilitation goal (e.g., is the primary goal to reduce impairment, disability or handicap).

The WHO is currently revising its terminology for a second edition of the International Classification of Functioning and Disability (ICIDH-2). It is likely that the term "disability" will be replaced by "activities", and the term "handicap" by "participation". Although the new framework will be formally approved and published by 2001, the new terminology is already being used by the MOHLTC's Rehabilitation Reference Group and the Canadian Institute for Health Information in its Development of Management Information Standards for Rehabilitation.



COORDINATED STROKE STRATEGY

EVIDENCE

4

- Clinicians experienced in stroke should carry out the initial assessment
- There should be access to specialized, interdisciplinary stroke rehabilitation
- Stroke survivors should have access to different levels of rehabilitation intensity
- Caregivers should have stroke rehabilitation support
- Long-term rehabilitation services should be widely available in nursing facilities, complex continuing care facilities, and in outpatient and community programs
- Strategies should be developed to prevent the recurrence of stroke
- Outcome data are required for stroke rehabilitation



Over 600 articles from the literature and rehabilitation data were reviewed, and their relative importance and contribution to the field of stroke rehabilitation were assessed. Research was reviewed from a broad range of areas including:

Stroke outcome measures

- functional outcome measures
- health-related quality of life measures

Comprehensive stroke rehabilitation programs

- stroke rehabilitation efficacy studies
- timing of stroke rehabilitation
- baseline assessment at the time of rehabilitation admission
- setting rehabilitation goals
- education and discharge planning
- monitoring progress during rehabilitation
- discharge from stroke rehabilitation

Outpatient rehabilitation

- durability of rehabilitation gains
- community-based vs. hospital-based initial stroke rehabilitation
- outpatient stroke therapy in the sub-acute phase
- rehabilitation in the chronic phase
- specific interventions in long-term rehabilitation

Stroke rehabilitation triage

- entry to rehabilitation
- stroke rehabilitation patient selection/triage
- mild strokes
- moderate/severe strokes
- age

Specific rehabilitation interventions

- medications in stroke recovery
- recurrent stroke risk
- medical comorbidities
- sensorimotor deficits and impaired mobility
- cognitive and perceptual deficits
- communication deficits
- dysphagia and aspiration post-stroke

- nutrition
- spasticity and contractures
- painful hemiplegic shoulder
- acupuncture in stroke
- bladder disorder post-stroke
- depression post-stroke

Reintegration into the community

- family problems
- socialization and community supports
- sexuality
- driving
- returning to work

This systematic review of research evidence was guided by the following levels of evidence framework:

- **Level 1a or Strong:** Supported by the results of two or more randomized controlled trials (RCT) or by a meta-analysis.
- **Level 1b or Moderate:** Supported by a single RCT or by two or more non-randomized analytic studies (case control or cohort studies).
- **Level 2 or Limited:** Supported by a single cohort or case-control study, by studies using quasi-experimental designs such as pre- and post-treatment comparisons.
- **Level 3 or Consensus:** Supported by a consensus statement from a panel of experts. This level implies no available evidence.

The reader is encouraged to refer to Appendix 5 for a summary of the research evidence on the effectiveness of stroke rehabilitation. Based on its review and assessment of the evidence, the Panel came to the following conclusions in seven key areas:

- initial assessment;
 - access to stroke rehabilitation;
 - levels of stroke rehabilitation care;
 - caregiver support and community reintegration;
 - long-term rehabilitation;
 - preventing stroke recurrence; and
 - outcome data.
-

Initial Assessment

1. Clinicians experienced in stroke should carry out the initial assessment.⁷

Acute stroke patients should be assessed by an experienced rehabilitation clinician(s). He or she should use objective assessment criteria to determine the rehabilitation intensity and setting most appropriate for the patient (Level 1a evidence). The triage system used should be relatively simple, transparent and evidence-based.

Access to Stroke Rehabilitation

2. There should be access to specialized, interdisciplinary stroke rehabilitation.⁸

Following an acute stroke, patients who meet the criteria should have access to specialized (interdisciplinary) stroke rehabilitation (Level 1a evidence). As soon as these patients are medically stable, they should be mobilized and transferred to a specialized interdisciplinary rehabilitation program (Level 1a evidence).

Levels of Stroke Rehabilitation Care

3. Stroke survivors should have access to different levels of rehabilitation intensity.¹⁰

Higher level stroke rehabilitation patients can be discharged following acute stroke care to outpatient or community-based interdisciplinary stroke rehabilitation programs (Level 1a evidence). Moderate and severe stroke patients should be managed on specialized inpatient rehab units (Level 1b evidence). Stroke patients should have access to outpatient interdisciplinary specialized stroke rehabilitation programs that can be hospital or community-based (Level 1a evidence).

Caregiver Support and Community Reintegration

5. Caregivers should have stroke rehabilitation support.¹¹

Stroke rehabilitation should include working with patients and caregivers to promote problem solving, ensure adequate community supports are available to caregivers, and facilitate reintegration of the stroke patient into valued family and social roles (Level 1b evidence). Resources need to be made available to support caregivers in the community. Such care should include homemaking support, respite, transportation and opportunities for re-socialization.

7 Alexander, 1994; Asberg and Nydevik, 1991; Borucki et al., 1992; Canadian Institute for Health Information, 1999; Carey et al., 1988; Garraway et al., 1981; Garraway, 1985; Kalra et al., 1993; Oczkowski and Barreca, 1993; Stineman et al., 1998a; Stineman and Granger, 1998b; Ween et al., 1996.

8 Access to Stroke Rehabilitation: Aitken et al., 1993; Cifu and Stewart, 1999; Garraway et al., 1980a, 1980b; Indredavik et al., 1991, 1998; Jorgenson et al., 1995; Judy et al., 1996; Kalra et al., 1993; Kalra and Eade, 1995; Kaste et al., 1995; Langhorne et al., 1993; Peacock et al., 1972; Sivenius et al., 1985; Smith et al., 1982; Stevens et al., 1984; Strand et al., 1985; Stroke Unit Trialists' Collaboration, 1997; Wood-Dauphinee et al., 1984. Early Transfer to Rehabilitation: Anderson et al., 1975; Bourstrom, 1967; Cifu and Stewart, 1999; Feigenson et al., 1977; Hayes and Carroll, 1986; Ottenbacher and Jannell, 1993; Shah et al., 1989; Wertz, 1990.

9 "Interdisciplinary" rehabilitation is provided by a diverse team of professionals who communicate regularly and use their varying expertise to work toward common goals. While "multidisciplinary" rehabilitation usually includes similar professionals, regular communication and common goal orientation are less consistent. There are eight high quality studies comparing these two approaches (Teasell, 2000).

10 Higher Level Care to Outpatient: Holmqvist et al., 1998; Rodgers et al., 1997; Rudd et al., 1997. Moderate to Severe Strokes to Inpatient: Ronning and Guldvog, 1998. Outpatient: Cifu and Stewart, 1999; Langhorne and Legg, 1999; Wade et al., 1992.

11 Evans et al., 1988, 1992; Han and Hanley, 1999.

Long-Term Rehabilitation

6. Long-term rehabilitation services should be widely available in nursing facilities, complex continuing care facilities, and in outpatient and community programs.¹²

Long-term rehabilitation services should be widely available to stroke patients. The services that are provided should be based on demonstrated need and improvements in functional outcomes, and will often involve only one discipline (Level 2 evidence). Resources should be easily accessible to stroke patients and their caregivers. These caregivers will require education in developing stroke-related skills.

Preventing Stroke Recurrence

6. Strategies should be developed to prevent the recurrence of stroke.¹³

Strategies to prevent the recurrence of stroke should be optimized (Level 1a evidence).

Outcome Data

7. Outcome data are required for stroke rehabilitation.¹⁴

An overall functional outcome score that is reliable, valid and easily administered should be used to assist with acute triaging, monitoring of rehabilitation progress and phasing out of rehabilitation support. Currently, the best overall functional measure is the Functional Independence Measure (FIM). It is highly reliable and valid, is well recognized across Canada, and has been endorsed by the Canadian Institute for Health Information (Level 1a evidence). Since FIM is inadequate for assessing communication and cognitive elements for stroke patients, additional elements or assessment tools in these areas will be necessary. The final standardized outcome measure should be applied uniformly along the continuum of stroke care.

¹² Aftonomos et al., 1999; Drummond and Walker, 1995; Hoen et al., 1997; Jongbloed and Morgan, 1991; Logan et al., 1997; Tangeman et al., 1990; Walker et al., 1996; Werner and Kessler, 1996.

¹³ Gresham et al., 1995; Hankey and Warlow, 1999.

¹⁴ Alexander, 1994; Canadian Institute for Health Information, 1999; Dodds et al., 1993; Grimby, 1994; Hamilton et al., 1991; Lyden and Hautson, 1998; Rockwood et al., 1993; Stineman et al., 1998a; Stineman and Granger, 1998b; Ween et al., 1996.



COORDINATED STROKE STRATEGY

5 ENVIRONMENTAL SCAN



- Current system has many limitations-falls short of ideal of well organized, well designed, high quality and well managed system
 - There are 15,000 to 20,000 strokes in Ontario each year
 - Emphasis is shifting to community-based rehabilitation
 - Stroke survivors stress importance of rehabilitation and identify many challenges facing themselves and their families
-

The environmental scan of stroke rehabilitation examined the incidence and prevalence of stroke and stroke rehabilitation in Ontario, provincial research and reports, and the Panel's observations on the limitations of stroke rehabilitation in Ontario.

INCIDENCE AND PREVALENCE OF STROKE AND STROKE REHABILITATION

Stroke

It is unclear exactly how many people have strokes in Ontario. The Heart and Stroke Foundation of Ontario estimates that there are 15,000 to 20,000 strokes a year. Another estimate by the Institute for Clinical Evaluative Sciences noted that there were 14,937 strokes in Ontario in 1998. This estimate does not include people who had strokes and were not hospitalized - the person did not go to the hospital or died before arriving - which may account for at least 10% more stroke cases (Williams et al., 1999). The estimate also does not include strokes resulting from complications (e.g., when a stroke occurs during or following surgery), which accounted for 424 strokes in Ontario in 1998 (CIHI, 1999). The estimate also does not include TIAs.

A longitudinal analysis of stroke from 1995 to 1998 found that the admission rate for stroke in Ontario was 157 per 100,000 population over the age of 20 (CIHI, 1999). It has been estimated that there are about six stroke survivors per 1,000 population (Dombovy, 1991; Greenwood et al., 1993). Extrapolating this to Ontario's population over the age of 20 indicates that there are about 50,000 stroke survivors in a year in the province.¹⁵ The National Population Health Survey (1996,1997) provides a higher estimate - 88,000 Ontarians in the community report living with the effects of stroke.¹⁶ In addition, 22% of institutionalized adults 65 years of age or older are estimated to have had a stroke.¹⁷

Stroke Rehabilitation

Determining the need for stroke rehabilitation is difficult since valid and reliable stroke rehabilitation data do not exist nor does an agreed-upon methodology to determine the need for rehabilitation. Although accurate data do not exist, it is reasonable to conclude that many people who suffer a stroke will require some rehabilitation. It is unclear, however, how much is actually needed since the level of neurological impairment, disability and handicap of these individuals varies considerably, as does the length and intensity of rehabilitation that is required. In Ontario, persons with a primary diagnosis of stroke are the largest category of patient in rehabilitation (facility and home care), and have the third longest length of stay in rehabilitation after spinal cord and brain dysfunction.

¹⁵ In 1996, Ontario's population was 8,274,344. Source: Statistics Canada, 1997.

¹⁶ Statistics Canada, 1999.

¹⁷ Statistics Canada, Oct. 27, 1995.

The Panel conducted an extensive review of various models that purport to measure the need for health services and explored their potential application for stroke rehabilitation. Three population-needs based models were identified as useful for measuring and monitoring the need for stroke rehabilitation (See Appendix 6).

1. Where there is good evidence that a rehabilitation procedure or program is therapeutic and its indications are clear, Frankel et al.'s (1999) methodology which incorporates one's capacity to benefit from treatment and the concept of health care "requirement" rather than "need", could be used to quantify the indications for a post-stroke procedure.
2. Where there is good evidence that defines when progressive disablement presents an increased risk to health and there is an effective rehabilitation intervention, the public health models of population needs-based planning could be used.
3. Stroke survivors and families could be asked what assistance they need to maintain a safe and reasonable quality of life, and/or to maintain their capacity to manage their disability.

The work of Gresham et al. (1995) provides an indication of the need for stroke rehabilitation. Although the research is not Ontario-based, the results are useful to examine. Gresham et al.'s analysis of stroke survivors found that 47% were physically independent six months after having a stroke, 32% are mildly dependent, 12% moderately dependent, 5% severely dependent and 4% very severely dependent. Disabilities that existed six months post-stroke and the percentage of stroke survivors who had these disabilities are presented in the table below.

Type of disability	Percentage at 6 months
Not oriented	27%
Marked communication problem	15
Motor loss (partial or complete)	53
Depression	11-68
Bowel incontinence	7
Urinary incontinence	11
Needs help with grooming	13
Needs help with toileting	20
Needs help with feeding	33
Needs help with dressing	31
Needs help with bathing	49
Needs help with transfers from bed to chair	19
Unable to walk independently	15

Source: Gresham et al., 1995: pp. 30,160.

ONTARIO RESEARCH AND REPORTS

The Panel examined trends in stroke and stroke rehabilitation, considered the important perspectives of Ontario stroke survivors and caregivers, and examined provincial stroke rehabilitation-related reports.

Trends in Stroke and Stroke Rehabilitation

A longitudinal analysis of stroke from 1995 to 1998 found that the admission rate for stroke in Ontario was 157 per 100,000 population over the age of 20 (CIHI, 1999). The average age for stroke patients was 74 years, with 51% being female. Mortality was about 19% in the first 30 days post-stroke and 33% in the first year. (Research shows a 50% mortality rate by the fifth year (Dombovy, 1991) and 87% by the tenth year (Indredavik et al., 1999)). The average hospital length of stay was 18 days. A significant number of stroke patients - 45% - were discharged home, whereas an additional 15% went home with home care. The remaining 40% were discharged to another facility: 14% went to rehabilitation hospitals, 12% to chronic care hospitals, 9% to nursing homes and 5% to acute care hospitals. Older patients were more likely to be discharged to chronic care facilities and nursing homes, whereas younger patients were more likely to be discharged home.

A 1991/92 study found that a major cost factor of stroke hospitalization in Toronto was the delay in discharging patients from acute care due to social factors. A follow-up study conducted in 1996/97 found that a greater proportion of stroke patients were being discharged directly to home, fewer went to rehabilitation, fewer went to nursing homes or long-term care facilities, and there were more deaths (this was probably a function of sample size) (Tran et al., 1999; Smurawska et al., 1994). These results suggest that stroke survivors may not be receiving the same level of care as before and fewer are receiving stroke rehabilitation.

Throughout the 1990s, there have been significant changes in how patients are managed in hospitals due to such factors as advancements in technology, the development of new drugs, the shift from institutions to community-based care, and hospital restructuring. Not surprisingly, these factors have impacted on how stroke survivors are managed by hospitals.

Traditionally rehabilitation has focused narrowly on inpatient rehabilitation and resources for rehabilitation have also tended to be concentrated on the inpatient component of care. This emphasis on inpatient stroke rehabilitation is shifting for a number of reasons:

- Hospital length of stays are decreasing with more treatment being provided at home.
 - The rehabilitation needs of ambulatory stroke survivors are being recognized.
 - Attention is shifting from surviving and improving functional outcomes of stroke, to psychosocial factors that influence post-stroke quality of life and subjective well being (Swartzman et al., 1998).
 - Resolving acute comorbidities at a later stage may finally enable rehabilitation to occur.
-

The concept of community-based rehabilitation calls for a greater proportion of rehabilitation to be provided in community settings, shaped by primary care providers, and responsive to the desire of people with disabilities to “maintain good health while managing a disability” (Edmonds and Peat, 1997). The shift from institution- to community-based care means that a greater proportion of rehabilitation is being provided in community settings. A recent review of home visits for stroke rehabilitation by two community care access centres in Ontario found that the number of home visits has increased. The number of visits conducted by the Toronto CCAC for stroke rehabilitation in 1996/97, increased 27% by 1997/98 and 37% by 1998/99. A similar trend was evident in the Lanark, Leeds and Grenville CCAC - stroke rehabilitation visits increased 23% from 1997/98 to 1998/99.

A number of innovative stroke integration projects that include rehabilitation are being conducted in Ontario. For example, the Peel District Health Council's Regional Program Planning Committee developed proposals to coordinate rehabilitation in Peel (1997). This helped set the stage for Peel to become part of a pilot project, with providers in West Toronto, on community-based stroke rehabilitation under the auspices of the Coordinated Stroke Strategy of the Heart and Stroke Foundation of Ontario.

Survivor and Caregiver Perspectives

As part of its work, the Consensus Panel sought input on stroke rehabilitation from consumers and providers. Surveys were distributed through a number of organizations and input was obtained from members of the Panel who were stroke survivors and caregiver-family members.

Survey of Stroke Survivors - York-Durham Aphasia Centre

A survey was distributed by the York-Durham Aphasia Centre to its clients. The vast majority of respondents were stroke survivors who expressed strong positive feelings about being asked their opinions. Most felt that rehabilitation should start right away and be concentrated from the onset of stroke to one month. It was acknowledged that different services are needed at different times, even after one year, and that it is important for rehabilitation to carry on after two years. From the perspective of stroke survivors who participated in this survey, rehabilitation was helped by speech language therapy, family, friends and neighbours, physiotherapy, social work, stroke groups, occupational therapy and faith. The most frustrating or challenging parts of rehabilitation were speech and mobility issues, fear of another stroke, understanding what happened, being socially isolated, waiting for therapy, family changes, and issues about driving. Issues with eating and continence were also identified as challenges. It was noted by stroke survivors that different therapies are needed at different times, and that survivors must deal with a lot of frustration, and loss of privacy and choice.

Survey of Stroke Survivors, Caregivers and Clinicians - Stroke Recovery Association of Ontario and the Heart and Stroke Foundation of Ontario's Living With Stroke Program

A second survey was targeted at stroke survivors, caregivers and clinicians through the Stroke Recovery Association of Ontario and the Heart and Stroke Foundation of Ontario's Living With Stroke program.

Stroke can be a devastating and traumatic experience that is difficult to accept. Stroke survivors commented on the importance of timely access to stroke rehabilitation. For example, a stroke survivor from a rural area attributed her current high quality of life to accessing five months of rehabilitation three weeks post-stroke. Another noted that rehabilitation should start as soon as the patient's condition is stabilized, and should continue as long as progress is practical and useful. Fine-tuning one's capacities can be a long process (e.g., speech can take up to four years to redevelop fully). This stroke survivor noted that much can be accomplished on one's own or with family members.

Appropriate access to stroke rehabilitation must take into account the condition of the stroke survivor. One stroke survivor noted that fatigue during the two years post-stroke limited the benefits that could have been derived from stroke rehabilitation. The value of rehabilitation after two years was emphasized by this person. Respondents recognized that access to stroke rehabilitation is an issue. One rural stroke survivor noted that more recent stroke survivors seem unable to receive the same level of service from the same facility, and the Living with Stroke program should be implemented in rural areas.

A caregiver-family member living in an urban area commented on accessibility to stroke rehabilitation by noting that survivors should not have to wait for a bed, and there should be sufficient staff to start rehabilitation immediately after a stroke. In terms of quality of care, this caregiver noted that professional and humane treatment of stroke patients should be the norm and be monitored, and that all nursing staff should be trained to work with stroke patients so they can be transferred safely on a regular basis. In terms of the rehabilitation setting, physical facilities should provide a therapeutic, pleasant and motivating environment for recuperation. The caregiver-family member finally noted that as long as there is progress and hope, time restrictions should not be placed on rehabilitation and recovery.

Urban-suburban health care professionals working in a rehabilitation facility identified four factors that reduce the effectiveness of rehabilitation:

- Lack of family support;
- Lack of understanding and unrealistic expectations by clients and their families about stroke and its effect on returning to functioning and recovery, and the institution's responsibility;
- Characteristics of the client including the inability to take full advantage of rehabilitation due to clinical, communication (aphasia), cognitive, motivational or social reasons, a poor pre-morbid medical condition, and poor motivation or depression;

- Availability of resources including inadequate space and equipment for treatment; lack of physiotherapy, occupational therapy, speech therapy and dietary clinical notes from acute care; insufficient professional skill; insufficient time for treatment; and no follow up with neurologists.

Input From Stroke Survivors and a Family-caregiver Member on the Consensus Panel

Two stroke survivors and a caregiver-partner who were members of the Panel, commented on their experiences with stroke rehabilitation. In terms of accessibility, it was noted that not all stroke survivors are offered rehabilitation so that a number of them slip through the rehabilitation system. As well, the health status of stroke survivors can change over time. Benefits can be derived from longer duration-lower intensity rehabilitation. Access to this care is becoming increasingly difficult with reductions in hospitals' length of stay and fewer beds for stroke rehabilitation. Benefits can also be derived from rehabilitation three to four years post-stroke. Unfortunately, it is not always easy to re-enter stroke rehabilitation programs. Access to family-caregiver support was recognized as important both for the caregiver and the stroke survivor.

In terms of continuity of care, typically rehabilitation therapists from different organizations are involved with the same stroke survivor. However, efforts are not made to identify a team leader to coordinate the services in the best interests of the patient. Finally, stroke survivors reported benefitting from complementary medicine. They did raise questions about the views that rehabilitation professionals have about this approach to care.

Provincial Stroke Rehabilitation-related Reports

The most recent provincial examination of rehabilitation was conducted by the Health Services Restructuring Commission (HSRC, 1998). Although the HSRC primarily focused on inpatient bed requirements, it recognized and addressed issues about providing a more coherent local and provincial approach to rehabilitation. For example, the HSRC recommended that the Ministry of Health endorse the establishment of local and provincial rehabilitation networks, both of which would have widespread representation from multiple stakeholders. One key responsibility of both local and provincial networks was to advance coordination and integration of rehabilitation services across the continuum. The HSRC emphasized the fundamental need for a good provincial information system to provide data on the population's need for rehabilitation. It also noted that research was needed to develop definitions for the full range of institution- and community-based rehabilitation services, to develop a planning guideline for outpatient and ambulatory rehabilitation, and to develop and evaluate standards of care, referral criteria and outcome assessments for rehabilitation services.

A number of recent reports have addressed the importance of population-needs based planning for funding rehabilitation. There is a growing awareness that objective data about the need for stroke rehabilitation in the population should be used to allocate resources equitably between communities (Joint Policy and Planning Committee, 1999). The Cardiac Care Network of Ontario developed a working model that brings together evidence-based medicine, data on the population's need for rehabilitation, and interdisciplinary consensus that leads to recommendations for new investments in, or reallocation of, health service resources (CCN, 1999). Yet a third report on the need for stroke service in Eastern Ontario, provides another example of population needs-based planning (Purdue et al., 1998).

LIMITATIONS OF STROKE REHABILITATION IN ONTARIO

As a result of conducting an environmental scan of the current system of stroke rehabilitation in Ontario, the Panel concluded that generally stroke survivors, their families and health professionals do not benefit from a well organized, well designed, high quality and well monitored system that provides effective stroke rehabilitation to reduce disability and handicap. The following limitations in the system of stroke rehabilitation in Ontario were identified by the Panel.

- There is inappropriate access to stroke rehabilitation where care is delayed, or is of the wrong intensity or duration.
 - There is inequitable access to stroke rehabilitation across the province. Examples of gaps include: specialized stroke services including outreach are not available in all communities; it is difficult to access interdisciplinary care even in the acute sector; there is inadequate transportation to stroke rehabilitation; there is inadequate provision for low intensity-longer duration rehabilitation; and there is insufficient home rehabilitation to treat the number of severe and moderate stroke survivors returning home.
 - A seamless, coordinated approach to stroke rehabilitation across the continuum of care does not exist.
 - Certain components of stroke rehabilitation are not that well developed. Examples include education for stroke survivors and their families, and understanding motivation in stroke survivors.
 - Funding for rehabilitation in the community is insufficient to meet the demand for these services.
 - There are limited positions to train stroke rehabilitation professionals.
 - There is a lack of routine outcome information on how well stroke rehabilitation is reducing functional disability and handicap.
 - An up-to-date reference for effective, evidence-based rehabilitation does not exist.
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COORDINATED STROKE STRATEGY

6 A SYSTEM FOR STROKE REHABILITATION



Vision

Individuals who experience a stroke will have timely access to the appropriate intensity and duration of rehabilitation services. These services will be provided in a comprehensive and coordinated way to patients and families, by agencies and health care providers who are expert in stroke care and practise rehabilitation principles.

VISION

The Panel's vision for stroke rehabilitation is:

Individuals who experience a stroke will have timely access to the appropriate intensity and duration of rehabilitation services. These services will be provided in a comprehensive and coordinated way to patients and families, by agencies and health care providers who are expert in stroke and practise rehabilitation principles.

GUIDING PRINCIPLES

The following principles guided the Panel's development of a stroke rehabilitation system for Ontario:

1. Stroke rehabilitation will be client-centred, and will meet the diverse and changing needs of stroke survivors and their families.
2. Stroke survivors will have their rehabilitation potential assessed by experts, and will have timely and appropriate access to stroke rehabilitation expertise throughout the care continuum. This access includes reaccessing stroke rehabilitation if and when the need arises. The care continuum will:
 - include well-coordinated local and regional resources, and be responsive to local and regional needs;
 - implement local strategies to optimize clinical coordination and case management;
 - balance the consolidation of specialized stroke rehabilitation services that require critical mass, concentrated skills and clinical, academic and research expertise, with having care as close to home as possible, recognizing the challenges faced by stroke survivors who are undergoing rehabilitation;
 - include effective transportation to ensure access to services.
3. Stroke rehabilitation expertise will be demonstrated formally through certification or informally through recognized clinical leadership in the community. Expertise will be maintained and enhanced by using rehabilitation principles, continuously working with stroke survivors, and engaging in continuing education. Consolidating stroke patients in each setting along the continuum of recovery helps to strengthen the development of rehabilitation expertise. (The settings include acute hospitals, rehabilitation facilities, complex continuing care facilities, outpatient settings, home care, nursing homes, homes for the aged, adult day programs, community health agencies and community support groups).

4. Stroke rehabilitation will incorporate high quality, accurate and timely information, and information management. This includes communicating information about stroke, stroke disability and recovery to stroke survivors, their families and significant others, and health-care providers. It also includes ensuring that information flows with the client and family across the continuum of care in a seamless and coordinated manner, while protecting the confidentiality of the client.
5. New technologies such as telehealth will be used to support rehabilitation consultation, education, and service to rural, northern and remote communities.
6. Stroke rehabilitation will be research and evidence-based.
7. Stroke rehabilitation will be supported with a sufficient number of appropriately trained health care providers (e.g., physicians, nurses, therapists and assistants).

DEVELOPMENT OF REGIONAL STROKE REHABILITATION SYSTEMS

The Panel's vision for stroke rehabilitation emphasizes accessibility to quality care that is provided in a coordinated manner that puts the stroke survivor at the centre of service delivery. The Panel believes that this vision can only be achieved with the development of regional stroke rehabilitation systems. These systems should be linked to other networks that have been proposed in Ontario. One example is the system of organized stroke care with three levels initially proposed by the Heart and Stroke Foundation of Ontario in its report, *Stroke Care Ontario*. Another example is the regional rehabilitation networks directed by the HSRC in several communities (e.g., Toronto, Greater Toronto Area/905).

The HSRC's definitions of 'short-term local', 'long-term local' and 'regional' rehabilitation services are presented to illustrate the different levels of rehabilitation that are part of the regional stroke rehabilitation system.¹⁸

- 'Short-term local' rehabilitation services will be provided in acute care facilities to reduce the number of patient transfers, make early intervention possible and strengthen the focus on community integration. These services are targeted at patients after an acute care episode. Patients requiring these services will have on average a rehabilitation inpatient stay of 14 days or less. Examples include musculoskeletal, stroke and other neurological conditions and geriatric rehabilitation.

¹⁸ These definitions were first presented in the Health Services Restructuring Commission's report, *Metropolitan Toronto Health Services Restructuring Report*, July 1997. The definitions were modified in two of the HSRC's subsequent documents, *Toronto Health Services Restructuring Report: Rehabilitation, Long-Term Care and Sub-Acute Care Services*, April 1998; and *GTA/905 Health Services Restructuring Report*, April 1998.

- 'Long-term local' rehabilitation services will be located in designated regional facilities, where these exist, to ensure clinical coherence of more specialized services, and a sufficient critical mass to provide high quality care and to support specialized care providers. (Where regional rehabilitation facilities do not exist, long-term programs will be located in chronic care facilities or colocated with short-term local programs in acute care facilities.) Patients requiring these services will have more complex requirements than short-term rehabilitation patients and will have on average a rehabilitation inpatient stay of more than 14 days including weekends. Examples of conditions requiring long-term services are similar to those requiring short-term rehabilitation but are more complex in nature. Long-term conditions may also include respiratory and oncology conditions.
- 'Regional' rehabilitation services will be provided in designated regional facilities to ensure sufficient critical mass and to support specialized care providers. These services include highly specialized programs targeted to clients with complex rehabilitation needs. These services have sufficiently low volume that providing them locally is neither feasible nor cost-effective. Examples include acquired brain injury, spinal cord injury, amputee, trauma, specialized respiratory and complex paediatric care.

A regional approach to stroke care will ensure that all Ontarians have timely access to the appropriate level of stroke rehabilitation services when they need them. Even persons who live in rural, northern or remote areas of the province will be able to access more specialized rehabilitation care that may not be available in their communities. A coordinated regional system will also ensure that when the rehabilitation care needs of stroke survivors change, they will be referred to the appropriate level of services in a coordinated manner. These services will be provided by caregivers who have appropriate stroke rehabilitation expertise.

Regional stroke rehabilitation systems will build on and improve current services. The development of these systems is a shared partnership between hospitals, community care access centres, other health care organizations, agencies and providers, the Heart and Stroke Foundation of Ontario, and the Ministry of Health and Long-Term Care.

Regional stroke rehabilitation systems will encourage integration of services, cooperation and collaboration between organizations, the development and renewal of leadership in rehabilitation, and a seamless continuum of programs and services. This continuum includes all levels of stroke rehabilitation as well as community supports such as transportation and housing.

A regional network will advance a common approach to initial triage and ongoing access to timely stroke rehabilitation, the development of stroke rehabilitation resources, strong links to primary and secondary prevention programs, a concerted response to regional requirements for professional training, continuing education and consultation, and common decision making protocols.

It is recommended that:

R1 Regional stroke rehabilitation systems be established that are linked to broader stroke networks and regional rehabilitation networks, to ensure a collaborative approach that is consistent with the vision for stroke rehabilitation presented in this report. This vision recognizes the importance of comprehensive and coordinated stroke rehabilitation that includes community supports such as transportation and housing.

The components of regional stroke rehabilitation systems and the benefits of establishing these systems are presented below.

Components of Regional Stroke Rehabilitation Systems

Regional stroke rehabilitation systems will be made up of three components:

- regional centres;
- local inpatient units;
- community-based rehabilitation.

Each of these components is described below.

Regional Centres

Regional rehabilitation centres will have patient care, education and research responsibilities in stroke rehabilitation.

With regard to patient care, these regional centres will have the expertise and inpatient beds to provide specialized stroke rehabilitation for the most complex cases in the region, as well as long-term local rehabilitation for the surrounding community. Regional centres will provide both in and outpatient programs. Outpatient care may include services such as an ambulatory stroke rehabilitation day hospital. Day hospitals that incorporate both medical and psychosocial dimensions of care, can help shorten the stroke survivor's stay in hospital, assist with community re-integration by involving stroke survivors in activities outside of their home environment, and provide short-term respite for family caregivers.

Colocating regional with long-term local cases in regional centres will enhance critical mass, support specialized skills and expertise, and enhance the opportunities for education and research in stroke rehabilitation. It is expected that all regional centres will be affiliated with an academic health science centre (AHSC) to support these academic activities. (This does not imply that regional centres will only be designated where AHSCs are located. For example, regional centres in north-east and north-west Ontario will be affiliated with AHSCs in the

south.) Regional centres will also be expected to transfer their knowledge of stroke rehabilitation principles, processes and practices to other institution- and community-based providers in the region through a comprehensive program of outreach services and expert consultations. Regional centres will benefit from their interaction with these other providers by gaining information and knowledge of community-based services and practices.

Local Inpatient Units

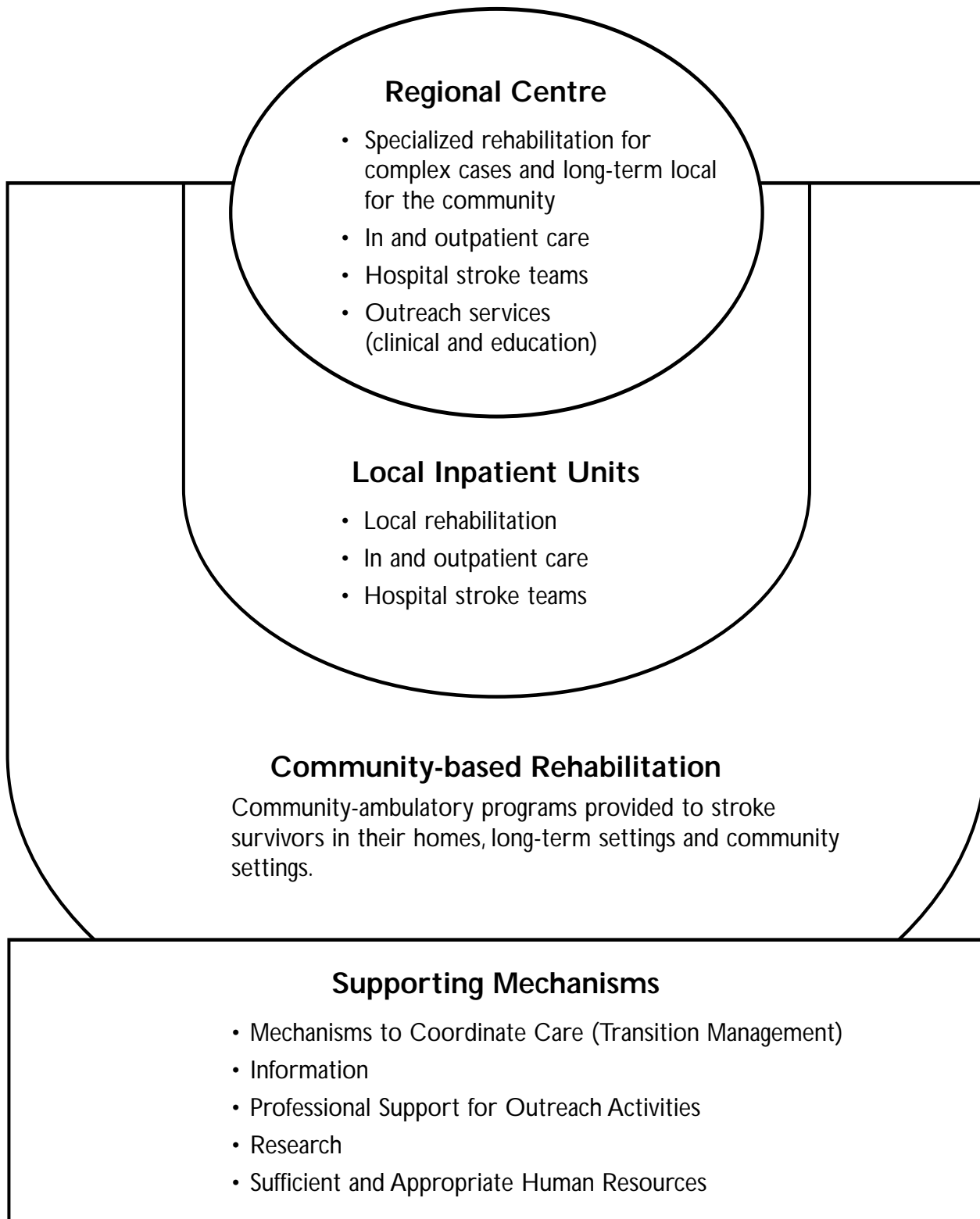
Local inpatient stroke rehabilitation units will be sited in selected hospitals in each regional system, and will be linked with a regional centre. Local units will consolidate patients and resources so that local expertise in stroke rehabilitation is developed and maintained. This expertise will support providing timely access to stroke rehabilitation on an in and outpatient basis, working with families of stroke survivors, and consulting with providers in long-term settings. Since there is evidence that local leadership has a more significant influence on local patterns of care than visiting clinicians, local inpatient units will play a critical role in local continuous improvement. Local inpatient units will also be expected to provide outreach services and expert consultation to other institution- and community-based providers, so that expertise in stroke rehabilitation is developed throughout the region. Since community care access centre case managers are located in hospitals, they will play a significant role coordinating care and bridging transitions as stroke survivors move through the system.

Each local unit should have a minimum of eight to ten beds to support a well-functioning specialized stroke team. The team will include a physician with stroke expertise, rehabilitation nurses, physical therapists, occupational therapists, speech and language pathologists, and other caregivers such as social workers.

Community-based Rehabilitation

Community-based rehabilitation maintains and builds on the gains a stroke-survivor has made while receiving hospital-based rehabilitation. Community-based rehabilitation includes ambulatory programs and services that are provided to stroke survivors who are living at home or in long-term settings. These programs and services go beyond providing assistance with the activities of daily living to include ambulatory rehabilitation that enables stroke survivors to participate actively in reaching their optimal level of functioning (e.g., adult day programs; community support groups; housing adapted to the needs of stroke survivors; programs in an ambulatory setting that help to overcome the social isolation frequently associated with strokes; physical fitness programs appropriate for stroke-related disabilities; return to work programs). Many community-based rehabilitation programs have the added benefit of providing respite for family caregivers. The success of community programs and community reintegration depends on effective, specialized transportation for disabled individuals.

Regional Stroke Rehabilitation System



Home-based Rehabilitation

Persons who have had more severe strokes and are discharged from hospital, and persons who have had mild strokes and can go home relatively quickly, benefit significantly from rehabilitation that is provided at home. Home-based rehabilitation can also benefit families of stroke survivors.

Home-based stroke rehabilitation can be provided on its own or in concert with a hospital outpatient program. Home-based rehabilitation includes a wide range of therapies such as occupational therapy, physical therapy, nutrition counselling, speech-language pathology and social work. Home-based stroke rehabilitation must be delivered by service providers who practise rehabilitation principles and have expertise in stroke rehabilitation. It is the responsibility of Community Care Access Centres (CCAC) to ensure that the service providers they contract with have this expertise. CCAC case managers have an important role to play coordinating care and bridging the transition from hospital to home-based rehabilitation.

Residents in Long-Term Settings

Long-term settings include complex continuing care hospitals and complex continuing care units in acute care hospitals, nursing homes, homes for the aged, supportive housing, private residences and retirement homes.¹⁹

Stroke survivors living in a long-term setting should have timely access to the same level of in and outpatient stroke expertise and the same opportunities to benefit from effective rehabilitation as if they were living in their own homes. These individuals should be admitted to the appropriate programs and referred to the appropriate health care professionals who will help them to reach their optimal level of functioning.

Stroke survivors living in long-term settings must have their needs routinely assessed to determine when there is a need to re-enter the rehabilitation system. A number of strategies should be used to ensure that stroke survivors maintain the functional levels they have gained through rehabilitation. One strategy is to educate staff in these facilities about the consequences of a stroke, practical care techniques that incorporate rehabilitation principles, how to provide ongoing psychosocial support and appropriate activities to enhance optimal functioning. A second strategy is for long-term settings to collaborate with regional centres or local inpatient stroke units. The expertise of these centres and units can be used to develop inhouse day programs, protocols can be established whereby staff in long-term settings can consult with rehabilitation experts in the regional centres and local units, and agreements can be established linking residents of long-term settings with in and outpatient programs in the regional and local rehabilitation facilities.

¹⁹ This definition is adapted from the Health Services Restructuring Commission, *Change and Transition: Planning Guidelines and Implementation Strategies for Home Care, Long-Term Care, Mental Health, Rehabilitation, and Sub-acute Care*, April 1998.

Benefits of a Regional Stroke Rehabilitation System

Regional stroke rehabilitation systems have a number of important benefits.

One, a regional system approach will help support a collaborative approach to stroke rehabilitation, where services are coordinated and integrated from the acute phase of stroke to all levels of stroke rehabilitation.

Assessment and triage of stroke survivors start in the emergency departments of acute hospitals. In this instance, health care professionals trained in stroke rehabilitation such as physiatrists and clinical nurse specialists should be available to provide knowledgeable advice about levels of rehabilitation, and available programs and services. This expertise should be brought to bear on initial medical management, diagnostic assessment, secondary prevention and early preparation for referral to rehabilitation. This expert consultation links the acute phase of stroke with stroke rehabilitation, and is critical for stroke survivors, regardless of the severity of the stroke. It ensures that stroke survivors receive the most appropriate level, intensity and duration of stroke rehabilitation. This may be referral to specialized stroke rehabilitation in a regional centre, referral to a local inpatient unit for less intense rehabilitation, or direct discharge from the emergency department to home or a long-term care setting.

The Panel supports the involvement of specific expertise in stroke rehabilitation throughout the early management phase, which is defined as one to five days post-stroke. The Stroke Treatment Education Program (STEP) is an educational resource for acute care facilities that should be used (Silver et al., nd).

Currently, there are wide variations in early access to stroke rehabilitation in Ontario hospitals (Tu and Porter, 1999). Every acute hospital should have a stroke team that includes rehabilitation expertise. This will help bridge the transition from acute care to rehabilitation, help improve timely access to rehabilitation, and ensure that services are provided as close to home as possible. There is good evidence that appropriate patients should be mobilized and transferred to a specialized interdisciplinary rehabilitation program as soon as medically stable. Appropriate and timely triage can help prevent complications and enhance optimal functioning.

The Panel believes that a standard for the transfer of medically stable patients from acute care to rehabilitation should be established for Ontario. Based on the experience of its members, the Panel suggests a standard of three days for access to inpatient rehabilitation and two working days for access to home-based and outpatient rehabilitation. Meeting this standard across the province will require new resources.

Excellence in stroke rehabilitation assessment is critical throughout the continuum of stroke recovery. In fact, regional centres and local inpatient rehabilitation units should also have stroke teams to ensure that stroke patients receive the appropriate intensity of resources and care to meet their needs. After the initial assessment and triage to rehabilitation, there may be a need

for periodic reassessment and re-entry to the stroke rehabilitation system. For example, an acute episode may eclipse opportunities for stroke rehabilitation for a period of time. The opportunity to benefit from rehabilitation will return once the acute episode is resolved. A key advantage of a regional system approach is that stroke patients flow in a timely fashion to the setting that meets their ongoing and episodic rehabilitation needs.

Two, a regional system approach will help ensure equitable access to a broad range of stroke rehabilitation services throughout the province.

Regional outreach programs for rehabilitation and community reintegration of stroke survivors will support community generalists, ensure that care is provided as close to home as possible, and ensure that there is equitable access to a consistent range of stroke rehabilitation services in every community in Ontario. Outreach programs will support:

- Early and timely access to coordinated rehabilitation services including secondary prevention, and ongoing access to care and periodic interdisciplinary reassessment for stroke rehabilitation. Regional centres and local stroke sites should have one phone number available to help clinicians access an urgent assessment, diagnostic resources for a definitive diagnosis, a psychiatric consultation and an alternative placement when local facilities are full.
- Access to professional education and specialized expertise using innovative communication technologies where necessary (e.g., telehealth). Education will include rehabilitation principles that address impairment, disability and handicap, and the psychosocial dimensions of stroke recovery for survivors and their families.
- Access to family-caregiver education and support (e.g., respite care).
- Advocacy about the cognitive, communication and other neurological impairments and disabilities faced by stroke survivors, and the rehabilitation needs of stroke survivors who live in long-term settings.
- Coordinated services including local linkages to diagnostic facilities for stroke and between CCACs, community-based rehabilitation, stroke recovery groups, and agencies that provide supportive housing and transportation aids.
- Public awareness of stroke, of the burden facing stroke survivors and their families, and of the potential for recovery from impairment, disability and handicap.
- Reintegration of stroke survivors into the community through such services as physical fitness programs appropriate for different stroke-related disabilities, social groups, advice and assistance with home renovations, return to work programs and vocational rehabilitation.

Rural, northern and remote areas of Ontario present challenges to the availability of comprehensive stroke rehabilitation services. A regional stroke rehabilitation system will help to overcome some of these challenges. Regional centres and local inpatient units have an important role to play providing outreach education and consultations in stroke rehabilitation. These activities can be supported by using various communication technologies, developing and sharing education materials, and distributing established care protocols.

In urban and suburban regions with rural areas, the regional centre and local inpatient units will easily supplement the general rehabilitation experience, knowledge and skills available in local communities. It is recognized, however, that in more remote settings, regional outreach may not be as comprehensive as it could be to meet the ongoing needs of stroke survivors for rehabilitation and reintegration into the community. For example, the catchment area for outpatient programs might be a 45 minute driving radius since some disabled stroke survivors cannot sustain longer travel times. Communities in more remote settings will need to develop community-based local stroke rehabilitation expertise that meets the needs of stroke survivors, and that is linked to more specialized inpatient expertise in the region.

Innovative local arrangements for stroke rehabilitation will need to be explored that are tailored to meet the needs of the local community and that take into account available resources. For example, a visiting therapist could provide rehabilitation to stroke survivors in various facilities and community settings, and lead community education programs.

Three, a regional system will help consolidate stroke rehabilitation expertise and resources.

The development of regional centres and inpatient rehabilitation units will minimize the fragmentation of specialized stroke rehabilitation by establishing units with sufficient critical mass to provide high quality care, maximize the efficiency and effectiveness of specialized and local care delivery, and support specialized skills and expertise in stroke rehabilitation. Opportunities should be sought to consolidate stroke survivors in rehabilitation facilities and units, and long-term settings wherever possible. This will help to avoid fragmentation of specialized stroke rehabilitation skills and expertise in these facilities, support education of staff, and lead to more comprehensive and coordinated approaches to stroke rehabilitation in all settings.

COMPONENTS OF THE CONTINUUM

The Panel addressed the two broad components of the continuum of stroke rehabilitation: inpatient beds, and ambulatory and home-based rehabilitation.

Inpatient Beds

A regional stroke rehabilitation system must have sufficient inpatient resources to meet the needs of the population. Although most people who survive a stroke will benefit from rehabilitation, the level of neurological impairment, disability and handicap of these individuals will vary considerably, as will the length and intensity of the rehabilitation each requires. The varying needs of stroke survivors for inpatient resources must be recognized. These inpatient resources include:

- beds for low intensity-long duration rehabilitation;
- beds for high intensity-short duration rehabilitation;
- beds for highly specialized and complex rehabilitation.

Both low intensity-long duration and high intensity-short duration rehabilitation beds should be available to those in need and should be located in inpatient stroke rehabilitation units. Currently, low intensity-long duration rehabilitation is hard to access because of the longer length of stay. Stroke survivors who cannot access low intensity-long duration rehabilitation when they need it may bypass inpatient rehabilitation and be transferred to a less appropriate setting where they do not get the rehabilitation that they require. This is a growing concern as Ontario's population ages, since stroke survivors who require low intensity-long duration rehabilitation are typically older, more frail and have multiple comorbidities. Realistically, intense rehabilitation is not appropriate for this client group.

It is important that a sufficient number of both low intensity-long duration rehabilitation beds, and high intensity-short duration rehabilitation beds be available to meet the needs of the population. It is recommended that:

R2 Hospitals with rehabilitation beds establish dedicated stroke units that include both short- and long-duration stroke rehabilitation beds. The regional stroke rehabilitation systems should monitor the demand for and use of these beds to determine appropriate benchmarks that will ensure access for stroke patients.

Regional rehabilitation facilities provide both highly specialized regional and long-term local services. These designated facilities are important regional resources. They play a valuable role in clinical service, education, research and outreach that goes beyond their local community to the broader region.

The Health Services Restructuring Commission categorized stroke rehabilitation as being either a short-term or long-term local service. In the HSRC's definitions, local services are not as highly specialized and are not targeted to clients with more complex rehabilitation needs. It must be recognized that the level of neurological impairment, disability and handicap of stroke survivors varies considerably and includes individuals with more complex rehabilitation needs. The Panel believes that the highly specialized regional component of stroke rehabilitation must be recognized, and sufficient resources sited in regional rehabilitation facilities to support the needs of these individuals. Professionals with highly specialized rehabilitation education and skills are available in these facilities to meet the complex needs of these stroke survivors. It is recommended that:

- R3 The Ministry of Health and Long-Term Care recognize that stroke rehabilitation includes a broad range of conditions, some of which require highly specialized services, and that the specialized component of stroke rehabilitation be reflected in regional bed allocations in the regional rehabilitation facilities.**

Ambulatory and Home-based Stroke Rehabilitation

Ambulatory and home-based rehabilitation plays an important role in the continuum of rehabilitation services. These services emphasize maximizing the stroke survivor's activities of daily living. The Panel's review and assessment of the research indicated that higher level stroke rehabilitation patients can be discharged following acute stroke care to outpatient or community-based interdisciplinary stroke rehabilitation programs (Level 1a evidence). Similarly, stroke patients should have access to outpatient interdisciplinary specialized stroke rehabilitation programs that can be hospital or community-based (Level 1a evidence).

Traditionally, stroke rehabilitation investments emphasized inpatient care. With an increasing emphasis on transferring stroke survivors from inpatient hospital care to ambulatory and home-based rehabilitation, the demand for these services must be assessed. Currently it is unclear how many people are waiting for ambulatory and home-based stroke rehabilitation and how long they wait. When the magnitude of the demand is determined, sufficient resources should be made available to provide these services in a timely manner upon discharge from hospital inpatient care.

It is recommended that:

- R4 The regional stroke systems monitor waiting lists and other indicators of need for ambulatory and home-based stroke rehabilitation, to determine the reinvestments required to meet regional needs, and to recommend to the Ministry of Health and Long-Term Care the resources that should be allocated to meet these needs.**

In its examination of home care services, the Health Services Restructuring Commission noted that proponents of home care believe that most patients, given the choice, would prefer to receive health care services in their homes rather than in hospital, and that their well-being is enhanced when they are allowed to remain within their own environment.²⁰ Some contend that home care can play a supportive role in assisting families and caregivers, whereas others believe that home care, if not adequately supported, may actually shift the burden and cost of care to the family.

The Panel believes that best practices for home-based stroke rehabilitation must be identified so that both patients and family members benefit. Wide disparities exist in Ontario due to population density, geography, transportation and the availability of health care resources. As a result, best practice models for home-based stroke rehabilitation may vary across the province such that best practices may be slightly different in urban, rural, northern and remote areas.

It is recommended that:

R5 The Ministry of Health and Long-Term Care fund pilot projects to identify best practices for home-based stroke rehabilitation. These pilot projects should examine best practices in a range of settings including urban, rural, northern and remote locations.

SUPPORTING MECHANISMS

The Panel identified a number of mechanisms to support the regional stroke rehabilitation system. These are:

- mechanisms to coordinate care across the continuum (transition management);
- information;
- professional support;
- research;
- human resources.

MECHANISMS TO COORDINATE CARE ACROSS THE CONTINUUM

The Panel's vision of stroke rehabilitation is a system where services are provided in a comprehensive and coordinated way. The client's experience of receiving different levels of stroke rehabilitation should be integrated and seamless.

²⁰ Health Services Restructuring Commission. *Change and Transition: Planning Guidelines and Implementation Strategies for Home Care, Long Term Care, Mental Health, Rehabilitation, and Sub-acute Care*, April 1998.

Timely triaging of stroke survivors to the appropriate level of care to meet their needs is necessary to maximize optimal functioning. Coordination of care across the continuum of stroke rehabilitation means taking a systems approach rather than an institution-specific approach to care. Health care organizations and providers should not only provide exemplary rehabilitation in their respective areas, but develop linkages and interdependencies with one another to create a seamless continuum of rehabilitation care for stroke survivors.

Excellence in transition management is a shared responsibility that is built on trusting relationships between individuals in different institutions and clinical services. Stroke survivors experience a number of significant transition points that include moving from an acute care to a rehabilitation bed, leaving the hospital to go back home, and re-entering the rehabilitation system for additional care. These transitions involve transferring clinical and case management responsibility between different care providers and organizations. Family physicians play an important role in managing the transition of stroke survivors from the hospital to the community. The patient's discharge summary should be forwarded to his or her family physician within a specified time period to ensure that the physician plays an active role in the patient's successful transition back to the community. As further transitions are made, one responsible person should always have a complete picture of the patient. This might be the family physician, a nurse in the follow-up clinic, or a case manager.

Good transition management can make a big difference in what stroke survivors and their families experience as they move along the continuum of stroke rehabilitation. Integrating care across the continuum requires a coordinated effort by all partners as well as investments in time, staff and funding. For example, standardized forms and assessment protocols should be developed and used by all facilities. A second example is creating "cross-organizational care teams" to coordinate services for patients who are receiving care from more than one organization. Yet a third example is a common identifier to improve the flow of information across the continuum. These activities need to be supported by all partners - hospitals, CCACs and other health care providers - so that coordination is improved. The MOHLTC should consider providing resources where possible to support these initiatives.

It is recommended that:

R6 Hospitals, community care access centres and other health care providers work in partnership to improve the coordination of stroke rehabilitation, especially in the transition from hospital to community-based care. The Ministry of Health and Long-Term Care should consider providing resources to support these initiatives.

There are a number of strategies that can be used to create a seamless continuum of stroke rehabilitation that is client-focused and has as its ultimate goal, the reintegration of the stroke survivor into the community. One strategy is to develop guidelines for stroke rehabilitation, such as communication protocols and care pathways, with special attention to hand-off points

where stroke survivors are transferred from one level of service to another. These should be developed by a regional stroke rehabilitation team(s) in partnership with other stroke rehabilitation providers in institutions and in the community. Guidelines would identify when patients should be transferred from one care provider to another, the admission and discharge criteria, who has responsibility for ensuring that appropriate transfers take place, and how these should occur. These guidelines should address all aspects of a patient transfer from the emergency room to discharge home or to a long-term setting, and re-entry back into the system when necessary. Clinical information should flow smoothly and rapidly between the providers in the continuum so that decisions are made in a timely manner.

It is recommended that:

- R7 Hospitals, community care access centres and other health care providers work in partnership to develop guidelines for stroke rehabilitation including care pathways across organizations, and to pay special attention to hand-off points so that a seamless continuum of care is created.**

A second strategy to create a seamless continuum of stroke rehabilitation is to develop common objective, scientifically-based assessment tools that will support joint decision making and appropriate triaging of stroke survivors.

Building expertise in assessment and triage throughout the region should be a shared responsibility of local clinical leaders with the active support of the regional centre. A standardized assessment and triage protocol should be developed and implemented within each region. The development of the protocol should be guided by a number of current measures such as the Functional Independence Measure (FIM), which is a measure of disability and the most widely used clinical data set for inpatient rehabilitation. Recognizing that FIM has limitations, other factors should also be considered when developing the protocol such as language, orientation, availability of psychosocial supports and transportation.

It is recommended that:

- R8 The Ministry of Health and Long-Term Care mandate the provincial use of an objective assessment tool(s) for stroke rehabilitation based on a modified Functional Independence Measure. This tool(s) should be used by stroke rehabilitation providers across the continuum to ensure reliable, standardized and comprehensive assessments.**

INFORMATION

One of the challenges faced by the Panel in conducting its review of stroke rehabilitation was the lack of valid and reliable information. This made it difficult to:

- estimate the burden of impairment, disability and handicap in the stroke survivor population;
- estimate the need for stroke rehabilitation services;
- determine what is currently being done in stroke rehabilitation;
- evaluate the quality of stroke rehabilitation;
- describe outcomes based on current practice.

The Panel determined that it did not have a single approach to assess how the current system for stroke rehabilitation is working in Ontario. Although there is a wide variety of population studies and limited cross-sectional data, it was not possible to obtain a quantitative picture of what is happening within the stroke rehabilitation system in Ontario (see Appendix 7).

It is important to establish a stroke rehabilitation information system to monitor the provision of stroke rehabilitation. This data set should:

- Measure impairment, disability and handicap.
- Use the conceptual framework of the International Classification of Impairments, Disabilities and Handicaps (ICIDH). This framework focuses on the consequences of disease or injury, which is more predictive of resource utilization and client outcome than a diagnosis. The data set includes measures of impairment, disability/activity, and handicap/participation.
- Use the conceptual framework of a modified FIM. The grouping methodology must accurately reflect resource utilization and predict outcome. FIM-FRG as the basis of a grouping methodology has been independently studied by the RAND corporation and concluded to be appropriate for a prospective payment system. Furthermore, FIM-FRG has been concluded by CIHI to be a suitable classification tool in the Canadian context.
- Include indicators of resource utilization and efficiency, client outcomes, sustainability of outcomes over time, health characteristics, sociodemographics and system access.
- Include data linkages to span the episode of care across a variety of service settings.
- Be a minimal data set, recognizing that the collection of data is time intensive and should, therefore, only include essential elements.

Consideration should also be given to including resources for stroke patients in the database, supplemented by a helpline to provide quick access to information on supportive housing, transportation programs, etc.

This provincial database will permit regions to develop outcome benchmarks and learn from each other on what works best. It will also facilitate the tracking of patients over time to ensure some are not inadvertently denied access to local resources that can assist them and their families. This database will eventually become a longitudinal stroke registry and will be invaluable for stroke rehabilitation planning and research.

It is recommended that:

- R9 The Ministry of Health and Long-Term Care support the development of a stroke rehabilitation information system to monitor the provision of stroke rehabilitation. This system should include a data set based on the conceptual framework of the International Classification of Impairments, Disabilities and Handicaps, and a modified Functional Independence Measure.**

PROFESSIONAL SUPPORT

Professional caregivers that provide stroke rehabilitation must have the appropriate education to ensure that stroke survivors receive appropriate and effective care based on the most up-to-date knowledge and research. This education will increase awareness of the importance of early rehabilitation for stroke, how to maintain functional gains over time, and prevent complications.

Professionals with specialized stroke rehabilitation expertise have a valuable role to play consulting with other providers in the regional stroke rehabilitation system. These consultations will help disseminate knowledge about the most effective approaches and techniques in stroke rehabilitation.

One of the key responsibilities of regional centres is to transfer their expertise and specialized knowledge of stroke rehabilitation to other institution- and community-based providers in the region. As well, local units are expected to provide outreach services and expert consultations to providers in their areas. This transfer of clinical knowledge through educational outreach and expert consultations should be based on the most up-to-date information on stroke rehabilitation principles, processes and practices. Innovations like telehealth technology can be used to advance the level of expertise in the system.

It is recommended that:

- R10 Regional centres and local units provide outreach services to support the education of professional caregivers and enhanced consultations throughout regional stroke rehabilitation systems. The Ministry of Health and Long-Term Care should endeavour to support these outreach activities.**

RESEARCH

Effective stroke rehabilitation is based on the most up-to-date applied research. This research is critical for evaluating new rehabilitation techniques, for developing effective evidence-based approaches to stroke rehabilitation, and for making system improvements. A coordinated approach to research on stroke rehabilitation should strive to:

- be of maximum relevance to health care providers;
- ensure all areas of stroke research are represented;
- build stroke rehabilitation research skills;
- build interdisciplinary stroke rehabilitation research teams;
- ensure research findings are used in future research;
- involve younger, inexperienced researchers;
- ensure Ontario stroke research appears in peer reviewed journals;
- ensure stroke research is translated into practice (adapted from Avison et al., 1992).

An Ontario research agenda in stroke rehabilitation should include a broad range of areas that impact on the health, well-being and functioning of stroke survivors. Important areas of potential research include:

- Comparing the benefits of specialized interdisciplinary stroke rehabilitation provided in an outpatient versus a community setting.
 - Comparing outpatient therapy provided in a hospital versus a community-setting.
 - Assessing the benefit of alternative therapies and approaches.
 - Studying the efficacy of d-amphetamines in promoting stroke recovery.
 - Studying the treatment of sensorimotor deficits and impaired mobility assessment on the efficacy of exercise and functional motor retraining. (New techniques such as body weight support in gait training and forced-use (constraint-induced) paradigms need to be more rigorously tested.)
 - Assessing the efficacy of goal-specific treatment strategies for cognitive and perceptual deficits.
 - Developing guidelines for the use of VMBS studies (Videofluoroscopic Modified Barium Swallow).
 - Studying the efficacy of dysphagia management.
 - Studying the efficacy of nutritional management.
 - Studying the efficacy and impact of family and patient education and counselling.
 - Studying the efficacy of long-term or chronic rehabilitation interventions.
 - Studying the efficacy and impact of increased support for stroke patients and their families in the community.
-

Regional centres have an important role to play in furthering stroke rehabilitation research. In addition, Ontario's Academic Health Science Centres can play a role in coordinating the research agenda.

It is recommended that:

R11 The Ministry of Health and Long-Term Care and the Heart and Stroke Foundation of Ontario fund stroke rehabilitation research, with Ontario's Academic Health Science Centres playing a role in coordinating the research agenda.

Not only is it important to access funds to support stroke rehabilitation research, but efforts must also be made to review and summarize the results of this research. This will help maintain timely and accurate information on effective stroke rehabilitation, identify areas for further research, support continuous peer review, and encourage improved evidence-based practice. Support from a suitable Ontario organization is required to house this growing, practical resource on stroke rehabilitation.

In its review and assessment of the research literature, the Panel came to a number of conclusions and recommendations based on the evidence. In addition to the recommendations based on Level 1 evidence that are presented in Chapter 4 (Expert Advice Based on Research Evidence), 21 other recommendations can be made based on Level 2 or Level 3 evidence:

1. At the time of entry to a rehabilitation program, rehabilitation clinicians experienced in evaluation and administration of standard assessment instruments should evaluate disability in basic ADLs, motor, cognitive and communication abnormalities and family caregiver support (Level 3 evidence).
2. Realistic short- and long-term rehabilitation goals should be mutually agreed to by the patient, family and rehabilitation team (Level 3 evidence).
3. Stroke patients and their families should be thoroughly educated about stroke, its consequences and post-stroke care (Level 1b evidence).
4. Stroke patients with leg paralysis/immobility should be treated with low-dose heparin prophylaxis, warfarin or compression stockings (Level 1a evidence).
5. Anticoagulant medications should be considered in patients who have had a post-stroke seizure (Level 3 evidence).
6. Stroke patients with functional sensorimotor deficits and some voluntary movements of the involved arm and leg should be offered exercise and functional training directed at improving strength and motor control, relearning sensorimotor relationships and improving functional performance (Level 3 evidence).

7. Stroke patients with persistent functional deficits unresponsive to remedial therapy should be taught compensatory methods for performing functional tasks (Level 3 evidence).
8. Stroke patients with cognitive and perceptual deficits that do not preclude rehabilitation should receive goal-directed treatment (Level 3 evidence).
9. Stroke patients with aphasia should be offered language therapy (Level 1a evidence).
10. Stroke patients at potential risk of dysphagia should be clinically assessed acutely for aspiration, and dysphagia management should be instituted where appropriate (Level 2 evidence).
11. Stroke patients should be assessed for malnutrition and any deficiencies corrected (Level 2 evidence).
12. Spasticity and contractures should be managed with stretching exercises and proper positioning/splinting (Level 3 evidence).
13. The hemiplegic shoulder, particularly early on, should be properly positioned and supported, preferably not with slings. Overly vigorous range of motion or pulley exercises should be avoided (Level 1b evidence).
14. Stroke patients with persistent urinary incontinence should have cause-specific treatment (Level 2 evidence).
15. All stroke patients should be clinically screened for depression and where depression is present, antidepressant therapy offered if there are no contraindications (Level 1a evidence).
16. Health-related quality of life measures add patient-focused input to functional outcome measures.
17. Rehabilitation teams should be in a position to assist stroke patients and their caregivers in obtaining community supports (Level 3 evidence).
18. Valued leisure activities of stroke patients should be identified and facilitated (Level 3 evidence).
19. Sexual issues should be discussed with the stroke patient and significant others (Level 3 evidence).
20. Stroke patients should be carefully assessed regarding driving (Level 2 evidence).
21. Stroke patients should be provided with vocational assessment and counselling where appropriate (Level 3 evidence).

The above recommendations illustrate the important findings that would be collected from an ongoing organized review of stroke rehabilitation research.

It is recommended that:

- R12 The Ministry of Health and Long-Term Care and the Heart and Stroke Foundation of Ontario jointly support an ongoing program to review and summarize the evidence of stroke rehabilitation research, with the purpose of maintaining timely and accurate information on effective stroke rehabilitation, identifying areas for further research, supporting continuous peer review, and encouraging improved evidence-based practice.**

HUMAN RESOURCES

A comprehensive and effective system for stroke rehabilitation is only possible if there is a sufficient number of appropriate stroke rehabilitation caregivers (e.g., physicians, nurses, therapists and assistants).

A regional stroke rehabilitation system will need a human resources plan to ensure that there are a sufficient number of appropriate caregivers with workloads that are consistent with professional standards. In addition to regional human resources plans, there must be an overarching provincial plan.

It is critical to plan for the education and support of these caregivers so that stroke survivors are not faced with shortages of staff.

It is recommended that:

- R13 The Ministry of Health and Long-Term Care, in partnership with the health care field, develop a provincial human resources plan that will ensure the education of a sufficient number of appropriate stroke rehabilitation caregivers to support the vision and recommendations of this report.**

FUTURE WORK

Over the course of its work on stroke rehabilitation, the Panel recognized the importance of community reintegration and the wide range of support services needed by stroke survivors and their families. Although the Panel discussed models for the provision of psychosocial and practical support, it was agreed that an indepth review of this component of the continuum was beyond the Panel's mandate. The Panel concluded that a review of community reintegration needs to be conducted.

It is recommended that:

R14 The Heart and Stroke Foundation of Ontario (HSFO) establish a Consensus Panel with the participation of the Ministry of Health and Long-Term Care (MOHLTC) to 1) develop models for addressing community integration including the psychosocial and practical needs of stroke survivors and their families, and 2) identify the role of the HSFO, MOHLTC and other key institutions and organizations in assisting communities to eliminate barriers, support community reintegration, and develop effective strategies to meet the needs of stroke survivors.

This is an exciting time for stroke care in Ontario. The Joint MOHLTC/HSFO Stroke Strategy Working Group is developing a province-wide stroke strategy across the continuum that includes health promotion and disease prevention, emergency and acute care, and rehabilitation. The Panel trusts that its work will be useful to the Joint Working Group. The recently announced Canadian Stroke Network will provide a focus for further research. There is still a great deal that needs to be done.

It is recommended that:

R15 The Heart and Stroke Foundation of Ontario continue to play an advocacy role linked to other organizations and initiatives like the Canadian Stroke Network.

The members of the Consensus Panel believe that their review of the evidence for stroke rehabilitation and the vision that they have developed for a regional stroke rehabilitation system, are important contributions to the development of a framework for enhanced stroke care.

SUMMARY OF RECOMMENDATIONS

Development of Regional Stroke Rehabilitation Systems

- 1 Regional stroke rehabilitation systems be established that are linked to broader stroke networks and regional rehabilitation networks, to ensure a collaborative approach that is consistent with the vision for stroke rehabilitation presented in this report. This vision recognizes the importance of comprehensive and coordinated stroke rehabilitation that includes community supports such as transportation and housing.

Components of the Continuum

- 2 Hospitals with rehabilitation beds establish dedicated stroke units that include both short- and long-duration stroke rehabilitation beds. The regional stroke rehabilitation systems should monitor the demand for and use of these beds to determine appropriate benchmarks that will ensure access for stroke patients.
- 3 The Ministry of Health and Long-Term Care recognize that stroke rehabilitation includes a broad range of conditions some of which require highly specialized services, and that the specialized component of stroke rehabilitation be reflected in regional bed allocations in the regional rehabilitation facilities.

Ambulatory and Home-based Stroke Rehabilitation

- 4 The regional stroke systems monitor waiting lists and other indicators of need for ambulatory and home-based stroke rehabilitation, to determine the reinvestments required to meet regional needs, and to recommend to the Ministry of Health and Long-Term Care the resources that should be allocated to meet these needs.
- 5 The Ministry of Health and Long-Term Care fund pilot projects to identify best practices for home-based stroke rehabilitation. These pilot projects should examine best practices in a range of settings including urban, rural, northern and remote locations.

Mechanisms to Coordinate Care Across the Continuum

- 6 Hospitals, community care access centres and other health care providers work in partnership to improve the coordination of stroke rehabilitation, especially in the transition from hospital to community-based care. The Ministry of Health and Long-Term Care should consider providing resources to support these initiatives.
- 7 Hospitals, community care access centres and other health care providers work in partnership to develop guidelines for stroke rehabilitation including care pathways across organizations, paying special attention to hand-off points so that a seamless continuum of care is created.
- 8 The Ministry of Health and Long-Term Care mandate the provincial use of an objective assessment tool(s) for stroke rehabilitation based on a modified Functional Independence Measure. This tool(s) should be used by stroke rehabilitation providers across the continuum to ensure reliable, standardized and comprehensive assessments.

Information

- 9 The Ministry of Health and Long-Term Care support the development of a stroke rehabilitation information system to monitor the provision of stroke rehabilitation. This system should include a data set based on the conceptual framework of the International Classification of Impairments, Disabilities and Handicaps, and a modified Functional Independence Measure.

Professional Support

- 10 Regional centres and local units provide outreach services to support the education of professional caregivers and enhanced consultations throughout regional stroke rehabilitation systems. The Ministry of Health and Long-Term Care should endeavour to support these outreach activities.

Research

- 11 The Ministry of Health and Long-Term Care and the Heart and Stroke Foundation of Ontario fund stroke rehabilitation research, with Ontario's Academic Health Science Centres playing a role in coordinating the research agenda.
- 12 The Ministry of Health and Long-Term Care and the Heart and Stroke Foundation of Ontario jointly support an ongoing program to review and summarize the evidence of stroke rehabilitation research, with the purpose of maintaining timely and accurate information on effective stroke rehabilitation, identifying areas for further research, supporting continuous peer review, and encouraging improved evidence-based practice.

Human Resources

- 13 The Ministry of Health and Long-Term Care, in partnership with the health care field, develop a provincial human resources plan that will ensure the education of a sufficient number of appropriate stroke rehabilitation caregivers to support the vision and recommendations of this report.

Future Work

- 14 The Heart and Stroke Foundation of Ontario (HSFO) establish a Consensus Panel with the participation of the Ministry of Health and Long-Term Care (MOHLTC) to 1) develop models for addressing community integration including the psychosocial and practical needs of stroke survivors and their families, and 2) identify the role of the HSFO, MOHLTC and other key institutions and organizations in assisting communities to eliminate barriers, support community reintegration, and develop effective strategies to meet the needs of stroke survivors.
 - 15 The Heart and Stroke Foundation of Ontario continue to play an advocacy role linked to other organizations and initiatives like the Canadian Stroke Network.
-

APPENDIX 1: CONSENSUS PANEL ON STROKE REHABILITATION: TERMS OF REFERENCE

The Heart and Stroke Foundation of Ontario (HSFO), in consultation with the Ministry of Health and Long-Term Care (MOHLTC), established a consensus panel on stroke rehabilitation in 1999. The HSFO concluded that a consensus panel, including clinical experts in stroke rehabilitation, should explore the opportunities and systems required to develop an integrated model of stroke rehabilitation for Ontario that supports the principles of quality care, accessibility and affordability.

The Consensus Panel on Stroke Rehabilitation will link with, and provide timely advice to, the Joint Stroke Strategy Working Group.

Terms of Reference²¹

The Panel's purpose is to improve stroke rehabilitation service access, effectiveness, efficiency and clinical outcomes at one year in Ontario. The Panel will make recommendations based on scientific, population and service delivery data from Ontario, where available, on information from other comparable jurisdictions, and expert opinion from within and external to the Panel.

The Panel will:

1. define stroke and stroke rehabilitation;
2. describe the current system (public, private, regional, provincial, rural, northern, care provided by families) and identify system barriers;
3. describe the need for stroke rehabilitation (individual/population);
4. summarize what experts currently recommend in stroke rehabilitation based on best evidence;
5. design a system for stroke rehabilitation (planning principles, system evaluation, performance outcomes and indicators);
6. propose ways to close gaps in the provision of stroke rehabilitation, including in rural and northern Ontario.

The Panel will give due regard to the principles of quality care, accessibility and affordability in keeping with Ministry of Health strategies.

²¹ Terms of reference of the Stroke Rehabilitation Consensus Panel. Heart and Stroke Foundation of Ontario, October 25, 1999.

Membership of the Panel

Chair

Physician experts

Nursing and allied health stroke rehabilitation experts

Heart and Stroke Foundation of Ontario representative

Consumer or community representative

Program administrators and health planners

Clinical epidemiologist

Coordinated Stroke Strategy regional coordinator

Ministry of Health and Long-Term Care representatives (ex-officio)

Chair, Stroke Strategy Steering Committee (ex-officio)

Project Manager (ex-officio)

Term

The panel will meet over a six-month period of time. It will work closely with and provide timely advice to the Joint Working Group. The report of the Panel is to be completed and submitted to the Stroke Strategy Steering Committee by mid-March 2000.

Accountability

The recommendations of the Panel will be provided to the Heart and Stroke Foundation of Ontario through the Stroke Strategy Steering Committee. Throughout its work, the Panel will ensure ongoing communications and advice to the Joint Working Group on matters related to rehabilitation.

Minutes

Minutes shall be kept of all meetings and distributed to the Panel members.

APPENDIX 2: HISTORY OF THE DEVELOPMENT OF THE CONSENSUS PANEL ON STROKE REHABILITATION

Increasingly, stroke has been receiving more public attention. A number of years ago, Ontario neurologists pointed to new opportunities in the emergency treatment of stroke patients and the need for public awareness of the importance to respond urgently to the initial symptoms of a stroke, as with the initial symptoms of a heart attack (Hakim et al., 1998). Stroke survivors also voiced concerns about their need for more support in the life-long, post-acute phase of stroke. Rather than an immediate public awareness campaign focusing on the early symptoms of stroke, the Heart and Stroke Foundation of Ontario (HSFO) decided in 1996 to launch a three-prong strategy of public awareness, professional awareness of the new clinical tools, and health system change.

The HSFO looked beyond acute care to the whole continuum of care for stroke patients. It submitted a broad proposal to the Minister of Health in 1997. In response, the Ministry requested a profile of the current system. A survey of hospitals was subsequently sponsored jointly by the HSFO, the Ministry of Health and Long-Term Care (MOHLTC), the Ontario Hospital Association and the Institute for Clinical Evaluative Sciences. The resulting report - *Stroke Care in Ontario: Hospital Survey Results* - showed that there were wide variations in the availability of stroke rehabilitation in Ontario's hospitals (Tu and Porter, 1999). The authors recommended that a provincial group be formed to develop evidence-based guidelines for stroke rehabilitation that included appropriate indications for physiotherapy, occupational therapy and speech pathology, and that articulated the maximum acceptable waiting time for each of these rehabilitation services. The authors also recommended that the guidelines be used to develop strategies to ensure that rehabilitation waiting times across the province were within acceptable limits.

In 1997, the HSFO began to work directly with health care leaders at the regional level. A proposal was developed to help the grassroots evolve a coordinated approach to acute stroke care by providing an organizational structure within which all local players could work together. In 1998, the HSFO launched the Coordinated Stroke Strategy to develop and test a model of regional coordinated stroke care across the continuum of care. A Stroke Strategy Steering Committee led this work and publicized the HSFO's interest in local approaches to improve coordination across the continuum of stroke care. Strong expressions of interest were received from Queen's University at Kingston, Hamilton Health Sciences Corporation and the London Health Sciences Centre. A community-based consortium of institutions and community organizations in the western part of the Greater Toronto Area including Peel joined later, focusing on community rehabilitation and reintegration. This bottom-up "community development" model at the four sites will be evaluated.

The Stroke Strategy Steering Committee recognized a need for a deeper understanding of the sizeable rehabilitation component in the stroke care continuum. In September 1998, the Foundation hosted a Round Table to develop a vision for stroke rehabilitation in Ontario. The views presented and discussed were captured in a brief report (Stroke Rehabilitation Round Table, 1998). While making a valuable contribution as a first step, there was agreement that the HSFO still needed a more comprehensive approach to address stroke rehabilitation system change.

The Steering Committee examined the work of the Cardiac Care Network of Ontario (CCN) as a model of a comprehensive approach to cardiac care. CCN has used the consensus panel methodology to generate a number of influential reports. The MOHLTC established CCN as a provincial advisory body that emphasizes knowledge-based leadership, data and the development of planning frameworks. These values and the CCN process were built into the terms of reference for HSFO's Consensus Panel on Stroke Rehabilitation. The Panel held its first of six meetings in October 1999.

The Consensus Panel had cross-representation with the MOHLTC's Rehabilitation Reference Group. This Group was charged with undertaking a review of the MOHLTC's rehabilitation policy and providing Ministry leadership to rehabilitation in Ontario. The Consensus Panel had the opportunity to review and comment on the Group's consultation report.

In response to *Stroke Care in Ontario: Hospital Survey Results*, the HSFO and the MOHLTC agreed to establish a Joint Stroke Strategy Working Group. Established in August 1999, the Group is examining stroke prevention, the emergency and acute care system, and the unique aspects of stroke rehabilitation in the context of general rehabilitation reforms. One of the four key mandates of the Working Group is to make recommendations to the MOHLTC to examine the unique challenges, opportunities and possible future approaches to stroke rehabilitation. Another mandate is to examine current applicable research and education into stroke prevention, care and rehabilitation, and identify gaps and critical research and education needs for Ontario.

The Consensus Panel on Stroke Rehabilitation will report its findings on stroke rehabilitation to the Joint Working Group as well as to the Heart and Stroke Foundation of Ontario.

APPENDIX 3: INTERNATIONAL ENVIRONMENT FOR STROKE REHABILITATION

This appendix presents a brief summary of recent international initiatives, studies and reports on stroke rehabilitation. This information is presented using the following topic areas:

- task force/consensus reports;
- rural health care;
- geriatrics;
- health care costs;
- evidence-based medicine;
- clinical and health service research;
- basic research on therapy for recovery of function;
- outcomes;
- managed care;
- challenges to the field of rehabilitation;
- World Health Organization;
- recent developments.

Caution is required when comparing the international literature to the Ontario context. For example, skilled nursing homes in the United States are comparable to Ontario's chronic care hospitals.

Task Force/Consensus Reports

A number of reports reflect a comprehensive approach to stroke rehabilitation.

- The fifth King's Fund Forum in 1988 produced a consensus statement that recognized a number of barriers to effective rehabilitation including the urgent need for research on the cost and effectiveness of "most components of care" (King's Fund Forum, 1988).
- A World Health Organization (WHO) task force, with a member from Ontario, published a report on stroke prevention, diagnosis and therapy including rehabilitation. The report provides a template for the design of local systems for stroke rehabilitation (WHO, 1989).
- In 1995, the WHO Regional Office for Europe sponsored the development of a consensus statement on stroke management including rehabilitation. The statement notes that by 2005, all stroke patients should have access to specialized stroke units or stroke teams, more than 70% of stroke survivors should be independent in their daily activities by three months post-stroke, and WHO member states should be routinely collecting data to evaluate quality of care across a two year continuum. The data to be collected is outlined in the report by Aboderin and Venables (1996).

- The 1997 Asia Pacific Consensus Forum on stroke management recognized the need for a framework on minimal standards for stroke management. The report included stroke rehabilitation (Asia Pacific Consensus Forum, 1998).
- The National Stroke Foundation in Australia funded the development of a National Stroke Strategy as well as a strategy for the province of Victoria (National Stroke Strategy, 1997). The national report reflects priorities for stroke rehabilitation, whereas the Victoria report includes specific recommendations to improve local stroke rehabilitation.

Rural Health Care

There seems to be a limited number of organized consensus reports on the rural needs for stroke rehabilitation. A U.S. conference produced a report in 1995 on providing general rehabilitation services in rural communities (Jones and Brand, 1995). An Ontario study of outreach rehabilitation programs provided information on the unique rehabilitation needs in rural settings and described a number of Ontario efforts to meet these needs (Sullivan et al., 1993). While the efforts have been well received, Sullivan reported that most outreach was for assessment and consultation rather than for services. He also noted that although recommendations can be made, they cannot necessarily be fulfilled locally due to a lack of resources.

Geriatrics

Stroke rehabilitation is recognized as a major component of geriatric rehabilitation. A 1997 conference in the U.S. focused on the contribution that geriatric rehabilitation could make to improved health outcomes. The conference proceedings analyzed the barriers, potential strategies and prospects for improving the efficiency as well as the effectiveness of rehabilitation for the geriatric population (Lohr, 1997).

Health Care Costs

National and international reviews indicated that stroke is a very costly disease for survivors, hospitals, insurers and governments (Hankey and Warlow, 1999). In Ontario, the direct cost of stroke in 1994/95 was estimated to be \$514 million (Chan and Hayes, 1998). This was equal to almost 3% of the operating expenditures of the Ministry of Health and Long-Term Care in fiscal 1994/95 (Ontario Ministry of Finance, 1996). This percentage is fairly similar to the experience in other jurisdictions (Holloway et al., 1999).

Stroke rehabilitation is sensitive to increasing efforts at cost control, especially in acute hospitals (Chan and Hayes, 1998; Mayo, 1989). U.S. hospitals have been using early discharge to deal with the cost control incentives inherent in diagnosis-related group codes (DRGs) since the 1980s (Petchers et al., 1987). More recently, the 1997 Balanced Budget Legislation in the U.S. added further "profound" opportunities for innovative improvement of care to stroke patients in the community including rehabilitation care (Schmidt et al., 1999).

In the U.S., ambulatory rehabilitation in general has grown significantly in the past 10 years (Gill, 1995). While Ontario's health care system differs, the province has passed legislation requiring balanced budgets (Ontario, 1999). If the public health system cannot keep up with the need for stroke rehabilitation in the community, there may be increased demands for private innovation and investment in stroke rehabilitation.

Evidence-based Medicine

The U.S. Agency for Health Care Policy and Research (AHCPR) published a unique review of the evidence on the effectiveness of post-stroke rehabilitation (Gresham et al., 1995). This review was probably the first time the emerging methods for evidence-based medicine were applied to stroke rehabilitation. The AHCPR chose stroke rehabilitation because of its human and economic burden, the wide variations in practice patterns, and continued controversy over the benefits of stroke rehabilitation. This U.S. report provides an international benchmark and draws attention to the paucity of high quality studies outside of acute and inpatient rehabilitation.

In the U.K., Langhorne (1995) called for the development of comprehensive stroke services including rehabilitation based on "an evidence-based approach".

A number of Ontario organizations are very skilled in developing evidence-based recommendations. The Panel investigated whether the same level of evidence framework to assess clinical interventions was available at the macro level of health service research. The answer was "no", according to the Hospital Management Research Unit and the Canadian Health Service Research Foundation.

Clinical and Health Service Research

The development of evidence-based medicine has had a profound impact on the indications for clinical care, what should be provided and the content of professional practice (Ellenberg, 1996). There has been difficulty building the research base in stroke rehabilitation that is required to support greater consistency in clinical practice and public policy. Although some of the issues have been reviewed in national conferences (Loomis, 1994), the situation appears to be limiting the impact of cost-effectiveness research about stroke-related diagnostic, preventive, and therapeutic interventions on health policy (Holloway, 1999). There is an urgent need for more standardized methodologies, accepted measuring tools and agreement on key outcomes (Ottenbacher, 1995; Bath et al., 1998; Granger, 1998).

The number of good studies on stroke rehabilitation is growing. Langhorne (1995) believes that these studies will shape what is effective stroke rehabilitation, and to an increasing degree, who will receive service.

Basic Research on Therapy for Recovery of Function²²

While the natural history of stroke recovery is relatively well defined, therapy for recovery of function has not been well developed. One reason is the belief that the mature brain is unable to adapt to injury. Another is that rapid developments in basic science are slow to be applied to the human situation.

The belief that the brain is static in nature is now unacceptable. "Evidence exists that the circuitry of the brain is maintained dynamically, modified by use, and can respond to injury by modifying its structure and function that correlates positively with behavioural recovery."

Understanding the "natural history of recovery from stroke, further elucidating the mechanisms underlying recovery, and devising potential treatments to improve recovery are essential to the development of the scientific basis of rehabilitative and restorative neurology. Improvement in the quality of life for the many disabled stroke survivors depends on such advances."

Outcomes

The term "outcome management" coined by Ellwood (1998), focuses attention on the need for better information to link medical interventions with clinical, financial and health outcomes so that decision-making in health care is improved.

The outcomes movement originated in response to the routine assumption that treatments are effective in the absence of objective quantifiable support (Kilgore, 1995). Professional groups in rehabilitation now recognize that outcomes management challenge them to demonstrate the effectiveness of what they do (Ellenberg, 1996).

The emphasis on outcomes can be addressed at the micro level where individual facilities and programs select the outcomes they want to achieve. It is a challenge to select one easily measurable rehabilitation outcome for all stroke survivors in a geographic population. It is also a challenge to select an outcome to guide continuous improvement in a regional stroke rehabilitation system and to focus research investments. Payors are expecting to be assured that they are buying both cost effective and clinically effective rehabilitation (Pearson, 1995). It must be recognized, however, that the new technical skills and information systems required to provide useful information in rehabilitation are considerable, especially in the post-acute continuum (Kilgore, 1995).

²² This section is taken from Dombrov, 1991.

Managed Care

Controlling costs through better management has been driving recent North American developments in health care (Ginzberg, 1997). Some feel that efficiency is the key measure of performance rather than just effectiveness: how much functional gain is achieved each day is important rather than just demonstrating that improvement has taken place. Fears have been expressed that payers will be happy if outcomes stay the same and costs are reduced (Kane, 1997). Kane (1997) goes on to suggest that rehabilitation, "must first identify what it does well and then find ways to achieve the results less expensively."

Challenges to the Field of Rehabilitation

A decade ago, Banja (1990) warned the rehabilitation community that it had to assess its ability to withstand the forces destabilizing and demoralizing acute care in the U.S. He felt that the field could no longer rest on the historically high social value that it had enjoyed. He identified a number of vulnerabilities in rehabilitation:

- considerable fractionation with an ever growing list of subspecialties;
- the social worth of certain rehabilitation outcomes is frequently unclear;
- the challenge to prove its role in promoting functional outcomes;
- it's "caring" rather than "curing" persona.

Banja (1990) recommended two strategies to address these vulnerabilities. One, continue to produce empirically grounded studies demonstrating favourable patient outcomes and two, explain rehabilitation's identity within a context of social values. By the mid 1990s, it could be said that the field of rehabilitation had addressed the first strategy by embracing the call for good outcome studies based on scientific measurement principles (Kilgore, 1995). The second strategy - articulating the social value of rehabilitation - remains to be fully addressed.

World Health Organization (WHO)

The WHO continues to be a presence in the field of stroke rehabilitation and action for people with disabilities. The WHO's International Classification of Functioning and Disability defines "impairment", "disability" and "handicap", three terms that provide a simple, easily understood conceptual framework within which professionals, patients, the public and payors can communicate clearly about stroke rehabilitation. Although various definitions of these terms exist (Mayo et al., 1999), the WHO's definitions have created valuable common ground for interdisciplinary and interorganizational work on rehabilitation reform in Ontario (Ontario Medical Association, 1994). The definitions provide the foundation for all versions of the FIM-FRG systems used by UDSmr to predict inpatient length of stay. The FIM-FRG is considered appropriate for prospective payment in the U.S. (Stineman and Granger, 1998).

The WHO framework is being updated and the new terminology will likely have an impact on service delivery, outcomes research and planning. It has been noted that the WHO classification has had some adverse effects. For example, it is said to have contributed to the lack of trials measuring the effect of interventions on handicap, such as reintegration and good health-related quality of life outcomes, which are the ultimate aims of rehabilitation (Mayo, n.d.).

Recent Developments

Mayo (1998) highlighted development in stroke rehabilitation over the last six years in her recent update of the epidemiology and recovery of stroke:

- More precise measurement of stroke recovery shows the importance of improvements to be made in the first five weeks post-stroke.
 - The health system outcomes pursued in stroke rehabilitation should be broadened and reflect the concepts of “activities” and “participation” in the new WHO International Classification of Impairment, Disability and Handicap.
 - The inclusion of health-related quality of life measures in stroke research is “the most striking change that has occurred over the past five years”.
-

APPENDIX 4: NEUROLOGICAL REHABILITATION AFTER STROKE

This appendix describes the underlying biological mechanisms by which rehabilitation helps stroke survivors rebuild their lives. The following is adapted from a previously published review (Heitzner and Teasell, 1998).

Conceptual Framework

The World Health Organization published its International Classification of Impairments, Disabilities and Handicaps in 1980. This conceptual model suggests disease may give rise to impairment, which in turn may lead to the development of disability. Handicap results when an impairment or disability limits or prevents fulfilment of a social role that is normal for a person. This simple outcome (recovery) continuum for stroke can be used as a basic foundation to discuss recovery and related issues.

Recovery Outline for Stroke

DISEASE	IMPAIRMENT	DISABILITY	HANDICAP
Type of lesion • Infarction • Hemorrhage Size and site of lesion	Signs of lesion: • Praxis* • Executive Functions* • Visual • Dysarthria* • Dysphagia* • Language • Attention/Spatial Functions • Memory	Limitations in activities of daily living Management of: • Bowel • Bladder • Dressing • Bathing • Eating • Communication • Locomotion	Limitation in social roles such as • Physical dependence • Mobility • Occupation • Economic self-sufficiency

* Praxis: actions and overt behaviour (Mosby's 4th Edition); Executive Functions: judgement and decision making; Dysarthria: difficult, poorly articulated speech, resulting from interference in the control over the muscles of speech (Mosby's 4th Edition); Dysphagia: difficulty in swallowing (Mosby's 4th Edition).

Functional Recovery from Stroke

Recovery following a stroke can be roughly divided into two levels:

1. spontaneous or intrinsic neurological recovery of impairments;
2. functional or adaptive recovery from disability.

1. Spontaneous or Intrinsic Neurological Recovery

As a rule, the severity of the initial deficit is inversely proportional to the prognosis for recovery. Most spontaneous recovery occurs during the first three to six months after the onset of stroke. The course of recovery negatively accelerates as a function of time and is a predictable and law-abiding phenomenon. This type of recovery has until recently been regarded as largely inaccessible to medical intervention or manipulation. Neurological deficits resulting from a stroke are often referred to as impairments. These are determined primarily by the site and extent of the stroke.

Peak neurological recovery from stroke occurs within the first one to three months. A number of studies have shown that recovery may continue at a slower pace for at least six months. In up to 5% of patients, recovery may continue for up to one year, especially in that group of patients most severely disabled at the time of initial examination. Progress towards recovery may be arrested or may plateau at any stage of recovery with only a very small percentage of those with moderate to severe stroke (about 10%) achieving full recovery.

The return of motor power is not synonymous with recovery of function. Function may be hampered by the inability to perform skilled coordinated movements, apraxias (inability to perform purposeful acts), sensory deficits, communication disorders and cognitive impairment. Functional improvements may occur in the absence of neurological recovery. Functional recovery (the ability to do activities despite limitations) and improvement in communication may continue for months after neurological recovery is complete.

2. Functional or Adaptive Recovery

Functional recovery refers to improvement of independence in such areas as self-care and mobility. It depends on the patient's motivation,²³ ability to learn and family supports as well as the quality and intensity of therapy. This type of recovery is accessible to intervention/manipulation and is influenced by, but may occur independently of, neurological recovery. Functional deficits are often referred to as disabilities and are measured in terms of ability to perform activities of daily living.

The ability to ambulate is an important outcome after stroke. However, many initially dependent walkers never achieve what would be considered walking speeds that are needed to become independent community ambulators. Thus, better rehabilitative strategies are needed to get more patients independent in walking longer distances at speeds that permit efficient community activities.

Upper extremity function is another important outcome. Arm and hand function for most patients tend to improve for up to 12 weeks. Patients who have fair function by three months, whereby they can flex and extend the affected fingers and wrist, can improve for more than a year in specifically practised tasks.

²³ Motivation is the drive to improve function and overcome disability, and is cited as an essential factor for successful rehabilitation. The perceived lack of motivation in elderly patients has been put forward as the reason for not accepting them into intensive stroke rehabilitation programs. Lack of motivation has often been linked to poor or modest outcomes. However little research has been done on the role of motivation in the rehabilitation process and the causes of poor motivation. The elderly patient's "lack of motivation" may be part of depression, an expression of personality, or the effect of comorbid illnesses. It may also represent a loss of hope or an expression of cultural/spiritual values.

Higher cerebral functions are also likely to show some improvement despite a serious initial impairment. Approximately 35% of acute stroke patients will have an aphasia on admission to an acute hospital, and approximately 18% at discharge from the acute and rehabilitation stay. Most improvement occurs within 12 weeks, although gains that are important for social functioning may continue for a year.

Multiple cognitive impairments that equate to a dementia are becoming increasingly recognized. Some patients will improve over the six months post-stroke. However, dementia was found in a community study to be nine times more frequent in the first year after stroke than expected (Kokmen et al., 1996). Dementia is a new potential issue complicating long term outcome in stroke, especially in the elderly.

Individual Studies Looking at Recovery

Jorgensen et al. (1995b) studied 1,197 acute stroke patients. His Copenhagen Stroke Study consisted of a large unselected community-based population. Impairments were classified using the Scandinavian Neurological Stroke Scale (SNSS) and functional disability was defined according to the Barthel Index (BI). The researchers found that 21% of stroke patients died. The initial impairments of the stroke survivors were 1/3 severe to very severe, 1/3 moderate and 1/3 mild. Typically, recovery for impairment and functional disability meant the highest recorded scores in SNSS and BI, respectively, with no further improvement.

Neurological recovery occurred an average of two weeks earlier than functional recovery. The table presents the recovery from neurological and functional disabilities over time. In stroke survivors, the best neurological recovery in 80% of the patients occurred within 4.5 weeks, while best ADL function was achieved by six weeks. The timing of neurological and functional recovery was strongly related to initial stroke severity and functional disability. Jorgensen et al. (1995b) demonstrated that 2/3 of stroke survivors have mild to moderate strokes and are able to achieve independence in activities of daily living.

Impairment and Functional Disability Outcome of the Survivors in the Copenhagen Stroke Study (Jorgensen et al., 1995b)

Impairment Recovery			Functional Disability Recovery		
Category	% of Survivors ¹	Weeks ²	Category	% of Survivors ¹	Weeks ²
Very Severe	4	10	Very Severe	14	11
Severe	7	9	Severe	6	11.5
Moderate	11	5.5	Moderate	8	6
Mild/No Disability	78	2.5	Mild	26	2.5
			No Disability	46	

¹ Percentage of survivors after rehabilitation was completed.

² Time required for best recovery reached in 80% of the patients after rehabilitation was completed.

Maintenance of Stroke Recovery

Once functional status remains relatively stable, it plateaus. Between six months and three years post-stroke, the average level of functional ability is maintained. Beyond five years, slight increases in institutionalization and deterioration in function are noted, most likely related to the effects of increasing age and comorbidity. Although overall function remains stable, there are differential shifts in performance of specific functions following stroke rehabilitation. Mobility and bowel incontinence continue to improve long term. However, activities of daily function tend to decline. This has been related to caregivers providing increasing assistance once patients are discharged home.

One significant finding is that following stroke several social activities decline. Socialization in and outside the home, as well as various hobbies, decline significantly. The stroke impairment itself does not fully account for the decrease in socialization.

Prognostic Factors

Several indicators predict the degree of recovery, outcome and the likelihood of making substantial gains in rehabilitation. These include:

- age;
- stroke severity;
- cognitive problems;
- medical comorbidities;
- supportive environment;
- incontinence;
- neglect or visual spatial difficulties;
- presence of a supportive caregiver;
- depression;
- functional abilities on entry into rehabilitation.

Comorbidity is particularly important in stroke rehabilitation. For example, patients with a history of congestive heart failure do significantly less well in rehabilitation as do persons with a history of previous strokes. Rehabilitation has also been shown to be ineffective in elderly stroke patients with severe dementia. The prognostic impact of comorbidities tends to be cumulative such that the aggregate impact of comorbidity affects outcomes.

Neurophysiological Basis of Recovery

Animal models that study recovery of motor function after stroke offer the potential to examine the mechanisms of specific rehabilitative strategies on brain recovery. It is likely that those techniques resulting in the most robust plasticity in brain will be those that result in the most extensive neurological recovery.

Terminology for Post-injury Gains (Adapted from Dobkin, 1997:Table 6)

Term	Definition	Dobkin's Comment
Recovery	Complete return of identical functions that were lost or impaired.	
Restitution	Tendency of a neural network to recover after an interruption as a consequence of internal, biologic events.	Relatively independent of external variables such as physical and cognitive stimulation. It includes the biochemical events that tend to recover in neural tissue.
Substitution	Functional adaptation of a defective but partially restored neural network that depends on external stimulation.	Depends on external stimuli such as rehabilitative interventions. Partially restored neural networks compensate for components lost or disrupted by the injury.
Sparing	Adequate function through residual neural pathways.	
Compensation	Functional adaptation for an impairment or disability	

Processes Involved in Spontaneous or Intrinsic Neurological Recovery

A number of processes have been identified in neurological recovery after a stroke. The role these factors play in intrinsic or spontaneous recovery is not completely understood. Recovery from stroke is often attributed to resolution of edema and return of circulation to the ischemic penumbra. However, these mechanisms do not account for the recovery that typically occurs several weeks after stroke.

Factors that contribute to recovery fall into three categories:

1. local central nervous system (CNS) processes (early recovery);
2. central nervous system reorganization (later recovery);
3. secondary peripheral factors.

Mechanisms of Recovery from Stroke (Adapted from Dombrov, 1991)

Mechanism	Time Frame of Occurrence
1. Local Processes <ul style="list-style-type: none"> • Resolution of edema • Resolution of ischemic penumbra • Resolution of remote functional depression (diaschisis) 	<ul style="list-style-type: none"> • Weeks to 2 months • Hours to weeks • Days to months
2. CNS Reorganization <ul style="list-style-type: none"> • Neurotransmitter alterations • Unmasking (release from inhibition) of ipsilateral and alternate pathways • Synaptogenesis 	<ul style="list-style-type: none"> • Immediate to a few months • Weeks to month • Weeks to years
3. Secondary Peripheral Factors	

1. Local Central Nervous System (CNS) Processes (Early Recovery)

These local processes leading to initial clinical improvement occur independent of behaviour or stimuli:

Local Edema

Post-stroke edema surrounding the lesion may disrupt nearby neuronal functioning. As the edema subsides, these neurons may regain function. Much of early recovery is probably due to resolution of edema surrounding the infarcted area. This process may continue for up to eight weeks but is generally completed much earlier. Cerebral hemorrhages tend to have more edema, which may take longer to subside.

Diaschisis

This is a state of depressed function that results from a sudden interruption of a major input to a part of the brain remote from, but functionally connected to, the site of brain damage. Injury to one area of the brain can suddenly deprive other areas of normal brain tissue of a major source of stimulation. The term diaschisis was coined to describe these distant effects which appear to be reversible. Neuronal function may return with resolution of diaschisis.

Reperfusion of the Ischemic Penumbra

A focal ischemic injury consists of a core of low blood flow that eventually infarcts, surrounded by a region of reduced blood flow, the ischemic penumbra, which is at risk of infarction but still salvageable. Reperfusion of this area can allow affected and previously non-functioning neurons to resume functioning with subsequent clinical improvement.

2. Central Nervous System Reorganization (Later Recovery)

Dombovy (1991) notes that some of the basic mechanisms thought to underlie the later return of function are, the bilaterality of the brain, dendritic sprouting and synaptogenesis, unmasking of alternative pathways, and development of cortical inhibition. In addition, numerous alterations in neurotransmitters and cerebral metabolism occur following brain injury. These contribute to the observed deficits via interactions, both at the site of injury and in remote areas of the brain (diaschisis).

Importance of Brain Plasticity

The potential for significant plasticity of the human central nervous system is widely accepted. With regard to the motor system, this neuroplasticity has broad implications for motor learning and functional recovery after a stroke.

Recovery of function can continue for months or years. Traditionally, neurology has emphasized the correlation between the localization of the lesion and the deficit in functioning. Certain areas of the brain control certain functions. When an area is destroyed that function is lost. While this approach is essential to an understanding of neurological symptoms and syndromes, it has frequently led to therapeutic nihilism. Greater emphasis is being placed on the plasticity of the brain and increased efforts to obtain maximum recovery and reorganization of function of the damaged nervous system. There is increasing evidence that much of the recovery after CNS insult depends upon adaptive restructuring of the residual functioning brain tissue. In large strokes, the deficit is greater and recovery more limited because there is less residual brain tissue.

Many mechanisms account for improvement following stroke. Much of the improvement is simply learning compensatory techniques. However, a range of potential biological mechanisms may contribute to gains through neuroplasticity, which in turn may interact with other variables, for instance, a higher premorbid level of education predicts better cognitive and functional outcomes. Age, the number of lesions, the timing of sequential lesions and genetic factors also contribute to the degree of neuroplasticity and the potential for neurorestoration.

Plasticity in the somatosensory cortex was shown in the early and mid-1980s. It was demonstrated in primates that sensory representation of the palms and fingers underwent substantial reorganization in the somatosensory cortex following a peripheral nerve injury or after differential sensory stimulation of restricted skin surfaces. Similar cortical changes, whereby adjacent neurons take over lost functions in primate motor systems in response to repetitive training, have been noted. During motor learning, multiple areas of adjacent cortex are "recruited". In human studies after stroke, functional imaging and cortical magnetic stimulation techniques show that multiple groups of neurons that represent aspects of a sensorimotor or cognitive behaviour can expand their representations to neighbouring cells that then participate in the behaviour.

Functional Role of Brain Structures

One explanation for these varying rates of recovery is that the rate of recovery depends on the functional role of the damaged structures. Recovery is delayed after injury to structures that control elementary functions requiring immediate execution (movement, sensation, vision, etc.). These functions involve precise neural networks. Injury results in slower recovery and long-lasting dysfunction. In contrast, the networks of structures mediating higher cortical functions are extensive and distributed. As a result, they are capable of adaptive restructuring with quicker and more complete return of the lost function (e.g., aphasia, apraxia, neglect). If there is a large lesion and the entire network responsible for the higher cortical function is destroyed, there may be little if any recovery (e.g., global aphasia).

The concept of a tight relationship between brain structure and a given cognitive or behavioural function has led to the belief that once a specific area of the brain is lost it results in irrevocable loss of function by that brain tissue. Laboratory and clinical findings do not always support strict localization, which provides support for recovery. For example, experimental results in animals show that brain damage created in two temporally separated surgeries, often produces much less behavioural dysfunction than when the same tissue is removed in one surgery. In addition, slowly evolving tumours often produce much less behavioural dysfunction than rapidly evolving strokes affecting the same region. As well, the structure determines function concept, and does not account for spontaneous recovery in the absence of lost tissue. This process of CNS reorganization or adaptation is not felt to be spontaneous but results from responses to stimuli or learning.

Learning vs. Recovery

Both neurological recovery and motor learning occur post-stroke. There are no data to contradict the supposition that individuals post-stroke can learn new motor skills using their involved limbs in a fashion similar (although attenuated) to healthy individuals. The ability to learn new motor skills likely represents a continuum based on the severity of neurologic deficits. Several studies have shown the ability of individuals post-stroke with chronic, stable motor deficits to improve their motor functioning after specialized intensive training. Also, the amount of improvement correlates with the intensity of rehabilitation. Is this neurological recovery or is it learning? Can the two phenomena truly be distinguished? Cortical mapping has demonstrated changes in the organization of the cerebral cortex associated with learning motor tasks in the intact brain, as well as in the injured brain.

3. Secondary Peripheral Factors

Secondary peripheral factors refer to general deconditioning and muscle weakness that accompany any prolonged period of bed rest. These factors add to already apparent neurologic deficits.

APPENDIX 5: SUMMARY OF THE RESEARCH EVIDENCE ON THE EFFECTIVENESS OF STROKE REHABILITATION

Dr. Robert Teasell reviewed the research literature on stroke rehabilitation with an emphasis on studies done after the Agency for Health Care Policy and Research report (AHCPR) (Gresham et al., 1995). The research methods and findings were written and circulated to a subgroup of the Consensus Panel for review. The brief summary prepared by Dr. Teasell for the Panel's deliberations is presented below. It includes recommendations showing how the evidence can be translated into practice.

Recommendations made in the ACHPR Stroke Rehabilitation Guidelines (Gresham, 1995) are indicated by “*”. The “major” recommendations appear in Chapter 4 as expert advice based on research evidence. The “minor” recommendations are presented in Chapter 6 to illustrate the various clinical guidelines that can come from a systematic ongoing review of the research evidence.

STROKE OUTCOME MEASURES

Functional Outcome Measures

- The Barthel Index is largely an activities of daily living scale (ADL), reliable and well-validated. It fails to measure cognitive or communication functions.
- The Functional Independence Measure (FIM) is more comprehensive than the Barthel; it is reliable and well-validated. It is limited in its ability to measure cognitive and communication measures.
- The PULSES Profile is a simpler functional outcome score. It is reliable and valid but suffers from an inability to measure discrete functions.
- The Canadian Institute for Health Information (CIHI) recommended FIM for use in facility-based settings. It was suggested, however, that additional cognitive and communication items would improve the usefulness of FIM in stroke.

Major Recommendation: *An overall functional outcome score that is reliable, valid and easily administered should be used to assist with acute triaging, monitoring of rehabilitation progress and phasing out of rehabilitation support. Currently, the best overall functional measure is FIM. It is highly reliable and valid, is well recognized across Canada and has been endorsed by CIHI (Level 1a evidence). Since FIM is inadequate for assessing communication and cognitive elements for stroke patients, additional elements or assessment tools in these areas will be necessary.*

Health-Related Quality of Life Measures (QOL)

- QOL measures enable broadening of the scope of outcome measures and provides for patient input. QOL measures are more subjective and are sometimes used to direct attention away from the lack of success of therapy when measured by more objective indicators.

Minor Recommendation: *Health-Related Quality of Life Measures can add patient-focused input to functional outcome measures.*

COMPREHENSIVE STROKE REHABILITATION PROGRAMS

Stroke Rehabilitation Efficacy Studies

- Strong (Level 1a) evidence that specialized (interdisciplinary) stroke rehabilitation units improve a variety of medical and functional outcomes when compared to rehabilitation delivered on general medical units.
- Strong (Level 1a) evidence that greater intensities of therapies result in improved functional outcomes, although the effect is modest.
- Strong (Level 1a) evidence that rehabilitation has an independent role in improving functional abilities beyond that explained by neurological recovery alone.
- Moderate (Level 1b) evidence that specialized stroke rehabilitation units provide better functional outcomes for the same resources as general rehabilitation units.

Major Recommendation: *Following an acute stroke, patients who meet the criteria should have access to specialized (interdisciplinary) stroke rehabilitation (Level 1a evidence).*

Timing of Stroke Rehabilitation

- Strong (Level 1a) evidence that earlier rehabilitation interventions are associated with improved functional outcomes.
- *Limited (Level 2) evidence that patients with an acute stroke should be mobilized as soon as is medically feasible.
- *Consensus (Level 3) evidence that stroke patients should be encouraged to perform self-care activities as soon as medically feasible and, if necessary, should be offered compensatory training to overcome disabilities.

Major Recommendation: *Following an acute stroke, appropriate patients should be mobilized and transferred to a specialized interdisciplinary rehabilitation unit as soon as medically stable (Level 1a evidence).*

Baseline Assessment at the Time of Rehabilitation Admission

- Functional outcome measures such as the FIM provide objective measures of functional ability.
- Strong (Level 1a) evidence that functional deficits at the time of admission to rehabilitation are correlated with functional outcomes at rehabilitation discharge and long-term follow-up.
- *Consensus (Level 3) opinion that a well-standardized measure of disabilities in basic ADL should be administered to all patients by a rehabilitation professional who is skilled in its use.
- *Consensus (Level 3) opinion that baseline assessment of motor function should include a thorough evaluation of motor control and muscle strength, mobility, balance, and coordination (using standardized instruments). Assessment should be performed by professionals who are experienced in rehabilitation, the evaluation of neurological impairments and the completion of these instruments.
- *Consensus (Level 3) opinion that a psychological examination should be performed in patients who show evidence of cognitive or emotional problems on clinical examination or a mental status screening test. Complete neuropsychological testing is required when more precise understanding of the deficits will facilitate treatment.
- *Consensus (Level 3) opinion that patients with problems in functional communication on routine testing should be evaluated using a motor-speech examination, a functional assessment of language and communication abilities, and selected standardized tests; assessment should be performed by a professional who is experienced in the evaluation of speech and language disorders and in the administration of these instruments.
- *Consensus (Level 3) opinion that assessment of family and potential caregiver support and of the living environment is an important part of baseline assessment. A well-standardized instrument should be used when applicable.

Minor Recommendation: *At the time of admission to a rehabilitation program, rehabilitation clinicians experienced in evaluation and administration of standard assessment instruments should evaluate disability in basic activities of daily living (ADLs), motor, cognitive and communication abnormalities and family and caregiver support (Level 3 evidence).*

Setting Rehabilitation Goals

- *Consensus (Level 3) opinion that both short- and longer-term goals need to be realistic in terms of current levels of disability and the potential for recovery; goals should be mutually agreed to by the patient, family, and rehabilitation team and should be documented in the medical record in explicit, measurable terms.

Minor Recommendation: *Realistic short- and long-term rehabilitation goals should be mutually agreed to by the patient, family and rehabilitation team (Level 3 evidence).*

Education and Discharge Planning

- *Consensus (Level 3) opinion that patients who survive the acute stroke, and their families, should be thoroughly instructed in the effects and prognosis of the stroke, potential complications, and the need and rationale for treatments.
- *Consensus (Level 3) opinion that families or involved others should be active participants in the rehabilitation process.
- *Consensus (Level 3) opinion that discharge planning should begin at the time of admission.
- *Moderate (Level 1b) evidence that patients, families and involved others should be given information and provided with ample opportunity to learn about the causes and consequences of stroke and the goals, process, and prognosis of rehabilitation. Family members and other potential caregivers should receive thorough training in techniques and problem-solving approaches required to provide effective support.

Monitoring Progress During Rehabilitation

- *Consensus (Level 3) opinion that the patient's progress during rehabilitation should be documented at least weekly during an intense rehabilitation program in an inpatient rehabilitation facility, and at least every other week during less intense inpatient or outpatient and home rehabilitation programs. A subset of the standardized measures administered at baseline assessment should be chosen, targetting those impairments and disabilities that have been the focus of treatments during the preceding period.

Discharge from Stroke Rehabilitation

- *Consensus (Level 3) opinion that discharge from a rehabilitation program should occur when reasonable treatment goals have been achieved. Absence of progress on two successive evaluations should lead to reconsideration of the treatment regimen or the appropriateness of the current setting.
- *Consensus (Level 3) opinion that assessment prior to discharge should include the patient's functional status, the proposed living environment, the adequacy of support by family or involved others, financial resources, and the availability of social and community supports.
- *Consensus (Level 3) opinion that discharge planning should begin at the time of admission. It should be a systematic, interdisciplinary process, coordinated by a single health provider. It should intimately involve the patient and family. It should include assessment of the patient's living environment, family/caregiver support, disability entitlements, and potential for vocational rehabilitation. To the maximum extent possible, all decisions should reflect a consensus among the patient, family/caregivers, and rehabilitation team.

OUTPATIENT REHABILITATION

Durability of Rehabilitation Gains

- Moderate (Level 1b) evidence that functional gains are maintained over the short-term.
- Moderate (Level 1b) evidence that functional gains decline over the long-term.

Community-Based vs. Hospital-Based Initial Stroke Rehabilitation

- Strong (Level 1a) evidence that higher level stroke patients can be discharged and rehabilitated in the community by interdisciplinary stroke rehabilitation teams rather than on an inpatient rehabilitation unit and achieve similar outcomes. Where introduced, such programs reduce hospital length of stay by approximately one week.
- Limited (Level 2) evidence that such programs do not significantly reduce overall costs.
- Moderate (Level 1b) evidence that discharging moderately or severely impaired stroke patients back to the community has significantly worse outcomes than admission to a specialized stroke rehabilitation unit.
- Moderate (Level 1b) evidence that discharging moderately or severely impaired stroke patients back to the community means that a significant number of patients will receive inadequate rehabilitation services in the rehabilitation phase.

Major Recommendation: *Higher level stroke rehabilitation patients can be discharged following acute stroke care to outpatient or community-based interdisciplinary stroke rehabilitation programs (Level 1a evidence).*

Major Recommendation: *Moderate and severe stroke patients should be managed on specialized inpatient rehabilitation units (Level 1b evidence).*

Outpatient Stroke Therapy in the Sub-acute Phase

- Strong (Level 1a) evidence that stroke patients benefit from outpatient rehabilitation programs when compared to no treatment.
- Conflicting evidence as to whether home-based outpatient therapy is superior to treatment in hospital-based outpatient therapy.
- *No consensus that one form of outpatient therapy delivery is superior to another.
- Limited (Level 2) evidence that for elderly frail stroke patients, day hospital services reduce death and institutionalization when compared to home-based outpatient therapy.
- Limited (Level 2) evidence that for younger stroke patients, home- or community-based outpatient rehabilitation improves functional and quality of life outcomes.

Major Recommendation: *Stroke patients should have access to outpatient interdisciplinary specialized, stroke rehabilitation programs, that can be hospital or community-based (Level 1a evidence).*

Rehabilitation in the Chronic Phase

- Limited (Level 2) evidence that long-term stroke rehabilitation is beneficial.
- *Consensus (Level 3) opinion that the stroke survivor's continuing care needs should be coordinated by a single physician or health care provider with the stroke survivor and the principal caregiver.
- *Consensus (Level 3) opinion that the stroke survivor's progress should be evaluated within one month after return to a community residence and at regular intervals during at least the first year, consistent with the person's condition and the preferences of the stroke survivor and family. Monitoring of physical, cognitive, and emotional functioning and integration into family and social roles is especially important.
- *Consensus (Level 3) opinion that continued rehabilitation services should be considered to help the stroke survivor sustain the gains from the rehabilitation program and to build on patient and family strengths and interests as that patient becomes reintegrated into the home and community. Services should be phased out as measurable benefit diminishes.

Specific Interventions in Long-Term Rehabilitation

- Moderate (Level 1b) evidence that physiotherapy/occupational therapy in the long-term phase improves functional and quality-of-life outcomes.
- Limited (Level 2) evidence that long-term aphasia treatment improves language impairments and functional communication.
- Limited (Level 2) evidence that leisure therapy counselling improves the number of leisure activities.

Major Recommendation: *Long-term rehabilitation services should be available to appropriate stroke patients. The services that are provided should be based on demonstrated need and improvements in functional outcomes, and will often involve only one discipline (Level 2 evidence).*

STROKE REHABILITATION TRIAGE

Entry to Rehabilitation

- *Consensus (Level 3) opinion that to the maximum extent possible, decisions about entry into a rehabilitation program should reflect a consensus among the patient, family or involved others, physician (in collaboration with care providers), and the rehabilitation program.
 - *Consensus (Level 3) opinion that the most important determinants of the need for a rehabilitation program are the patient's type/types and severity/severities of impairments and functional disabilities, the ability to learn, and physical activity endurance.
-

- *Consensus (Level 3) opinion that admission to an interdisciplinary rehabilitation program should generally be limited to patients with disabilities in two or more of the following areas of function: mobility, performance of the basic activities of daily living, bowel or bladder control, cognition, emotional functioning, pain management, swallowing and communication.
- Consensus (Level 3) opinion that health care providers and hospitals who refer patients to rehabilitation programs should be knowledgeable about the capabilities of programs in their communities.

Major Recommendation: *Acute stroke patients should be assessed by an experienced rehabilitation clinician(s). He or she should use objective assessment criteria to determine the intensity and setting most appropriate for the patient (Level 1a evidence).*

Stroke Rehabilitation Patient Selection/Triage

- The two most powerful predictors of functional recovery and eventual discharge home are initial stroke severity and the patient's age and these can be used to determine appropriate stroke rehabilitation triage.
- Patients can be divided up into three groups based on stroke severity: mild, moderate and severe.

Mild Strokes

- Strong (Level 1a) evidence that mild stroke patients can be rehabilitated in an outpatient setting.
- *Consensus (Level 3) opinion that stroke patients who met threshold criteria and require only supervision or minimal assistance in mobility or ADL are usually candidates for home or outpatient rehabilitation if the home environment and support are adequate, or for a nursing facility if they are not.
- *Consensus (Level 3) opinion that stroke patients who have a mild functional deficit but are able to live independently and manage both basic or more complex activities of daily living may benefit from selected rehabilitation services, but do not require an interdisciplinary rehabilitation program.

Moderate/Severe Strokes

- Moderate (Level 1b) evidence that moderately severe strokes are best managed in comprehensive intensive stroke rehabilitation units.
- Limited (Level 2) evidence that severe strokes are best managed in more long-term less intensive stroke rehabilitation units as compared to comprehensive intensive stroke rehabilitation units.
- *Limited (Level 2) evidence that patients who meet threshold criteria and need moderate to total assistance in mobility or performing basic activities of daily living are candidates for an intense rehabilitation program, if they are able to tolerate three or more hours of physical activity each day, or less intense programs if they are not.

Age

- Limited (Level 2) evidence that younger stroke patients <55 years of age should be admitted to inpatient intensive rehabilitation units even if severe.
- Limited (Level 2) evidence that elderly stroke patients >75 years of age in the lower half of the middle severity group should be admitted to less-intensive stroke rehabilitation units.

SPECIFIC REHABILITATION INTERVENTIONS

Medications in Stroke Recovery

- Conflicting evidence that d-amphetamines improve neurological recovery following a stroke.
- Suggestion, based on animal studies, that certain medications may inhibit neurological recovery.

Recurrent Stroke Risk

- *Strong (Level 1a) evidence that cause-specific measures to prevent recurrent strokes should be considered and implemented in all patients.

Major Recommendations: *Strategies to prevent the recurrence of strokes should be optimized (Level 1a evidence).*

Medical Comorbidities

- *Strong (Level 1a) evidence that measures to prevent deep venous thrombosis (DVT) are effective in markedly reducing the risk. Preferred treatments for DVT prophylaxis are low-dose heparin and low molecular weight heparin. Warfarin, intermittent pneumatic compression and the use of elastic stockings are also effective.
- *Consensus (Level 3) evidence that patients who have had seizures after stroke should be given anticonvulsant medications to prevent recurrent seizures.

Minor Recommendation: *Stroke patients with leg paralysis/immobility should be treated with low-dose heparin prophylaxis, warfarin or compression stockings (Level 1a evidence).*

Minor Recommendation: *Anticonvulsant medications should be considered in patients who have had a post-stroke seizure (Level 3 evidence).*

Sensorimotor Deficits and Impaired Mobility

- *Limited (Level 2) evidence that stroke patients, who have functional deficits and at least some voluntary control over movements of the involved arm or leg, will benefit from being encouraged to use the limb in functional tasks and be offered exercise and functional training directed at improving strength and motor control, relearning sensorimotor relationships, and improving functional performance.
- *Consensus (Level 3) opinion that patients with persistent, nonremediable, functional deficits should be taught compensatory methods for performing important tasks and activities, using the affected limb when possible, and when not, the unaffected limb.
- Moderate (Level 1b) evidence that for carefully selected chronic stroke patients the forced-use paradigm can improve functional outcomes of the upper extremity.
- Moderate (Level 1b) evidence that use of body weight support in gait training improves functional outcomes.
- Strong (Level 1a) evidence that EMG biofeedback is superior to conventional physiotherapy in improving ankle dorsiflexion strength.
- Strong (Level 1a) evidence that EMG biofeedback is not superior to conventional physiotherapy in treating upper extremity paresis/dysfunction.

Minor Recommendation: *Stroke patients with functional sensorimotor deficits and some voluntary movements of the involved arm and leg should be offered exercise and functional training directed at improving strength and motor control, relearning sensorimotor relationships and improving functional performance.*

Minor Recommendation: *Stroke patients with persistent functional deficits unresponsive to remedial therapy should be taught compensatory methods for performing functional tasks.*

Cognitive and Perceptual Deficits

- *Cognitive deficits that preclude effective learning are contraindications to rehabilitation.
- *Consensus (Level 3) evidence that cognitive and perceptual problems not severe enough to preclude rehabilitation require goal-directed treatment plans.

Minor Recommendation: *Stroke patients with cognitive and perceptual deficits that do not preclude rehabilitation should receive goal-directed treatment.*

Communication Deficits

- Strong (Level 1a) evidence that language therapy is efficacious in the management of aphasia; this benefit is greater when initiated earlier (before spontaneous recovery is complete) than when initiated after spontaneous recovery is complete.
- Limited (Level 3) evidence that trained volunteers are as effective as language therapists.

Minor Recommendation: *Stroke patients with aphasia should be offered language therapy (Level 1a evidence).*

Dysphagia and Aspiration Post-Stroke

- Strong (Level 1a) evidence that aspiration following stroke puts patients at substantially higher risk of developing pneumonia.
- VMBS (videofluoroscopic modified barium swallow) studies are the “gold standard” for determining aspiration; there are no proven guidelines for determining who should receive VMBS studies.
- Limited (Level 2) evidence that VMBS studies performed in hemispheric stroke rehabilitation patients over two weeks post-stroke do not reduce the incidence of pneumonia.
- Moderate (Level 1b) evidence that two weeks of intensive dysphagia monitoring by a therapist four weeks following a stroke does not alter the outcome.
- Limited (Level 3) evidence that early swallowing assessment and dysphagia management reduces the risk of pneumonia in stroke patients.
- Moderate (Level 1b) evidence that gastrostomy feeding tubes are superior to nasogastric tube feeding.

Minor Recommendation: *Stroke patients at potential risk of dysphagia should be clinically assessed in acute care for aspiration. Dysphagia management should be instituted where appropriate (Level 2 evidence).*

Nutrition

- Malnutrition is a common but often underestimated problem in hospitalized stroke patients.
- Moderate (Level 1b) evidence that malnutrition is associated with poorer functional outcomes and longer lengths of stay in hospital.
- Limited (Level 2) evidence that malnutrition is associated with an increased risk of medical complications.
- Limited (Level 2) evidence that improvement in nutritional status of malnourished stroke patients improves responses to rehabilitation therapies.

Minor Recommendation: *Stroke patients should be assessed for malnutrition and any deficiencies corrected (Level 2 evidence).*

Spasticity and Contractures

- *Consensus (Level 3) opinion that spasticity and contractures should be prevented/treated by antispastic pattern positioning, range-of-motion exercises, stretching, and/or splinting.

Minor Recommendation: *Spasticity and contractures should be managed with stretching exercises and proper positioning/splinting (Level 3 evidence).*

Painful Hemiplegic Shoulder

- While shoulder subluxation is not always associated with shoulder pain, spasticity generally is.
- Hemiplegic shoulder pain appears to be due to a combination of spastic muscle imbalance and a frozen contracted shoulder.
- Moderate (Level 1b) evidence that shoulder slings are not that effective in reducing shoulder subluxation; slings may contribute to shoulder contractures.
- *Moderate (Level 1b) evidence that the prevention of shoulder injuries should emphasize proper positioning and support, and avoidance of overly vigorous range-of-motion exercises.
- Moderate (Level 1b) evidence that overhead pulleys lead to hemiplegic shoulder pain.
- Limited (Level 2) evidence that Phenol and Botox injections of the subscapularis and pectoralis major muscle improve shoulder range of motion and decrease shoulder pain; the benefit appears to be short-lived.

Minor Recommendation: *The hemiplegic shoulder, particularly early on, should be properly positioned and supported, preferably not with slings. Overly vigorous range of motion or pulley exercises should be avoided (Level 1b evidence).*

Acupuncture in Stroke

- Limited (Level 2) evidence that acupuncture is beneficial in the treatment of stroke. There is contradictory evidence in RCTs but there is enough cumulative evidence to suggest that acupuncture is beneficial in the acute stage.

Bladder Disorder Post-Stroke

- *Limited (Level 2) evidence that persistent urinary incontinence after a stroke should be evaluated to determine its etiology, and cause-specific treatment should be implemented.

Minor Recommendation: *Stroke patients with persistent urinary incontinence should have cause-specific treatment (Level 2 evidence).*

Depression Post-Stroke

- Depression post stroke is quite common, being highest in the sub-acute or rehabilitation group.
- Depression is predictive of functional outcome months to years post-discharge.
- *Strong (Level 1a) evidence that a high index of suspicion needs to be maintained and appropriate steps should be taken to determine the presence and cause of depression. The diagnosis of depression depends primarily on the clinical examination, supplemented when necessary by the use of selected depression scales.
- Strong (Level 1a) evidence antidepressant medications improve post-stroke depression.
- Limited (Level 2) evidence methylphenidate (Ritalin) is as effective as other antidepressant medications and acts more quickly.
- Limited (Level 2) evidence that antidepressant medications improve functional outcomes.

Minor Recommendation: *All stroke patients should be clinically screened for depression and where depression is present, antidepressant therapy offered if there are no contraindications (Level 1a evidence).*

REINTEGRATION INTO THE COMMUNITY

Family Problems

- Families, particularly one primary caregiver, bear the brunt of stroke patient care in the community.
- Strong (Level 1a) evidence that caregivers experience significant adjustment difficulties, in particular higher rates of depression, greater deterioration in their own health, greater use of health care resources and serious lifestyle disruption. After two to three years, one third of caregivers are still having trouble adjusting.
- Moderate (Level 1b) evidence that family education and counselling provided in the early stages following a stroke results in better family coping.
- *Moderate (Level 1b) evidence that clinicians need to be sensitive to potential adverse effects of caregiving on family functioning and the health of the caregiver. They should work with the patient and caregivers to avoid negative effects, promote problem solving, and facilitate reintegration of the patient into valued family and social roles

Major Recommendation: *Stroke rehabilitation should include working with patients and caregivers to promote problem solving, ensure adequate community supports are available to caregivers, and facilitate reintegration of the stroke patient into valued family and social roles (Level 1b evidence).*

Socialization and Community Supports

- *Consensus (Level 3) opinion that acute care hospitals and rehabilitation facilities should maintain up-to-date inventories of community resources, provide this information to stroke survivors and their families/caregivers, and offer assistance in obtaining needed services.
- *Limited (Level 2) evidence that valued leisure activities should be identified, encouraged and enabled.

Minor Recommendation: Rehabilitation teams should be in a position to assist stroke patients and their caregivers in obtaining community supports (Level 3 evidence).

Minor Recommendation: Valued leisure activities of stroke patients should be identified and facilitated (Level 2 evidence).

Sexuality

- *Consensus (Level 3) opinion that sexual issues should be discussed during rehabilitation and addressed again after transition to the community when the stroke survivor and significant other are ready.

Minor Recommendation: Sexual issues should be discussed with the stroke patient and significant other (Level 3 evidence).

Driving

- *Limited (Level 2) evidence that the assessment of the ability of a disabled stroke survivor to drive a car should be based on a neurological examination, behavioural observations, and evaluation by the provincial agency responsible for issuing driver's licenses (including a standardized driving test). Neuropsychological testing should be obtained in persons with cognitive or behavioural disorders. Referral to adaptive driving instruction should be considered.

Minor Recommendation: Stroke patients should be carefully assessed regarding driving (Level 2 evidence).

Returning to Work

- *Consensus (Level 3) opinion that stroke survivors who worked prior to their strokes, should, if their condition permits, be encouraged to be evaluated for the potential to return to work. Vocational counselling should be offered when appropriate.

Minor Recommendation: Stroke patients should be provided with vocational assessment and counselling where appropriate (Level 3 evidence).

APPENDIX 6: BACKGROUND ON METHODS TO ASSESS THE NEED FOR STROKE REHABILITATION IN ONTARIO

The Panel's terms of reference included a description of the population's need for stroke rehabilitation. A review of the literature determined the following:

1. Those who use the term "need" use different tools to measure different things (Ministry of Health and Long-Term Care, hospitals, the Joint Policy and Planning Committee, public health, epidemiologists, stroke survivors, families).
2. It is not clear whether the amount of illness/disability in a population determines health service need or whether health services define need.
3. The need for stroke rehabilitation may be defined by the community as who deserves the services.
4. System design, system performance indicators, and data collection may change depending on how need is defined.

Measuring Need

There are a number of ways to measure need.

Need Measured Using Historical Expenditure Patterns

It is assumed by some that resources are spent in the areas that have the greatest need. Thus, historical expenditure patterns are seen to reflect health care need.

In 1995, the Resource Management Committee of The Premier's Council recommended to the government that Ontario should "move towards the allocation of resources based on the health needs of residents in a geographic area rather than allocation based on existing or historical expenditure patterns". It called for a research program to develop the required decision making tools. The ability to determine objectively a population's need for health services will demonstrate that some regions are not getting enough health resources whereas others have too much.

Need Measured by the Comparative Lack of Resources

Ontario's Joint Policy and Planning Committee (JPPC) reviewed population-based models used in many jurisdictions to predict the consumption of hospital resources, particularly inpatient acute medical services. An interim report noted that the community's need for hospital services is based partly on specific attributes of the population found to be associated with hospital service volumes (JPPC, 1999). These factors were further analysed to determine which ones predicted most of the day-to-day service load in a community. For example, the level of mortality and potential years of life lost in a community are two factors that predict the level of health services required in the community. This approach is limited, however. Although stroke

contributes to the mortality in a community and the potential years of life lost (PYLL), mortality and PYLL do not predict the need for stroke rehabilitation.

The JPPC focused on hospital-based services. Ideally, Ontario's population needs-based methodology would relate the community's need for a type of health service to all potential services that could meet this need (e.g., both community- and institution-based providers).

Need Measured Using Social Concepts

The Central West Health Planning Information Network (CWHPIN) provided background information on the concepts of normative, felt, expressed and comparative need for health services in a geographic population.

- Normative need exists when the population's health has not met standards set by experts.
- Comparative need stems from shortfalls in a community's health status compared to similar jurisdictions.

The work of the Ontario Cervical Screening Collaborative Group to achieve a 50% reduction in cervical cancer mortality in Ontario by 2005 is an example of meeting normative and comparative health needs at the provincial level. The Consensus Panel on Stroke Rehabilitation is the result of felt and expressed needs from stroke survivors and physicians for more attention to stroke rehabilitation in Ontario.

Need Measured as Health Deficit or Health Risk

In its 1996 report, the Ministry of Health Needs/Impact-Based Planning Committee defined need as a "measurable health status deficit" or a "measurable opportunity to maintain or enhance health". A number of indicators are listed to define deficits in the health status of a community. The report also includes different ways to assign priority to various health needs. CWHPIN is developing a method to assess the population's need for rehabilitation services. It will be using the four social concepts of "need" and the work of the Ministry of Health Needs/Impact-Based Planning Steering Committee.

Some types of disability, some combination of functional limitations, and some level of severity may present a risk to health that is responsive to rehabilitation. The concept of disablement in gerontology provides a link between illness and progressive disability. Models of disablement are being developed to describe the causal mechanisms of how illness induces functional limitations that become a disability (Lawrence and Jette, 1996). The concept of disablement and supporting research can provide a useful way to understand why some disabilities progress to greater disability or to increased risk of illness. This understanding provides a basis for designing rehabilitation interventions to slow deterioration.

Ontario Assessments of the Need for Rehabilitation

The Institute for Work and Health published a comprehensive review of rehabilitation in Ontario in 1995. This review summarized various models to estimate the need for rehabilitation services. The authors concluded that given the complexity of the subject, designing a model to assess the need for rehabilitation was beyond their scope.

A needs/impact-based planning model currently does not exist for the entire population of stroke survivors. There are two disease-specific needs assessments that have applications to stroke rehabilitation. One is the Health Information Partnership - Eastern Ontario Region and the other is the Cardiac Care Network of Ontario's work on cardiac rehabilitation. Both of these initiatives are briefly described below.

The Health Information Partnership - Eastern Ontario Region

The Health Information Partnership - Eastern Ontario Region (HIP) and Queen's University published an epidemiological estimate of the need for evidence-based acute stroke services including rehabilitation.

HIP proposed an epidemiological approach to estimating the need for stroke services in Eastern Ontario. The study's aim was to estimate the number of persons with a stroke-related condition with the potential to benefit from effective interventions. Need for a health service was defined as the capacity to benefit from the service. This definition of need may differ from what people ask for and what the system provides, and seems independent of social policy, politics and culture. HIP distinguishes between core stroke rehabilitation services needed by all stroke patients and restricted stroke rehabilitation services provided only to some patients for a variety of reasons. The report is written for acute care but its language and four-step method can be adapted for stroke rehabilitation:

Step 1: Identify stroke related impairments and disabilities.

Step 2: Estimate the incidence/prevalence of these stroke-related conditions.

Step 3: Identify effective rehabilitation services targetting each stroke-related condition.

Step 4: Link these steps to estimate the number of rehabilitation services required.

Secondary sources are used to carry out these steps. For example, information from stroke registries used to identify the impairments and disabilities post-stroke, found that 50% of stroke survivors can benefit from rehabilitation at week one. Another example, the 1990 *Ontario Health Survey*, was used to estimate the prevalence of stroke survivors in Eastern Ontario with one or more chronic disabilities. HIP concluded that 100% of stroke survivors need supportive services.

The report used the level of evidence framework from the U.S. Agency for Health Care Policy and Research to determine effective rehabilitation interventions. The report lists these evidence-based rehabilitation services for stroke patients in the acute phase and supportive services in the chronic phase of disability.

The HIP model outlines how to determine the need for stroke rehabilitation based on incidence and prevalence of impairments and disabilities that respond to evidence-based interventions. There is no mention of inpatient stroke rehabilitation or rehabilitation in long-term care settings or home care.

Key concepts from HIP:

- Impairment and disability can be estimated using data from longitudinal studies from other jurisdictions.
- The “capacity to benefit” must be considered.
- Effectiveness of rehabilitation interventions must be considered.

The Cardiac Care Network of Ontario

The Cardiac Care Network of Ontario (CCN) prepared a *Report on Cardiac Rehabilitation* in June 1999. It estimated the need for cardiac rehabilitation in a population of patients with established heart disease. Unlike the HIP report, CCN's work compared need with the community's service capacity.

CCN provides a level of evidence framework used in several of its previous reports. As a result, the Panel establishes that there is, “...unequivocal scientific evidence demonstrating that cardiac rehabilitation and secondary prevention services ... decrease mortality, decrease the need for interventional procedures, reduce the incidence of subsequent...MI...as well as improve quality of life, functional capacity, emotional well-being and successful return to work.”

Although it appears that everyone with established heart disease can benefit from cardiac rehabilitation, CCN's report focused on two specific subgroups - patients with and without a medical event. The number of patients with an event (e.g., hospitalized) was calculated using CIHI data. The number of persons without an event was estimated using an Ontario population survey from the ICES Atlas: *Cardiovascular Health and Services in Ontario, 1999*.

Different rehabilitation participation rates were applied to the two different groups of eligible patients. The report concluded that approximately 100,000 people per year in Ontario have the capacity to benefit from completing a full program of evidence-based cardiac rehabilitation.

The number of places (existing and planned growth) in cardiac rehabilitation was determined through a survey of the 10 larger, formal programs and compared to the projected need. A survey of hospitals with cardiac rehabilitation programs projected growth over the next three years to 8,500 patients. This capacity falls far short of the annual volume of 100,000 new patients who could benefit from cardiac rehabilitation and who could be expected to seek cardiac rehabilitation from the existing programs. This finding argues for a substantial increase in cardiac rehabilitation capacity in Ontario.

Key concepts from CCN:

- Participation rates must be considered as a factor to assess the need for service.
- The ability to count the number of people formally receiving rehabilitation is important.

Discussion

The HIP and CCN models for estimating population-based need for rehabilitation services work well when 1) there is good evidence for a health burden; 2) there is consensus that the impact of the disability on daily living is significant; 3) there is good evidence that several interventions can reduce this burden; and 4) one service program meets the needs of the main sub-groups of patients.

The need of stroke survivors for rehabilitation may be more complex than for cardiac rehabilitation. One cardiac rehabilitation program may fit two different populations. As a result, estimating the size of the population in need may be relatively easy. In contrast, stroke survivors have many different impairments, disabilities and handicaps that can respond to many different forms of rehabilitation. Stroke survivors are in acute care, rehabilitation hospitals, home care and long-term care settings. Only the number of stroke patients requiring acute care rehabilitation can be estimated on the basis of a geographic population and its incidence of stroke. The rehabilitation needs of all stroke patients would have to go beyond assessing the attributes of a geographic population to include such factors as the process of acute stroke care, the process of medical triage, the individual's recovery and his or her need for ongoing rehabilitation.

Stroke rehabilitation must be flexible to meet the needs of different clinical populations with different types and levels of stroke impairment, and changing disabilities over time. These conditions respond to different evidence-based interventions and require different service providers.

The geographic population-based model of assessing the need for health services and their outcomes has to be applied to clinically different stroke populations in the three post stroke recovery phases of acute, inpatient rehabilitation and community settings. The instruments required to detect and measure changing disabilities will vary. The significant data early on will reflect impairment and disability, whereas the latter data will include more about handicap.

Patient and family perspectives of need become increasingly important with time and can be captured in quality of life or reintegration measures. At each stage stroke survivors are uniquely vulnerable to loss of caregiver support and the effects of age.

The Panel recognizes the concept of "participation rates" used by CCN. Not everyone who can benefit from stroke rehabilitation on scientific grounds will be able, or want to participate in programs that address an impairment or disability.

The HIP model demonstrates the role of stroke registry information to determine the incidence and prevalence of impairments and disabilities that respond to evidence-based interventions. Once a community establishes the need for stroke rehabilitation, (at least in the acute and inpatient settings), CCN shows how the need can be compared to the formal service capacity in place.

New and Emerging Needs for Stroke Rehabilitation

The Panel recognized the need for more guidance on how to address the concept of need where the health burden is demonstrated with good evidence, but there are conflicting opinions on its seriousness and no research evidence on effective interventions for clinical management.

The lack of research can result from a lack of effective measuring tools (Granger, 1998), a lack of funding, social attitudes or a lack of interest. In the absence of proven interventions, the health burden of stroke may go unrecognized in formal planning initiatives.

About half of stroke survivors are discharged home with no formal rehabilitation. There is evidence that 40% of these people can be plagued by softer neurological impairments such as slow gait and an inability to drive (Jorgensen et al., 1995a; Mayo 1998). These individuals may not be able to return easily to the Medicare-funded rehabilitation system for help.

A needs-based model that emphasizes evidence of effective interventions must also take into account health burden, possible conflict in what is considered serious, and the lack of proven clinical interventions.

Population-based Health Care Requirements

Frankel et al. (1999) agree that health care needs in a geographic population can be determined from the individual's capacity to benefit from treatment. However, these researchers believe too many ambiguities in the concept of need present difficulties at the planning level. As a result, they recommend using the concept of a health care requirement rather than need for planning health care services in a community.

The number of people with a particular condition in a geographic population does not determine the requirement for service for a number of reasons. One, the way people with the condition are identified may not be very precise (Malmgren et al., 1987). Two, even though the diagnosis may be accurate, some people will not need active treatment. For example, some individuals may only require monitoring or a wait and see approach, whereas others may have comorbid conditions or frailties that exclude them from treatment. As well, more robust patients may refuse the treatment offered.

Frankel (1991) recommends starting with a specific health care service. For example, he assessed the need for primary hip replacement surgery in the UK (Frankel et al., 1999). Frankel's work helps to clarify the steps involved in determining the need for stroke rehabilitation in Ontario based on the capacity to benefit.

The following is an outline of how Frankel's framework might look for stroke rehabilitation. There are six steps for establishing the objective need for stroke rehabilitation in a population:

Step 1

Select a condition experienced by stroke survivors for which there is a rehabilitation intervention supported by strong evidence. The intervention may be a clinical service or a program, or a combination of services and/or programs.

Step 2

The clinical indications for the intervention have to be made as precise as possible using the data from research evidence. Not everyone with the condition has benefitted from the intervention.

Step 3

Count the number of people in the population who have the precise indications. If these data are not available, patients can be surveyed. People reporting the indications may need to have this fact confirmed by clinical examination.

Step 4

Exclude people with comorbidities that are contraindications to the service, and those who are not interested in receiving the service. The number remaining represents the total number of people who require the service in the population.

Step 5

This step is some justification for stroke rehabilitation based on the cost benefit of the service, compared to competing health services. Although this step can start with objective data, eventually it is likely to reflect someone's preferences (Frankel, 1991). Sometimes the relative cost benefit of functional improvement in stroke survivors is not clear. Studies into stroke outcome and triage will address this lack of information (Ween et al., 1996). Stroke survivors for whom stroke rehabilitation is not cost effective, will drop out of the population requiring service. The remaining population is then compared with the population currently receiving rehabilitation for the specific condition.

Step 6

The number of people who are receiving the rehabilitation service is compared to the number requiring the service. This comparison shows the balance between need and service, and overuse or underuse. Further analysis of the health system is required to determine inappropriate use of rehabilitation. When overuse, underuse or misuse is found, the response will likely require a service development approach rather than the dissemination of guidelines (Peckham, 1999).

Good evidence of clinical benefit or an authoritative consensus is required to assess the adequacy of treatment services in a community. This information will help a community determine whether the patients who will benefit from a service actually receive it.

Although Frankel demonstrates how to use objective data to determine need, he recognizes that there is also a subjective approach. Where the symptoms relevant to stroke rehabilitation are more distressing than life threatening, each of the six steps may be defined by patient or community preference rather than objective data and scientific evidence (Frankel, 1991). Stroke rehabilitation that is provided will rely more on skilled use of subjective methods to assess need and consensus building, especially as one moves from acute to sub-acute, to ongoing stroke-related impairment and disability (Peckham, 1999).

The Panel acknowledges that, “without proof that rehabilitation is an effective strategy to reduce the impact of the sequelae of stroke, it is unlikely that the priority for stroke care will shift towards rehabilitation” (Mayo, 1989).

Need as Quality of Life and Self-management

Using Frankel's method to determine the requirement for stroke rehabilitation works well when there is good evidence for a specific intervention. However, there are a number of concerns with Frankel's approach.

One concern is that Frankel's approach fits the therapeutic context of rehabilitation only for specific impairments and disabilities. The approach may not provide a model to determine the population's need for rehabilitation in the context of handicap, quality of living and self-management. Where one clearly defined therapeutic procedure is not sufficient, stroke survivors may experience diminished quality of life and the need for assistance in self-management.

A second concern is that Frankel's procedure is grounded in high quality evidence. Research is just beginning to identify effective interventions and assistance for improving the capacity of stroke survivors to manage their disabilities and/or retain a safe and reasonably adequate quality of life. The indications for specific assistance cannot be precisely defined in the absence of high quality evidence. Without precise clinical indications, Frankel's method cannot be completed. As research becomes available, Frankel's method should be tested as an approach to population-needs based planning for interventions aimed at quality of life and improved self-management outcomes.

A third concern is that Frankel's approach to measuring population need is “supply side”. A “demand side” approach must also be used to determine survivor-defined needs.

The Panel examined population-needs based models used for other chronic conditions that incorporate quality of life considerations. A literature review was conducted and a number of researchers were consulted (Nancy Mayo at McGill University, Molly Verrier and Karen Yosida in the School of Rehabilitation Sciences at the University of Toronto, Tom Abernathy who is

examining diabetes at the Health Intelligence Research Unit in Hamilton, and the Ontario March of Dimes Research Department). It was determined that a wide variety of conditions face similar measurement challenges including cancer rehabilitation, mental health, chronic pain, multiple sclerosis, rheumatoid arthritis, traumatic brain lesions and irritable bowel syndrome.

Studies indicate that researchers define the need for services in the disabled population based on quality of living and self-management. Factors within these two parameters include:

Quality of Living

- Understanding what makes up quality of life for people with chronic or progressive conditions over the long-term.
- Understanding the situations that reduce quality of life.
- Understanding when quality of life reductions put health at risk.
- Documenting the nature and prevalence of reduced quality of life in a clinical population.
- Evaluating when an intervention has improved a person's quality of life.

Self-management

- Understanding what makes up the capacity for satisfactory self-management of a chronic or progressive condition over the long-term.
- Understanding the situations that significantly interfere with successful self-management.
- Understanding when reductions in the capacity for self management begin to put health at risk.
- Documenting the nature and prevalence of reduced capacity for self-management in a clinical population.
- Evaluating when an intervention has improved a person's capacity for self-management.

It is reasonable to conclude that a simple approach to determining need is to ask people with stroke-related disabilities what would assist them to improve their quality of life or manage their disability. This common sense approach is the first step in population needs-based planning. This approach has been demonstrated in *An Even Break: The Needs of Persons with Physical Disabilities in Ontario* (Ontario March of Dimes Research Department, 1993).

Public health uses population needs-based planning models to determine where to reduce risks to health in the general population. The interventions used should be evidence-based.

Conclusion

After conducting an extensive review of various models that purport to measure the need for health services, and exploring their potential application for stroke rehabilitation, three population-needs based models were regarded as useful for measuring and monitoring the need for stroke rehabilitation:

1. Where there is good evidence that a rehabilitation procedure or program is therapeutic and its indications are clear, Frankel et al.'s (1999) methodology, which incorporates one's capacity to benefit from treatment and the concept of health care "requirement" rather than "need", could be used to quantify the indications for a post-stroke procedure.
2. Where there is good evidence that defines when progressive disablement presents an increased risk to health and there is an effective rehabilitation intervention, the public health models of population needs-based planning could be used.
3. Stroke survivors and families could be asked what assistance they need to maintain a safe and reasonable quality of life, and/or to maintain their capacity to manage their disability.

An on-going provincial forum could be used to advance the knowledge, skill and data Ontario requires to measure the need for stroke rehabilitation, to develop the stroke rehabilitation services required at the local level, and to help the health care system make necessary adjustments to bring need and service into balance.

APPENDIX 7: A FRAMEWORK FOR ONTARIO DATA ON STROKE REHABILITATION

There is a need for good Ontario data to:

- estimate the burden of impairment, disability and handicap in the stroke survivor population;
- estimate the need for stroke rehabilitation services;
- determine what is currently being done in stroke rehabilitation;
- evaluate the quality of stroke management;
- describe outcomes based on current practice.

The Panel recognized early on that it did not have a single approach to assess how the current system for stroke rehabilitation is working in Ontario. Although there is a wide variety of population studies and sources of limited cross-sectional data, it was not possible to obtain a quantitative picture of the stroke rehabilitation system and how well it is performing. It became evident that there is an absence of an agreed-upon planning framework setting out the boundaries of the stroke rehabilitation system, its goals, and the information required to support improvement.

Literature Review on the Data Required to Support the Goal of the Rehabilitation System in Ontario

The rehabilitation system for stroke survivors should be evaluated on how well it meets the goal of providing adequate rehabilitation to everyone experiencing a stroke in Ontario. A literature review was conducted to identify information that would support this goal, and be transferable to Ontario. Longitudinal studies were examined to determine what routine information would be helpful for planning.

A study of stroke care in New Zealand (1988) identified data that determined whether stroke survivors most in need of rehabilitation were treated and if limited resources were directed at those who could benefit the most (Bonita, 1988). Although the study did not address issues of quality and effectiveness, it concluded that the stroke system in Auckland had reached its goal because, "the majority of patients with a persisting motor deficit six months after the stroke had received physiotherapy and occupational therapy services at some stage of their illness." The same conclusion was reached for speech therapy. Attempts to extrapolate the methodology to Ontario for the Consensus Panel were unsuccessful due to a lack of data.

The McGill Stroke Rehabilitation Research Program identified the following performance indicator for stroke rehabilitation: the size of the population of survivors with mild stroke who were discharged home with no formal rehabilitation from the hospital or the community. Although the Consensus Panel tried to find Ontario data on stroke patients discharged home from the hospital without any rehabilitation, there was no information on how many experience mild neurological impairments and disabilities in daily living, and the number who seek access to public or private rehabilitation in the community.

Using data from a Cincinnati epidemiological study, Schmidt et al. (1999) looked for patient and community characteristics to guide the placement of community nursing services in the US. The authors focused on patients with more severe strokes. Cincinnati has a high percentage of Medicare stroke survivors readmitted to acute care settings, a very low amount of home health services, and the largest group of stroke patients receiving no institutional or ambulatory rehabilitation services. It has been shown that poor follow-up care in Cincinnati results in readmissions. The authors noted that a shorter length of stay, "without follow-up rehabilitation and control of comorbidities can result in a high risk of confounding recovery and readmission to acute care hospitals". This study suggests that hospital readmission rates for stroke patients might be an early warning that some patients are not receiving adequate rehabilitation across the continuum of care. The Institute of Clinical Evaluative Sciences reported, however, that the probability of readmission in stroke is unrelated to hospital length of stay (Goel et al., 1996).

Dombovy et al.'s (1987) study in Rochester emphasized the value of having longitudinal data on an entire population of stroke survivors for health planning. This avoids bias from patient selection and provides a firmer foundation to estimate the requirement for rehabilitation services. The authors note that information on the prevalence and severity of short- and long-term disability in stroke survivors in a defined population is required to allocate services appropriately. Longitudinal data on stroke survivors in Ontario does not exist.

Information Required for Stroke Rehabilitation Planning in Ontario

Since the Rochester study addressed health planning issues, its data elements along with some from other studies, were identified as providing a good basis for a stroke rehabilitation information system. This information should be used to assess the degree to which stroke rehabilitation has helped stroke survivors:

- avoid and reduce life-threatening medical complications;
- maintain remaining functional abilities;
- maximize the use of functional abilities post-stroke;
- learn new ways to compensate for what is lost (Senelick et al., 1999).

Information that is required for planning stroke rehabilitation in Ontario includes:

- background trends on the severity of first strokes;
- prevalence of disability shortly after stroke;
- percentage and rate of patients requiring acute/inpatient rehabilitation;
- prevalence of ongoing disability after stroke (1, 3, 5 years post stroke);
- prevalence of short- and long-term comorbidity and hospital complications;
- disposition at different assessment dates (1, 3, 5 years post stroke);
- rates of patients requiring institutional care post-stroke;

- severity of ongoing disability after stroke;
- percentage and rate of patients requiring later rehabilitation;
- percentage and rate of patients receiving rehabilitation;
- profile of the rehabilitation received:
- time after onset of stroke at which therapy was begun;
- whether patients received speech language pathology, physiotherapy, occupational therapy;
- access to other clinical specialties: psychology, dietetics, social work, pharmacy, etc.;
- type and intensity of inpatient rehabilitation;
- transfer to rehabilitation;
- rehabilitation provided as an outpatient including number of therapy sessions, duration of therapy, and content of individual physical and occupational therapy, and speech-language pathology sessions;
- percentage and rate of patients receiving no rehabilitation;
- readmission rates for patients with a first stroke;
- survivor and caregiver satisfaction with rehabilitation services across the continuum.

Evaluating the Quality of Stroke Management

A recent consensus report called for the routine collection of data to evaluate the quality of stroke management in each World Health Organization member state by 2005 (Aboderin and Venables, 1996). Both process and outcome are part of this evaluation. Information that was recommended includes:

- diagnosis and assessment;
- acute care and complications;
- late survival and rehabilitation;
- community care;
- patients' perception of the quality of care;
- caregivers and families' perceptions of the quality of care.

The recommended domains for late survival and rehabilitation were:

- case fatality at 2 years;
- proportion with access to interdisciplinary rehabilitation;
- time to start of active or passive rehabilitation;
- proportion in whom level of disability, goal setting, and regular review is recorded;
- personal and instrumental activities of daily living at three months;
- personal and instrumental activities of daily living at 12 months;
- place of residence at three months and 12 months or number of days in post-acute institutional care.
- key indicator for immediate use.

Information Available in Ontario

Longitudinal data on stroke survivors are not available in Ontario, nor are clear accepted definitions of rehabilitation (e.g., at what point is the original stroke “left behind” and when is a new episode of illness or geriatric deconditioning being addressed) (Harris et al., 1995).

Information on Data Sources for the Consensus Panel on Stroke

Stroke rehabilitation and stroke patients in:	Source of information/data	What information and data are available?
Acute Hospitals	CIHI Abstracts	Stroke diagnosis for inpatients annually by defined ICD-9 codes ALC Beds by diagnosis
Acute and Rehabilitation hospitals	ICES Atlas	LOS for each episode of hospitalization 92/93, 94/95 by hospital
Hospital Outpatient Rehabilitation Hosp and Complex Cont. Care	MOHLTC	Information not available Some data is available from public hospitals only
Nursing Homes (private) Homes for the Aged (private)	MOHLTC	1998 Levels of Care Classification, Prov. Summary Data
Nursing Homes (non-profit) Homes for the Aged (non-profit)	MOHLTC	1998 Levels of Care Classification, Prov. Summary Data
Supportive Housing with 24 hour personal care	MOH funded Facilities	Information only available from individual facilities
Follow up FIM data six months after hospital discharge	UDSmr- U.S. CIHI Standard Rehabilitation Data Project.	Gresham, GE PH&R Clinics of NA. 10 (4) Nov 1999, p. 957-966 CIHI Sample Reports
Change in modified FIM on admis- sion and discharge.	UDS data for subscribers only CIHI Pilot Project on Rehabilitation Data Standards	UDS - USA CIHI Sample reports
Residents in LTC Facilities, home care, general rehabilitation, acute care, psychiatric settings	MOHLTC	Resident Assessment Instrument/Minimum Data Set (RAI/MDS)
CCAC funded services in Toronto	Toronto DHC	Three years - number of admis- sions, homemaking hours and nursing visits by “Diagnosis” (but not by ICD-9)
Community Support Services (non-profit)	Ontario Community Support Association	Information not available
Community Support Services (private)	Ontario Home Health Care Providers Association	Information not available
Elderly Persons Centers	Older Adults Centre Association	Not determined
Stroke survivors living at home	Stroke Recovery	Survey

Stroke rehabilitation and stroke patients in:	Source of information/data	What information and data are available?
home	Association/ Community service agencies/HSFO	
Stroke survivors living at home	VON	Information not available
Stroke survivors living at home	St. Elizabeth Health Care	Nursing and rehabilitation admissions for Ontario
OHIP Funded Physiotherapy Clinics	MOHLTC	information not available
Federal Program Information: Veterans, CPP, Disability, etc	HRDC	No information obtained
National Population Health Survey, 1995	Statscan/MOH	Data on those experiencing the effects of stroke
1990 Ontario Health Survey 1996 data	MOH	Correlation of variables, e.g., speech, disability due to stroke. Prevalence of paralysis or speech problem due to stroke
Aboriginal perspective	Assembly of First Nations	No information obtained
Francophone perspective	Ontario Network of Coordinators for French Language Health Services	CIHI Sample reports
Informal care to seniors with long-term health/activity limitation	1996 General Social Survey for Canada	No information obtained
Problems in stroke rehabilitation reaching public attention	Media	Articles
Health Activity and Limitations Survey (HALS) 1991	Statscan	"Diagnosis" (but not by ICD-9) Information not available
Home Care and Informal Care Giving	The Berger Monitor	Survey
Visits to the U.S. for stroke rehabilitation not available in Ontario	OHIP	Information not available

Stroke Rehabilitation Data Collection in Ontario

A standardized system of data collection for rehabilitation does not exist in Ontario. In addition, there is no central depository for stroke-specific rehabilitation information to support the development of benchmarks and comparative analysis of performance, outcome and client characteristics.

Currently, a classification/grouping methodology/case mix tool does not exist to identify clinically homogeneous client groups in rehabilitation, to predict resource use and client outcome.

FIM-FRGs (Functional Independence Measure - Functionally-related Groups) have been extensively studied by the RAND Corporation in the U.S. It was determined that FIM-FRGs are a robust and effective predictor of resource use. RAND recommended enhancing the data by adding service interruptions, complications and comorbidities. RAND concluded that the FIM-FRG system is feasible, replicable and suitable for a rehabilitation prospective payment system.

The Canadian Institute of Health Information completed a landmark study to develop and evaluate a minimum data set and grouping methodology for rehabilitation services across service settings in Canada. The pilot study concluded that:

- The data set is reliable and valid for a range of adult rehabilitation client groups in inpatient facilities.
- The use of FIM is supported based on analysis and pilot site input.
- CIHI items enhanced FIM in the cognitive domain by 25%.
- The FIM-FRG is appropriate for a Canadian classification system.
- ICIDH-2 is an appropriate model.

The data set is based on the International classification of impairment, disability and handicap model (ICIDH). Indicators of health status, system access, functional status, outcome, care efficiency and care effectiveness have been developed. The data set incorporates a follow-up component to study sustainability of outcomes over time. The system will use the FIM-FRG as the basis of its grouping methodology. The data system has been endorsed by the Canadian Council of Health Services Accreditation (CCHSA). CIHI will begin accepting data from rehabilitation sites wishing to participate starting April 1, 2000.

Field testing has begun on of the Minimal Data Set - Post Acute Care (MDS-PAC) in six facilities in Ontario. At the present time, the grouping methodology and indicator development are not complete. Uniform Data System (U.D.S.) has been working with the developers of MDS-PAC to make it more FIM-like. The MDS-PAC is one of a family of tools developed by interRAI. The MDS 2.0 is now used for all Ontario chronic care beds. Chronic care beds will be funded using the RUGS III classification tool associated with MDS 2.0 commencing April 1, 2000. The MDS-PAC is not as far in its development as the CIHI tool.

Conclusions

Stroke rehabilitation services include a variety of service provider groups, payors and service settings (acute, specialized rehabilitation facilities, outpatient, community based, home, school and work). There is a need for standardized information products to support service providers, administrators, program planners and health policy experts to plan, deliver and evaluate rehabilitation services more effectively, and to track activity, utilization, efficiency and cost effectiveness. There should be an ability to compare a patient's functional change within an organization, over time and across organizations and service settings.

A diagnostic-based grouping methodology is inappropriate in rehabilitation. A rehabilitation methodology needs to reflect functional status and the impact of impairments.

Data collection methods need to be compatible between service settings and data linked across the continuum. The Rehabilitation Funding Subcommittee of the Joint Policy and Planning Committee has begun work to develop and recommend a data collection and classification system for inpatient rehabilitation facilities in Ontario. The system will be used to determine funding for rehabilitation services.

A stroke rehabilitation data set should be based on the conceptual framework of the International Classification of Impairments, Disabilities and Handicaps (ICIDH). This framework focuses on the consequences of disease or injury that is more predictive of resource utilization and client outcome than a diagnosis. The data set should include measures of impairment, disability and handicap.

The Functional Independence Measure (FIM) should be part of the data set. As noted previously, FIM is a measure of disability and is the most widely used clinical data set for inpatient rehabilitation. The grouping methodology must accurately reflect resource utilization and predict outcome.

Rehabilitation data must be linked across the full continuum of care and include the broad range of service providers.

The stroke rehabilitation data set must be a minimal data set. Since collecting data is time and resource intensive, it should only include the essential elements. The data set should provide indicators of resource utilization/efficiency, client outcomes, sustainability of outcomes over time, health characteristics, socio-demographics and system access.

REFERENCES

- Aboderin, I., and Venables, G. 1996. Stroke management in Europe. *Journal of Internal Medicine*. 240: 173-180.
- Aftonomous, L. B., Appelbaum, J.S., and Steele, R.D. 1999. Improving outcomes for persons with aphasia in advanced community-based treatment programs. *Stroke*. 30: 1370-1379.
- Alexander, M. 1994. Stroke rehabilitation outcome: A potential use of predictive variables to establish levels of stroke. *Stroke*. 25:128-134.
- Asia Pacific consensus forum on stroke management. 1998. *Stroke*. 29: 1730-1736.
- Aitken P.D., et al. 1993. General medical or geriatric unit care for acute stroke? A controlled trial. *Age Ageing*. 22(suppl 2): 4-5.
- Alexander, M. 1994. Stroke rehabilitation outcome: A potential use of predictive variables to establish levels of stroke. *Stroke*. 25: 128-34.
- Asberg, K.H., and Nydevik, I. 1991. Early prognosis of stroke outcome by means of Katz index of activities of daily living. *Scan. J. Rehabil. Med*. 23: 187-91.
- Avison, W. R., Verrier, M., and Wood-Dauphinee, S. 1992. Opening address. Rehabilitation outcome measures: Where do we stand? *Canadian Journal of Public Health*. July-August, Supplement 2: S4-S6.
- Bamford, J. 1992. Clinical examination in diagnosis and subclassification of stroke. *The Lancet*. 339: 400-5.
- Banjn, J.D. 1990. Rehabilitation and empowerment. *Arch. Phys. Med. Rehabil*. 71: 614-15.
- Bath, F. J., Owen, V. E., and Bath, P. M. 1998. Quality of full and final publications reporting acute stroke trials: A systematic review. *Stroke*. 29: 2203-10.
- Bonita, R. 1988. Rehabilitation services received by stroke patients: The Auckland stroke study. *NZ Med J*. 101: 595-7.
- Borucki, S., Volpe, B., and Reding, M. 1992. The effect of age on maintenance of functional gains following stroke rehabilitation. *J. Neuro. Rehab*. 6: 1-5.
- Browman, G. P., Levine, M. N., Mohide, E. A., Hayward, S. A., Pritchard, K. I., Gafni, A., and Laupacis, A. 1995. The practice guidelines development cycle: A conceptual tool for practice guidelines development and implementation. *Journal of Clinical Oncology*. 13: 502-12.
- Browne, G., Roberts, J., Watt, S., Gafni, A., Stockwell, M., and Alcock, S. 1994. Community rehabilitation: Strategies, outcomes, expenditures. *Canadian Journal of Rehabilitation*. 8: 9-22.

- Canadian Institute for Health Information, Registered Persons Database. 1995-1998.
- Canadian Institute for Health Information. 1999. Rehabilitation Data Standards for Canada, Pilot Project Report. Canadian Institute for Health Information, Ottawa.
- Canadian Paraplegic Association. 1999. Rehabilitation Services Framework. Canadian Paraplegic Association, Ottawa.
- Cardiac Care Network of Ontario. 1999. Consensus Panel on cardiac rehabilitation & secondary prevention services in Ontario. Final report and recommendations, Toronto.
- Care Delivery Network Project. 1999a. Integration - a functional framework. Queen's University, Kingston.
- Care Delivery Network Project. 1999b. A regional coordinated stroke program in Southeastern Ontario. Queen's University, Kingston.
- Carey, R.G., Seibert, J.H., and Posavac, E.J. 1988. Who makes the most progress in inpatient rehabilitation? An analysis of functional gain. *Arch. Phys. Med. Rehabil.* 69: 337-43.
- Chan, B., and Hayes, B. 1998. Cost of stroke in Ontario, 1994/95. *CMAJ.* 159 (6 Suppl): S2-S7.
- Churchill, C. 1993. Social problems post stroke. In *Physical medicine and rehabilitation: State of the art reviews*. Edited by R.W. Teasell. Hanley & Belfus, Inc., Philadelphia.
- Churchill, C. 1998. Social problems poststroke. In *Physical medicine and rehabilitation: State of the art reviews*. Edited by R.W. Teasell. Hanley & Belfus, Inc., Philadelphia.
- Cifu, D.X., and Stewart, D.G. 1999. Factors affecting functional outcome after stroke: A critical review of rehabilitation interventions. *Arch. Phys. Med. Rehabil.* 80(5 Suppl 1): S35-39.
- Deyo, R.A., Cherkin, D. C., and Ciol, M.A. 1992. Adapting a clinical comorbidity index for use with ICD-9CM administrative databases. *J. Clin. Epidemiol.* 45: 613-19.
- Devins, G., M., and Binik, Y. M. 1996. Facilitating coping with chronic physical illness. In *Handbook of coping: Theory, research, applications*. Edited by M. Zeidner and N. S. Endler. Wiley, New York. pp. 640-96.
- Dobkin, B. H. 1997. Impairments, disabilities, and bases for neurological rehabilitation after stroke. *Journal of Stroke and Cerebrovascular Diseases.* 6: 221-6.
- Dodds, T.A., Martin, D.P., Stolov, W.C., et al. 1993. A validation of the functional independence measurement and its performance among rehabilitation inpatients. *Arch. Phys. Med. Rehabil.* 74: 531-6.

Dombovy, M. L., Basford, J. R., Whisnant, J. P., and Bergstralh, E. J. 1987. Disability and use of rehabilitation services following stroke in Rochester, Minnesota, 1975-1979. *Stroke*. 18: 830-6.

Dombovy, M. L. 1991. Stroke: Clinical course and neurophysiologic mechanisms of recovery. *Crit. Rev. Phys. Rehabil. Med.* 2: 171-88.

Drummond, A., and Walker, M.F. 1995. A randomized controlled trial of leisure rehabilitation after stroke. *Clinical Rehabilitation*. 9: 283-90.

Edmonds, L. J., and Peat, M. 1997. Community based rehabilitation (cbr) and health reform: A timely strategy. *Canadian Journal of Rehabilitation*. 10: 273-83.

Ellenberg, D. B. 1996. Outcomes research: The history, debate, and implications for the field of occupational therapy. *The American Journal of Occupational Therapy*. 50: 435-41.

Ellwood, P. M. 1988. Outcomes management. A technology of patient experience. Shattuck Lecture. *NEJM*. 318: 1549-56

Evans, R.L., Bishop, D.S., and Dusley, R.T. 1992. Providing care to persons with disability. Effect on family caregivers. *Am. J. Phys. Med. Rehabil.* 71: 140-4.

Evans, R.L., Matlock, A.L., Bishop, D.S., Stranahan, S., and Pederson, C. 1988. Family intervention after stroke: Does counselling or education help? *Stroke*. 19: 1243-9.

Feigenson, J., S., McCarthy, M., L., Greenberg, S., D., and Feigenson, W., D. 1977. Factors influencing outcome and length of stay in a stroke rehabilitation unit. Part 2. Comparison of 318 screened and 248 unscreened patients. *Stroke*. 8: 657-62.

Fink, A., Kosecoff, J., Chassin, M., and Brook, R. H. 1984. Consensus Methods: Characteristics and guidelines for use. *AJPH*. 74: 979-83.

Frankel, S. 1991. Health needs, health-care requirements, and the myth of infinite demand. *The Lancet*. 337: 1588-90.

Frankel, S., Eachus, J., Pearson, N., Greenwood, R., Chan, P., Peters, T. J., Donovan, J., Smith, G. D., and Dieppe, P. 1999. Population requirement for primary hip-replacement surgery: A cross-sectional study. *The Lancet*. 353: 1304-9.

Garraway, W., M. 1985. Stroke rehabilitation units: Concepts, evaluation and unresolved issues. *Stroke*. 16: 178-81.

Garraway, W.M., Akhtar, A.J., Prescott, R.J., and Hockey, L. 1980(a). Management of acute stroke in the elderly: Preliminary results of a controlled trial. *BMJ*. 280(6220): 1040-3.

- Garraway, W.M., Akhtar, A.J., Hockey, L., and Prescott, R.J. 1980(b). Management of acute stroke in the elderly: Follow-up of a controlled trial. *BMJ*. 281(6244): 827-9.
- Garraway, W.M., Akhtar, A.J., Smith, D.L., and Smith, M.E. 1981. The triage of stroke rehabilitation. *J. Epidemiol. Community Health*. 35: 39-44.
- Gill, H. S. 1995. The changing nature of ambulatory rehabilitation programs and services in a managed care environment. *Arch. Phys. Med. Rehabil*. 76: SC10-SC15.
- Ginzberg, E. 1997. Managed care - a look back and a look ahead. Sounding board. *NEJM*. 336: 1018-20.
- Goel, V. et al., (eds.). *Patterns of Health Care in Ontario. The ICES Practice Atlas. 2nd Edition.* (Ottawa: Canadian Medical Association, 1996).
- Granger, C.V. 1998. The emerging science of functional assessment: our tool for outcomes analysis. *Arch. Phys. Med. Rehabil*. 79: 235-40.
- Greenwood, R., Barnes, M. P., McMillan, T. M., and Ward, C. D. 1993. *Neurological Rehabilitation.* Churchill Livingstone, Edinburgh.
- Gresham, G. E., Duncan, P.W., Stason, W.B., et al. 1995. Poststroke rehabilitation. Clinical Practice Guideline No. 16 (AHCPR Publication No. 95-0662). U.S. Department of Health and Human Services. Agency for Health Care Policy and Research, Rockville, MD.
- Grimby, G. 1994. Quantification of disability after stroke. *Cerebrovasc. Dis*. 4(Suppl 2): 15-18.
- Hakim, A. M., Silver, F., and Hodgson, C. 1998. Organized stroke care: A new era in stroke prevention and treatment. *CMAJ*. 159 (6 Suppl): S1.
- Hamilton, B.B., Laughlin, J.A., Granger, C.V., et al. 1991. Interrater agreement of the seven level Functional Independence Measures (FIM). *Arch. Phys. Med. Rehabil*. 72: 790.
- Han, B., and Haley, W.E. 1999. Family caregiving for patients with stroke. Review and analysis. *Stroke*. 30: 1478-85.
- Hankey, G. J., and Warlow, C. P. 1999. Treatment and secondary prevention of stroke: evidence, costs, and effects on individuals and populations. *The Lancet*. 354: 1457-63.
- Harris, R. E., O'Hara, P.A., and Harper, D.W. 1995. Functional status of geriatric rehabilitation patients: A one-year follow-up study. *J. Am. Geriatr. Soc*. 43: 51-5.
- Hayes, S.H., and Carroll, S.R. 1986. Early intervention care in the acute stroke patient. *Arch. Phys. Med. Rehabil*. 67: 319-21.
-

- Health Services Restructuring Commission. 1998. Change and transition. Planning guidelines and implementation strategies for home care, long term care, mental health, rehabilitation, and sub-acute care. Health Services Restructuring Commission, Toronto.
- Heitzner, J. D., and Teasell, R. W. 1998. Clinical consequences of stroke. In *Physical medicine and rehabilitation: State of the art reviews*. Edited by R. W. Teasell. Hanley & Belfus, Inc., 387-404.
- Hoen, B., Thelander, M., and Worsley, J. 1997. Improvement in psychological well-being of people with aphasia and their families: Evaluation of a community-based programme. *Aphasiology*. 11: 681-91.
- Holloway, R. G., Benesch, C. G., Rahilly, C. R., and Courtright, C. E. 1999. A systematic review of cost-effectiveness research of stroke evaluation and treatment. *Stroke*. 30: 1340-9.
- Holmqvist, L. W., von Koch, L., Kostulas, V., Holm, M., Widsell, G., Tegler, H., Johansson, K., Almazan, J., and de Pedro-Cuesta, J. 1998. A randomized controlled trial of rehabilitation at home after stroke in southwest Stockholm. *Stroke*. 29: 591-7.
- Holyoke, P., and Elkan, L. 1995. Rehabilitation Services Inventory & Quality Project. Phase One Report. Institute for Work & Health, Toronto.
- Indredavik, B., Bakke, F., Slordahl, S.A., Rokseth, R., Haheim, L.L. 1998. Stroke unit treatment improves long-term quality of life: A randomized controlled trial. *Stroke*. 29: 895-9.
- Indredavik, B., Bakke, F., Slordahl, S.A., Rokseth, R., and Haheim, L.L. 1999. Stroke unit treatment 10-year follow-up. *Stroke*. 30: 1524-27.
- Indredavik, B., Bakke, F., Solberg, R., Rokseth, R., Haaheim, L.L., Holme, I. 1991. Benefit of a stroke unit: A randomized controlled trial. *Stroke*. 22: 1026-31.
- Jadad, A. R., and Haynes, R. B. 1998. The Cochrane Collaboration - advances and challenges in improving evidence-based decision making. *Medical Decision Making*. 18: 2-8.
- Joint Committee for Stroke Facilities, American Neurological Association. 1972. I. Epidemiology for stroke facilities planning. II. Stroke Rehabilitation. *Stroke*. 3: 360-407.
- Joint Policy and Planning Committee. 1999. Predicting hospital volumes for communities - the JPPC's rate & volume equity hospital funding formula. An Ontario Ministry of Health and Ontario Hospital Association Partnership, Toronto.
- Jones, H. P., and Brand, M. K. 1995. Providing rehabilitative services in rural communities: Report of a conference. *The Journal of Rural Health*. 11: 122-7.
-

Jongbloed, L., and Morgan, D. 1991. An investigation of involvement in leisure activities after a stroke. *Am. J. Occup. Ther.* 45: 420-7.

Jorgensen, H. S., Nakayama, H., Raaschou, H., Vive-Larsen, J., Stoier, M., and Olsen, T. 1995. Outcome and time course of recovery in stroke. Part I: Outcome. The Copenhagen Stroke Study. *Arch. Phys. Med. Rehabil.* 76: 399-405.

Jorgensen, H.S., Nakayama H., Raaschou H., et al. 1995. Outcome and time course of recovery in stroke. Part II: Time Course. The Copenhagen Stroke Study. *Arch. Phys. Med. Rehabil.* 76: 406-12.

Jorgensen, H.S., and Hirafumi, N., et al. 1995. The effect of a stroke unit: Reductions in mortality, discharge rate to nursing home, length of hospital stay, and cost: A community-based study. *Stroke.* 26: 1178-82(d).

Judy L.C., Lincoln N.B., Berman P., et al. 1996. The effect of a stroke rehabilitation unit on functional and psychological outcome. *Cerebrovasc Dis.* 6: 106-110.

Kalra, L., and Eade, J. 1995. Role of stroke rehabilitation units in managing severe disability after stroke. *Stroke.* 26: 2031-4.

Kalra, L., Dale, P., and Crome, P. 1993. Improving stroke rehabilitation. A controlled study. *Stroke.* 24: 1462-7.

Kane, R. L. 1997. Improving outcomes in rehabilitation. A call to arms (and legs). *Medical Care.* 35 (6): JS21-JS27 (Supplement).

Kaste, M., Palomaki, H., and Sarna, S. 1995. Where and how should elderly stroke patients be treated? A randomized trial. *Stroke.* 26: 249-53.

Kilgore, K. M. 1995. Measuring outcomes in the postacute continuum. *Arch. Phys. Med. Rehabil.* 76: SC-21-6.

King's Fund Forum. 1988. Treatment of stroke. *BMJ.* 297: 126-28.

Kokmen, E., Whisnant, J. P., O'Fallon, W. M., Chu, C. P., and Beard, C. M. 1996. Dementia after ischemic stroke: A population-based study in Rochester, Minnesota (1960-1984). *Neurology.* 19: 154-59.

Langhorne, P., Williams, B.O., Gilchrist, W., and Howie, K. 1993. Do stroke units save lives? *The Lancet.* 342: 395-8.

Langhorne, P. 1995. Developing comprehensive stroke services: An evidence-based approach. *Postgrad. Med. J.* 71: 733-7.

- Langhorne, P., and Legg, L. 1999. Therapy for stroke patients living at home. Outpatient therapy trialists. *The Lancet*. 354 (9191): 1730-1.
- Lawrence, R. H., and Jette, A. M. 1996. Disentangling the disablement process. *Journal of Gerontology: SOCIAL SCIENCES*. 518: S173-S182.
- Logan, P.A., Ahern, J., Gladman J.R., Lincoln, N.B. 1997. A randomized controlled trial of enhanced social service occupational therapy for stroke patients. *Clin. Rehabil.* 11: 107-13.
- Lohr, K. 1997. Improving health care outcomes through geriatric rehabilitation. Conference summary. *Medical Care*. 35: JS121-JS130.
- Loomis, J. 1994. Rehabilitation outcomes: The clinicians's perspective. *Canadian Journal of Rehabilitation*. 7: 165-70.
- Lyden, P.D., and Hautson, L. 1998. Assessment scales for the evaluation of stroke patients. *J. Stroke and Cerebrovascular Diseases*. 7(2): 113-27.
- Malmgren, R., Bamford, J., Warlow, C., and Sandercock, P. 1987. Geographical and secular trends in stroke incidence. *The Lancet*. November: 1196-1200.
- Mayo, N. E., Wood-Dauphinee, S. n.d. Stroke systems. 6. Community reintegration. Health Canada. Laboratory Center for Disease Control, Ottawa.
- Mayo, N. E., Hendlisz, J., and Korner-Bitensky, N. 1989. A model for cost-effective stroke care. *Canadian Journal of Rehabilitation*. 2: 155-62.
- Mayo, N. E. 1998. Epidemiology and recovery of stroke. In R.W. Teasell (Ed.), *Physical medicine and rehabilitation: State of the art reviews*. 12: 355-65.
- Mayo, N. E., Wood-Dauphinee, S. Ahmed, S., Gordon, C., Higgins, J., McEwen, S., and Salbach, N. 1999. Disablement following stroke. *Disability and Rehabilitation*. 21: 258-68.
- National Stroke Strategy. 1997. Melbourne: National Stroke Foundation, Australia.
- Oczkowski, W.J., and Barreca, S. 1993. The functional independence measure: Its use to identify rehabilitation needs in stroke survivors. *Arch. Phys. Med. Rehabil.* 74: 1291-4.
- Ontario. 1999. Legislature. Bill 7. An act to protect taxpayers against tax increases, to establish a process requiring voter approval for proposed tax increases and to ensure that the provincial budget is a balanced budget. 37th Legislature, 1st Session. Legislative Assembly of Ontario, Toronto.
-

- Ontario Council of University Programs in Rehabilitation Sciences. 1999. Rehabilitation research report 1997-98. Council of Ontario Universities, Toronto.
- Ontario March of Dimes Research Department. 1993. An even break. The needs of persons with physical disabilities in Ontario. Ontario March of Dimes, Toronto.
- Ontario Medical Association. 1994. Position in support of timely return to work programs and the role of the primary care physician. Ontario Medical Association, Toronto.
- Ontario Ministry of Finance. 1996. 1996 Ontario budget. Budget papers presented to members of the Legislative Assembly of Ontario. Government of Ontario, Toronto.
- Ontario Ministry of Health. 1993. Rehabilitation Strategic Framework. Working Document. Toronto.
- Ottenbacher, K.J., and Jannell, S. 1993. The results of clinical trials in stroke rehabilitation research. *Arch. Neurol.* 50: 37-44.
- Ottenbacher, K. J. 1995. Why rehabilitation research does not work. *Arch. Phys. Med. Rehabil.* 76: 123-9.
- Peacock, P.B., Riley, C.P., Lampton, T.D., Raffel, S.S., and Walker, J.S. 1972. The Birmingham stroke epidemiology and rehabilitation study. In: G. T. Steward (Ed.), *Trends in epidemiology* (pp. 131-145). Charles C. Thomas, Springfield.
- Pearson, V.A. H. 1995. Speech and language therapy: Is it effective? *Public Health.* 109: 143-53
- Peckham, M. 1999. Developing the National Health Service: A model for public services. *The Lancet.* 354: 1539-45.
- Peel District Health Council. 1997. Coordinating rehabilitation in Peel. Mississauga.
- Petchers, M. K., Roy, A.W., and Brickner, A. 1987. A post-hospital nursing home rehabilitation program. *The Gerontologist.* 27: 752-55.
- Purdue, M., Hunter, D., Spasoff, R., and Dorland, J. 1998. Estimating the need for evidence-based stroke services in Eastern Ontario. Health Information Partnership, Eastern Ontario Region, Kingston.
- Reddy, M. P., and Reddy, V. 1997. Stroke rehabilitation. *American Family Physician.* 55: 1742-48.
- Registered Nurses' Association of Ontario. 1999. The Canada Health Act: To preserve & protect. The Registered Nurses' Association of Ontario, Toronto.
-

Ontario Hospital Association. 1999. Rehabilitation Program Definitions. The Rehabilitation Program Definitions Task Group of the OHA Rehabilitation Working Group, Toronto.

Rockwood, K., Stolee, P., and Fox, R.A. 1993. Use of goal attainment scaling in measuring clinically important change in the frail elderly. *J. Clin. Epidemiol.* 46: 1113-8.

Rodgers, A., Neal, B., and MacMahon, S. 1997. The effect of blood pressure lowering in cerebrovascular disease. *Neurol. Rev. Int.* 2(1): 12-15.

Ronning, O.M., and Guldvog, B. 1998. Outcome of subacute rehabilitation: A randomized controlled trial. *Stroke.* 29: 779-84.

Roth, E. J., Heinemann, A. W., Lovell, L. L., Harvey, R. L., McGuire, J. R., and Diaz, S. 1998. Impairment and disability: Their relation during stroke rehabilitation. *Arch. Phys. Med. Rehabil.* 79: 329-35.

Rudd, A.G., Wolfe, C.D., Tilling, K., and Beech, R. 1997. Randomized controlled trial to evaluate early discharge scheme for patients with stroke. *BMJ.* 315(7115): 1039-44.

Schmidt, S. M., Guo, L., Scheer, S., Boydston, J., Pelino, C., and Berger, S. K. 1999. *JONA.* 29: 40-47.

Senelick, R. C., Rossi, P.W., and Dougherty, K. 1999. *Living with stroke: A guide for families.* Rev. ed. Contemporary Books, Chicago.

Shah, S., Vanclay, F., and Cooper, B. 1989. Improving the sensitivity of the Barthel Index for stroke rehabilitation. *J. Clin. Epidemiol.* 42: 703-9.

Shah, S., Vanclay, F., and Cooper, B. 1989. Predicting discharge status at commencement of stroke rehabilitation. *Stroke.* 20: 766-9.

Shortell, S. M., Gillies, R. R., Anderson, D.A., Mitchell, J. B., and Morgan, K. L. 1993. Creating organized delivery systems: The barriers and facilitators. *Hosp. Health Serv. Adm.* 38: 447-66

Sibbald, W. J., and Kossuth, J. D. 1998. The Ontario Health Care Evaluation Network and the Critical Care Research Network as vehicles for research transfer. *Medical Decision Making.* 18: 9-15.

Silver, F., Arts, R., Black, S., et al. n.d. *Stroke Treatment Education Program: The latest in optimal stroke management for emergency and acute care.* Heart and Stroke Foundation of Canada. Canadian Stroke Society.

Sivenius, J., Pyorala, K., and Heinonen, O.P. 1985. The significance of intensity of rehabilitation of stroke: A controlled trial. *Stroke.* 16: 928-31.

Smith, M.E., Garraway, W.M., Smith, D.L., and Akhtar, A.J. 1982. Therapy impact on functional outcome in a controlled trial of stroke rehabilitation. *Arch. Phys. Med. Rehabil.* 63: 21-4.

Smurawska, L. T., Alexandrov, A.V., Bladin, C. F., and Norris, J.W. 1994. Cost of acute stroke care in Toronto, Canada. 25: 1628-31.

Statistics Canada. 1999. National Population Health Survey, 1996-97. Public Use Microdata Files, Cat no. 82M00009XCB, Ottawa.

Statistics Canada. Oct. 27, 1995. National Population Health Survey: Residents of health care institutions. *The Daily*, Ottawa.

Stevens, R.S., Ambler, N.R., and Warren, M.D. 1984. A randomized controlled trial of a stroke rehabilitation ward. *Age Ageing.* 13: 65-75.

Stineman, M. G., and Granger, C.V. 1998(b). Outcome efficiency and time-trend pattern analyses for stroke rehabilitation. *Am. J. Phys. Med. Rehabil.* 77: 193-201.

Stineman, M.G., Fiedler, R. C., Granger, C.V., and Maislin, G. 1998(a). Functional task benchmarks for stroke rehabilitation. *Arch. Phys. Med. Rehabil.* 79: 497-504.

Strand, T., Asplund, K., Eriksson, S., Hagg, E., Lithner, F., and Wester, P.O. 1985. A non-intensive stroke unit reduces functional disability and the need for long-term hospitalization. *Stroke.* 16: 29-34.

Stroke Rehabilitation Round Table. 1998. Vision for Stroke Rehabilitation in Ontario. Heart and Stroke Foundation of Ontario, Toronto.

Stroke Unit Trialists' Collaboration. 1997. Collaborative systematic review of the randomized trials of organized inpatient (stroke unit) care after stroke. *BMJ.* 314: 1151-9.

Sullivan, M. J. L., Lascells, M.A., Cappon, P., and Ware, M. L. 1993. Current Status of out-reach rehabilitation in Canada. *Canadian Journal of Rehabilitation.* 6: 208-17.

Swartzman, L., and Teasell, R.W. 1993. Psychological consequences of stroke. In R.W. Teasell (Ed.) *Physical medicine and rehabilitation: State of the art reviews.* 7: 179-93.

Swartzman, L., Gibson, M.C., and Armstrong, T. L. 1998. Psychosocial considerations in adjustment to stroke. In R.W. Teasell (Ed.) *Physical medicine and rehabilitation: State of the art reviews.* 12: 519-41.

Tangeman, P.T., Banaitis, D.A., and Williams, A.K. 1990. Rehabilitation of chronic stroke patients: Changes in functional performance. *Arch. Phys. Med. Rehabil.* 71: 876-80.

Teasell, R.W. 2000. Stroke rehabilitation. Unpublished.

Tran, C., Nadareishvili, Z., Smurawska, L, Oh, P. I.T., and Norris, J.W. 1999. Letter to the Editor. *Stroke*. 30: 185-6.

Tu, J.V., and Porter, J. 1999. Stroke Care in Ontario: Hospital Survey Results. Heart and Stroke Foundation of Ontario, Ontario Ministry of Health, Institute for Clinical Evaluative Sciences in Ontario, Ontario Hospital Association, Toronto.

Victorian Stroke Strategy. n.d. Melbourne: National Stroke Foundation, Australia.

Wade, D.T., Collen, F.M., Robb, G.F., and Warlow, C.P. 1992. Physiotherapy intervention late after stroke and mobility. *BMJ*. 304(6827): 609-13.

Walker, M.F., Drummond, A., and Lincoln, N.B. 1996. Evaluation of dressing practice for stroke patients after discharge from hospital: A crossover design study. *Clinical Rehabilitation*. 10: 23-31.

Ween, J. E., Alexander, M. P., D'Esposito, M., and Roberts, M. 1996. Factors predictive of stroke outcome in a rehabilitation setting. *Neurology* 47: 388-92.

Werner, R.A., and Kessler, S. 1996. Effectiveness of an intensive outpatient rehabilitation program for postacute stroke patients. *Am. J. Phys. Med. Rehabil.* 75: 114-20.

Wertz, R.T. 1990. Communication skills in stroke survivors: An overview of classification and treatment. *Stroke*. 21 (9 Suppl):II16-8.

Williams, G. R., Jiang, J. G., Matchar, D. B., and Samsa, G. P. 1999. Incidence and occurrence of total (first-ever and recurrent) stroke. *Stroke*. 30: 2523-28.

Wolfe, C. D.A., Tilling, K., Beech, R., and Rudd, A. G. 1999. Variations in case fatality and dependency from stroke in western and central Europe. *Stroke*. 30: 350-56.

Wood-Dauphinee, S.L., Shapiro, S., Bass, E., Fletcher, C., Georges, P., Hensby, V., and Mendelsohn, B. 1984. A randomized trial of team care following stroke. *Stroke*. 15: 864-72.

World Health Organization. 1980. The international classification of impairments, disabilities and handicaps. World Health Organization, Geneva.

World Health Organization. 1983. World programme of action concerning disabled persons. United Nations, New York.

World Health Organization. 1989. Stroke - 1989. Recommendations on stroke prevention, diagnosis, and therapy. *Stroke*. 20: 1407-31.

World Health Organization. 1999a. <http://www.who.int/icidh/introduction.htm>.

World Health Organization. 1999b. International classification of functioning and disability: A news release from World Health Organization. Note for the Press.
