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Canadian Stroke Network
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CANADIAN BEST PRACTICE RECOMMENDATIONS FOR STROKE CARE

Fourth Edition

Lindsay MP, Gubitz G, Bayley M, Phillips S (Editors),
on Behalf of the Canadian Stroke Best Practices and Standards Working Group

CHAPTER 6

Managing Stroke Transitions of Care

(UPDATE Fall 2013)

Lindsay MP and Gilmore P (Co-Chairs)
on Behalf of the Stroke Transitions of Care
Best Practices Writing Group 2013

Canadian Best Practice Recommendations for Stroke Care
Managing Stroke Transitions of Care ~ Fourth Edition
(Updated October 2013)

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CANADIAN BEST PRACTICE RECOMMENDATIONS FOR STROKE CARE

The *Canadian Best Practice Recommendations for Stroke Care* is intended to provide up-to-date evidence-based guidelines for the prevention and management of stroke. The goal of disseminating and implementing these recommendations is to reduce practice variations in the care of stroke patients across Canada, and to reduce the gap between knowledge and practice. Recommendations are updated on a rotating cycle every two years to ensure they continue to reflect contemporary stroke research evidence and leading expert opinion. Each update involves critical review of the current medical literature, which informs decisions regarding modification of the recommendations and the performance measures used to assess their impact. Every attempt is made to coordinate with other Canadian groups who are developing guidelines that relate to stroke, such as hypertension, atrial fibrillation and diabetes. As well, if significant new evidence becomes available in between update cycles, a process is in place to conduct a modified Delphi process to rigorously review the new evidence and gain consensus on the impact of that evidence on current recommendations. Modifications that are required through the consensus process will be made as soon as they are available, which is readily enabled through the web-based format of the Canadian stroke best practices.

This is the fourth edition of the *Canadian Best Practice Recommendations for Stroke Care,* which was first released in 2006. The theme of the 2012 – 2013 update is ***TAKING ACTION,*** and stresses the critical role and responsibility of healthcare providers at every stage of the continuum of care to ensure that best practice recommendations are implemented and adhered to. ***TAKING ACTION*** will lead to optimal outcomes for each stroke patient by providing the best care within the most appropriate setting. This includes rapid and efficient access to diagnostic services, stroke expertise and medical and surgical interventions, rehabilitation and support for ongoing recovery and community reintegration.

TAKING ACTION requires a committed team approach and strong coordination of care across regions and networks, with pre-hospital, acute care, rehabilitation and community-based healthcare providers working together to ensure optimal outcomes for patients and their families, regardless of geographic location.

TAKING ACTION also applies to patients who have experienced a stroke, their families and informal caregivers. Stroke patients and their families need to actively participate in their recovery and openly communicate with their healthcare team. Patients and families must participate in setting the goals they want to achieve during recovery from a stroke, and share concerns, as well as physical, social, psychological, and emotional issues with their healthcare team members. This ongoing communication and interaction will lead to the care required for optimal recovery and achievement of all aspects of health and psychosocial goal attainment.

ALL CANADIAN BEST PRACTICE RECOMMENDATIONS FOR STROKE CARE,
AS WELL AS SUPPORTING DOCUMENTS AND IMPLEMENTATION TOOLS CAN BE ACCESSED
THROUGH OUR STROKE BEST PRACTICES WEBSITE AT:

WWW.STROKEBESTPRACTICES.CA

SECTION 6.0 STROKE TRANSITIONS OF CARE

TAKING ACTION IN STROKE TRANSITIONS OF CARE

TAKING ACTION is an imperative for stroke systems of care, healthcare providers, patients, families, and the broader community. The primary underpinning of '*taking action in stroke transitions of care'* is to provide patient and family-centred care across all transition points and ensure effective and efficient transfers of care and information to the next stage and setting of care. By not carefully monitoring the later transition points in the continuum of stroke care, it could put patients and families at risk for safety and hinder their progress made during the initial recovery stage.

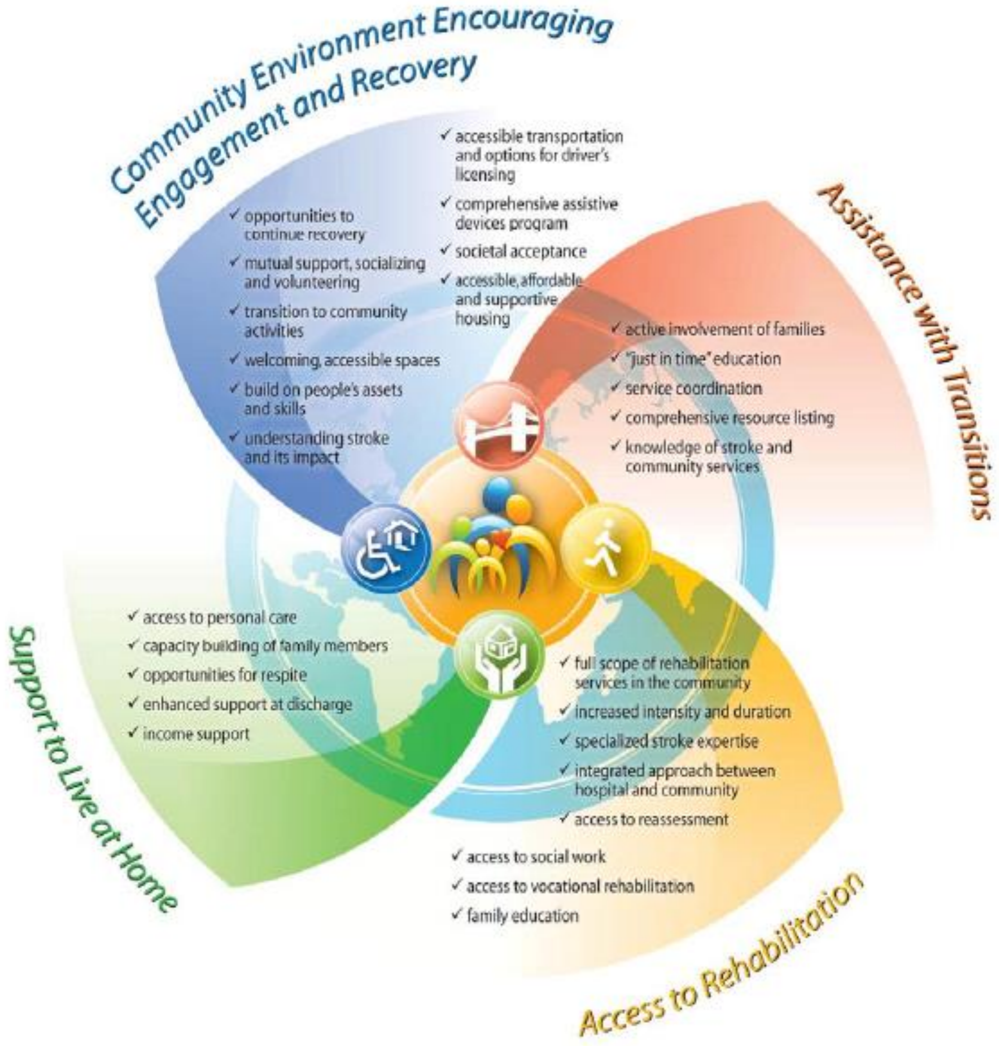


Figure 6.1:
Pathways for People with Stroke to Live Fully in the Community
Developed by Southwestern Ontario Stroke Strategy, 2008. *Reproduced with permission.*

All members of the healthcare team for stroke patients and families are responsible for ***taking action*** to ensure successful transitions and facilitate a successful return to the community following stroke. Figure 6.1 depicts a pathway and steps for successful transitions, developed through an extensive consensus process (Gilmore et al, 2008).

Key components of successful transitions include:

- ✓ collaborative goal setting between the healthcare team, patients and families, where patients and family members actively participate in discussions and planning with the healthcare team and are involved in shared decision-making;
- ✓ ongoing education for patients, families and informal caregivers that reinforces key information and verifies understanding;
- ✓ patient, family and informal caregiver education needs to occur for all stroke patients, regardless of setting; this includes in the emergency department, primary care, acute inpatient care (regardless of location of patient within the hospital), rehabilitation settings, outpatient and community settings;
- ✓ skills training appropriate to needs and goals of patients to facilitate safe transitions;
- ✓ discharge planning that begins soon after stroke admission and all relevant support services, such as home assessments and access to ambulatory and community-based rehabilitation;
- ✓ assessment of family and informal caregiver capacity to provide ongoing care for the patient with stroke, as well as their individual support needs and potential burden of care;
- ✓ timely transfer of medical information between stages of care to ensure smooth transitions in care;
- ✓ identification of and linkages to community resources, long term care and home-based care;
- ✓ ongoing surveillance of physical, psychological, social and emotional recovery, coping and adaptation following discharge from inpatient acute care and rehabilitation settings.

A coordinated and seamless system taking all these components into account will minimize challenges and complications for patients and families between stages and settings for stroke care, and lead to better recovery outcomes. Stroke case managers and/or stroke system navigators are valuable additions to the stroke care team, and where resources permit should be made available to patients, families and informal caregivers. Stroke navigators empower patients and families to be involved in their own care, build self-management skills and confidence, and aid in access to community resources, support groups and linkages. Providing support mechanisms like these may reduce the burden to the health system and to health care professionals providing reactive care; evidence shows that this is typically more costly to the health system and an increased care burden on health providers.

TAKING ACTION in the area of stroke care transitions is also directed to researchers and research funding organizations. The body of evidence for many of the topics addressed in this chapter based on observational studies, small qualitative research initiatives and cohort studies. In many areas, randomized controlled trials and systematic reviews are lacking. Even with the availability of lower levels of evidence, the topics covered in this chapter have strong significance for patients and families and therefore are presented based on moderate evidence and expert opinion.

HIGHLIGHTS OF MANAGING STROKE TRANSITIONS OF CARE UPDATE 2013

The 2013 update of the Managing Stroke Transitions of Care Chapter of the *Canadian Best Practice Recommendations for Stroke Care* reinforces the growing and changing body of research evidence available to guide ongoing screening, assessment and management of patients who have experienced a stroke and ensure they move from one phase and stage of care to the next without 'falling through the cracks" or 'getting lost out of the system'.

Key messages for 2013 and significant changes to previous recommendations include:

- ✓ ***BE AWARE***: strong emphasis on educating patients and families to understand the nature and cause of stroke, the signs and symptoms, the impact and the ongoing needs of the patient who has experienced a stroke;
- ✓ ***BE AWARE***: that stroke affects the whole family unit and places a burden on family members both in the immediate decision-making and management, and in the ongoing and long-term recovery for the patient who experienced the stroke;
- ✓ ***BE AWARE***: these recommendations introduce the experience of post-stroke fatigue that is under-recognized and under-diagnosed among stroke patients. It is important for healthcare professionals to discuss fatigue and prepare patients for the experience of fatigue, and energy-conservation techniques, otherwise fatigue can negatively impact recovery and increase the risk for post-stroke depression;
- ✓ ***BE INVOLVED***: The patient, family members and informal caregivers should be considered active members of the stroke team and be involved in decision-making, goal setting and care planning throughout the stroke care continuum;
- ✓ ***TAKE ACTION***: these stroke recommendations clearly state that all healthcare professionals are responsible for delivering education and support on an ongoing basis, regardless of patient location within the healthcare system, including providing new information at the right teachable time, reinforcing previously taught information, and assessing ongoing learning needs; these information needs evolve as the patient moves through the continuum of care and into longer term recovery;
- ✓ ***TAKE ACTION***: these stroke recommendations promote self-management and active participation in ongoing care, following rehabilitation plans and actively engaging in recovery, and following though with decisions to take prescribed medications;
- ✓ ***TAKE ACTION***: these stroke recommendations introduce new educational recommendations and assessment steps for both home-care professionals and staff members working with stroke patients in long-term care facilities.

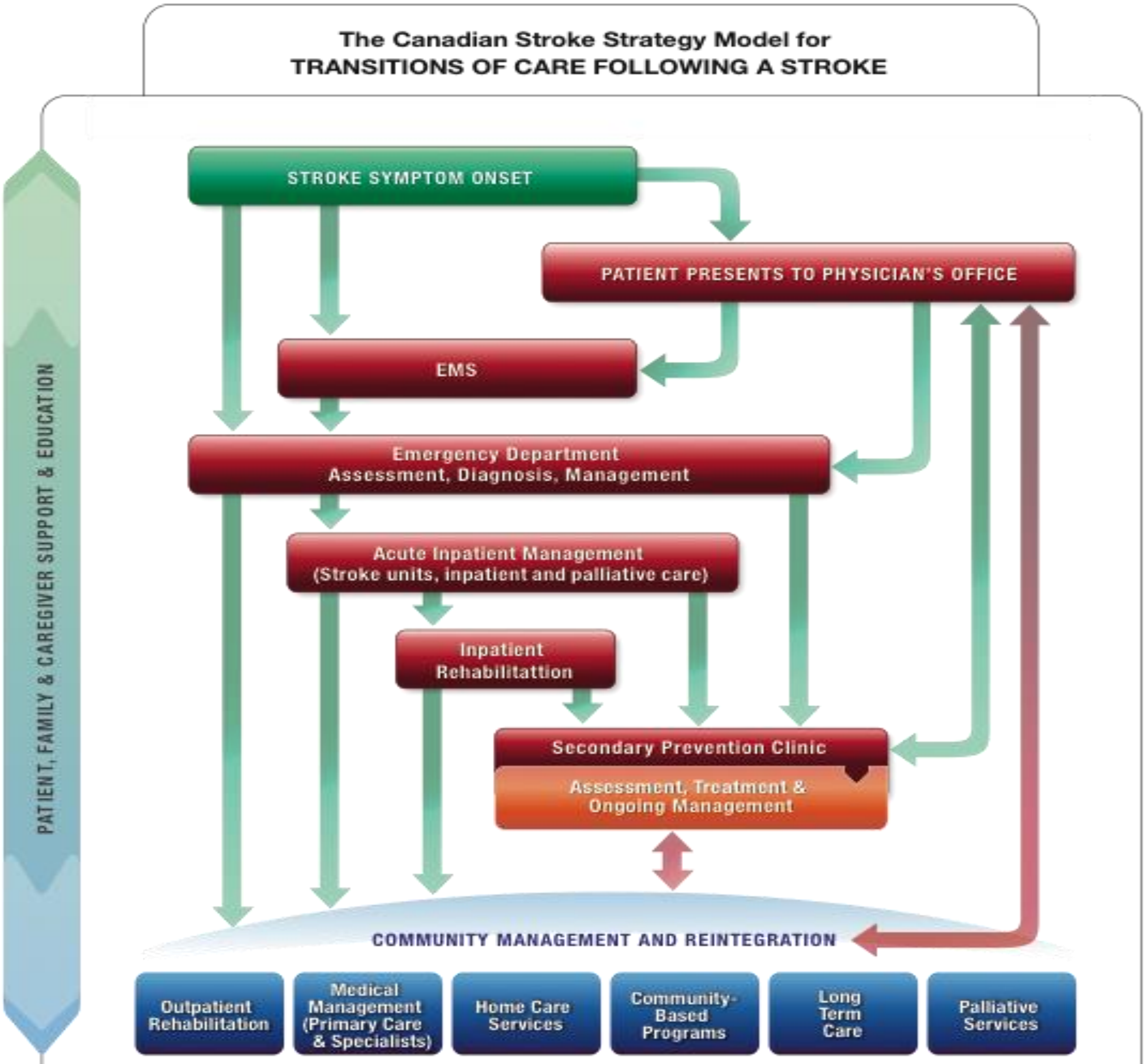
MANAGING STROKE TRANSITIONS OF CARE UPDATE 2013 RESOURCE PACKAGE INCLUDES:

i. Stroke Best Practice Recommendations for Managing Stroke Transitions of Care, evidence summaries and evidence tables with reference list
ii. ***TAKING ACTION TOWARDS OPTIMAL STROKE CARE*** manual and educational slide deck on stroke transitions of care
iii. Winnipeg Regional Health Authority (WRHA) Transition Management Pathway
iv. Canadian Stroke Best Practices Assessment Tool Summary Tables
v. Links to additional implementation resources for all topic areas

STROKE TRANSITIONS OF CARE MODEL AND DEFINITIONS

Figure 6.2: The Canadian Best Practices Model for Transitions of Care Following a Stroke

The Canadian Stroke ***Transitions of Stroke Care Model*** *identifies the most common points of transition for stroke patients along the continuum of care. The arrows are presented as unidirectional for simplicity of the diagram. However, in many instances stroke patients will move back and forth between different stages or settings of care during short-term and long-term recovery and reintegration.*



The Canadian Stroke Strategy *Transitions of Stroke Care Model* identifies the most common points of transition for stroke patients along the continuum of care. The arrows are presented as unidirectional for simplicity of the diagram. However, in many instances stroke patients will move back and forth between different stages or settings of care during short-term and long-term recovery and reintegration.

STROKE TRANSITIONS OF CARE DEFINITIONS

- **Transition** refers to the movement of patients among healthcare locations, providers, different goals of care, and across the various settings where healthcare services are received. *Refer to Figure 6.2 The Canadian Best Practices Model for Transitions of Care Following a Stroke.*

- **Transition management** includes working with patients, families, and informal caregivers to establish and implement a transition plan that includes goal setting and that has the flexibility to respond to evolving needs. Successful transition management requires interprofessional collaboration between healthcare providers, clients, families, and informal caregivers. It encompasses the organization, coordination, education, and communication required as patients, families and informal caregivers move through the stages and settings for stroke treatment, recovery, reintegration, adaptation, and end-of-life care.

- **The goal of transition management** is to facilitate and support seamless patient, family, and informal caregiver transitions across the continuum of care, and to achieve and maintain optimal adaptation, outcomes, and quality of life for the family system following a stroke. This incorporates physical, emotional, environmental, financial and social influences.

- **Support** for patients and families following stroke refers to providing care, services, and facilitate linkages to resources to ensure that patient, family and informal caregiver needs are met throughout the journey of recovery from a stroke, from many perspectives. The goal of patient, family and informal caregiver support is to equip each individual with tools and information to manage their recovery or the recovery of a loved one after stroke and optimize participation and fulfillment of life roles; tailored to unique needs, coping mechanisms, strengths, challenges and living situation.

- **Stroke Navigator/Case Manager –** a specific role of a health care professional to provide person centred support to stroke survivors and their families, ensuring they receive the information, education, support and advice they need to successfully transition across the stroke care continuum and settings of care. The stroke navigator/case manager is often a social worker or similarly trained professional, and is often engaged in the acute care phase, and continues on in many regions for the first six months following stroke, depending on patient and family needs. A key role for the stroke navigator/case manager is to provide emotional support to stroke patients, families and informal caregivers, and assist with the practical aspects of adaptation following stroke (Stroke Foundation, United Kingdom).

  The stroke navigator/case manager works closely with other health, social care, voluntary and community providers to ensure a seamless delivery of service. This is accomplished by providing information on available services, processing referrals, linking with primary care providers and other medical specialists required by the patient, and assisting patients and families to address and access financial, transportation, and other concerns that may negatively impact achieving optimal recovery and successful transitions. They should also facilitate contact with stroke support organizations and local peer support groups for patients and families following stroke.

- **Community –** within the context of the Canadian Best Practice Recommendations for Stroke Care, 'community' is defined from a multi-dimensional perspective: as the physical, social, and care environment where individuals reside after experiencing a stroke. Community as an environment would include any setting that is outside the acute care and inpatient rehabilitation settings, where a person would reside and resume life roles and activities following a stroke. Therefore, community as an environment would include family home, assisted living, long-term care, and other residential settings where a person may live once a person is discharged from acute and sub-acute care.

- **Community Reintegration –** A return to participation in desired and meaningful activities of daily living, community interests and life roles following a stroke event. The term encompasses the return to mainstream family and active community living and continuing to contribute to one's social groups and family life. Community reintegration is a component in the continuum of care post stroke; rehabilitation helps clients identify meaningful goals for community reintegration and through structured interventions facilitates resumption of these activities to the best of their abilities. The stroke survivor, family, friends, stroke recovery associations, rehabilitation programs and the community at large are all integral to successful community reintegration.

  Successful community reintegration may require health services and community-support services that aim to optimize patient and family functioning and maximize quality of life after return to the community. To achieve these goals, the following are examples of services that may be required for stroke patients, their families and informal caregivers: social support, monitoring of caregiver burden, depression and family interactions, family education interventions, adaptation of social and leisure activities post stroke, leisure therapy, and encouragement to actively participate in all aspects of society.

- **Home Health Care –** also referred to as 'home-care', is defined in these recommendations as rendering medical, nursing, rehabilitation and personal care related services to clients in a home setting rather than in a medical facility. These services would be provided to patients who return to their homes following a stroke or TIA. The home care services help patients to safely increase their ability to tend to their everyday needs at home, continue their rehabilitation therapy, promote ongoing recovery, identify risks, facilitate home-modifications, and provide assistance for personal care and mobility, and gain independence to enable patients to remain safely in their home for as long as possible.

  Home health care may include skilled nursing, and social work services, in addition to speech-language pathology, occupational therapy, physiotherapy, home care attendants and/or home support workers. Home-based care may be provided exclusively in the home or combined with care in the community (such as in day centres or under arrangements made for respite care). In parts of Canada, some home care services, such as rehabilitation services, are also available for residents in assisted living and long-term care settings.

  Home health care may include skilled nursing services and social workers, in addition to speech-language pathologists, occupational and physical therapy, and personal care workers. In many cases, it includes assistance with cooking and other household chores, and assistance with financial management. A key element of home-care services is to develop strong links between the client, their family and informal caregivers with their primary care providers to ensure smooth transitions of services, and monitoring of ongoing medical and rehabilitation needs, medication compliance and management, access to disability services, vocational assistance, and informal caregiver support and burden.

- **Supported Living Environments –** refers to residential living locations where individuals may transition following acute and sub-acute care for a stroke, and where they continue to receive healthcare services within a coordinated and organized system. The levels of support and service received are dependent on the individual's physical, functional and cognitive abilities and ongoing health care needs, as well as available social support from family members and informal caregivers. Supported living environments are settings where people can maintain as much control over their lives as possible, while receiving the supports they need to maintain their activities of daily living.

  The principles of supportive living are to maximize independence of the resident, provide respect for individuality, maximize control of their environment, maximize resident decision-making, maximize privacy, and provide flexibility of the environment to accommodate changing needs and declines in health status and independent functioning (Alberta Health Services).

  Supportive living environments may include a range of settings and support service levels, such as: private home or residence where health care services are brought to the stroke survivor; group settings such as lodges, transitional care or respite centres where the person with stroke resides with others with similar care and support needs; assisted living settings where the individual has their own private rooms within a residential setting and have access to personal care support, group meals, organized social activities, and transportation; advanced assisted living and full care environments such as nursing home settings.

- **Long-Term Care –** Long-term care is the provision of formal organized institutional care for three or more unrelated people in the same place. Long term care is provided for people of all ages who have long-term health problems and need assistance with the activities of daily living (ADL) in order to enjoy a reasonable quality of life *(World Health Organization, 2000)*. The goal of long-term care is to ensure that an individual who is not fully capable of long-term self-care can maintain the best possible quality of life, with the greatest possible degree of independence, autonomy, participation, personal fulfilment, and human dignity.

  The need for long-term care following a stroke is influenced by changing physical, mental, and/or cognitive functional capacities, their abilities and levels of independence prior to the stroke, and the availability of family and informal caregivers. Many people may regain lost functional capacities over a shorter or longer period of time following stroke, while others decline. The type of care needed and the duration of such care are thus often difficult to predict (WHO).

  Each long term care home provides an organized 24 hour program of nursing, personal support, medical, pharmacy and interdisciplinary care services based on the assessed needs of residents and guided by an individual written plan of care. Appropriate long-term care includes respect for each individual's values, preferences, and needs. In many provinces in Canada, each long term care home is considered to be primarily the home of its residents. It is to be operated to promote and maximize independence of each resident as well as to provide dignity and security, safety and comfort and to meet the physical, psychological, social, spiritual and cultural needs of its resident population. Admission to a long term care home is based on provincial health insurance eligibility and an independent assessment by a case manager or community-care service provider (Ontario Long Term Care Association).

CANADIAN STROKE BEST PRACTICES FRAMEWORK FOR OPTIMAL STROKE SERVICES DELIVERY

There are variations in the levels of stroke care service provided within the Canadian health care system. These services can be arranged along a continuum from minimal, non-specialized services, provided in facilities that offer general medical and surgical care, to more advanced and comprehensive stroke care centres (See Figure 6.3). The goal for each organization involved in the delivery of stroke care services is to continue to develop the expertise and processes needed to provide optimal patient care, taking into consideration that organization's geographic location, patient population, structural resources, and relationship to other centres within their healthcare region or system. Once a level of stroke services has been achieved, the organization should strive to develop and incorporate components of the next higher level for ongoing growth of stroke services where appropriate, as well as continuous quality improvement within the level of service currently provided.

Figure 6.3: ***CANADIAN STROKE BEST PRACTICES FRAMEWORK FOR OPTIMAL STROKE SERVICES DELIVERY***

FOR ADDITIONAL INFORMATION AND DETAILS ABOUT THE STROKE SERVICES FRAMEWORK, PLEASE REFER TO THE "TAKING ACTION TOWARDS OPTIMAL STROKE CARE" RESOURCE

WWW. STROKEBESTPRACTICES.CA

DEVELOPMENT OF THE *CANADIAN BEST PRACTICE RECOMMENDATIONS FOR STROKE CARE*

For detailed methodology on the development and dissemination of the *Canadian Best Practice Recommendations for Stroke Care* please refer to the stroke best practices website at http://www.strokebestpractices.ca/index.php/overview/methods/

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Comments

We invite comments, suggestions, and inquiries on the development and application of the *Canadian Best Practice Recommendations for Stroke Care and ongoing updates.*

Please forward comments to the Heart and Stroke Foundation *Stroke Best Practices and Performance* team at bestpractices@hsf.ca

CANADIAN BEST PRACTICE RECOMMENDATIONS FOR STROKE CARE

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Managing Stroke Transitions of Care
Best Practice Recommendations
Update October 2013

SECTION 6.1 MANAGING STROKE TRANSITIONS OF CARE

Note: Throughout this section, it is acknowledged that a body of sound research evidence is in the early stages of development for some of the topics addressed. Randomized controlled trials are challenging to complete for many the topics addressed in this chapter. There are a growing number of qualitative studies and observational studies that have provided the basis for some recommendations, and others are based on the expert opinion of the writing group members. Although the evidence is less mature, these areas have been identified through formal and informal interviews with patients and families, where they have stated that these topics often cause the greatest challenges for them. Therefore, these topics are included in the Canadian Best practice Recommendations for Stroke Care. Their inclusion is intended to facilitate a holistic approach to stroke patient care, and ensure all issues important to patients and families which will promote optimal recovery are addressed.

Best Practice Recommendation 6.1 *Update 2013*
Supporting Patients, Families and Informal Caregivers Following Stroke

6.1 Patients, families, and informal caregivers should be prepared for their transitions between care environments by being provided with information, education, training, emotional support, and community services specific to the transition they are undergoing [Evidence Level B].

6.1.1 Screening and Assessment

i. Patients, families and informal caregivers should be screened at each transition of care stage for their readiness to learn and integrate knowledge into the recovery process, level of coping, risk for depression, and other psychosocial and physical issues (such as residual physical deficits, including aphasia) as appropriate to the individual [Evidence Level B]. *Refer to recommendations 7.1, 5.4 and 4.3 for additional information.*

   a. Family members and informal caregivers should be included in the screening process, and if issues identified, they should be advised to contact their healthcare providers and other services as appropriate [Evidence Level C].

   b. Validated screening tools should be used whenever possible to ensure a consistent approach to identifying potential issues during transitions [Evidence Level C]. *Refer to implementation tools and resources section below for additional information.*

ii. Patients, families and informal caregivers should be assessed at each transition point (starting with first contact with the healthcare system through primary care or the emergency department), and when there is a change in health status or other appropriate indication, to determine their needs and readiness for information, education, training, psychosocial support, and health and social services [Evidence

Level B]. *Refer to recommendation 6.2 for additional information on education and training.*

a. Family members and informal caregivers should be assessed for the following issues as they relate to their ability to care for the patient affected by stroke:
    - caregiver capabilities and experience in providing care to the person affected by stroke [Evidence Level C];
    - caregivers' current health status, employment and social responsibilities, and how those will be managed in providing stroke care [Evidence Level B];
    - resource issues such as income, financial situation, housing, transportation, healthcare benefits, medication cost coverage [Evidence Level C];
    - social support from other family members, relatives and social networks [Evidence Level C].

b. The type and depth of assessments should be appropriate to the individual patient's needs, issues identified during screening, and the care setting (e.g., home with or without home care services, inpatient rehabilitation, assisted living, and long-term care) where the patient is transitioning [Evidence Level C].

iii. When issues are identified through screening and assessments, referrals to appropriate care providers should be initiated to address the issues and promote optimal recovery after stroke (e.g., mental health experts, social services, etc.) [Evidence Level B].

6.1.2 Patient, Family and Caregiver Support

i. Patients, families and informal caregivers should be prepared with appropriate and realistic expectations regarding role changes, and the availability of services and resources within changing care environments [Evidence Level C].

ii. Support for patients, families and informal caregivers should begin at the time of admission and continue throughout the healthcare episode until discharge to the next healthcare setting or back to the community (either from the emergency department, acute care or inpatient rehabilitation, and with or without home support services in place at time of discharge) [Evidence Level B].

iii. Support should include:

a. Written discharge instructions from healthcare providers that identify action plans, follow-up care, and goals, provided to the patient, family, and primary care giver [Evidence Level B]. *Refer to recommendation 6.2 for additional information.*

b. Access to a contact person in the hospital or community (e.g., designated social worker, case manager or system navigator) for post-discharge queries [Evidence Level C].

c. Access to and advice from health and social service organizations appropriate to their needs and stage of transition and recovery (ideally through single points of access to all organizations where available) [Evidence Level C].

d. Referrals to community agencies such as stroke survivor groups, peer survivor visiting programs, meal provider agencies, and other services and agencies

[Evidence Level C]. *Refer to recommendation 6.5 for additional information.*

iv. Support when patients are being discharged from acute care and admitted to inpatient rehabilitation should include:
   a. Accurate and up-to-date information about the inpatient rehabilitation setting: what the patient and family can expect and what would be expected of them (e.g. participation in rehabilitation, providing home/community type clothing, providing money for community-practice events) [Evidence Level C].
   b. Active participation of patients and family members in the development of an individualized rehabilitation plan that incorporates shared decision-making and reflects the patient's recovery goals [Evidence Level C]. *Refer to stroke rehabilitation recommendations in Chapter 5 for additional information.*
   c. Discharge planning meetings and assessments to ensure all necessary training, equipment and home modifications are in place [Evidence Level B].
   d. Written discharge instructions from care providers that identify action plans, follow-up care, and goals, provided to the patient, family, and primary care giver [Evidence Level B]. *Refer to recommendation 6.2 and 6.4 for additional information.*

v. Support when patients are being transitioned to long-term care should include:
   a. Counseling, preparation and ongoing assessment for adjustment to change of living setting, change in physical needs and increased dependency, change in social roles and leisure activities, impact on other family members (e.g., living spouse or partner, children), loss of home environment, and potential resource issues [Evidence Level C].
   b. Access to restorative care and active rehabilitation to improve and/or maintain function based on individualized care planning [Evidence Level B]. Refer *to Section 5.6 for additional information.*
   c. Providing advanced care planning, palliative care and end of life care as applicable [Evidence Level C]. *Refer to Section 4.3 for additional information.*
   d. Access to a contact person in the long-term care setting (designated case manager or system navigator) for individualized care and rehabilitation planning, re-engagement in social and leisure activities, and other needs of patients and family members [Evidence Level C].
   e. Where possible, access to a peer (survivor/family) who has experienced the transition and who can help the patient better understand the transition [Evidence Level C].

vi. Processes should be in place for post-discharge telephone follow-up with patients and informal caregivers; topics to address should include problem solving, educational information, and linkages with community services for ongoing support [Evidence Level B].

vii. The use of telemedicine technology modalities (e.g., video, and web-based technologies and services such as web-based support groups, tele-rehabilitation), should be considered to increase access to ongoing support services, healthcare services and rehabilitation therapies for patients following transitions to the community, when patients and family members are unable to travel into the facility for care and services [Evidence Level B]. *Refer to recommendation 8.1 for additional information.*

Rationale:

The goal of this recommendation is to emphasize the need for a holistic approach to care and help individuals and families to navigate the healthcare system, primarily following the initial acute stage of care; define components of support; focus on patients and their families and highlighting the patient and family-centred care approach to people who have had a stroke and addressing needs beyond the physical impact of stroke.

Stroke is a life-altering event that may require an extended recovery period and often leaves patients with ongoing functional impairments. Increasingly, families and informal caregivers are expected to take on tasks and responsibilities that require knowledge and skills that may be beyond their scope. This increases the caregiver burden, which often results in depression among caregivers of stroke patients (as high as 60 percent has been reported). Similar post-stroke depression rates occur in patients and are linked to poorer recovery outcomes.

Increased screening, assessment and surveillance of patient, family and informal caregiver needs and coping will provide a holistic patient-centred approach to stroke care and optimally lead to better recovery and adaptation.

System Implications

- Transitions of care support and actions are applicable across the continuum of care, including in primary care, the emergency department, acute care, rehabilitation settings, complex care/transitional bed settings, long-term care and community settings. Processes and mechanisms should be in place in all these settings to address patient, family and informal caregiver support.
- Protocols to involve families in healthcare team transition planning meetings and collaborative decision-making regarding goal setting at all transition points.
- Resources and mechanisms to plan and deliver community-based services which consider the needs of the survivor and family/caregiver (e.g., home care services).
- Models of care that include technology such as telemedicine, regular telephone follow-up and web-based support.
- Hospitals, rehabilitation facilities, home care services, long-term care and other community settings that care for stroke patients should be appropriately resourced and have identified contact people and case managers/system navigators to coordinate manage stroke care transitions.
- Ongoing education and training of healthcare professionals on patient and family-centred stroke care should be in place in all settings that care for stroke patients.
- Pool of stroke survivors, families and caregivers who have received sufficient training to provide peer support when requested.

Performance Measures

1. **The change in burden of care for family members and informal caregivers measured at transition points throughout the recovery period and following changes in patient health status.**
2. The number and proportion of patients diagnosed with post-stroke depression, measured at each transition point as a proportion of all stroke patients.
3. The number and proportion of patients readmitted to acute care for reasons related to physical decline or failure to cope, following an initial stroke hospital stay.

Measurement Notes

- Standardized and validated measures of depression and informal caregiver burden should be used to track occurrence and changes to these areas.

- Failure to cope diagnosis should be made based on appropriate ICD10 codes.

Implementation Resources and Knowledge Transfer Tools

- Canadian Stroke Strategy Patient and Family Guide to Stroke Best Practices [http://www.strokebestpractices.ca/wp-content/uploads/2011/11/CSN_PatientsGuide2011_English_WEB1.pdf]
- Heast and Stroke Foundation Trasition Information Plan (TIP) [http://www.heartandstroke.on.ca/site/c.pvl3IeNWJwE/b.5395543/k.41ED/Transition_Information_Plan_TIP.htm]
- Living with Stroke™ program [http://www.heartandstroke.com/site/c.iklQLcMWJtE/b.3936679/k.7231/Stroke__Living_with_StrokeTM_program.htm]
- Life After Stroke [http://www.lifeafterstroke.ca/stroke/]
- Transition Manangement Pathway [http://www.strokebestpractices.ca/wp-content/uploads/2013/10/WRHA-Transition-Management-PathwayOctober-24-2013.pdf]
- Timing it Right (Cameron & Gignac 2008) [http://www.ncbi.nlm.nih.gov/pubmed/?term=18155388]
- CareLiving: Caring for yourself and a stroke survivor [http://www.stroke.org/site/DocServer/CarelivingGuide_Full.pdf?docID=9070]
- World Stroke Organization Stroke Support Site [http://www.world-stroke.org/for-patients/stroke-support-organizations]
- Registered Nurses' Association of Ontario Guideline: Client Centred Care [http://rnao.ca/sites/rnao-ca/files/Client_Centred_Care.pdf]
- My Stroke Passport [http://www.strokebestpractices.ca/wp-content/uploads/2013/10/My-Stroke-Passport.pdf]
- Life After Stroke: Managing the effects of stroke and getting back into life [http://www.strokebestpractices.ca/wp-content/uploads/2013/10/My-Stroke-Passport_Life-After-Stroke.pdf]
- Pill Labels [http://www.strokebestpractices.ca/wp-content/uploads/2013/10/Pill-labels.pdf]
- Care Transition Measure [http://www.caretransitions.org/ctm_main.asp]
- Ways of Coping Questionnaire [http://www.mindgarden.com/products/wayss.htm]

Summary of the Evidence

Following stroke, patients, families and informal caregivers are typically faced with multiple life changes and challenges that evolve as the patient transitions between the stages of recovery. Gallacher et al. (2013) reviewed the concept of patient burden following stroke, highlighting the impact it may have on the effectiveness of interventions and patient satisfaction with health care services. The authors performed a systematic review of qualitative studies to identify the components of stroke recovery that were particularly burdensome to patients. Receiving information, interacting with others, comparing treatment options, managing in different environments (acute care, inpatient rehabilitation, community, society) and adjusting to daily activities were some of the concerns highlighted in this review (Gallacher et al., 2013). Patient burden may also be affected by a disconnect between the delivery of support interventions and a patients' readiness to learn. Vanetzian (1997) defined a patients' readiness to learn as "evidence of motivation and ability to learn at a particular time; a dynamic state that influences the outcomes of patient teaching", and stressed the importance of this assessment before engaging the patient in learning interventions.

Families and informal caregivers are often highly engaged in supporting the stroke patient through their recovery. In addition to a patient requiring support as they recover, families and informal caregivers will often experience needs at equivalent time points. The "timing it right" framework conceptualized by Cameron & Gignac (2008) highlighted the stages that a caregiver may experience as the patient recovers from a stroke. The authors identified 5 stages in the framework, defined by the changing information, training, emotional and feedback needs of caregivers. These phases include (Cameron & Gignac, 2008): 1) Event/Diagnosis, 2) Stabilization, 3) Preparation, 4) Implementation, and 5) Adaptation. The first two phases (event/diagnosis and stabilization) typically occur in the acute care setting, preparation in the acute or rehabilitation setting, and the last two phases in the home (Cameron & Gignac, 2008). As a patient moves from the hospital to the home environment, the information and training needs of the caregiver increase in scope and complexity. The "timing it right" framework is helpful in demonstrating that the needs of patient, family and informal caregiver are constantly changing and evolving and should therefore be reassessed at each stage of care.

Navigating through the post-stroke continuum has been highlighted as a frequent source of dissatisfaction for patients and informal caregivers in their recovery from stroke (Allen & Rixson, 2008; Allison et al., 2011; Egan et al., 2010; Mitchell et al., 2008; Wissel et al., 2013). This dissatisfaction is particularly problematic during the transition from hospital to community. In light of these concerns, several studies have been conducted to assess methods of organizing care services. The effectiveness of care coordinators, discharge planning, integrated care pathways, and standardized discharge orders have been assessed. A review by Wissel et al. (2013) also highlighted the need for electronic medical records and rehabilitation guidelines to support the success of post-acute care coordination.

There are a multitude of names and definitions for an individual who has been designated to coordinate access to appropriate services for patients recovering from stroke (e.g. stroke navigator, case manager, care coordinator, system navigator etc.). These individuals are often a designated member of the health care team and can take on many roles including: care coordination, client and family support, "just in time" education, coaching, accompaniment, and advocacy (Egan et al., 2010). The implementation of a registered occupational therapist as a community stroke navigator in Egan et al. (2010) found significant improvements in the reintegration to normal living index for patients having received the support (pre-test mean 54.1 (SD 12.7) to post-test mean 59.3 (SD 13.4), P=0.02, effect size 0.43). No significant improvements were seen in the 2-minute walk test, depression outcomes, or any caregiver outcomes (Egan et al., 2010).

Integrated care pathways or models of care that involve the primary care physician as a patients first point of contact after discharge from hospital formed the basis of the systematic review by Allison et al. (2011). Allison and colleagues assessed the effectiveness of models of follow-up care that involved the engagement of a patient's primary care provider. Nine studies were included in the review with a total of 1425 patients. No significant differences were found between the control and intervention groups for physical functioning, mood, quality of life or health service use (Allison et al., 2011). The intervention group in two studies were found to have greater perceived knowledge of stroke and one study found improved caregiver outcomes (Allison et al., 2011). A single study by Joubert et al. (2009) did, however, find significantly improved outcomes with the implementation of an integrated care model involving a care coordinator, the patients' general practitioner (GP) and a stroke specialist. The intervention included pre-arranged visits with the GP every 3 months and educational information regarding stroke risk factors from the care coordinator. In addition to equipping the patient with knowledge, GPs overseeing patients in the intervention group received a discharge summary containing medication and management information, a screening tool for depression prior to a patients visit and post-visit phone calls. Patients in the intervention group had statistically significant decreases in systolic blood pressure (P=0.04) and body mass index (P=0.007), and significant increases in the number of walks (P<0.001), Rankin score (P=0.003) and quality of life (P=0.012) (Joubert et al., 2009). No differences were found in the Barthel index, MMSE, cholesterol levels, presence of atrial fibrillation or alcohol consumption (Joubert et al., 2009).

Tele-rehabilitation has emerged as a potentially valuable tool for increasing access to appropriate stroke care services. The quality and safety of these services were summarized in a 2013 systematic review of technologies used for remote support services, including support for patient self-management (McLean et al., 2013). The findings of the review suggested that the evidence for the safety and effectiveness of these technologies was limited. The quality of studies was generally poor, interventions were not well described, patient safety data was not reported and few studies assessed cost-effectiveness. The review also suggested that technologies may not be suitable for all patients, but patients at greatest risk of adverse outcomes may be the ideal candidates for these interventions (McLean et al., 2013).

Evidence Table 6.1 and Reference list

Best Practice Recommendation 6.2 Update 2013
Patient, Family and Informal Caregiver Education

6.2 Stroke patient, family and informal caregiver education is an integral part of stroke care that must be addressed at all stages across the continuum and at all transition points of stroke care [Evidence Level A].

6.2.1 Assessment of Patient, Family and Informal Caregiver Learning Needs

i. Throughout each stage along the continuum of stroke care, patient, family and informal caregiver learning needs and goals should be assessed and documented by members of the healthcare team [Evidence Level B]. *Note: This applies to all settings including ambulatory care and emergency departments where there is shorter interaction time with patients and greater risk of learning needs being unmet*.

ii. Assessment should include inquiry about previous information received, information retention, and new and ongoing learning needs, and ensure patients and family are active participants [Evidence Level C].

iii. Based on findings of educational assessments, a formalized educational plan should be developed for each stroke patient, their families and informal caregivers based on shared discussions and decision-making, and documented in patient records [Evidence Level C].

    a. Stroke patient education plans and decisions should be documented in the patient record and with healthcare providers as the patient transitions across settings [Evidence Level C].

    b. Patient, caregiver and family educational needs should be assessed before leaving one healthcare setting and when entering into another care setting to ensure changing educational needs are met [Evidence Level C].

iv. Families and informal caregivers should be assessed for their understanding of the ongoing needs of the patient with stroke, to determine whether the patient, family and informal caregivers have the capability to meet the ongoing and changing needs of stroke patients in a caregiver role [Evidence Level C].

6.2.2 Delivery of Individualized Patient, Family and Informal Caregiver Education

i. Patient, family and informal caregiver education should include information sharing, teaching patients self-management skills, and training of family and informal caregivers to participate in and provide safe stroke patient care (Evidence Level B].

ii. Patient, caregiver and family education should be goal-oriented and facilitate decision-making regarding care and recovery [Evidence Level C].

iii. Educational content should be specific to the phase of care or recovery and appropriate to the readiness and needs of the stroke survivor, family, and informal caregiver [Evidence Level B]. *Refer to Box 6.2A for summary of key educational content specific to each phase of stroke care.*

iv. Education should be interactive, up to date, ongoing, repetitive, and provided in a variety of languages and formats (e.g., written, oral, instructive, and group counseling approaches); it should address varying levels of health literacy and ensure access to communication devices for stroke survivors (e.g., appropriate resources to help patients with aphasia and cognitive deficits or impairments communicate more effectively) [Evidence Level B].

v. Specific team members should be designated to provide and document educational activities and skills training sessions [Evidence Level C].

vi. The scope of stroke educational content should cover all aspects of stroke care and recovery [Evidence Level A].

   a. Depending on the needs and phase of care of the patient, education topics may include:

      - a description of the roles of all members of the healthcare team, and how and when they will be involved in the individual patient's recovery;
      - the role of the patient, family and informal caregivers as members of the team, and the need for them to be active participants in decision-making and planning;
      - stroke symptom awareness and risk of recurrent stroke;
      - treatment goals within each care setting and environment;
      - information regarding discharge planning options and settings available following acute care to help support decision-making for care setting selection based on individual needs and functional status following stroke (e.g., benefits and costs of long-term care);
      - medical information and information regarding type and cause of stroke, physical, psychological, functional and emotional impact of stroke and expectations for recovery;
      - change in social and family roles and relationships;
      - prevention of recurring stroke including risk factor modification and medication non-compliance;
      - availability of and access to community services;
      - information about community resources that should be broadly encompassing (e.g., the broad range of therapy and treatment resources available, home renovation resources, financial/tax consultants);
      - on-going practical information and how to seek help if problems develop;
      - information about the availability and potential benefits of local stroke groups;
      - information on stroke patient advocacy within the healthcare system and within the community.

vii. Processes should be in place to ensure that patient, family and informal caregiver educational episodes are documented in the patient record and accessed by all members of the healthcare team [Evidence Level B]. *Refer to 6.2 Implementation Tools* *section for examples of standardized patient education documentation tools.*

viii. Processes should be in place to assess patient, family and informal caregiver understanding and retention of previously taught information [Evidence Level A].

ix. Ongoing education should be individualized and coordinated across transition points, and across the continuum, and include reinforcement of information previously taught, especially critical information that has not been retained (e.g., medication information and management) [Evidence Level B].

x. Acute care hospitals, rehabilitation facilities, home care and long-term care facilities should maintain up-to-date inventories of community resources, and provide this information to stroke patients and their families and informal caregivers, and offer assistance in obtaining needed services [Evidence Level C].

6.2.3 Promoting Self-Management for Patients, Family and Informal Caregivers following Stroke

i. Patient education should promote self-efficacy through mastering self-management skills, including action planning, modeling behaviors, problem-solving and decision-making strategies, reinterpreting symptoms, identification of risks within current and ideal lifestyle, level of risk is the patient willing to accept to maintain or improve health status following stroke (e.g., decision-making regarding smoking, diet, blood pressure management) [Evidence Level B].

   a. Key topics in self-management training should include exercise, symptom management techniques, risk factor management, secondary stroke prevention, nutrition, fatigue and sleep management, use of medications, managing emotions of fear, anger and depression, cognitive and memory changes, training in communication with health professionals and others, and health-related problem-solving and decision making [Evidence Level B].

ii. Family and informal caregiver education should include training in personal care techniques, communication strategies, physical handling techniques, and food preparation and modifications for patients with dysphagia [Evidence Level B]; education on the self-management model to encourage them to allow patient to do things on their own when possible, other daily living activity goals and preferences, how to access community services and resources, problem-solving techniques, and ongoing health system navigation [Evidence Level C].

iii. With the patient's permission, family members and information caregivers should be invited and encouraged to attend therapy sessions with the patient, and have their questions addressed [Evidence Level C].

iv. Family and informal caregivers should be taught proper patient care skills and provided with opportunities for demonstration and feedback to ensure safe care delivery for both the patient and informal caregiver (e.g. in transfers from bed to chair, feeding techniques, and positioning of the hemiplegic limb) [Evidence Level C].

v. As part of self-management, patients should be encouraged to be evaluated for return to work if they were working prior to stroke, re-engage in leisure activities, and learn appropriate modifications that may be required to continue participation in meaningful roles and activities following stroke [Evidence Level C]. *Refer to Recommendations*

5.11and 6.5 for additional information.

BOX 6.2 Overview of Educational Needs Across the Continuum

Patient Education Across the Continuum Quick Reference Guide
[http://www.strokebestpractices.ca/wp-content/uploads/2013/10/SBP-Transitions-Patient-Ed-Quick-Reference_4.pdf]

Rationale

Education is an ongoing and vital part of the recovery process for stroke, which must reach the survivor, family members and informal caregivers. Research demonstrates that patients generally retain less than 25% of information and education provided in hospital. Education about stroke facilitates better understanding and supports coping and self-management, and must be repeated and reinforced with consistency across transitions of care. Skills training for caregivers may increase participation and safety, clarify expectations, improve quality of life, and reduce depression and perceived burden. The information provided at each phase of acute care, rehabilitation, community reintegration and long-term recovery should be relevant to the patient's and the family's changing needs. Simple distribution of pamphlets is not sufficient; the delivery should be interactive and adapted to the cognitive and communication challenges faced by some stroke survivors, including receptive and expressive language, processing speed, hearing, or visual impairment.

System Implications

- Transitions of care support and actions are applicable across the continuum of care, including in primary care, the emergency department, acute care, rehabilitation settings, complex care/transitional bed settings, long-term care and community settings. Processes and mechanisms should be in place in all these settings to address patient, family and informal caregiver educational needs.
- Coordinated efforts among stakeholders such as the Heart and Stroke Foundation, Canadian Stroke Network, Canadian Partnership for Stroke Recovery, public health agencies, ministries of health, non-government organizations (NGOs), hospitals and clinics, and individual care providers across the continuum of stroke care to produce patient, family and informal caregiver education materials with consistent information.
- Resources, such as stroke recovery support groups, available in the community to provide ongoing support and education following hospital discharge.
- Coordinated process for ensuring access to and awareness of educational materials, programs, activities and other media related to stroke by healthcare professionals, patients and informal caregivers, including advertising the availability of educational material, effective dissemination mechanisms and follow-up.
- Access to training for care providers in programs that facilitate communication with stroke survivors with aphasia.
- Educational resources that are available in a variety of languages (as appropriate to the ethnic groups that may be concentrated in the healthcare catchment area); are culturally, ethnically, and linguistically appropriate; and that address the needs of patients with aphasia.

Performance Measures

1. **Proportion of stroke patients with documentation of education provided to patient, family and/or caregivers at each stage throughout the stroke management and recovery process (core).**

2. Total time spent on patient/family education during a healthcare encounter for stroke.
3. Change in patient and family knowledge of stroke-related content before and after a teaching session.
4. Percentage of patients discharged with a copy of their discharge plan and patient educational materials.

Measurement Notes

- Quantity and method of patient education are very important elements of this recommendation. Measurement of patient and family education should be expanded when feasible to capture these aspects.
- Data sources include all documents, charts, and records related to patient care across the healthcare system (primary care, acute care, follow-up clinics, inpatient and outpatient rehabilitation programs, community programs and services) and may be obtained through primary chart audit or review, and various logging and audit practices of individual groups.
- Documentation quality by healthcare professionals involved in the patient's care may affect ability to monitor this indicator reliably.

Implementation Resources and Knowledge Transfer Tools

- The Patient and Family Guide to Canadian Best Practice Recommendations for Stroke Care [http://www.strokebestpractices.ca/wp-content/uploads/2011/11/CSN_PatientsGuide2011_English_WEB1.pdf]
- A Family Guide to Pediatric Stroke [http://www.strokebestpractices.ca/wp-content/uploads/2011/10/PEDSGuide-EN.pdf]
- HSF Stroke Resources Directory [http://www.heartandstroke.com/site/c.iklQLcMWJtE/b.8598311/k.97BA/Stroke_Resources_Directory/apps/kb/cs/contactsearch.asp]
- HSF Health Information: Stroke [http://www.heartandstroke.com/site/c.iklQLcMWJtE/b.3483933/k.CD67/Stroke.htm]
- Living with Stroke™ Program [http://www.heartandstroke.com/site/c.iklQLcMWJtE/b.3936679/k.7231/Stroke__Living_with_StrokeTM_program.htm]
- Life After Stroke [http://www.lifeafterstroke.ca/stroke/]
- Lets Talk About Stroke [http://www.heartandstroke.com/atf/cf/%7B99452d8b-e7f1-4bd6-a57d-b136ce6c95bf%7D/LETSTALKABOUTSTROKE_LR.PDF]
- Getting On with the Rest of Your Life After Stroke [http://www.strokebestpractices.ca/wp-content/uploads/2011/09/GettingOn2-EN1.pdf]
- Stroke Support Group Toolkit [http://www.lifeafterstroke.ca/wp-content/uploads/2011/09/SupportGroupToolkit-EN1.pdf]
- Accreditation Canada Stroke Distinction Program: Stroke Services Client and Family Education [http://www.strokebestpractices.ca/wp-content/uploads/2013/10/Accreditation-Stroke-Distinction-Client-and-Family-Education-Sep-2010.pdf]
- Timing it Right study (Cameron & Gignac 2008) [http://www.ncbi.nlm.nih.gov/pubmed/?term=18155388]
- Aphasia institute [http://www.aphasia.ca/health-care-professionals/]
- Registered Nurses' Association of Ontario: Self Management Guidelines [http://rnao.ca/bpg/guidelines/strategies-support-selfmanagement-chronic-

conditions-collaboration-clients]

- Transition Management Pathway [http://www.strokebestpractices.ca/wp-content/uploads/2013/10/WRHA-Transition-Management-PathwayOctober-24-2013.pdf]

Summary of the Evidence

Patient, family and informal caregiver education across the continuum of care is important for supporting patient and informal caregiver needs and to provide a foundation for secondary stroke prevention and self-management. A Canadian study by Johansen et al. (2006) reported that 6%-10% of individuals who were admitted to hospital for a stroke experienced a recurrent stroke within one year. Also within one year following stroke, up to 37% of individuals were hospitalized for reasons other than recurrent stroke (Johansen et al., 2006). With an increased risk of recurrent stroke and the need to manage co-occurring conditions and stroke induced deficits, there is a strong need for patient and informal caregiver education during the post-stroke period.

As detailed in Section 6.1, the "timing it right" framework conceptualized by Cameron & Gignac (2008) highlights the stages that a caregiver may experience as a patient recovers from stroke. The information and training needs identified for each of these stages is detailed below (Cameron & Gignac, 2008):

1. Event/Diagnosis: Information related to diagnosis and prognosis; no training required.
2. Stabilization: Information related to etiology and current care needs; require initial training to help with patients' daily activities and therapy.
3. Preparation: Information related to resource availability and accessibility; require some training practice.
4. Implementation: Information related to everyday management and the potential impact of caregiving on their well-being; support training required.
5. Adaptation: Information related to patient and informal caregiver community reintegration, and future outcomes; training related to assisting with community reintegration required.

A 2012 Cochrane review assessed interventions related to the provision of information for stroke survivors and their caregivers (Forster et al., 2012). The review updated a 2009 Cochrane review (4 additional trials were published since the 2009 version) and consisted of 21 studies with 2289 patients and 1290 carers. Meta-analyses were possible for knowledge outcomes, and outcomes for psychological distress, satisfaction with stroke information and satisfaction with service information. Patients receiving an intervention had improved knowledge of stroke services (SMD=0.29, 95% CI 0.12 to 0.46, $P<0.001$) and greater satisfaction with stroke information (OR=2.07, 95% CI 1.33 to 3.23, $P<0.001$) compared to patients in the control group (Forster et al., 2012). Patients receiving an intervention also experienced improvements in depression scores (MD=-0.52, 95% CI -0.93 to -0.10, $P<0.05$) with greater effects associated with interventions that were considered "active". Interventions were considered active if there was patient or carer engagement during the sessions. Engagement could include the opportunity to ask questions, request additional information, be provided with hands-on training, or involve the use of an interactive workbook and/or some means of follow-up reinforcement (Forster et al., 2012).

There was substantial heterogeneity in the aforementioned Cochrane review, signifying the wide variability in design of interventions for patient and informal caregiver education. Two randomized trials, one by Lowe et al. (2007) and one by Eames et al. (2013) evaluated the effects of information and support packages for patients and their caregivers following stroke. Lowe et al. (2007) evaluated the use of a "CareFile", an information package containing relevant support services and secondary prevention resources that was individualized to each patient. One hundred patients participated in the study, 50 randomized to the intervention group and 50 to the control group. Patients in the intervention group demonstrated greater risk factor knowledge than patients in the control group at 3 and 6 months after stroke (Mean difference 0.5, 95% CI 0.0 to 1.1; Mean Difference 0.8, 95% CI 0.3 to 1.4) (Lowe et al., 2007). The intervention by Eames et al. (2013) involved an individually tailored education and support package with verbal reinforcement and was also found to be effective compared to the usual care group (unstructured, informal education). Patients reported greater self-efficacy ($P<0.01$), felt that they were well informed ($P<0.01$), and had greater satisfaction with the information received (medical information $P<0.001$; practical information $P<0.01$; service and benefit information $P<0.05$; and secondary prevention information $P<0.001$)(Eames et al., 2013). These studies suggest the importance of individualized, structured and reinforced education for stroke patients and their caregivers following stroke.

Studies assessing the impact of caregiver education and skills training have also reported the benefits of active or "hands-on" interventions. A randomized controlled trial by Kalra et al. (2004) allocated patient/caregiver dyads to receive structured caregiver training (hands-on training in basic nursing techniques) or conventional instruction (information and advice). The length of the intervention was dependent on patient need, consisting of between three to five sessions in the inpatient rehabilitation setting. Patients experienced reductions in anxiety and depression at 12 months ($P<0.001$) and increased quality of life at 3 and 12 months ($P<0.05$). No differences between mortality, institutionalization or functional ability were reported between intervention and control groups (Kalra et al., 2004).

The implementation of education and skills training programs ultimately aim to increase the self-efficacy of patients and informal caregivers for their own self-management. Lennon et al. (2013) conducted a systematic review of studies (including randomized and non-randomized controlled trials) that assessed "self-management" interventions for patients recovering from stroke. Interventions included in the review were quite variable, ranging from group programs to one-on-one interventions consisting of workbooks, DVDs or exercise sessions. Several interventions were based on the Stanford Chronic Disease Self-Management programme, which consists of workshops, a companion book and a relaxation CD. However, due to the variability in outcomes assessed, pooling of results was not possible. Some of the largest randomized controlled trials included in the review demonstrated improvement in physical domains, quality of life, and dependency (Lennon et al., 2013).

The "Moving on After Stroke" (MOST) program is another example of a self-management focused program, consisting of 16 group sessions with an hour of education and an hour of exercise. Education sessions included topics such as secondary prevention, medications, sleep, nutrition, and self-management. Huijbregts et al. (2008) compared this program to the Living with Stroke (LWS) program that offered 6 group education sessions consisting of 90 minutes of education on topics such as the causes of stroke, physical effects, and therapies. There were no statistically significant differences in outcomes between the groups; however, patients in the MOST group had increases in FIM scores ($F=3.97$, $P<0.05$), improvements in the reintegration into normal living index ($F=3.43$, $P<0.05$) and improvements in the activity-specific balance scale ($F=8.94$, $P<0.005$) (Huijbregts et al., 2008).

Caregiver focused self-management programs also have evidence for effectiveness. Grant et al. (2002) and Bakas et al. (2009) conducted studies randomly assigning primary caregivers to skill-based interventions. A telephone intervention that involved training on social problem solving skills to manage problems and cope with stress was effective in improving social functioning ($P=0.0176$), general health (vitality $P=0.013$; role limitations related to emotional problems $P=0.007$; mental health $P=0.001$), problem solving (negative problem orientation $P<0.001$, rational problem solving $P=0.025$, impulsivity/carelessness $P=0.007$), caregiver preparedness ($P<0.001$) and informal caregiver depression ($P<0.001$) (Grant et al., 2002). Another telephone based intervention, the Telephone Assessment and Skill Building Kit (TASK), included the receipt of a notebook containing skill building tips, a stress management workbook and a brochure on family caregiving (Bakas et al., 2009). Caregivers also received weekly phone calls from a nurse for a period of 8 weeks that involved discussion of patient identified priority areas. Caregivers in the intervention group were more optimistic at 4, 8 and 12 week follow up ($P=0.02$; $P=0.02$; $P=0.02$), experienced lower levels of task difficulty at 4 weeks ($P=0.03$) and had improved threat appraisal skills at 8 weeks and 12 weeks ($P=0.02$; $P=0.01$). There was no change in depressive symptoms, life changes or general health perception (Bakas et al., 2009).

Evidence Table 6.2 and Reference List

Best Practice Recommendation 6.3 *Update 2013*
Interprofessional Communication

A process should be in place to ensure timely and effective transfer of relevant patient-related information at all points of access and transition in the healthcare system to ensure seamless transitions and continuity of care [Evidence Level B].

i. All members of the interdisciplinary stroke team should share timely and up-to-date information with healthcare providers at the next stage of care (e.g., from the emergency department to inpatient care or primary care, acute care to rehabilitation specialists, community service providers, primary care providers, and long-term care providers) [Evidence Level B].
    a. Transfer of information should occur ideally within one week of patient discharge or transfer [Evidence Level C].
    b. Information shared across transitions should be complete, up-to-date, accurate and appropriate to the transition settings and information needs of the receiving healthcare providers [Evidence Level B].

ii. A social worker, system navigator, case manager or care coordinator should be a part of the healthcare team, and should facilitate transfer of patient-related information, patient referrals to appropriate follow-up services; and ensure patient and family educational needs have been addressed [Evidence Level B].

iii. The patient and family should be given an up-to-date care plan at the time of discharge that defines ongoing medical, functional, rehabilitation, cognitive, communication, and psychosocial needs [Evidence Level C]. *Ideally, the care plan should be initiated in the emergency department and continue through the continuum of care with the patient.*
    a. The care plan should be patient-centred, incorporate the agreed-upon goals and preferences of the patient, family, and healthcare team based on shared decision-making, and be culturally appropriate [Evidence Level C].
    b. The patient care plan should be utilized to facilitate timely discussion with healthcare providers, family and informal caregivers at the next stages of care, to ensure continued progress towards stated goals [Evidence Level C].
    c. The patient and healthcare providers should review the care plan regularly, at transition points and when changes/improvements in health status occur, and together up-date the care plan to reflect changing needs, evolving goals and progress through the recovery process [Evidence Level B].

iv. Written discharge instructions should be included as a component of patient care plans, and should address the following issues as appropriate: functional ability at the time of transfer, risks and safety considerations, action plans for recovery, medications at discharge and instructions for adjustment, follow-up care, and follow-up care provider contact information [Evidence Level B].

Rationale

Stroke patient care tends to be complex and require ongoing monitoring and management. Clear communication in a timely manner is essential to ensure continuity of care, patient safety, and reduce risk of complications and adverse events resulting from the confusion and ambiguity that can arise during transition points.

System Implications

- Transitions of care support and actions are applicable across the continuum of care, including in primary care, the emergency department, acute care, rehabilitation settings, complex care/transitional bed settings, long-term care and community settings. Processes and mechanisms should be in place in all these settings to address efficient communication between settings and healthcare providers.
- Standards, processes and tools will be required to ensure timely discharge summaries sent to primary care and other relevant healthcare professionals to facilitate continuity of care at transition points.
- Processes across primary, secondary and tertiary healthcare providers will need to be developed in the coordination of ongoing medical management through to primary care, community services, follow-up, and access to required healthcare services (e.g., ongoing rehabilitation or acute care).
- Resource capacity available to enable appropriate and timely access to services at the next stage of care with the required specialties, intensity, and frequency.
- Following stroke, providing the right care and services in the right settings at the right times.
- Staff who are aware of patient/client's right to privacy and who comply with privacy legislation and patient preferences when releasing patient/client information.

Performance Measures

1. **Percentage of patients for whom a discharge summary is completed within 48 hours of transition and received by the patient/family and the care provider at the next stage of care.**
2. Percentage of patients with documentation that a plan of care has been established on discharge from acute care and/or inpatient rehabilitation, and with the patient's primary care provider after discharge to the community.
3. Percentage of patients who are given a copy of their completed discharge plan at the time of discharge from acute inpatient care or inpatient rehabilitation.

Measurement Notes

- Performance measure 1: A copy the discharge summary should be included in acute care or inpatient rehabilitation chart, and in the chart of the primary care provider. It can be electronic or hard copy.
- Performance measure 2: Applies at all transition points across the continuum.

Implementation Resources and Knowledge Transfer Tools

- Transition Management Pathway [http://www.strokebestpractices.ca/wp-content/uploads/2013/10/WRHA-Transition-Management-PathwayOctober-24-2013.pdf]
- Canadian Interprofessional Health Collaborative [http://www.cihc.ca]
- Centre for Advancement of Interprofessional Education [http://www.caipe.org.uk/]
- Centre for Interprofessional Education (University of Toronto) [http://www.ipe.utoronto.ca]

Summary of the Evidence

Transitions between and within health care settings pose a safety and quality of care concern for patients recovering from stroke. Behera et al. (2005) outlined a conceptual framework for studying transitions and staff shift changes within the acute care setting, noting the complexity of these time points and their risks for patient safety. A consensus policy statement by the American College of Physicians in 2009 also highlighted concerns of patient safety at transition points, particularly between inpatient and outpatient care (Snow et al., 2009). A stroke survivor is vulnerable to many of these transition points as they progress through the acute, sub-acute and chronic stages of recovery, interacting with a range of physicians in several different health care settings. Communication between these physicians and care settings is critical for ensuring patient safety and quality of care (Snow et al., 2009).

The occurrence of these transition points is multiplied by the frequency of rehabilitation needs and comorbid conditions in survivors of stroke. In a prospective cohort of patients attending hospital for stroke in Canada between 2005 and 2009, the majority of patients were diagnosed with at least one comorbid condition. Of the 232 patients included in the study, 57.8% of patients were diagnosed with hypertension, 51.7% with dyslipidemia and 23.3% with diabetes (Mittmann et al., 2012). Only 23.3% of patients were reported to have no comorbid conditions (Mittmann et al., 2012). If rehabilitation is indicated, patients may also be interacting with several allied health professionals such as physiotherapists, occupational therapists and speech language pathologists, in addition to their regular care providers.

A review of literature assessing patient and informal caregiver experiences as they transition between health care settings suggested possible fragmentation in care and information services (Cameron et al., 2008). Patients and informal caregivers reported to have unmet information and training needs, poor timing of follow up care, and difficulty identifying and arranging their follow up care in the community (Cameron et al., 2008). The authors suggest several strategies to overcome these deficiencies, including increased communication and information sharing between health care providers, the implementation of central care coordinator or case manager, and individualized patient care plans (Cameron et al., 2008). Two of these foresights were shared by Venketasubramanian et al. (2008), who highlighted the importance of collaboration and communication between primary and secondary care, and continuous involvement and education of the patient.

Evidence exists for the deleterious effects of lack of communication between providers of a patients' health care team, and between the health care team and the patient. This is particularly problematic when a patient is discharged from hospital. The occurrence of adverse events as a result of incomplete exchange of information between care settings has been reported. A study assessing the incidence of adverse events in patients who were discharged from a general medical ward to the home environment found that 30% of the reported events were preventable, 50% of which were due to an adverse drug event (Forster et al., 2003). The authors note that more detailed discharge notes (such as advice on follow-up care and timing) and more communication with the patient and their family may be beneficial (Forster et al., 2003). Areas of communication deficits were reported in a systematic review by Kripalani et al. (2007). Discharge letters were missing a main diagnosis in 7%-48% of cases, in hospital treatment details in 22%-45%, medications at discharge for 7%-48%, plans for follow-up in 23%-48%, and notes on patient or family counselling in 92%-97% of cases (Kripalani et al., 2007). Another potential gap in communication was reported by Walz et al. (2010) who found that for patients with stroke, 29% of laboratory reports were pending at discharge. For patients with dysphagia, Kind et al. (2011) compared the prevalence of dysphagia recommendations on the discharge summary to those in the hospital chart note and found that missing information was common. 45% of patients did not have dysphagia recommendations reported and 42% had one or more missing recommendation in their discharge summaries (Kind et al., 2011).

Several reviews exist that assess standardized programs to facilitate a coordinated approach to follow-up care for patients with stroke (Allen & Rixson, 2008; Allison et al., 2011; Mitchell et al., 2008, Brown et al., 2008). Due to the heterogeneity between care models, meta-analyses were not conducted for these reviews. However, there was evidence that an integrated care pathway improved service coordination (Allen & Rixson, 2008), and that a care management model or the involvement of a health care manager improved stroke knowledge and informal caregiver outcomes (Allison et al., 2011). Models of care that were associated with early supported discharge were found to improve patient independence at 6 and 12 months (Mitchell et al., 2008). Lincoln et al. (2003) also identified increased knowledge and satisfaction in information received with the involvement of a family support organizer. Information sharing through the use of standardized discharge orders resulted in statistically significant improvements in optimal treatment, however, when compared to control hospitals, these results were not significant (OR 1.39; 95% CI 0.71-2.76; P=0.27) (Johnston et al., 2010). In addition to standardized processes of care, the American Heart Association also recommends the use of a patient care plan to enhance communication between providers and between patients and providers (Summers et al., 2009). They recommend that this care plan be updated on a regular basis to reflect the changing needs of the patient.

Evidence Table 6.3 and Reference List

Best Practice Recommendation 6.4 **Update 2013**
Discharge Planning

Discharge planning should be initiated as soon as possible after the patient is admitted to each phase of care (e.g., emergency department, inpatient acute care, rehabilitation, complex continuing care, home care) [Evidence Level B].

i. A process should be established to ensure that patients, families, and informal caregivers are involved in discharge planning [Evidence Level B]. *Refer to 6.3 Interprofessional Communication for additional information.*
   a. Formulate goal oriented discharge plan with individual and family in collaboration with the interdisciplinary team for transition to community, rehabilitation, retirement home, and long-term care facilities [Evidence Level B].
   b. Identify possible discharge issues and patient needs which could potentially delay discharge and address early in the discharge planning process [Evidence Level B]. These may include issues of the patient, family, caregivers and/or environment.
   c. Patients discharged back to the community directly from the emergency department should have their discharge planning needs addressed prior to leaving the emergency department [Evidence Level C]. This may include stroke education, information regarding follow-up tests, appointments and referrals to stroke prevention clinics and primary care as appropriate to the individual patient.

ii. A social worker, system navigator, case manager/coordinator or other team member (e.g., social worker) should be designated to facilitate the development of the discharge plan, including ongoing reviews and updates until the time of discharge [Evidence Level C].

iii. Discharge planning activities should include:
   a. A pre-discharge needs assessment of patient physical needs, caregiver capacity, patient and family/caregiver psychosocial needs, care history information, and decision-making needs [Evidence Level C].
   b. Home-visits for patients being discharged to the community to identify home modifications required for access and safety [Evidence Level B].
   c. Meetings between the interdisciplinary team, patient, and family/caregiver to set goals of care, expectations for discharge dates, and identify potential transitional care needs and living setting [Evidence Level B].
   d. Caregiver training specific to the current and ongoing needs of the individual patient with stroke [Evidence Level B]; *Refer to Recommendation 6.1 and 6.2 for additional information.*
   e. Day, weekend and overnight passes to determine readiness for discharge, and to identify potential barriers to discharge and address psychosocial, emotional, physical, and financial needs of patients and families for successful discharge [Evidence Level B].
   f. A post-discharge follow-up plan, including identification of key contacts and healthcare providers at the next stage of care, appointments, treatments, and contact information to re-access healthcare services as required [Evidence Level B].
   g. Communication with team members at the next phase of care [Evidence Level C]. *Refer to 6.3 Interprofessional Communication for additional information*

iv. Discharge planning discussions, decisions, and activities should be ongoing to reflect the patients changing needs, evolving goals and progress through the recovery process [Evidence Level B].

Rationale

Effective discharge planning is essential for smooth transitions through the continuum of stroke care. Delayed or incomplete planning leads to prolonged hospital stays and an increased risk of adverse events following discharge. Patients, family members and healthcare providers involved in each phase of care should all be involved in discharge planning to ensure effective and safe transitions.

System Implications

- Transitions of care support and actions are applicable across the continuum of care, including in primary care, the emergency department, acute care, rehabilitation settings, complex care/transitional bed settings, long-term care and community settings. Processes and mechanisms should be in place in all these settings to address efficient and safe discharge planning.
- Adequately resourced community health and support services for stroke patients.
- Capacity for social workers and other case management or healthcare personnel with dedicated responsibilities for discharge planning.
- Protocols and pathways for stroke care along the continuum that address discharge planning throughout the stage of care.
- Strong relationships and formal agreements among healthcare providers within regions to increase the efficient and timely transition of patients.
- Processes, protocols, and resources for conducting home assessments by interprofessional team members soon after the stroke.
- Access to patient self-management and informal caregiver training and support services as required ensuring a smooth transition.

Performance Measures

1. **Proportion of acute stroke patients who have at least one alternate level of care day during their index acute care admission for stroke.**
2. Average number of alternate level of care days per stroke patient in acute care settings.
3. Median length of stay of stroke patients in acute inpatient care (core).
4. Percentage of patients who are given a copy of their completed discharge plan at the time of discharge from acute inpatient care or inpatient rehabilitation.
5. Proportion of stroke patients who return to the hospital post-discharge for non-medical reasons (i.e., failure to cope).
6. Readmission rate for stroke patients discharged from hospital for all reasons, within 90 days, 6 months and one year.

Measurement Notes

- Length of stay should be calculated as total length of stay, and then also measured against active and alternate level of care components.
- Median values should be reported for length of stay.
- Use Canadian Institute for Health Information standardized definitions and methods to calculate alternate level of care days in hospital.

Implementation Resources and Knowledge Transfer Tools

- Transition Management Pathway [http://www.strokebestpractices.ca/wp-content/uploads/2013/10/WRHA-Transition-Management-PathwayOctober-24-2013.pdf]
- Care and Discharge Planning: A Guide for Service Providers [http://www.ncss.org.sg/documents/CareandDischargeGuide-Jan-final6.pdf]
- Stroke Foundation Discharge Planning Tool: My Stroke Care Plan [http://strokefoundation.com.au/site/media/NSF_MyStrokeCarePlan_web2.pdf]
- Re-Engineered Discharge (RED) Toolkit [http://www.ahrq.gov/professionals/systems/hospital/toolkit/redtoolkit.pdf]
- Talking Care of Myself: A Guide for When I Leave the Hospital [http://www.ahrq.gov/patients-consumers/diagnosis-treatment/hospitals-clinics/goinghome/goinghomeguide.pdf]
- Improving Hospital Discharge Planning and Patient Transitions in the Toronto Central LHIN [http://www.torontocentrallhin.on.ca/uploadedFiles/Home_Page/Report_and_Publications/Discharge%20Planning%20-%20LS%20ALC%20report.pdf]
- Handbook of Operating Procedures: Patient Discharge Planning [http://www.rncasemanager.com/articles/PatientDischargePlanning.pdf]
- Discharge Summary Template [http://www.obgyn.ubc.ca/Education/Residency/docs/LMHIMDischargeSummaryTemplateFinal.pdf]

Summary of the Evidence

Discharge planning should begin as soon as possible during each phase of care and should involve the patient, family/caregivers, and all members of the interprofessional team. The goal of discharge planning is to ensure a safe and efficient transition between care settings while maintaining a continuity of care and coordination of services that optimize recovery and secondary prevention, as appropriate (Sheppard et al. 2013; Clark et al. 2005; Summers et al. 2009). Discharge planning activities should include a pre-discharge needs assessment, home visits, meetings between the care team, patient, and family/caregivers, a post-discharge follow-up plan, and communication with team members at the next phase of care.

In a recent Cochrane review investigating discharge planning for patients discharged from hospital (including patients with conditions other than stroke), Shepperd and colleges identified 24 RCTs, representing 8039 patients (Shepperd et al. 2013). Of these, 16 trials recruited patients with a medical condition (as opposed to a surgical or psychiatric condition) and a single trial (Sulch et al. 2000) investigated discharge planning specifically within a stroke population. Hospital length of stay (MD -0.91, 95% CI -1.55 to -0.27) and three-month readmission rates (RR 0.82, 95% CI 0.73 to 0.92) were both found to be significantly reduced for patients with a medical condition who received discharge planning, as compared to care as usual. No significant between group differences were reported in terms of discharge destination (RR 1.03, 95% CI 0.93 to 1.14) and mortality (RR 0.99, 95% CI 0.78 to 1.25) (Shepperd et al. 2013).

In the only RCT identified that specifically recruited stroke patients, Sulch et al. (2000) randomized 152 patients within two-weeks of stroke onset to receive discharge planning according to an integrated care pathway or care as usual. No significant between group differences were reported with respect to six-month mortality (13% vs. 8%), institutionalization (13% vs. 21%), or length of stay (50±19 vs. 45±23). However, those randomized to receive conventional care experienced significantly greater change on the Barthel Index from 4 to 12 weeks (median change = 6 vs. 2, $p<0.01$) and reported significantly greater scores on the EuroQol at six-months (72 vs. 63, $p<0.01$). Given that trials investigating patients with other medical conditions have not reported similar findings (Shepperd et al. 2013); further research is needed to investigate the effect of discharge planning on health outcomes.

Observational studies and case reports suggest that effective discharge planning includes assessment of patient and family needs and preferences, an understanding of expected outcomes, the goals for recovery and reintegration into the community, and communication between team members and the patient, family, and informal caregivers. (Almborg et al. 2008; Naylor et al. 1999; Patel et al. 1998). The literature on transition management for stroke is more extensive and describes the importance and impact of communication and information transfer throughout the continuum of care in reducing adverse events and increasing the likelihood of a smooth and efficient transition (Please refer to the Evidence Summary for Recommendation 6.1 for additional information on transition management).

Evidence Table 6.4 and Reference List

Best Practice Recommendation 6.5 Update 2013
Community Reintegration Following Stroke

6.5 Patients and families should be provided with information, support and access to services throughout transitions to the community following a stroke to optimize the return to life roles and activities [Evidence Level B].

6.5.1 Physical Health Management Following Stroke:

i. People with stroke living in the community should have regular and ongoing follow-up to assess recovery, prevent deterioration, maximize functional and psychosocial outcomes, and improve quality of life [Evidence Level B].

ii. Post–acute stroke patients should receive follow-up by a primary care provider to address aggressive secondary stroke prevention, risk factor management, and ongoing treatment of comorbidities and sequelae of stroke [Evidence Level C].

  a. Initial review with primary care provider should occur within first two to four weeks following acute hospital discharge, and additional visits should occur at least every six months for at least three years following stroke [Evidence Level C]. *Refer to Recommendations 3.1 and 5.11 for additional information.*

  b. During primary care visits, medication lists, dosage, effectiveness, patient adherence, need for adjustment, potential interactions, and adverse side effects should be monitored and any concerns addressed [Evidence Level B]. *Refer to Recommendations in Section 2, Prevention of stroke for additional information.*

  c. Primary care providers should screen patients for ongoing physical issues including dysphagia, nutrition, hydration, continence, and pain [Evidence Level C]. *Refer to Recommendations 4.2, 5.7, and 5.9 for additional information.*

  d. Primary care providers should screen patients for *n*ew or ongoing cognitive concerns, mental health issues (i.e., depression), and psychosocial issues [Evidence Level B]. *Refer to Recommendations 7.1 and 7.2 for additional information.*

  e. Additional in-depth assessments should be conducted if screening indicates a potential issue; or referrals made as required to other healthcare providers with expertise in post-stroke functional, psychosocial, mood/depression or cognitive concerns as appropriate to meet patient needs [Evidence Level C]. *Refer to Recommendations 4.2, 5.11, and Section 7 for additional information.*

iii. Secondary prevention of stroke should be aggressively managed and risk factor reduction strategies optimized in all living settings (e.g., long term care) [Evidence Level A]. Referrals to stroke prevention clinics and services should be initiated at hospital discharge where appropriate, and in the community at the discretion of the primary care provider. *Refer to Recommendations in Section 2, Prevention of stroke for additional information.*

iv. Infants and children who have experienced a stroke should have ongoing follow-up screening and assessments throughout their development, especially if new motor, language, behavioral or cognitive deficits emerge [Evidence Level B].

  a. Developmental screening and assessments should include cognitive, motor, social, behavioral, emotional and physical aspects, as the full extent of stroke-related deficits may not become apparent until different ages and stages of development [Evidence Level C].

6.5.2 Functional and Psychological Health Management:

i. Post-acute stroke survivors living in the community who experience a change/decline in functional status, physical activity, activities of daily living, or mobility should receive targeted interventions, as appropriate, even if the decline occurs six months or later post-stroke [Evidence Level A].

ii. Processes should be in place for stroke survivors to re-access rehabilitation services during longer-term recovery [Evidence Level C]. This may include physical therapy, occupational therapy, speech therapy, recreation therapy and other services as required to address individual patient needs. *Refer to Recommendations in Section 5, Stroke Rehabilitation, for additional information.*

iii. Stroke survivors living in the community should be screened for continuing or new signs of depression and/or cognitive impairment by healthcare providers (including primary care providers, nurses, occupational therapists providing home-based care, and other healthcare providers) during follow-up visits (e.g., stroke and prevention specialists) [Evidence Level B].

   a. Additional in-depth assessments should be conducted if screening indicates a potential issue; or referrals made as required to other healthcare providers with expertise in post-stroke emotional, psychosocial or cognitive concerns as appropriate to address patient-specific needs [Evidence Level B]. *Refer to Recommendations 7.1 and 7.2 for additional information*.

   b. Patients should be screened for depression and cognitive changes at least annually for the first 3 years following stroke, and ideally every six months [Evidence Level C]. *Refer to Recommendations 7.1 and 7.2 for additional information*.

iv. Stroke survivors should be screened for communication deficits and receive support as required by community-based aphasia programs [Evidence Level C]. *Refer to Recommendation 5.10 for additional Information.*

v. The use of telemedicine technology modalities (e.g., video, and web-based technologies and services such as web-based support groups, tele-rehabilitation), should be considered to increase access to ongoing support services, healthcare services and rehabilitation therapies for patients following transitions to the community, when patients and family members are unable to travel into the facility for care and services [Evidence Level B]. *Refer to recommendation 8.1 for additional information.*

6.5.3 Reintegration to Social and Life Roles Following Stroke

A. Vocations

i. Patients, especially those <65 years of age, should be asked about vocational interests (i.e., work, school, volunteering) and be assessed for their potential to return to their vocations [Evidence Level C]. *Refer to Recommendation 5.11 for additional information.*

   a. This initial screening should take place early in the rehabilitation phase and when planning transitions from acute care and/or inpatient rehabilitation to the community [Evidence Level C].

   b. A detailed cognitive assessment including a neuropsychological evaluation, where appropriate and available, is recommended to assist in determining the patient's ability to meet the needs of their current or potential employment requirements, and contribute to vocational planning [Evidence Level C]. Results of assessments should be incorporated into the individualized patient goal setting and planning for return to the community following stroke.

   c. Vocational counsellors, social workers and other team members should provide counselling and information to patients on employment benefits and legal rights. Referral should be initiated to social work, occupational therapy and/or vocational counsellors as appropriate to assist patients and families in re-engaging in vocational activities as part of transitions to the community [Evidence Level C].

ii. Resumption of vocational interests should be encouraged where possible. A gradual resumption should occur when fatigue is a concern [Evidence Level C].

iii. School age stroke survivors in the community should have ongoing assessment of educational and vocational needs throughout their development [Evidence Level C].

iv. Primary care providers/healthcare team should work with employers/educators to devise an appropriate return to work plan [Evidence Level C].

v. The use of telemedicine technology modalities (e.g., video, and web-based technologies and services) should be considered to support return to work and skills attainment where possible [Evidence Level C]. *Refer to recommendation 8.1 for additional information.*

vi. Patients who are unable to return to work following stroke should be provided counselling regarding financial concerns and planning [Evidence Level C]. Referrals to these services should be provided by members of the healthcare team.

B. Leisure Activities

i. Patients should be given the opportunity to discuss pre-stroke leisure pursuits and be assessed for rehabilitative needs to resume these activities. Participation in leisure activities should be encouraged where possible [Evidence Level B]. *Refer to Recommendations 5.11 for additional information.*

ii. Patients who experience difficulty engaging in leisure activities should receive targeted therapeutic interventions and individualized plans for participation in leisure activities based on collaborative goal-setting with their healthcare team [Evidence Level: Adult-Level A; Pediatric-Level C].

iii. Children affected by stroke should be offered advice and treatment aimed at achieving play and leisure related skills that are developmentally relevant and appropriate in their home, community, and school environments [Evidence Level C].

iv. Patients should be provided with a list of community-based resources for engaging in aerobic and leisure activities in the community prior to discharge; they should be referred to relevant agencies as appropriate to provide support in re-engaging in leisure activities [Evidence Level C].

v. Community-based therapy for individuals with stroke should include the development of problem solving skills for overcoming the barriers to engagement in physical activity and leisure pursuits [Evidence Level C].

C. Disability Supports in the Community

i. Community based healthcare professionals across disciplines should provide patients and families with information and linkages regarding access to disability support services within their region [Evidence Level C].

   a. Healthcare providers should work with patients and families to develop a mobility access plan prior to transition to a home or community-based living setting [Evidence Level C]. This plan should identify mobility issues, assessment of access barriers, safety concerns, environment modifications, and equipment that may be required to ensure the safety and accessibility for patients with functional, communicative and/or cognitive deficits following stroke [Evidence Level C].

   b. Many regions and provinces have formal disability legislation and guidelines in place and these should be explained to patients and families in preparation for transitions; appropriate documentation and applications should be completed by healthcare professionals as required in a timely manner in collaboration with patients and families to minimize delays in access to eligible services [Evidence level C].
   c. Social workers or case managers should be involved with families to ensure appropriate services and equipment is accessed in a timely manner and to help patients and families navigate through the system [Evidence Level C].

D. Advanced Care Planning and Community-Based Palliative Care

i. Patients surviving a stroke, as well as their families and informal caregivers, should be approached by the stroke healthcare team to participate in advance care planning prior to or soon after transitions to the community following an acute stroke [Evidence Level C]. *Refer to Recommendations 4.3 and 4.4 for additional information.*
ii. The primary goal of advance care planning conversations is to determine the individual's goals of care [Evidence Level B].
   a. Advance care planning may include identifying a substitute decision-maker (proxy or agent), implementing a personal directive [Evidence Level C], and discussion of the patient's preferences and the medical appropriateness of therapies such as feeding tubes, hydration, treatment of the current illness, admission to intensive care, ventilation, cardio-pulmonary resuscitation, and place of care [Evidence Level B].
   b. Advanced care planning discussions should be documented in the patient's chart and any relevant hospital-specific forms should be completed and signed by the patient or decision-maker and a member of the healthcare team [Evidence Level C].
iii. The patient's goals of care and advanced care planning decisions should be revisited periodically, such as when there is a change in the patient's health status [Evidence Level B].
iv. The interprofessional team should have the appropriate communication skills and knowledge to address the physical, spiritual, psychological, ethical, and social needs of stroke patients, their families, and informal caregivers [Evidence Level C].
   a. Respectful discussion of patient's values, wishes and decisions should be balanced with information regarding medically appropriate treatment related to ongoing stroke management and future medical care [Evidence Level C].

6.5.4 Family and Caregiver Support and Well-being

i. Family members and informal caregivers should be advised by members of the healthcare team to have regular ongoing assessment of their physical, psychosocial, and mental well-being with their primary healthcare providers [Evidence Level C]. *Refer to Recommendations 6.1 and 6.2 for additional information.*

ii. Caregivers of stroke survivors should receive education and support to assist them in their role as a caregiver [Evidence Level C]. *Refer to Recommendations 6.1 and 6.2 for additional information.*

iii. Patients and families should be provided with information regarding peer support groups in their community, and initial connection with these groups should be encouraged where available [Evidence Level C]. *Refer to Recommendations 6.1 and 6.2 for additional information.*

iv. Where hospital-based peer support visit programs exist, arrangements should be made for peer-support introductions during hospitalization [Evidence Level C].

Rationale

The post-discharge period is consistently reported by stroke survivors and their families to be a stressful and challenging time as they adjust to new roles and potentially altered functional and cognitive abilities of the stroke survivor. Patients and their families often lose the social, emotional, and practical support offered by an inpatient stroke service. The evidence shows that when there is coordination of care beyond the inpatient setting and community support services are provided, patient outcomes and patient and informal caregiver satisfaction improves.

In children, regular follow-up is necessary to screen for other neurologic sequelae, as 30 percent of pediatric stroke survivors develop concurrent neurologic complications, including seizures, migraine, headaches, and movement disorders that may not manifest in the immediate acute and post-acute phases of stroke.

The addition of recommendations for long term care are a response to data showing that stroke patients are among the largest patient population receiving long-term care, and their number is steadily increasing worldwide. Stroke patients who transition to long-term care should continue to have rehabilitation and recovery goals and plans that focus on restorative care, maintenance of function, and support for health declines, and be cared for by staff knowledgeable in stroke maximize outcome goals.

System Implications

- Education and training in shared decision making skills and strategies should be provided to all healthcare professionals, patients and family members.
- Adequate follow-up stroke care in all provinces and territories to support community reintegration of stroke survivors.
- Assistance for stroke survivors and their families with an evolving care plan and regular follow-up assessments.
- Access to appropriate public transportation that supports people with disabilities.
- Programs that support timely and affordable access to mobility and other assistive devices for patients with stroke.
- Healthcare professionals and informal caregivers in the community and long-term care settings with stroke care expertise and access to ongoing education.
- Ongoing support in the form of community programs, respite care, and educational opportunities available to support caregivers who are balancing personal needs with caregiving responsibilities.
- Strategies to assist stroke survivors to maintain, enhance, and develop appropriate social support, and to re-engage in desired vocational, social, and recreational activities.
- Lists of community resources and processes to access these resources provided to all patients and families.

Performance Measures

1. **Proportion of stroke patients who are discharged from acute care who receive a referral for home care or community supportive services.**
2. **Proportion of readmissions to acute care for stroke-related causes following discharge to the community, stratified by type of stroke.**
3. Proportion of patients who return to the emergency department or hospital setting for non-physical issues following stroke (e.g., failure to cope).
4. Number of stroke patients with documentation that information was given to patient or family on formal and informal educational programs, care after stroke, available services, process to access available services, and services covered by health insurance.
5. Documentation of shared and collaborative decision-making between healthcare professionals and patients regarding individualized transition plans.
6. Number of patients referred to a secondary prevention team by the rehabilitation team.
7. Number of visits to primary care within specified time frames for stroke-related issues.
8. Number of visits to an emergency department within specified time frames.
9. Percentage of patients who return home following stroke rehabilitation who require community health services (e.g., home care or respite care).
10. Length of time from hospital discharge (whether from acute care or inpatient rehabilitation) to initiation of community health services.
11. Frequency and duration of community health services, stratified by the type of service provided.
12. Number of readmissions from stroke rehabilitation to acute care for stroke-related causes.
13. Percentage of patients who return to the community from acute hospital stay or following an inpatient rehabilitation stay who require admission to long-term care or a nursing home within six months or one year.
14. Median wait time from referral to admission to nursing home, complex continuing care or long-term care facility.
15. Documentation to indicate that assessment of fitness to drive and related patient counseling was performed.
16. Number of patients referred for driving assessment by occupational therapist in the community.
17. Measure of burden of care for family and informal caregivers of stroke survivors living in the community.

Measurement Notes

- Performance measure 1: data may be obtained from inpatient chart documentation or community support services documentation. Informal education or education received by primary care providers may be difficult to track unless specific audit tools are developed and implemented in local areas. *Also refer to some of the performance measures listed in recommendation 2.1.*
- Emergency department visits can be tracked through the Canadian Institute for Health Information database for participating institutions or hospital records if the patient returns to the emergency department of the hospital where inpatient stay occurred.
- The Canadian Institute for Health Information holds an administrative data set for complex continuing care and long term care, which uses a minimal data set that is mandated in several regions across Canada. This data set uses the Resident Assessment Instrument tool for assessing functional status. At this time there are no validated comparison models between the Functional Impact Measure and the Resident Assessment Instrument.

- Hospital readmissions from inpatient rehabilitation to acute care can be obtained from hospital administrative data nationally and provincially.
- Visits to primary care and indicators related to information and education are difficult to measure. They could be obtained through surveys and standardized audit tools at the local or regional level.

Implementation Resources and Knowledge Transfer Tools

- Living with Stroke™ Program [http://www.heartandstroke.com/site/c.ikIQLcMWJtE/b.3936679/k.7231/Stroke__Living_with_StrokeTM_program.htm]
- Living With stroke: Stroke Support Group Toolkit [http://www.lifeafterstroke.ca/wp-content/uploads/2011/09/SupportGroupToolkit-EN1.pdf]
- Life After Stroke: Managing the Effects of Stroke and Getting Back Into Life [http://www.strokebestpractices.ca/wp-content/uploads/2013/10/My-Stroke-Passport_Life-After-Stroke.pdf]
- Medication Reconciliation in Canada: Raising the Bar [http://www.ismp-canada.org/download/MedRec/20121101MedRecCanadaENG.pdf]
- The Functional Independence Measure (FIM®) [http://www.udsmr.org/WebModules/FIM/Fim_About.aspx]
- The Chedoke-McMaster Stroke Assessment [http://www.rehabmeasures.org/PDF%20Library/CMSA%20Manual%20and%20Score%20Form.pdf]
- The Reintegration to Normal Living Index [http://strokengine.ca/assess/pdf/RNLI.pdf]
- The Assessment of Life Habits (LIFE-H) [http://strokengine.ca/assess/module_lifeh_indepth-en.html]
- The Stroke Impact Scale [http://ph.kumc.edu/sis/SIS_pg2.htm]
- The Craig Handicap Assessment and Reporting Technique [http://www.craighospital.org/repository/documents/Research%20Instruments/CHART%20Manual.pdf]
- The Stroke-Adapted Sickness Impact Scale Profile [http://strokengine.ca/assess/PDF/SASIP30scale.doc]
- The London Handicap Scale [http://www.cebp.nl/vault_public/filesystem/?ID=1382]
- The Community Integration Measure [http://www.disabilitypolicyalliance.ca/wp-content/uploads/2013/06/CIM.pdf]
- The Stroke Specific Quality of Life [http://strokengine.ca/assess/PDF/Stroke-SpecificQOLseethetool.pdf]
- The Subjective Index of Physical and Social Outcome [http://www.ncbi.nlm.nih.gov/pubmed/10868724]
- The Maleka Stroke Community Reintegration Measure [http://wiredspace.wits.ac.za/handle/10539/10661]

Summary of the Evidence

The post-discharge period is consistently reported by stroke survivors and their families to be a difficult time (Anderson 1992; Stanton 2000). Patients and their families often lose the social, emotional and practical support offered by an inpatient stroke service Royal College of Physicians of London 2008). In one study, only 10 percent of families were actively in contact with professional rehabilitation services after hospital discharge (Anderson 1992). In general, caregivers cope with physical limitations better than cognitive or emotional ones. When the psychosocial needs of patients and their caregivers are regularly addressed through social support, improved outcomes are observed, including reduced caregiver burden, reduced incidence of anxiety, reduced emotionalism and depression, reduced hospital readmissions and failed discharges, and facilitated reintegration of the patient in family and social roles (Duncan et al. 2005; Anderson 1992). The evidence shows that when support services are provided, patient and informal caregiver satisfaction improves (Royal College of Physicians of London 2008; Pound et al. 1995).

Regular and ongoing follow up with a primary care provider following a stroke is essential for continuing assessment of patient needs. Early and frequent evaluation of physical and cognitive disability is the key to preventing avoidable complications and to planning rehabilitation. Secondary prevention education services are important for reducing the risk of recurrent stroke and improving long term patient outcomes. Risk management strategies have been found to have some evidence supporting their effectiveness in areas such as blood pressure control, falls prevention, medication adherence, depressive symptom awareness, body mass index monitoring, and increasing physical activity (Allen 2002; Joubert et al. 2009). These considerations are also important for children and adolescents. Following childhood stroke, there may be significant issues in accessing therapy. A coherent care plan for rehabilitation is integral to the process and should take into account all of the child's needs and practical resources to ensure the needs are met in the community (Paediatric Stroke Working Group 2004). Ongoing follow-up and assessment are crucial to the well-being of the child and family, as lasting cognitive deficits will affect all areas of daily functioning.

Ongoing rehabilitation (beyond six months after stroke) can further improve activities of daily living and fitness. Stroke rehabilitation involves programs to reduce impairments, enhance recovery and adapt to persisting disabilities. Current evidence demonstrates that patients may, in some cases, continue to decline following stroke. The risk of deterioration in ability can be reduced or reversed by further rehabilitation input (Royal College of Physicians of London 2008). Therapy-based rehabilitation services can reduce poor outcomes (i.e., prevent hospital readmission), promote participation in desired activities, increase activities of daily living and reduce external home care supports. Evidence also exists to support the effectiveness of interventions initiated in the chronic stage of stroke recovery for a range of functional deficits (Teasell et. al. 2012). For every 100 stroke patients living in the community and receiving therapy-based rehabilitation services, seven patients are spared a poor outcome (Outpatient Service trialists 2003).

Declines may also occur in the areas of cognition and communication deficits. A number of studies have noted an increasing prevalence of cognitive impairment over time following stroke (Teasell et al. 2012). Furthermore, a recent review of therapies for aphasia initiated more than 6 months post stroke has found some evidence of effectiveness (Teasell et. al. 2012). As a result, ongoing assessment in these areas is also recommended to allow for further rehabilitation intervention if warranted.

Reintegration to former vocational and social life roles may be an important goal for the stroke survivor. Estimated rate of return to work in those employed prior to stroke range from 12-49% (Baldwin & Brusco 2011), and return to work programs are not well studied in randomized controlled trials. However, assessment and management of post stroke disabilities may enhance one's ability to return to employment following a stroke.

The resumption of pre-stroke social and leisure pursuits is an additional component of reintegration back into pre-stroke life. "Rehabilitation after stroke must also address 'participation.' This may require planned withdrawal of medical and rehabilitation services and substituting them with leisure and social activity to encourage independence and reintegration to normal life" (Royal College of Physicians of London 2008). Health care providers should encourage the use of community resources such as peer and/or family support groups, social and recreational activities and transportation resources. "Community support can help buffer the effects of disability on the patient, family and informal caregivers. Living with disabilities after a stroke is a lifelong challenge. For many stroke patients and their families, the real work of recovery begins after formal rehabilitation" (Duncan et al. 2005). Community service providers would serve 3 major roles for patients and informal caregivers: provide caregiver training related to life at home following stroke; provide feedback and guidance regarding linkages to community resources; and, conduct follow-up with stroke survivors and informal caregivers at regular intervals. Educational interventions to support return to social and leisure activities have also been demonstrated to be effective, resulting in both greater amounts of time spent involved in leisure activity, as well as increased satisfaction (Desrosiers et al. 2007).

Studies looking at quality of life up to 4 years post stroke found the percentage of depression for caregivers is high. As a result, it is important that caregivers receive ongoing assessment. Anderson examined the effect of stroke on 173 patients and their family caregivers, finding that more than a third of people who cared for stroke patients at home regarded their own health as only fair or poor (Anderson 1992). The author reported that access to help from professional rehabilitation services was patchy and inconsistently available, and that "care became a burden rather than a pleasure, social function and personal relationships deteriorated, and contact with the outside world slipped away." Low mood was a major influence of outcome and a main component of quality of life. For caregivers, it contributed substantially to the burden of care. To alleviate the suffering, Anderson stated that the social, psychological, family and economic aspects of stroke must be directly addressed (Anderson 1992). Pound and associates, in exploring the components of care most valued by patients, undertook a qualitative study using in-depth interviews of stroke patients and their caregivers 10 months after the stroke (Pound et al. 1995). These researchers found that as the acute phase of stroke passes, patients and informal caregivers increasingly desired support related to rehabilitation, discharge, prognosis, etc. The researchers stated, "more information is needed about the stages of the stroke caregiver so that care may be tailored to respond sensitively and flexibly to the different stages."

Interventions for caregivers of stroke patients have demonstrated some effectiveness. Group support programs have been found to result in greater confidence in patient care, as well as enhanced coping strategies (van den Heuvel et al. 2002). Educational programs have also been found to increase rates of depressive symptoms in caregivers (Smith et. al. 2012). Support and education programs for caregivers may facilitate better outcomes through an increase use of social and peer supports.

Evidence Table 6.5 and Reference List

Best Practice Recommendation 6.6 **Update 2013**

Transition of Patients to Long-Term Care Following a Stroke

6.6 Patients who have experienced a stroke and are transitioned to long-term care should continue to have their physical, functional, emotional, cognitive and social needs addressed to optimize quality of life and meet their ongoing goals of care.

6.6.1 Patient Assessment and Care Planning

i. All patients who transition to a long-term care setting following a stroke should have an initial assessment, conducted by medical, nursing and rehabilitation professionals, as soon as possible after admission [Evidence Level A].

   a. The initial assessment of functional status, physical status, and cognitive status should be aligned with existing assessment processes (e.g., Minimal Data Set-Resident Assessment Inventory – MDS_RAI) where possible [Evidence Level C].

   b. The results of the assessment should be used to develop an individualized plan of care for each patient who transitions to a long-term care setting following a stroke to optimize quality of life and meet physical, functional, emotional, cognitive and social needs [Evidence Level C].

   c. Follow-up assessments should be conducted on a regular basis (e.g., every 3 to 6 months) and when changes in health status occur [Evidence Level C].

   d. When areas of decline are identified in reassessments, individualized care plans should be updated to incorporate changes in care requirements, address issues of safety, and the potential need for referrals to appropriate healthcare professionals for further consultation [Evidence Level C].

ii. All patients who have experienced a stroke and are admitted to a long-term care setting should be cared for by staff members who are educated and knowledgeable in stroke care and recovery goals and therapies, and stroke best practice recommendations [Evidence Level C].

6.6.2 Rehabilitation and Restorative Care

i. All patients with stroke living in long-term care settings should live within an active and complex stimulating environment focused on restorative care, and maintaining or improving physical, functional and cognitive status, and based on individualized assessments and potential [Evidence Level C].

   a. Residents in long-term care should have access to recreation therapy encompassing group activities, one-on-one activities and outings into the community if appropriate [Evidence Level C].

ii. Stroke survivors with ongoing rehabilitation goals should continue to have access to specialized stroke services following admission to a community living setting [Evidence Level A], including within a long-term care setting. *Refer to Recommendation 5.4 for additional information.*

iii. At any point in their recovery, stroke survivors living in long-term care who have experienced a change/improvement in functional status and who would benefit from rehabilitation services should be offered a trial of active inpatient or outpatient rehabilitation [Evidence Level B].

6.6.3 Patient and Family Support and Education

i. Families of stroke patients living in long-term care should have regular meetings with the healthcare team to review health status, quality of life, improvements or declines, opportunities and training for participation in care, and updated goals of care [Evidence Level C], at least once annually and when changes in health status occur.

ii. All patients and family members should be provided interactive and timely education on stroke, recovery and prevention, based on individualized learning needs [Evidence Level C]. *Refer to Recommendation 6.2 for additional information.*

iii. Family members should be offered peer support information and counseling to address issues of changing life roles and coping with now having a family member living in a long-term care setting, and encouraged to seek help from their own primary care team members to address issues [Evidence Level C].

iv. Patients living in long-term care and their families should be provided information and counseling on appointing an Alternate Decision Maker, developing advanced directives for care, and palliative care options as appropriate [Evidence Level C]. *Refer to Recommendations 4.3 and 4.4 for additional information.*

    a. Patients, families and informal caregivers should receive training on how to advocate for active participation in care planning and shared decision-making [Evidence Level C].

Rationale

Health care surveillance data indicates that stroke patients are among the largest patient population receiving long-term care, and their number is steadily increasing worldwide. Stroke patients who transition to long-term care should be cared for in an environment that is supportive, with staff knowledgeable and competent in meeting the specific needs of stroke patients and their families within this setting. This will enable the stroke survivor to maintain quality of life and dignity, and have rehabilitation and recovery goals and plans that focus on restorative care, maintenance of function, support for health declines, and sensitivity to family needs. The post-discharge period is consistently reported by stroke survivors and their families to be a stressful and challenging time as they adjust to new roles, altered functional and cognitive abilities, and changes in living setting for patients admitted to long-term care following an acute stroke.

System Implications

- Adequate follow-up care providers in all provinces and territories to support ongoing access to rehabilitation services for stroke survivors allowing transition to long-term care settings.
- Assistance for stroke survivors and their families with an evolving care plan and regular follow-up assessments.
- Programs that support timely and affordable access to mobility and other assistive devices for patients with stroke in long-term care.
- Healthcare professionals and informal caregivers in the community and long-term care settings are provided with ongoing stroke specific education and training to increase stroke care expertise. Training to be provided by a range of healthcare disciplines, such as physiotherapy, occupational therapy, speech language pathology, and dietitians.
- Strategies and services to assist stroke survivors to maintain, enhance, and develop appropriate social support, and to re-engage in desired social, and recreational activities.

Performance Measures

1. **Proportion of patients who are discharged from acute care directly to a long-term care setting following an acute stroke.**
2. **Percentage of readmissions to acute care for stroke-related causes following discharge to long-term care, stratified by type of stroke.**
3. Changes in functional status from time of admission compared at 3 months, 6 months and one year following admission to long-term care.
4. Number of visits to an emergency department within 3 months, 6 months and one year following admission to long-term care.
5. Measure of burden of care for family and informal caregivers of stroke survivors living in the community.

Measurement Notes

- The Canadian Institute for Health Information holds an administrative data set for complex continuing care and long term care, which uses a minimal data set that is mandated in several regions across Canada. This data set uses the Resident Assessment Instrument tool for assessing functional status. At this time there are no validated comparison models between the Functional Impact Measure and the Resident Assessment Instrument.
- Hospital readmissions from inpatient rehabilitation to acute care can be obtained from hospital administrative data nationally and provincially.

Implementation Resources and Knowledge Transfer Tools

- Tips and Tools: A guide for Stroke Caregivers [http://www.heartandstroke.on.ca/site/chttp://www.heartandstroke.on.ca/site/c.pvl3leNWJwE/b.6194819/k.FEB1/Tips_and_Tools__2010.htmpvl3leNWJwE/b.6194819/k.FEB1/Tips_and_Tools__2010.htm]
- Transition Information Plan (TIP) [http://www.heartandstroke.on.ca/site/c.pvl3leNWJwE/b.5395543/k.41ED/Transition_Information_Plan_TIP.htm]
- Deciding on Long-Term Care [http://www.strokecenter.org/patients/caregiver-and-patient-resources/caregiving-guide-for-african-americans/deciding-on-long-term-care/]
- Registered Nurses' Assoiciation of Ontario: Long-Term Care Best Practices Initiative [http://rnao.ca/bpg/initiatives/longterm-care-best-practices-initiative]
- Registered Nurses' Association of Ontario: Positioning Techniques in Long-Term Care [http://rnao.ca/sites/rnao-ca/files/Positioning_Techniques_in_Long-Term_Care_-_Self-directed_learning_package_for_health_care_providers.pdf]
- The Functional Independence Measure (FIM®) [http://www.udsmr.org/WebModules/FIM/Fim_About.aspx]
- The Chedoke-McMaster Stroke Assessment [http://www.rehabmeasures.org/PDF%20Library/CMSA%20Manual%20and%20Score%20Form.pdf]
- The Reintegration to Normal Living Index [http://strokengine.ca/assess/pdf/RNLI.pdf]
- The Assessment of Life Habits (LIFE-H) [http://strokengine.ca/assess/module_lifeh_indepth-en.html]
- The Stroke Impact Scale [http://ph.kumc.edu/sis/SIS_pg2.htm]

Summary of the Evidence

Following a stroke event, high levels of disability may warrant admission to a long term care institution. Estimates for admission to long term care following stroke range from 10-14% (Chaung 2005; Portelli 2005). Four years following a stroke, up to 40% of individuals may require institutional care (Walsh 2008). Individuals who are discharged to a long term care facility may experience more severe functional deficits, higher levels of dependency, as well as more medical co-morbidities, requiring a greater degree of medical and nursing management (Chiu 1998).

Patients discharged to long term care require discharge planning much like individuals returning to their own homes. Several studies have examined factors for effective discharge communication between inpatient hospital care and institutional care facilities. Clear communication between facilities regarding nutritional needs, functional status, communication abilities, risk assessment, and medical management is necessary for an optimal transition. (Sackley & Pound 2002; Sackley & Pound 2002).

Individuals residing in skilled nursing facilities with staff trained in stroke management, and who have access to post stroke therapy resources, may experience better quality of life. In a study (Brajkovic 2009) examining individuals living in a nursing home who received 24 hour care including access to psychiatric care, physician visits, daily physiotherapy, and weekly massage services, nursing home residents experienced greater quality of physical, psychological, social, and environmental quality of life scores when compared with individuals living in their own homes receiving many of the same services. Nursing home residing individuals also experienced better perceived quality of life and health status than their residentially residing counterparts. It has also been found that amount of additional therapy received in a nursing home facility may have a dose-response relationship with likelihood of being discharged back into a person's own home (Wodchis 2005).

Caregiver and family involvement are also important components of long term care and these individuals should be considered as care partners (Levine 2010). It has been suggested that "enhancing their involvement, training, and support will contribute to reducing unnecessary rehospitalizations and improving patient outcomes" (Levine 2010). Caregiver of stroke patients living in long term care should also be provided with opportunities for education and peer support to reduce the likelihood of depressive symptoms and other negative outcomes (Smith et. al. 2012).

Evidence Table 6.6 and Reference List

Best Practice Recommendation 6.7 *NEW 2013*
Post-Stroke Fatigue

6.7 Post-stroke fatigue is a VERY common condition, and can be experienced by stroke survivors at ANY point during the recovery process. Unfortunately, post-stroke fatigue is often under-recognized. Therefore, healthcare professionals should anticipate the possibility of post-stroke fatigue, and prepare patients and families to mitigate fatigue through assessment, education, and interventions at any point during the stroke-recovery continuum.

i. Prior to discharge from hospital ward, stroke unit or the emergency department, stroke survivors, their families and informal caregivers should be provided with basic information regarding the frequency and experience of post-stroke fatigue [Evidence Level C].

ii. Stroke survivors, their families and informal caregivers should be taught to recognize their current physical and cognitive limitations, and to help set realistic goals to help increase endurance and manage fatigue as they continue their stroke recovery [Evidence Level C].

iii. Stroke survivors should be routinely asked about post-stroke fatigue during healthcare visits (e.g., primary care, home care, and outpatient) following return to the community and at transition points [Evidence Level C].

iv. Patients, who experience post-stroke fatigue, and their families and informal caregivers, should be provided with strategies for energy conservation and fatigue management that address the following components [Evidence Level C].

Note: many interventions listed here are well documented in the literature for general fatigue; there is a gap in this literature specific to stroke, however these strategies are all very applicable based on expert opinion, information from the occupational therapy literature, and qualitative patient feedback. Refer to Evidence Table 6.7 and Reference List.

a. Structuring day to include a balance of activity and scheduled periods of rest;
b. Keeping an agenda of daily activities, planning higher energy activities immediately following a period of rest, planning activities a day in advance, anticipating energy requirements for each task, prioritizing tasks and energy requirements;
c. Organizing physical environment to minimize efforts to move around, reduce stair climbing, and have ready access to the most frequently used items;
d. Sitting rather than standing when doing chores such as ironing or washing dishes;
e. Teaching body mechanics, posture and sitting positions and locations (i.e. rest in bed, rather than chair);
f. Engaging in exercise appropriate to tolerance level and with a plan for gradual increase in intensity and duration as advised in discussions with healthcare team members;
g. Establishing good sleep patterns, and avoidance of sedating drugs and excessive alcohol;
h. Using energy saving equipment and technology to reduce physical efforts (e.g., electric can opener, online shopping);
i. Engaging in enjoyable vocational and leisure activities that are planned ahead to ensure stroke survivor is well rested prior to activities;
j. Delegating activities that are low priority or can be done by someone else, such as family members;
k. Communicating energy status and rest needs to family members, caregivers and social groups;
l. Developing a plan for healthy diet or proper nutrition to help with energy levels.

v. Stroke patients should be cared for by healthcare professionals who are knowledgeable in the symptoms of fatigue and its management. In situations where such knowledge does not exist among the providers caring for a patient with post-stroke fatigue, a referral for expert consultation (e.g., by an occupational therapist) is appropriate [Evidence Level C].

vi. Stroke survivors who experience post-stroke fatigue should be screened for signs of depression or other mood-related conditions and for sleep patterns as these are often associated with fatigue following stroke [Evidence Level B].

vii. There is insufficient evidence to recommend specific pharmacological treatment for post-stroke fatigue at this time [Evidence Level B] (Cochrane Review, McGeogh 2009).

Rationale:

Post-stroke fatigue is generally under-diagnosed and not routinely assessed in patients who have experienced a stroke. However, symptoms of fatigue are often reported by patients in both the acute and chronic stages of recovery following a stroke. Prevalence rates of post stroke fatigue (HSF) are substantial, varying between 38 and 73%. Additionally these rates have not shown marked decline after the post acute stage to even years following the injury. It can occur in any stroke patient and has not been found to be dependently related to size, location or severity of stroke. It is commonly associated with low mood and sleep disturbances, but can arise in their absence. However, it has been shown to negatively impact a patient's ability to actively participate in rehabilitation, which has been associated with poorer long-term outcomes. Therefore, new recommendation shave been added to the Canadian Best Practice Recommendations for Stroke Care in 2013 to raise awareness of the frequency of post-stroke fatigue, the physical and emotional impact of PSF on patients and the negative impact on recovery and outcomes.

System Implications

- Protocols for the inclusion of post-stroke fatigue in patient screening and assessments at all transition points and stages of care following a stroke
- Resources and mechanisms to plan and deliver community-based services which consider the needs of the survivor and family/caregiver and are focused on energy conservation (e.g., access to assistive devices, transportation, counseling)
- Models of care that include technology such as telemedicine, regular telephone follow-up and web-based support to reduce excess visits to healthc are providers that consume energy.

Performance Measures

1. The number and proportion of patients who report symptoms of post-stroke fatigue, measured at each transition point as a proportion of all stroke patients.
2. The proportion of stroke patients who return to the emergency department or are readmitted to hospital for failure to cope or other fatigue-related reasons.

Measurement Notes

- Standardized and validated measures of post-stroke fatigue have not been published for this population. Many validated scales for fatigue as a condition may be applicable and are reasonable choices at this time.

Implementation Resources and Knowledge Transfer Tools

- Stroke Association: Fatigue After Stroke [http://www.stroke.org.uk/sites/default/files/Fatigue%20after%20stroke.pdf]
- Stroke Association: Fatigue Resource [http://www.stroke.org.uk/about/fatigue]
- National Stroke Association: Fatiue Resource [http://www.stroke.org/site/PageServer?pagename=fatigue]
- Let's Talk About Feeling Tired After Stroke [http://www.strokeassociation.org/idc/groups/stroke-public/@wcm/@hcm/documents/downloadable/ucm_309719.pdf]
- Activity Journal [http://www.cdc.gov/healthyweight/pdf/physical_activity_diary_cdc.pdf]
- Fatigue severity scale [http://www.saintalphonsus.org/documents/boise/sleep-Fatigue-Severity-Scale.pdf]
- Multidimensional Fatigue Inventory [http://www.google.ca/url?sa=t&rct=j&q=&esrc=s&frm=1&source=web&cd=12&cad=rja&sqi=2&ved=0CG4QFjAL&url=http%3A%2F%2Fwww.reginfo.gov%2Fpublic%2Fdo%2FDownloadDocument%3FdocumentID%3D60899%26version%3D1&ei=w1pYUu6XGYm6yAH0Tg&usg=AFQjCNGGwYNYrBXCJXncR__VaYGTqzPLyw]

Summary of the Evidence

Post-stroke fatigue (PSF) has not been well studied, but it is known to occur commonly, is associated with mood disorders and pain, and negatively impacts recovery. The incidence of post-stroke fatigue is difficult to estimate given that many patients report symptoms of pre-stroke fatigue (Lerdal et al. 2011). Estimates of incidence/prevalence also vary depending on when fatigue is assessed in the recovery process and which tool is used for assessment. At the time of admission for inpatient rehabilitation, fatigue was present in 51.5% of patients (Schepers et al. (2006) and at the point of discharge, in 58.3% of patients (Van Eijsden et al. 2012). Schepers et al. (2006) reported that fatigue was present in 64.1% and 69.5%, respectively at 6 months and 1 year. Overall, fatigue was present in 37.7% of patients and absent in 17.4%, at all assessment points. Of the patients reporting fatigue at 1 year, 29.3% were also depressed. Van der Port et al. (2007) reported that the percentages of patients considered fatigued at 6, 12 and 36 months were 68%, 74% and 58%, respectively, in 223 acute stroke patients followed prospectively. In all of these studies, the presence of fatigue was identified based on a score of 4 or greater on the Fatigue Severity Scale. Two years following stroke, of 5,189 patients who were alive and included in the Riks-Stroke national stroke registry, 10% and 29.2% of respondents reported "always" or "often" being tired (Glader et al. 2002) in a postal survey. The clinical course of PSF is unclear; therefore it's even unknown if PSF increases or decreases over time. Snaphaan et al. (2011) reported that the prevalence of fatigue was 35% at 2 months post stroke and 33% at 18 months. 26% of patients reported fatigue at both assessment points, while 9% reported fatigue at baseline but not at follow-up, and 8% reported no fatigue at baseline but did at follow-up. Independent predictors of fatigue that have been identified include increasing age, female sex, depression, low levels of physical functioning, and pre-stroke fatigue.

A few controlled studies have been conducted comparing fatigue in persons recovering from stroke with persons from the general population and in cases of TIA. When compared with 1,069 person of similar ages selected from the general population, the fatigue scores of 165 patients with acute stroke were significantly higher after adjusting for age, sex and living arrangements. Of the 5 subscale components of the Multidimensional Fatigue Inventory (MFI-20), stroke patients had significantly higher general and physical fatigue scores and also higher reduced activity scores at 3 months (Christensen et al. 2008). Winward et al. (2009) compared 73 subjects with minor stroke and 76 subjects with TIA who were participants in the Oxford Vascular study. At 6 months, a higher proportion of participants with stroke reported significant fatigue, assessed using the Chalder Fatigue Scale (56% vs. 29%, $p=0.008$). A higher proportion of subjects with stroke, who had initial NIHSS scores of 0 reported significant fatigue compared with TIAs with initial NIHSS scores of 0 (57% vs. 29%, $p=0.015$). Subjects who felt they had not made a full recovery were more likely to be fatigued compared to those who felt they had (72% vs. 23%, $p<0.0001$).

There are few treatments for post-stroke fatigue that have been evaluated. A Cochrane review (McGeough et al. 2009) included the results from 3 RCTs, each examining different therapy approaches. The results from all 3 were equivocal. In one trial, 83 subjects with post-stroke emotional disturbances, an average of 14 months after stroke onset, were randomized to receive 20 mg/day of fluoxetine (n=40) or placebo, (n=43) for 3 months (Choi-Kwon et al. 2007). At the end of treatment, there were no significant differences in the number of patients with PSF. At 6 months, 34 patients (85%) in the fluoxetine group reported PSF compared with 40 (93%) in the control group. However, at 3 months, fewer patients in the fluoxetine group reported excessive/inappropriate crying (n=16, 40% vs. n=27, 62.8%, p=0.038), and at 6 months fewer patients in the fluoxetine group were identified with depression (n=5, 12.5% vs. n=13, 30.2%, p=0.05). In another trial, 831 participants with a variety of chronic disease conditions who may or may not have suffered from fatigue at study entry were randomized to participate in a 6-month chronic disease self-management program (CDSMP) immediately after randomization, or after a 6 month delay (Lorig et al. 2001). The program was provided over 7 weeks, for 2.5 hours weekly. The authors acquired data reporting on the subset of 125 patients with stroke in the trial. The mean fatigue scale change scores (1-5) at 6 months were 0.246 for controls and 0.087 for those who received the active treatment condition, indicating that fatigue became worse for wait list controls, although the difference was not significant (p=0.253). Finally, 31 women in the acute stage of SAH who may or may not have suffered from fatigue were randomized to receive tirilazad mesylate vs. placebo for 10 consecutive days. In women who survived and could be assessed for fatigue at 3 months, significantly fewer patients in the intervention group reported debilitating fatigue (4/9 vs. 9/9, p<0.01).

Evidence Table 6.7 and Reference List