

Recovery and Transitions of Care Area Overview/Statement of Problem

In August 2006, the North Carolina Legislature directed the Justus-Warren Heart Disease and Stroke Prevention Task Force (JWTF) to establish a Stroke Advisory Council (SAC) and charged that group with developing a stroke system of care for North Carolina. A report and recommendations were due and delivered to the General Assembly in February of 2007 on the occasion of the Task Force's biennial Legislative Heart Health Day.

Due to the extreme time constraints, the first year's work focused on the acute phase of the stroke continuum of care and built on a number of key partnerships and existing accomplishments, including the NC Collaborative Stroke Registry, now known as the NC Stroke Care Collaborative (NCSCC). In recognition of the importance of NC's efforts to improve the quality of acute stroke care, the General Assembly appropriated funding to support the recommendations of the SAC and to continue its operations in order to address both pre- and post-hospital aspects of stroke care.

In reviewing the charge to determine what should be addressed in year two, the Council decided to focus on stroke prevention and rehabilitation. Two new work groups were established, and new expertise was recruited to advise in these areas. This input was used to develop recommendations to be brought before the Council and the Task Force for approval before being reported to the 2008 Legislative Session.

The Council adopted a recommendation from the Rehabilitation Work Group to identify and publish an inventory of stroke services and resources by county. The Rehabilitation Work Group (Appendix H, SAC Stroke Rehabilitation Work Group) decided that addressing public and provider awareness of post-acute stroke services in the community would be a practical first step and objective for the short term. The Work Group believed that identifying and disseminating information about available resources for stroke recovery would result in a number of advantages in moving toward development of a system of stroke care for the state. These advantages would include: (1) Providing a public service for stroke patients, their providers, and families; (2) Establishing a baseline for stroke services and identifying gaps; (3) Aligning with one of the American Heart Association/American Stroke Association's recommended rehabilitation progress markers identified in the Ideal Stroke System of Care; and (4) Assisting with addressing identified problems with transitions in care from the acute to the post-acute stage.

The importance of increasing the public's awareness of available community services was supported by the NCSCC's¹³ discharge destination data which showed that 43% of all stroke

¹³ The NCSCC assesses the use of best practice guidelines for stroke treatment by conducting real-time data collection on stroke treatment within North Carolina hospitals. The NCSCC's website can be accessed at <http://www.ncstrokeregistry.com>.

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cases (excluding transient ischemic attacks) were being discharged to home care or self care. This finding supported the need for providers and families to be aware of, and have ready access to, information about services available in and around their community. The Rehabilitation Work Group found an invaluable partner in the state-funded NCcareLINK¹⁴ health information portal. This partnership provided a way to disseminate information to providers and the public about post-acute stroke services that are available in each county. In addition to utilizing NCcareLINK as a searchable online resource, a printed guide was developed to provide a snapshot in time of available resources for recovery. (Appendix H, List of Members of the Rehabilitation Advisory Group that oversaw development of the printed guide). NCcareLINK continues to provide up-to-date information about new programs and changes to existing programs. Every effort was made to widely distribute the published guides and to publicize the availability of the on-line database.

Beyond the development of the database and the printed guide, the Rehabilitation work group investigated issues related to transitions of care and found that:

- Programs are needed which integrate primary care, rehabilitation, and community settings.
- Providing care consistent with guidelines improves functional outcomes at six months and increases the probability of being discharged home.
- Based on stroke survivor accounts and the opinions of SAC members, stroke patients and their families generally do not receive adequate information to meaningfully assist them through the recovery phase of their experience.
- Some of the observed recurrent strokes might have been avoided through improved patient/caregiver education.
- There is a need to provide hospitals and providers with resources to assist with improving stroke education to reduce the recurrence of stroke and to assist patients and their families in coping with life after stroke.
- There is also a need to identify programs and resources to assist hospitals in improving patient and caregiver education and to better transition patients back into their communities and physicians' care.

Many members of the original Rehabilitation Work Group participated in the August 30, 2010 meeting of the SAC/ASTHO group to begin the development of recommendations for the Stroke Systems of Care Plan. They returned to participate in the newly named Recovery/Transitions of Care Work Group and identified additional members with the needed expertise (Appendix I, SAC/ASTHO SSoC Recovery/Transitions of Care Work Group). That group identified a number of strengths, along with gaps and opportunities for improvement, of the stroke system of care in NC. Existing assets to build upon included: stroke coalitions; stroke networks; stroke coordinators; primary stroke centers; the NCSCC and its participating hospitals; Get With the Guidelines – Stroke; leading inpatient rehabilitation centers; CARF-accredited centers (Appendix J, NC CARF Accredited Facilities with a Stroke Specialty Program); evidence-based rehabilitation guidelines; Rehabilitation Resource Guide and NCcareLink on-line database; NC Stroke Association and its “Beyond the Hospital” Program; national research; Transitions of

¹⁴ NCcareLINK is a state health information portal. It can be accessed at <https://www.nccarelink.gov>.

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Care Association; Continuing Care Hospital Concept (bundled payment); abundant tools and literature available; NC Division of Aging; and Area Agencies on Aging.

The Recovery/Transitions of Care Work Group also listed gaps and barriers including: reimbursement issues; NCSCC quality improvement (QI) efforts ending at hospital discharge; key indicators needed for the post-acute stage; primary care providers and rehabilitation professionals are in short supply, especially in rural areas; long term care (LTC) workforce issues; prescription management/health literacy; rehabilitation is frequently delivered at skilled nursing facilities or LTC facilities; quality initiatives are not in place; gaps between research and practice; younger stroke patients (frequently African American) are not eligible for Division of Aging services; and lack of opportunity for reintegration into the community.

The Work Group then condensed the list of gaps and barriers into three main areas for development of initial recommendations. Three subgroups were formed and have worked to develop recommendations related to their respective topic areas as follows:

- Extending Registries/Quality Improvement (QI) into the Post-hospital Phase
- Managing Transitions of Care
- Reimbursement

Recommendations

A. Extending Registries/QI into the Post-Hospital Phase

Despite progress in acute stroke care management, the majority of stroke survivors are discharged home with persistent neurological symptoms and significant disability. Follow up on these patients has revealed recurrent stroke, high rates of rehospitalizations, multiple falls, high risk of fractures, and decline in functional abilities. State systems of stroke care must develop strategies to enhance post-acute stroke management and quality of life for stroke survivors. Better management of stroke recovery will require liaisons between hospitals, communities, programs and services.

To develop effective stroke systems of care, three initiatives are recommended:

- 1. Pursue funding to carry out a preliminary study modeled after the EMS Data Linkage Project that demonstrated the feasibility of linking PREMIS data with NCSCC hospital data (Mears et. al., 2010). The objective of the study would be to examine patterns of care for stroke patients who have been discharged from hospitals participating in the NCSCC. It is proposed to utilize medical claims data on provider and patient services available from CMS Medicare records for the purpose of evaluating the continuum of care for NCSSC patients following their discharge from the hospital. The goal is to provide a comprehensive description of the patterns of outpatient care, use of rehabilitation services, and hospital**

readmissions and evaluate contributing factors to help inform future alignment of health care resources for the care of stroke patients.

Specific aims of this study are to:

- a. Establish the feasibility of linking the NCSCC data with CMS Medicare data.
- b. Describe, using the linked NCSCC/CMS Medicare data, patterns of care for stroke patients discharged from NCSCC hospitals following a stroke-related hospitalization.
- c. Conduct a prospective pilot follow-up study to examine trajectories of functional status, quality of life, and medication adherence among the NCSCC patients.

It is envisioned that initial funding for this project will support a pilot study aimed at establishing the parameters (positive predictive value) of the linkage of the CMS data with the NCSCC data. Funding for this portion of the study will be sought from the North Carolina Translational and Clinical Sciences Institute (NCTraCS) at UNC-CH. The pilot study will then serve as the basis for an R01 proposal to the National Institute of Neurological Disorders and Stroke (NINDS). Partners in the study will include the funders, the NCSCC, the UNC-Chapel Hill Department of Cardiovascular Epidemiology (specifically, Professor Wayne Rosamond and Dr. Anna Kucharska-Newton), the Duke University Doctor of Physical Therapy Program (specifically, Professor Pamela Duncan), the Carolinas Center for Medical Excellence (CCME), and participating hospitals.

- 2. Once feasibility is established, pursue funding to create a recovery phase registry that would link this registry to the NCSCC registry in order to track survivor outcomes at least one year post-acute hospital discharge. An outside agency should be identified and contracted with in order to perform the data tracking for this linkage project.**
- 3. Stroke performance measures have been developed to monitor and improve the quality of care related primarily to the acute hospital component of stroke systems of care. There are very few stroke quality measures that address the care provided in the post-hospital recovery period or for the transitions that occur for patients moving from hospital to home. The best management of stroke will require care coordination between health care facilities, providers, and the community and measures of quality outcomes that span the entire continuum.**

In an effort to improve care, the National Quality Forum (NQF) has recently published a proposed draft of Preferred Practices and Performance Measures for Measuring and Reporting Care Coordination (Appendix K, NQF Preferred Practices and Performance Measures for Measuring and Reporting Care Coordination). Although developed for

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cardiovascular disease, many of these practices and measures lend themselves to supporting stroke recovery and could be modified to address the delivery of care over the stroke recovery period. In addition, the Commission on Accreditation of Rehabilitation Facilities (CARF) has revised stroke specialty standards to include gathering of information post discharge on the following measures:

- a. Aspiration pneumonia
- b. Falls
- c. Falls with injuries
- d. Rehospitalization
- e. Unplanned medical visits/encounters

CARF will also require that accredited stroke rehabilitation programs have indicators to measure the percentage of individuals recovering from stroke who, at discharge and during the transition phase, are in compliance with evidence-based guidelines to manage:

- a. Diabetes
- b. Hyperlipidemia
- c. Hypertension
- d. Stroke prophylaxis

Recommendation: Develop measures for the recovery phase of stroke systems of care in NC, and consider the NQF measures and the CARF Stroke Specialty Standards as the foundation for focusing on health outcomes at one, three, six and twelve months post-discharge from the acute care hospital.

The development and implementation of such measures will require a work group with representatives of many partner organizations including but not limited to the NCSCC and its participating hospitals, NQF, CARF and NC's accredited rehab facilities, and academic centers.

B. Managing Transitions of Care

- 1. Develop projects and programs to educate primary care physicians about stroke patient recovery opportunities.**

These education programs should be developed in collaboration with partners such as the NC Medical Society's Medical Education Committee, NC Academy of Family Physicians, NC Chapter of the American College of Physicians, Community Care of NC, NC Community Health Center Association, NC Association of Free Clinics, NC Stroke Association, American Heart Association/American Stroke Association Mid-Atlantic Affiliate, NC Area Health Education Center (AHEC), NC Division of Public Health, local health departments, NC Stroke Advisory Council, NC HDSP Branch, and

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universities. The costs that are associated with this recommendation include the funding needed for developing, disseminating, and evaluating the impact of the educational programs on physician knowledge and/or patient outcomes. For example, the educational courses may need funding for CME credits, for publicizing course availability, and for any class materials. Also, consideration should be given to indirect costs of the time that must be sacrificed by providers who would benefit from this program and the individuals who would be providing the education.

2. Create a NC post-acute stroke resource center with the purpose of empowering caregivers and families.

This resource center would be developed in collaboration with partners such as the NC Hospital Association, NC Stroke Advisory Council, NC AHEC, NC Division of Public Health, local health departments, National Stroke Association, NC Stroke Association, American Heart Association/American Stroke Association (AHA/ASA), AHA/ASA Mid-Atlantic Affiliate, NC Office of Citizen Services, NC Division of Aging and Adult Services, local Area Agencies on Aging, NC Agricultural Extension Program, NC System of Community Colleges, National Consortium of Stroke Coordinators, National Family Caregivers Association, the National Alliance for Caregiving, the Family Caregiver Alliance, NC Chapter of the American Case Management Association, the NC Chapter of the National Association of Social Workers, NC Council of Churches and other faith-based institutions, NC Department of Commerce and local businesses, senior centers, public libraries, universities, and the media. The cost of creating and evaluating educational resources would be the initial cost. In addition, the stroke resource center would require funding for the center's infrastructure and staff to support it. Other costs to consider would be the costs assumed by agencies that may lose and/or gain a particular segment of the market for their resources as a result of supporting the center's creation.

3. Acknowledge the importance of addressing caregiver health, and design interventions to deal with this issue.

National, state, and local agencies should collaborate on strategies to increase public awareness of the importance of addressing caregiver health. The Recovery/Transitions of Care Workgroup should cooperate with the Prevention/Public Awareness Work Group to identify stakeholders to increase awareness of this issue. In addition, interventions should be created that include detailed caregiver assessments and individualized caregiver education on secondary stroke prevention (risk factor management), medication compliance, depression, social isolation, and coping strategies that emphasize the caregiver's understanding of stroke survivors' learning capabilities. Interventions should be developed in collaboration with agencies such as the NC Hospital Association; NC Medical Society; NC Division of Aging and Adult Services' Chronic Disease Self-Management Program; NC Division of Public Health; local health departments; NC Division of Mental Health, Substance Abuse, and Developmental Disabilities; NC

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Division of Health Service Regulation; NC Council of Churches and other faith-based institutions; NC Alliance for Healthy Communities; Community Care of NC; NC Community Health Center Association; NC Association of Free Clinics; NC Chapter of the National Association of Social Workers; National Stroke Association; NC Stroke Association; American Heart Association/American Stroke Association; AHA/ASA Mid-Atlantic Affiliate; NC Department of Commerce and local businesses; home health agencies; senior centers; public libraries; universities; and the media. The main cost associated with this strategy would be the funding needed to initiate the public awareness campaign, caregiver assessments, interventions, and referral pathways.

- 4. Enhance stroke recovery care coordination by providing consistent patient information to health care providers at various points of care which would include the providers' ability to share patients' medical records across a variety of care environments.**

Upon identifying these points of care by examining national and state algorithms such as Dr. Vu Nguyen's Healthcare Interface, state and local resources should be surveyed in order to discover potential ways to link survivors, caregivers, and families with appropriate state and local programs across NC. This linkage should take into account the growing number of young stroke survivors across NC that face unique social challenges. Partner agencies are the same as those in Recommendation 3. In the end, there would be funding needed to create a state transitions of care database along with the potential that additional funding would be needed to improve the linkage of acute care and community facilities with state programs.

- 5. Telehealth should be incorporated into stroke recovery transitions of care.** Telehealth is the delivery of health-related services and information via telecommunications technologies. Telehealth encompasses preventive, promotive and therapeutic aspects of health care. Telehealth activities have demonstrated the removal of time and distance barriers for the delivery of health care services or related health care activities which potentially can improve quality and reduce health care costs. Telerehabilitation is the judicious application of telehealth technology to services long provided by rehabilitation professionals. Research and reports to date confirm that telerehabilitation can significantly overcome barriers to access for needed services caused by distance, unavailability of specialists and/or subspecialists, and impaired mobility.

Introduction of a bill in the North Carolina Legislature is recommended, within the next five years, mandating that health insurers, health care subscription plans and health maintenance organizations (HMO) fully cover the cost of all telerehabilitation services that are routinely reimbursed in a typical rehabilitation provider in-person intervention. Also, the development of language in North Carolina state licensure statutes supporting providers' adoption of telerehabilitation for all rehabilitation service providers, much like the language established by the

North Carolina Board of Examiners for Speech and Language Pathologists and Audiologists is recommended.

The Recovery/Transitions of Care Work Group will collaborate with the Telemedicine Work Group on this recommendation. To that end, it is recommended that support be requested from licensure boards to move this initiative forward. Furthermore, it is recommended that support be sought from research institutions in NC in contributing to the evidence that telerehabilitation provides a quality service for the citizens of NC and helps to reduce overall health care costs. These institutions would be asked to show that telerehabilitation provides the same quality of service that a person would receive from a provider in person. There will be costs associated with telerehabilitation research as well as advocacy/lobbying for a bill and state licensure.

- 6. Broader telehealth strategies adoption is recommended. Existing telehealth networks should be examined in order to identify opportunities for them to expand their value to members and the community by connecting rural and remote providers to the Internet across existing infrastructures.**

While telehealth and health information technology (IT) have historically operated on relatively separate tracks with limited crossover, it is recognized that their goals and activities are complementary and synergistic. This is especially true of the broader systems-based approach needed to deliver effective and efficient care in NC. For example, telehealth networks provide the infrastructure that enables Internet access and drives health information exchange (HIE) in areas where commercial broadband is lacking or cost prohibitive. Likewise, health IT offers enabling components for remote care and provides complementary tools and systems, such as electronic health records (EHRs) and digital data/information sharing (Thielst, 2010). Individuals who serve on the North Carolina Health Information Exchange (NCHIE) Board and the North Carolina Healthcare Information & Communications Alliance, Inc. (NCHICA) should be identified. These individuals would work to ensure interoperability and a blended vision for both health IT and telehealth. It is desired and anticipated that these partners would become champions for efforts to link telehealth, which would include telestroke, telerehabilitation, and chronic disease prevention/management education via similar technologies, with that of the advancing health information technology and electronic health record infrastructure. Initial costs of this strategy appear to be non-monetary, given that the first step would involve connecting key stakeholders. However, there may be costs associated with the time needed on behalf of all stakeholders in order to reach consensus about individual and organizational visions of the future of telehealth in NC. Potentially, monetary costs would arise in the long term as possible changes to the developing state health information technology infrastructure are discussed.

C. Reimbursement

When transitioning stroke patients from one level of care to another, the goal should be to obtain the right level of care for the patient at the time he/she most needs it. In looking at

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reimbursement issues related to the transitioning of stroke patients, one would expect that reimbursement would reflect optimal care as well. However, reimbursement issues often pose a barrier to stroke patients being transitioned appropriately. Stroke patients are at high risk for bouncing back, with 20% of acute stroke patients experiencing at least one bounce-back and 16% experiencing two or more bounce-backs within 30 days of hospital discharge (Kind et. al., 2008). Improper transitions can be costly to not only the patient and his/her family but also can lead to readmissions. To complicate this issue further, the new health care reform law will have unforeseen effects on the treatment and rehabilitation of stroke patients and on reimbursement.

In order to successfully implement the recovery/transitions of care recommendations, the Stroke Advisory Council (SAC) needs to recognize the costs of inappropriate care transitions. These include not only costs related to poor outcomes but costs to the health care system as well. In NC, there are an estimated 37,763 Medicaid recipients. Total annual cost to Medicaid for stroke treatment is \$279,781,000 or \$7,410 per Medicaid beneficiary (Chronic Disease Cost Calculator). To completely understand reimbursement issues in relation to rehabilitation, obtaining the most useful, accurate and current data will be critical.

To develop effective stroke systems of care, three initiatives are recommended:

- 1. Collect data from all willing and available sources on discharge destinations, length-of-stay, readmission rates, readmission primary diagnoses, availability of beds by payor, and information on patients who have maximized their recovery dollars who still require treatment. It is recommended that the proposed Recovery Phase Registry could be designed to track these data.**
- 2. Include experts, when making decisions, who understand reimbursement at each level of care, since different payment structures and regulations govern each.**

Partnerships with the Division of Medical Assistance, Department of Insurance, Blue Cross and Blue Shield, and Carolinas Centers for Medical Excellence should be developed and maintained. The Reimbursement Sub Work Group should also seek information from experts who can speak to how the new health care reform legislation is likely to affect reimbursement for stroke patients. Utilizing such specialty knowledge, along with the appropriate data, will allow for the development of model pathways for patient flow with the goal of optimizing outpatient therapy.

- 3. Identify opportunities for funding demonstration projects or other similar programs.**

There are several existing recommendations for demonstration projects, including partnering with health care systems on establishing model pathways for transitions. This would require the development of a document which could be used as a resource across

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the state. In difficult economic times, acquiring funding would be essential to successful implementation. Locating outside funding would provide momentum for the NC stroke system of care and might provide other unanticipated benefits as well.

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APPENDICES

Stroke Advisory Council Stroke Rehabilitation Work Group

Stroke Advisory Council/Association of State and Territorial Health Officials Stroke System of Care Recovery/Transitions of Care Work Group

NC CARF Accredited Facilities with a Stroke Specialty Program

NQF Preferred Practices and Performance Measures for Measuring and Reporting Care Coordination