

The NorthEast Cerebrovascular Consortium

54C Wayside Avenue • West Springfield, MA 01089 • (508) 656-2082 • www.thenecc.org

The NECC Subacute Care and Secondary Prevention Project Abstract

The NECC Recommendations:

Up-to-date educational resources and “best practices” for hospital-based stroke prevention and education should be gathered from hospitals across The NECC Region. This material should be made freely available in a forum that supports interactive dialogue among individuals involved in stroke care.

Discharge packets should include patient and caregiver education materials covering the 5 areas specified in the harmonized consensus measure set (AHA, CDC, TJC) and systems established to ensure that all patients have an opportunity for face-to-face discussion during the inpatient admission.

Goal:

The goal for the sub acute and secondary prevention working group is create a pilot project where a minimum of 10 acute care hospitals will survey of patients at discharge and again within sixty days or at the first follow up visit after discharge, to assess the efficacy of education efforts. The results of this survey will be utilized to develop an implementation strategy to address any gaps in how stroke education is delivered and the type of materials used in discharge education packets.

Intervention:

Each participating hospital will need to identify one or more individuals who will be responsible for data collection. We anticipate that these individuals may be stroke coordinators, designated nurses, physical, occupational, or speech therapists, stroke fellows or other physicians, or other members of the stroke team. We will strive to select a representative sample of hospitals in The NECC region, but recognize that the pilot nature of this project may not provide a fully balanced sample. Our goal is to have 10-15% of annual acute stroke admissions within the participating institutions included in this data collection effort during the six-month data collection period, excluding those who expire during the hospital stay. Data entry will be a paper survey format that hospital staff can either submit to The NECC for data entry or enter directly into an online Zoomerang Survey site. Each participating hospital will be asked to survey six months of stroke discharge patients with a goal of having a minimum of 100 surveys completed in aggregate for the pilot project. The pilot study will begin January 1, 2012 and conclude June 30, 2012.

Hospital staff will conduct an initial survey at discharge and a second survey at the follow up appointment or by phone not less than 14 days but within sixty days of discharge. Patients will include those with ischemic stroke but not hemorrhagic stroke or TIA.

Outcomes:

This survey will inform subsequent intervention pilot projects to better address the needs of stroke patients in discharge education materials and delivery of the information.

Methodology for measurement of outcomes:

The method of delivery of education as well as the content of the education for stroke patients and their caregivers upon discharge will be evaluated and the survey will help to determine any gaps that need to be addressed through the pilot project.

Tools available:

This project will use a survey that has been reviewed by the sub acute work group members and created in a paper collection format. Additional resources will include an informational postcard about the project for the patient and caregiver to be distributed at discharge. If hospitals have resource limitations that prevent them from entering the paper versions of the survey into an online Zoomerang tool The NECC will support them by completing the data entry.

Project Narrative:

Multiple factors influence the retention of education and the ability to receive education for patients who have recently suffered an acute stroke. In this project, we are hoping to gain better insight into relative contributions of these various factors. The insights gained can be used for subsequent training of hospital staff on how to deliver their hospital discharge education information to best meet the needs of the patient and the caregiver.

Limitations:

This project does not take into consideration all of the factors that may influence patients recall of patient education delivered upon discharge. Also, participation in this project is voluntary and data will be collected from a small number of hospitals in the NECC region; thus, it may not provide a representative sample.

IRB Issues:

Each participating hospital will work within its own IRB process to obtain approval. As a questionnaire-based study of educational methods, this study would normally be exempt from IRB review. Informed consent will be obtained at discharge as well as at the beginning of the online survey and follow up phone call. Data analysis for research/publication purposes will be performed at a coordinating center, where IRB review will be performed.

Timeline:

Baseline data from the participating pilot hospitals will be collected for a 6-month period from January 1, 2012 through June 30, 2012.

Potential Venue for Presenting Results:

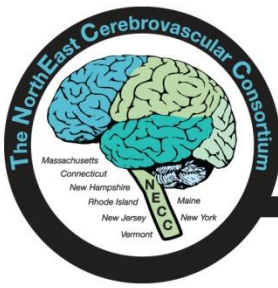
The NECC 2012 Summit Poster Presentation session or the 2013 International Stroke Conference.

Questions: Questions regarding this project can be directed to:

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The NECC Sub Acute Care and Secondary Prevention Project

Stroke Survivor Education Survey

Manual of Operations

Introduction

A minimum of 10-20 acute care hospitals will survey patients with a recent cerebral infarction to assess how patients receive education following their stroke. Each participating site will be expected to enroll 10-15% of their annual acute stroke admissions with a minimum of 5-10 participants. This work is viewed as a *pilot project* that explores one aspect of stroke education, from the perspective of the *patient*, around the *acute* inpatient and *early* outpatient phases of care. Hopefully this work will foster future strategies to address gaps in stroke education across the spectrum of care for both patients and caregivers.

Eligibility Procedure

The study population includes both men and women with a recent hospitalization for ischemic stroke. Sites will be asked to survey these patients via concurrent review for a six-month period in order to select participants who meet eligibility criteria. The survey will be completed by persons who have experienced stroke, not family members or caregivers.

The Inclusion Criteria Include

- Persons 18 years of age or older hospitalized with a primary diagnosis of acute ischemic stroke
- An ability and willingness to provide informed consent and complete the surveys

The Exclusion Criteria Include:

- Persons with a diagnosis of hemorrhagic stroke
- Persons with discharge diagnosis of TIA

Enrollment Procedure

Informed Consent will be obtained prior to the patient's participation in the study anytime during the hospitalization including the day of discharge if mandated by the site's institutional IRB.

A survey will be administered as close to the time of discharge as is feasible and again at the start of the first clinic follow-up visit that occurs within 60 days. See Appendix A

The survey will consist of 19 questions including demographic information as well as questions about the participant's primary language. The participant will be asked whether or not they received stroke

educational materials and the exact mechanism of delivery. A simplified 4-point Likert scale will capture the participant's perception of understanding of education provided. Responses to questions regarding stroke warning signs, risk factors and the need to call 911 will be captured in free text format. Additional questions are aimed at assessing the patient's knowledge of prescribed medications and follow up appointments. The participant will be provided an opportunity to select topics related to stroke that require additional education. Staff at each site are encouraged to clarify questions as needed but not influence the responses otherwise. Staff are asked to record basic demographic data and the actual medications prescribed and provide suggestions regarding the logistics of administering the survey that will be used for future optimization of the survey.

Data Collection

Data may be collected in a variety of ways. All collection methods listed below are acceptable

- Initial survey collected on paper by stroke survivor at time of discharge with study staff entering data via Zoomerang (or paper form submitted to The NECC for data entry)
- Follow up survey collected on paper by stroke survivor at time of follow up visit or within 60 days of discharge with study staff entering data via Zoomerang (or paper form submitted to The NECC for data entry)

A standardized approach to data submission will be adopted. Survey results are to be submitted within 10 days of hospital discharge or follow up visit/telephone call. Only the patient is allowed to complete the survey upon discharge and at 60 days.

Sites will need to keep a record of the assigned facility code and patient code for each survey completed to be able to code the follow up survey appropriately. This system will vary by institution.

Analysis

The following variables will be analyzed:

- Demographics (percentage in each age category by decade, percentage with each primary language, percentage in each mode of admission).
- "Satisfaction" with education will be assessed by the questions using the 4-point Likert scale responses (total score for each patient and responses for each question will be calculated).
- Accuracy of knowledge about medications prescribed will be assessed and compared across type of medication.
- Follow-up appointments made with each type of provider and number of patients stating they are not aware or do not have any appointments.
- For each patient, the following will be calculated: the number of correct responses given for stroke warning signs, whether a correct action was listed when experiencing a warning sign, whether a risk factor was correctly explained and if 2 were listed.

- The number of respondents requesting additional information for each specified area and additional areas provided in an open-ended question will be collected.
- Suggestions for improving the survey provided by patients and site staff will be recorded.
- Responses obtained at discharge will be compared to those obtained at the clinic follow-up visit.
- Site staff will be asked to record number of ischemic stroke cases hospitalized during period of survey administration and reasons for not completing survey in individual cases not surveyed (including patient ineligible because not able to understand or cooperate, patient refused, patient missed).
- Number of cases “lost” for the follow-up visit will be reported.

Code Assignments

Individual patient and facility codes will be assigned in the following manner:

- Facilities will be provided codes as they enroll in the pilot project. The NECC will assign the code 01 to the first center to enroll in the pilot (submit a signed Participation Form) Additional facilities will be coded sequentially as they enroll by submitting their signed Participation Form) i.e., 01, 02, 03, 04 etc.
- The first patient enrolled at a site will begin the code assignment by assuming the number 01. Additional patients will be coded sequentially, i.e., 02, 03, 04 etc.

Example: The *first* site to enroll would be 01; therefore their first patient will be coded 0101. The next patient enrolled at that site will be 0102, etc.

Appendix A

Stroke Survivor Survey Contact Timetable

	Hospital Admission Day 1	Hospital Day 2-to Discharge	Hospital Discharge	Within 60 days or 1 st follow up appointment
Review All Ischemic Stroke Admissions and log those excluded	X			
Provide Stroke Education as usual	X [^]	X [^]	X [^]	
Obtain Informed Consent	X [*]	X [*]	X [*]	
Complete Survey			X	
Schedule follow up appointment or telephone contact within 60 days			X	
Complete Follow up Survey				X

X[^] Stroke education provided throughout hospitalization

X^{*} Informed consent obtained once anytime during hospitalization

Procedure for Missed Appointment or Telephone Contact

If the researcher is unable to make contact with the participant via telephone or by follow up visit, a letter will be sent with a request to contact the study staff. If this fails, contact with the next of kin will be attempted. If contact is not reestablished, the survey will be considered *missed*.

Stroke Survivor Survey Completed at Discharge

The purpose of this survey is to look at how we educate stroke patients. In this survey “stroke education” means anything that was done to provide you with information about stroke or skills to cope with stroke complications. This includes pamphlets, books, other written materials, internet content, video, television programs, and face-to-face discussion.

Please answer these questions honestly to help us improve. If you have a very important issue or question that needs to be addressed today, please tell your nurse or other provider before you leave (not just in this survey).

Please answer the questions as they relate to the time you were in the hospital.

1. Did anyone teach you about stroke? (including verbal information, pamphlets, other written materials, video)

- Yes
 No (go to question 8)

2. Was the teaching in your primary language?

- Yes
 No

3. How was the stroke education material presented to you?
Check all that apply

- Written
 Talked through
 Video
 Other (please describe): _____

4. If English is not your primary language, was a translator involved in your stroke education?

- Not applicable, I speak and understand English
 Yes
 No

5. If a translator was used to provide stroke education, were they a family member/friend or someone provided by the hospital?

- Not applicable, I did not use a translator
 Family member/friend
 Someone provided by the hospital

6. How well have your questions about stroke been answered?

- Not at all
- Not very well
- Somewhat well
- Very well

7. How well was the cause of your stroke explained?

- Not at all
- Not very well
- Somewhat well
- Very well

8. How well do you understand the *reason for* your stroke-related medications?

- Not at all
- Not very well
- Somewhat well
- Very well

9. How well do you understand the instructions for taking your stroke-related medications?

- Not at all
- Not very well
- Somewhat well
- Very well

10. Which of these medications are being prescribed for you at the time you complete this survey?
Check all that apply

- Anticoagulant medication such as warfarin (Coumadin), Lovenox, heparin, dabigatran (Pradaxa) or Rivaroxaban (Xarelto)
- Antiplatelet medication such as aspirin, clopidogrel (Plavix), dipyridamole/aspirin (Aggrenox)
- Cholesterol-lowering medication including "statins"
- Blood pressure lowering medication
- Smoking cessation medications such as wellbutrin (Zyban), varenicline (Chantix), nicotine replacement
- I am not sure if I am being prescribed any of these medications

11. How well do you understand the purpose of your follow-up appointments?

- Not at all
- Not very well
- Somewhat well
- Very well

12. How well do you understand the details (when/where/with whom) of your follow-up appointments?

- Not at all
- Not very well
- Somewhat well
- Very well

13. With whom do you have follow up appointments scheduled at the time of discharge?
Check all that apply

- Neurologist/Neurology Nurse Practitioner
- Cardiologist
- Endocrinologist
- Outpatient Rehabilitation therapist
- Dietician
- Smoking Cessation Councilor
- Primary Care Provider
- I do not know if I have any follow-up appointments
- I do not have any follow-up appointments
- Other, please specify: _____

14. Please list as many of the stroke warning signs that you know?

15. What would you do if you were experiencing a stroke warning sign?

16. Do you know what a stroke risk factor is and can you name two?

17. What should we spend more time teaching patients about?

Check all that apply

- The warning signs of stroke
- Important lifestyle changes after stroke (for example, diet and exercise)
- Medications to prevent stroke
- Treatments of depression, fatigue, pain, incontinence
- Where to find books or written materials about stroke
- Information on support groups or organizations that can help
- Other, (please specify):

18. Do you have any suggestions for how we could improve this survey or improve the stroke education we provide?

See next page for Facility Use

INTERNAL FACILITY USE ONLY:

1. Please answer the following:

Facility Code/Patient Code: _____

Date of HOSPITAL ADMISSION: _____

Date of DISCHARGE Survey: _____

2. What is the patient's age?

- Under 30 years
- 30 - 40
- 40 - 50
- 50 - 60
- 60 - 70
- Older than 70

3. What is the patient's primary language?

- English
- Spanish
- Other (please specify):

4. At the time this survey was completed, the patient was prescribed:

Check all that apply

- Anticoagulant medication including Warfarin (Coumadin), Lovenox, heparin, Dabigatran (Pradaxa) or Rivaroxaban (Xarelto)
- Antiplatelet medication including aspirin, clopidogrel (Plavix), dipyridamole/aspirin (Aggrenox)
- Cholesterol-lowering medication including statins
- Blood pressure lowering medication
- Smoking cessation medications such as wellbutrin (Zyban), varenicline (Chantix), nicotine replacement

Stroke Survivor Survey Completed Within 60 Days of Discharge

The purpose of this survey is to look at how we educate stroke patients. In this survey “stroke education” means anything that was done to provide you with information about stroke or skills to cope with stroke complications. This includes pamphlets, books, other written materials, internet content, video, television programs, and face-to-face discussion.

Please answer these questions honestly to help us improve. If you have a very important issue or question that needs to be addressed today, please tell your nurse or other provider before you leave (not just in this survey).

Please answer the questions as they relate to the time when you were in the hospital unless otherwise specified.

1. Did anyone teach you about stroke? (including verbal information, pamphlets, other written materials, video)

- Yes
 No (go to question 8)

2. Was the teaching in your primary language?

- Yes
 No

3. How was the stroke education material presented to you?
Check all that apply

- Written
 Talked through
 Video
 Other (please describe): _____

4. If English is not your primary language, was a translator involved in your stroke education?

- Not applicable, I speak and understand English
 Yes
 No

5. If a translator was used to provide stroke education, were they a family member/friend or someone provided by the hospital?

- Not applicable, I did not use a translator
 Family member/friend
 Someone provided by the hospital

6. How well were your questions about stroke answered?

- Not at all
- Not very well
- Somewhat well
- Very well

7. How well was the cause of your stroke explained?

- Not at all
- Not very well
- Somewhat well
- Very well

8. How well do you understand the *reason for* your CURRENT stroke-related medications?

- Not at all
- Not very well
- Somewhat well
- Very well

9. How well do you understand the instructions for taking your CURRENT stroke-related medications?

- Not at all
- Not very well
- Somewhat well
- Very well

10. Which of these medications ARE NOW being prescribed for you?

Check all that apply

- Anticoagulant medication such as warfarin (Coumadin), Lovenox, heparin, dabigatran (Pradaxa) or Rivaroxaban (Xarelto)
- Antiplatelet medication such as aspirin, clopidogrel (Plavix), dipyridamole/aspirin (Aggrenox)
- Cholesterol-lowering medication including "statins"
- Blood pressure lowering medication
- Smoking cessation medications including wellbutrin (Zyban), varenicline (Chantix), nicotine replacement
- I am not sure if I am being prescribed any of these medications

11. Of the medications that ARE BEING prescribed, which ones ARE YOU CURRENTLY taking?

Check all that apply

- Anticoagulant medication such as warfarin (Coumadin), Lovenox, heparin, dabigatran (Pradaxa)
- Antiplatelet medication such as aspirin, clopidogrel (Plavix), dipyridamole/aspirin (Aggrenox)

- Cholesterol-lowering medication including “statins”
- Blood pressure lowering medication
- Smoking cessation medications including wellbutrin (Zyban), varenicline (Chantix), nicotine replacement
- I am not sure if I am being prescribed any of these medications
- I am not taking the prescribed medications

12. How well do you understand the purpose of your future follow-up appointments?

- Not at all
- Not very well
- Somewhat well
- Very well

13. How well do you understand the details (when/where/with whom) of your future follow-up appointments?

- Not at all
- Not very well
- Somewhat well
- Very well

14. With whom do you have appointments scheduled in the future?

Check all that apply

- Neurologist/Neurology Nurse Practitioner
- Cardiologist
- Endocrinologist
- Outpatient Rehabilitation therapist
- Dietician
- Smoking Cessation Councilor
- Primary Care Provider
- I do not know if I have any follow-up appointments
- I do not have any follow-up appointments
- Other, please specify: _____

15. Please list as many of the stroke warning signs that you know?

16. What would you do if you were experiencing a stroke warning sign?

17. Do you know what a stroke risk factor is and can you name two?

18. What should we spend more time teaching patients about?

Check all that apply

- The warning signs of stroke
- Important lifestyle changes after stroke (for example, diet and exercise)
- Medications to prevent stroke
- Treatments of depression, fatigue, pain, incontinence
- Where to find books or written materials about stroke
- Information on support groups or organizations that can help
- Other, (please specify):

19. Do you have any suggestions for how we could improve this survey or improve the stroke education we provide?

INTERNAL FACILITY USE ONLY:

1. Please answer the following:

Facility Code/Patient Code: _____

Date of HOSPITAL DISCHARGE: _____

Date of FOLLOW-UP Survey: _____

2. What is the patient's age?

- Under 30 years
- 30 - 40
- 40 - 50
- 50 - 60
- 60 - 70
- Older than 70

3. What is the patient's primary language?

- English
- Spanish
- Other (please specify):

4. At the time this survey was completed, the patient was prescribed:

Check all that apply

- Anticoagulant medication including Warfarin (Coumadin), Lovenox, heparin, Dabigatran (Pradaxa) or Rivaroxaban (Xarelto)
- Antiplatelet medication including aspirin, clopidogrel (Plavix), dipyridamole/aspirin (Aggrenox)
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