Development of a Neuroscience Research Registry

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There is little data on the long-term health outcomes of patients with neurological conditions treated at long-term acute care specialty hospitals. In order to learn more about these patients and the most effective way to care for them, Bethesda Hospital in St. Paul created a neuroscience research registry. The registry’s target population is patients with complex neurological conditions such as aneurysm or intracranial bleed, stroke, seizures, delirium and confusion and traumatic brain injury. This article describes the development of the registry, which has enrolled 857 patients thus far, and what is being learned about those patients.

Patients cared for at Bethesda Hospital, a long-term acute care specialty hospital (LTACH) in St. Paul, include those with complex neurological conditions. In most cases, LTACH patients have survived an initial medical event but are still suffering from persistent emotional, social and financial effects of it. Some may be ventilator-dependent and experiencing multi-organ system failure, extreme weakness and cognitive dysfunction. Most arrive from the intensive care units of short-term acute care hospitals (STACHs). Their average length of stay at Bethesda is 25 days.

Currently, there is little data on the long-term health outcomes (five-plus years) of these patients; in addition, there is limited clinical evidence on how best to care for them once they leave the ICU. Published studies have had a limited impact on practice because of small scale, lack of long-term follow-up and insufficient funding. Thus, we have had little insight into how to help patients achieve optimal outcomes cost-effectively.

About three years ago, Bethesda Hospital decided to build a neuroscience research registry in order to gather data on the care provided to this vulnerable patient population and the costs associated with that care. The goal is to identify which care pathways and protocols are most strongly associated with successful long-term outcomes. The hope is that better understanding can lead to better, more appropriate care and services for this patient population. The data collected through the registry will be shared within HealthEast Care System (Bethesda’s parent organization), among its community partners and with the broader medical community.

Specifically, the information will be used to help promote evidence-based, cost-effective patient management; address the lack of standardized management of this patient population; identify new diagnostic and therapeutic interventions; control overutilization; help families make more informed care decisions; and improve outcomes. Our overarching goal is to redefine the standard of care provided to LTACH patients with neurological conditions. We are not aware of any other data collection project of this magnitude focused on this patient population in the United States.

About the Registry

The registry’s target population is patients with complex neurological conditions such as aneurysm or intracranial bleed, stroke, seizures, delirium and confusion and traumatic brain injury. These are the patients with the most challenging care needs, as some are also ventilator-dependent and have other chronic medical conditions or complex wounds, are transplant recipients, or require multi-specialty support from infectious disease, hematology, oncology, nephrology, cardiology or endocrinology. They have been admitted to Bethesda Hos-
hospital after being in an ICU for two weeks or longer and are unable to ambulate independently.

The registry uses REDCap tools to capture demographic, physiological, treatment, cost and long-term follow-up data (up to 10 years post-discharge) from the electronic medical records of participating patients. Data are also gathered through questionnaires filled out by patients. Informed consent is obtained from all registry participants and/or from a legally authorized representative.

The registry tracks
- Demographic information including the patient’s name, date of birth, medical record number, address, phone number, race, education level
- Significant medical history including history of stroke, neuropathy, myopathy, COPD, Parkinson’s disease and congestive heart failure; smoking status; and
- Diagnosis and treatment data including results of laboratory tests and radiographic assessments, medication use, number and type of interventional procedures performed, and blood pressure, temperature and respiratory status
- Results of physical, cognitive and neuropsychological assessments such as the Glasgow Coma Scale, Barthel Index, Modified Rankin and Fisher Grade scores
- Indicators of long-term outcome including discharge disposition; survival time; functional status at three, six and 12 months post-discharge and yearly thereafter
- Employment status (or activity level if retired)
- How frequently the patient sees family or friends
- Number of times the patient has returned to a hospital for an unscheduled visit.

**Preliminary Data**

Since November of 2011, the registry has enrolled 857 patients, with an average of 285 new patients enrolled each year. To date, 68% of registry patients have completed their one-year follow-up. None of these individuals has received monetary incentive for participation.

Demographic information is shown in the Figure and Table 1. A preliminary analysis suggests that participant demographics closely mirror the hospital’s overall inpatient population. Registry patients are discharged from Bethesda Hospital primarily to transitional care units (29.7%), short-term acute care hospitals (25.2%) and home (20.6%) (Table 2).

Registry participants between the ages of 56 and 65 years represent the highest proportion (28.3%) of patients discharged to a STACH. The reasons patients return to STACHs vary but include planned second surgical procedures (eg, a second intracranial procedure necessary for the patient’s recovery). A majority of these patients return to Bethesda at some point in time. Two-thirds (66.5%) of discharged patients have indicated at their three-month follow-up assessment that they have not experienced an unplanned STACH visit since leaving the facility (Table 3). An in-depth analysis of complication rates, deaths and STACH re-admissions is underway to clarify the causes of re-admissions, identify trends and reduce complications. Data review and analysis should be completed within the next six to 12 months.

Additional information on procedures, therapies and follow-up assessments will be collected and used for research on such...
things as the cost of care during the acute rehabilitation phase and the effects of psychotropic medication use on short- and long-term recovery.

Conclusion
We hope the knowledge generated from this registry will be used to advance medical science and to guide local and national policy makers, including CMS and MedPAC, in future health care reform efforts. Thus far, registry data have been shared with representatives from Medica, the University of Minnesota, national LTACH groups and a delegation of hospital CEOs from China. Our goal is to publish or present on this work within the next 12 months. To date, we are not aware of any changes in care related to this data.

Our initial goal has been to raise awareness of the registry and to populate it with patient information. Now that we are successfully accomplishing that, we can begin looking at the data and sharing what we are learning with others. MM

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TABLE 3

| STACH Visits Three Months following Discharge from Bethesda | 64% | 19% | 9% | 5% | 1% | 1% |

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REFERENCES