

HEART MURMURS



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Children's Hospital Boston

THE NIGHTINGALE METRICS

FROM FLORENCE NIGHTINGALE TO THE CARDIOVASCULAR PROGRAM

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This is a unique time in nursing. Consistent with the national agenda for patient safety, hospitals are focusing on quality, efficiency, and outcome measurement. Data are being generated that link nursing care to patient outcomes, which allows nurses to understand and describe what they do to influence the patient's experience and what patients can expect to receive from nurses.

The potential for measurement in nursing is limitless. But to be meaningful, the data should bring to life what is usually invisible in nursing, rather than what is only visible when it is absent. For example, invisible are the large numbers of patients at risk for pressure ulcers who never develop them because of preventative nursing care; visible are the few patients who develop the ulcers. And who else but Florence Nightingale is noted for calling attention to the importance of the fundamentals of nursing care? Her vision reflected what nursing has to do "... to put the patient in the best condition for nature to act upon him." Nurses provide care and an environment that sustains and supports the patient's and family's capacity to heal. The nursing staff of the Cardiovascular Program have identified what they believe to be important aspects of care for their patients and families, and initiated a Nightingale Metrics Project to measure outcomes and drive improvement in practices.

DEVELOPING NURSING CARE INDICATORS

In the Children's Cardiovascular Program, a nurse scientist facilitated the process by meeting with staff from each clinical area and focusing discussions on what nursing care they believed was important to the outcomes of their patients. Traditionally, nurses have used exemplars to articulate their individual contributions to patient outcomes, but these sessions helped the unit-based team of nurses articulate their collective contributions.

The initial nursing care indicators were selected based on established standards of care and/or evidence to support the practice. Also important was the ability to measure and audit. To begin, numerous indicators were pilot-tested using a three-month rapid-cycle measurement process, which

resulted in a set of unit-based core Nightingale metrics that staff nurses identified as important aspects of care unique to their patient/family population. From this baseline, data are collected every three months, providing staff enough time to implement process improvements and see change. If the results show the need for immediate improvement, monthly audits are instituted. Also, if the results show three consecutive audits at benchmark, indicators are retired to a yearly spot-check.

Selected Nightingale metrics from different clinical nursing areas are shown in Table 1 (see page 4). Data are collected quarterly on a random day through chart audits and/or direct observation at the time of data collection. The time interval for chart audits is limited to the previous seven days. The Nightingale metrics also include nurse recognition and response to rapidly evolving clinical situations. For example, nurses in the inpatient cardiology unit are pioneering a "time-to-critical-intervention" indicator, auditing the principal reason for transfer to the Cardiac Intensive Care Unit (CICU) and the time interval from the patient's first symptom of distress in the inpatient unit to patient transfer. Some Nightingale indicators cut across all patient-care areas in the Cardiovascular Program. Items that are common to more than one unit are defined in the same way so that cross-unit comparison and learning can occur.

CONTINUITY OF CARE INDEX

Models of care delivery should limit the number of different nurses assigned to care for each patient. While the importance of nurses "knowing" their patient has been well described, in our experience it is equally important for families to "know" their nurse. Decreasing the number of nurses exposed to the family increases the opportunity for family members to come to know their nurses and, it is hoped, contributes to their ability to develop a trusting relationship. Providing continuity in care may also unburden parents from feeling that they have to be hypervigilant when an unfamiliar nurse is at their child's bedside.

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FONTAN PROCEDURE

RISK FOR THROMBOEMBOLIC COMPLICATIONS

CATHERINE ALLEN, MD, ASSISTANT IN CARDIOLOGY, AND
KIRSTEN ODEGARD, MD, SENIOR ASSOCIATE IN ANESTHESIA

Since the original Fontan operation was described nearly 40 years ago, several modifications have been undertaken that have improved early and late morbidity, and mortality. Nevertheless, complications that include ventricular dysfunction, thromboembolic events, dysrhythmias, and protein-losing enteropathy may compromise longer-term function and outcome. Thromboembolic complications, reported in as many as 15–33% of patients who have undergone the Fontan operation, are an important cause of morbidity and mortality.

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REPORTING THROMBOEMBOLIC EVENTS

Thromboembolic events may occur in the immediate postoperative period, when patients are in low output state, with increased pulmonary vascular resistance resulting in decreased flow through the Fontan pathway, or they may be a late complication. Factors that may predispose to thrombus formation include stasis of blood flow through the Fontan pathway and pulmonary circulation, presence of atrial suture lines and distention, increased venous pressure, atrial arrhythmias, ventricular dysfunction, and a hypercoagulable state secondary to low levels of the naturally occurring anticoagulants protein C and protein S. In addition, recent work from our group and others has identified a large spectrum of abnormalities in both pro- and anticoagulant proteins following the Fontan procedure, including factors II, V, VII, X, plasminogen, and antithrombin III.

Of note, we have described elevation of Factor VIII levels following the Fontan procedure as a possible predisposing factor to thrombus formation. In addition, we have demonstrated that both pro- and anticoagulant factor level abnormalities occur earlier in the course of staged surgical palliation for patients with single ventricle CHD, i.e., preceding the Fontan operation and physiology, and we have speculated that a “functional balance” also exists in these patients that prevents thrombophilia. We have recently completed a prospective, longitudinal study evaluating changes in coagulation and hemodynamic profiles in patients with

hypoplastic left heart syndrome from Stage I palliation through completion of the Fontan operation. This study has shown that Factor VIII was significantly higher post-Fontan compared to pre-Fontan; 44% had a factor VIII value >160% but there were no specific hemodynamic variables predictive of coagulation abnormalities. The large increase in factor VIII post-Fontan procedure appears to be an acquired defect, the cause of which remains to be determined. Elevated factor VIII level is an independent risk factor for thrombosis in adults, and could help determine a subset of Fontan patients who would benefit from long-term anticoagulation.

PREVENTION OF CLOT FORMATION

Although our observations regarding the changes in Factor VIII levels following the Fontan procedure are promising in terms of determining risk factors for thrombosis, several studies have suggested that thrombus formation and coagulation profile abnormalities are independent of hemodynamic variables, presence of atrial arrhythmias, and type of Fontan connection. These observations indicate that hemodynamics, anatomy, or coagulant factor changes alone do not explain the propensity toward clot formation. One hypothesis is that the occurrence of polymorphisms in specific coagulation proteins, such as those known to increase the risk of deep venous thrombosis or pulmonary embolism (e.g., Factor V Leiden, PT20210, etc.), are important risk factors for thromboembolism in Fontan patients. The combination of

multiple risk factors, including elevation of Factor VIII levels, the presence of thrombophilic mutations, and hemodynamic factors may therefore lead to increased propensity for thrombus formation.

TARGETED THERAPY, IMPROVED OUTCOMES

With our large database we are now in the process of conducting a longitudinal study to look for associations between particular clotting factor abnormalities and thromboembolic complications over time. Additionally, we can now undertake screening for genetic polymorphisms in coagulation proteins to try to begin to unravel the complex, multifactorial nature of this important clinical problem. Current practices for anticoagulation of Fontan patients are strictly empiric, vary widely, are of unknown efficacy, and are based upon small and retrospective analyses. Because of the difficulty and potential morbidity of long-term anticoagulation, particularly in young children following the Fontan procedure, identifying patients who are at increased risk for thrombosis would allow for targeted therapy with improved outcome. ♥



CATHERINE ALLEN, MD



KIRSTEN ODEGARD, MD

5TH FRONTIERS IN CONGENITAL HEART DISEASE

FALL 2007

HONORING THE MEMORY OF DR. STELLA VAN PRAAGH

Sponsored by the Cardiovascular Program
at Children's Hospital Boston

This interactive, state-of-the-art program will include:

- New strategies for management of hypoplastic left heart syndrome (fetal, perinatal, and midterm management)
- Tetralogy of Fallot following repair
- Afternoon sessions interspersed with direct feeds of cases from the operating room and cardiac catheterization laboratory
- Cardiac Intensive Care Unit bedside rounds and patient management discussions
- Hands-on 3-D echo

For further information, please contact Janet Horgan (Janet.Horgan@cardio.chboston.org) or check our website at www.childrenshospital.org/cardiovascular/frontiers2007



Stella Van Praagh, MD *A Remembrance*

Dr. Stella Van Praagh died on June 3, 2006. Her dedication to education in the field of congenital heart disease was legendary. She was a master teacher, but she always demurred and said, “the hearts are the best teachers.” To the hundreds of pediatric cardiologists, pathologists, and cardiac surgeons who visited the Cardiac Registry, Stella is best remembered for her baklava, bread, and the kindness she showed to junior trainees who wanted to learn even a fraction of all she understood of the heart. She was a superb clinical cardiologist whose primary goal was to do the best for her patients and their families. Stella was dedicated to her own family, and following her retirement, she devoted her time to her grandchildren and to pursuing her enormous intellectual curiosity across many disciplines, including history and languages.

Stella had a wonderful collection of Greek proverbs that summed up universal truths in a few words. One of my favorites is “Kame to kalo kai riksto sto yialo,” which translates as “take a good thing and throw it in the sea.” As with most things in life, there are multiple interpretations: one is that we cannot hold on to things too tightly; another is that we need to share the good things that life brings us. Stella’s generosity of spirit touched countless lives through the doctors she taught and the patients they continue to care for.

At the memorial service for colleague Dick Rowe in 1988, Stella said, “In times like these, when a very special friend is gone forever, I wish I had the talent of a poet to intertwine my sorrow with a scene from nature and create a lasting wreath of love, which I could dedicate to the memory of the lost friend.” May these words create a wreath for Stella—to continue her legacy of compassion, education, and intellectual curiosity. ♥

Amy Juraszek, MD
Associate in Cardiology

While most of the Nightingale metrics are process indicators that describe how nursing care is provided in each unit, we also monitor a system indicator that describes one unique aspect of nurse staffing, termed the continuity of care index (CCI). This measure is calculated by counting the number of shifts in which the patient is hospitalized and dividing it by the number of different nurses caring for that patient. For instance, in a unit with 12-hour shifts, a patient with a 4-day length of stay could potentially receive care from 8 different nurses (CCI = 1.0).

We have applied the CCI in our Cardiac, Pediatric, and Neonatal Intensive Care Units at Children's, and because it is important to evaluate the CCI in relation to the patient's needs, CCI is reported by the unit's typical patient length of stay (LOS). While the optimal CCI varies with LOS, higher values indicate less continuity and lower values indicate more continuity. Figure 1 shows the CCI in three different ICUs. Focusing on the third quartile, for example, the CCI decreased in ICU3 after the unit-based Leadership Council formalized their process for establishing nursing care teams early in the course of a patient's illness, while the CCI increased in ICU2 after the unit transitioned to a new location, disrupting how nursing assignments were typically delineated.

OUTCOMES

Nurses' perceptions of care were often different from the data, but they performed better than expected in many areas and identified opportunities for improvement. Although it would have been easy for staff to select measures where they were confident of good performance, the point of Nightingale-style measurement is to highlight opportunities for improvement and to show systematic progress in areas that are important to patients and families. As demonstrated by the questions asked and the answers sought, the wisdom of Florence Nightingale continues to influence contemporary nursing practice.

CARDIOVASCULAR PROGRAM NIGHTINGALE TEAM

CICU: Nancy Braudis, RN, MS, Jeanne Ahern, RN, CCRN, and Paula Moynihan, RN, BSN, CCRN, CNA

Cardiovascular Inpatient Unit: Jeanne Boisvert, RN, BSN, and Suzanne Reidy, RN, MS, CNA

Cardiac Catheterization Laboratory: Joshua Bourgeois, RN, BSN, and Cheryl O'Connell, RN, BSN, MBA, CNA; Assistant: Elizabeth Mitchell, BS

Nurse Scientist: Martha A. Q. Curley, RN, PhD, FAAN

Vice President: Patricia Hickey, RN, MS, MBA, CNAA ♥



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R: MARTHA A. Q. CURLEY,
RN, PhD, FAAN

TABLE 1

Inpatient Cardiology Unit

- Strict fluid balance and daily weight if at risk for heart failure
- Discharge planning for newborns
- If patient is on a cardiac monitor, appropriate monitoring limits set
- Time to Critical Intervention: Number of unplanned patient transfers to the CICU

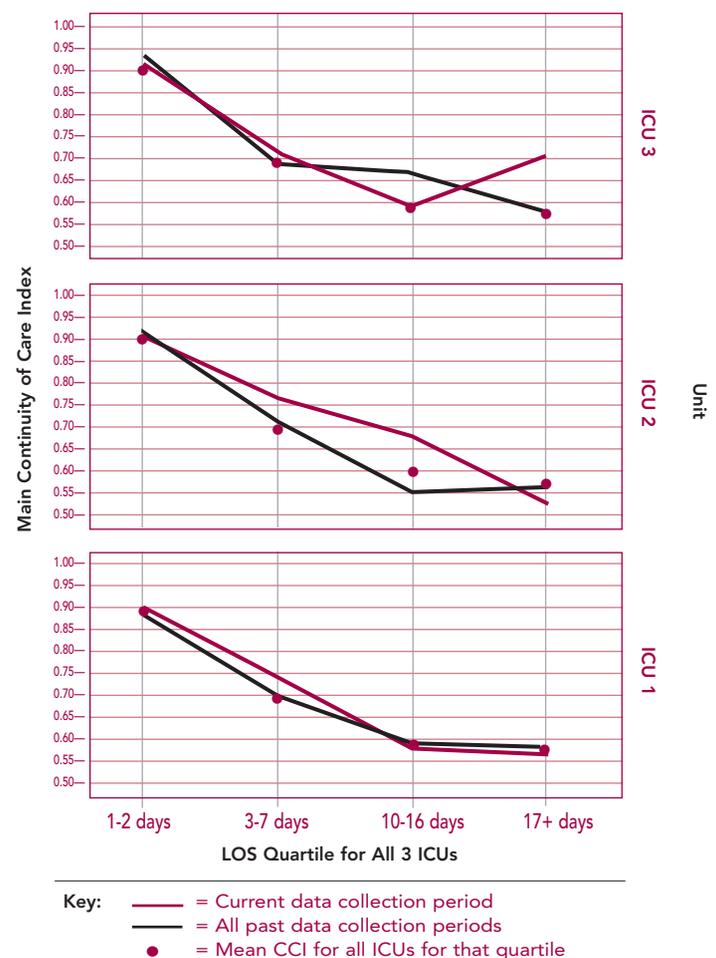
Cardiac Intensive Care Unit

- PR-interval documented at the start of each shift
- Central line blood return checked at the start of each shift
- Pressure abrasion from SpO₂ probes
- Adult care bundle: If on bed rest, patient has compression boots and TED stockings, patient's potassium is maintained >4 meq/L; if extubated, out of bed before 10 a.m.; patient has a health care proxy
- Neonatal care bundle: physical boundary in place; admission HC documented; temperature maintained between 36.5 and 36.7° C.; if < 2 kg, then patient in an isolette; glucose checked every shift
- Time to Critical Intervention: Interval between fever (over 38.5° C.) and administration of first antipyretic intervention

Cardiac Catheterization Laboratory

- The frequency of hypothermia
- Pain documentation
- Documentation of adequate pulses and intact dressing
- Documentation of post-cath handoff
- Any alteration in skin integrity
- Monitoring of nurse sedation

FIGURE 1



Continuity of Care Index (CCI) for three separate ICUs presented by the length of stay (LOS) quartile of all three units. The CCI decreases over time so that the patients with the longest LOS have better continuity in care.

HEART TRANSPLANT UPDATE

INCREASING FOCUS ON REDUCING POST-TRANSPLANT MORBIDITY

T. P. SINGH, MD, MS, ASSOCIATE IN CARDIOLOGY

Heart transplantation is currently the only definitive therapy for children with end-stage heart failure. At Children's Hospital Boston, more than 160 children have undergone heart transplantation, which is recommended for a patient when it offers higher life expectancy and/or better quality of life than alternative options. Children usually have excellent quality of life after transplant — they are able to participate in most aerobic sports without restrictions, for example. However, heart transplantation is not a cure; recipients require lifelong immune suppression, monitoring of graft function, and surveillance for potential complications. In addition, adverse effects of immune-suppression medications, some of which may be cumulative, often result in morbidities such as hypertension, renal dysfunction, diabetes, and abnormal lipid profile.

IMPROVING SURVIVAL RATES BEYOND THE FIRST YEAR

Post-transplant survival at Children's Hospital Boston surpasses national averages for comparable severity of recipients and has continued to advance over the years. A similar finding of improved post-transplant outcome in children has been described as “era effect” in national databases so that the survival of any five-year cohort of transplant recipients is better than that of recipients of all preceding years. While that is gratifying, almost all of this era effect can be attributed to improved first-year survival. After the first year, there is an annual attrition of transplant patients (which varies with age at transplant: overall 3% per year, 2% per year for infants), which hasn't improved much over the last 20 years. This finding, although somewhat surprising, provides an opportunity to think of ways to improve post-transplant survival in patients after the first year. The solution will likely require a strategy that aims to maximize the number of zero-rejectors during the first year after transplant (patients with no rejection during the first year have better long-term survival than those with any rejection episode) and minimize the prevalence of

co-morbidities (hypertension, diabetes, renal dysfunction, and hyperlipidemia) in transplant recipients, which may lower the incidence of post-transplant coronary artery disease, one of the major causes of ongoing attrition after the first year. Furthermore, the need for fewer medications for co-morbidities may improve long-term patient compliance with the all-important anti-rejection medications. Because these morbidities are caused mostly by steroids and calcineurin inhibitors (cyclosporine more so than tacrolimus), reducing exposure to these agents should lower their prevalence and should be attempted if it can be done safely.

NEW PROTOCOL

With that goal in mind, we have recently changed the routine immune suppression for heart transplant recipients. The two key elements of the new protocol are induction and steroid avoidance. Patients now receive a five-day induction therapy with thymoglobulin and low-dose steroids immediately after transplant. The steroids are then discontinued. Tacrolimus is started later and at a lower dose than before. After the first five days, patients are on only two immune-suppression agents, tacrolimus and mycophenolate. The first few patients on this protocol have done well and are being followed closely. The post-transplant clinical course of these patients in the Cardiovascular Intensive Care Unit (CICU) has been less complicated.

The frequency of surveillance endomyocardial biopsies in the past was determined by the weaning schedule of steroids (to rule out rejection after every step in steroid weaning). With the new protocol, we seek to reduce the number of routine cardiac biopsies if there is no early rejection. It is hoped that the success in reducing patient morbidity will translate into better quality of life and improved survival on long-term follow-up of these patients. ♥



T. P. SINGH, MD, MS

2006 KAPLAN FELLOW FOCUSES RESEARCH ON DEVELOPING COUNTRIES

The reach of Children's Hospital Trust is truly worldwide, as shown by the recent naming of Alesandro Larrazabal, MD, the recipient of the 2006 Tommy Kaplan Fellowship. A native of Guatemala, Dr. Larrazabal is now at Children's Hospital Boston conducting research under the guidance of Kathy Jenkins, MD, and Emile Bacha, MD. Among the areas his work explores are improvement in mortality for congenital heart surgery in Guatemala; measurement of technical performance in congenital heart surgery; predictors of active clinical progression in Shone's syndrome; and study of Stage I palliation for hypoplastic left heart syndrome and related anomalies, with emphasis on high-risk patients and impact of fetal therapies.

Much of Dr. Larrazabal's work focuses on care in Guatemala as a model for that nation and other developing countries. The infant mortality rate in Guatemala is currently 39 per 1,000 live births, compared to 6.5 per 1,000 in the United States. Eighty percent of the population lives below the poverty line and health-care access in most rural areas is poor. In a recent presentation, Dr. Larrazabal discussed the lack of access to cardiac surgical care for



DR. ALESANDRO LARRAZABAL
CHECKING ON A PATIENT IN THE
GUATEMALAN COUNTRYSIDE.

children with congenital heart disease in the developing world. Although some programs have been created in recent years, he pointed out, there is no method available to evaluate improvement and systematic data collection is rare. Under the Kaplan Fellowship, he hopes to disseminate new findings and establish a pediatric cardiac surgery database for developing countries.

The Tommy Kaplan Fellowship was established in 1997 by David and Nancy Kaplan, longtime benefactors of the Cardiovascular Program at Children's Hospital Boston, to support the work of bright young researchers and clinicians in cardiology, cardiovascular surgery, and basic cardiovascular research. The yearlong fellowship was

named in memory of the Kaplans' son, Tommy, who was born with congenital heart disease and died at the age of nine as a result of his condition.

Former Kaplan Fellows are already making their mark in cardiology and cardiovascular programs in a variety of settings. The fraternity of Kaplan Fellows includes Adrian M. Moran, MD, who practices pediatric cardiology in Portland, Maine; Kathryn Collins, MD, director of the Pediatric Arrhythmia Center at the University of California at San Francisco; Kristine Guleserian, MD, whose specialty is pediatric cardiothoracic surgery at the Children's Medical Center in Dallas; Betsy Navarro, PhD, and Elena Oancea, MD, researchers in Dr. David Clapham's laboratory at Children's Hospital Boston; Susan Foerster, MD, who specializes in pediatric cardiology at St. Louis Children's Hospital; Nathalie Roy, MD, a research fellow in Dr. Pedro del Nido's lab at Children's; and Christopher Almond, MD, an assistant in cardiology at Children's and instructor in pediatrics at Harvard Medical School. Dr. Larrazabal adds his name to a distinguished list of young clinicians, researchers, and academics. ♥



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