Risk Factors for Readmission to Medicine Critical Care Units at Boston Children's Hospital

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SCHOLARLY REPORT SUBMITTED IN PARTIAL FULFILLMENT OF THE
M.D. DEGREE AT HARVARD MEDICAL SCHOOL

DATE:  27 June 2017

STUDENT NAME:  Carlos Eduardo Estrada Alamo

SCHOLARLY REPORT TITLE:  RISK FACTORS FOR READMISSION TO MEDICINE CRITICAL CARE UNITS AT
BOSTON CHILDREN’S HOSPITAL

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Intermediate Care Program, Instructor in Pediatrics, Boston Children’s Hospital

COLLABORATORS, WITH AFFILIATIONS:  Elliot Melendez, MD, Critical Care Medicine, Johns Hopkins All
Children's Hospital
ABSTRACT

RISK FACTORS FOR READMISION TO MEDICINE CRITICAL CARE UNITS AT BOSTON CHILDREN’S HOSPITAL

Statement of the Problem/Background
Nationally, there is increasing focus on hospital readmission rates as an indicator of quality of care. Thirty-day readmission rates range from approximately 5% for pediatric hospital discharges overall to up to 25% for children with complex care needs. For children with complex chronic conditions, dependence on medical technology has been significantly associated with increased readmission rates. Due to technology dependence, some children may be directly discharged from an intensive care or intermediate care units. It is yet unclear which factors contribute to the risk of readmission in patients discharged directly from these units.

Research Question/Hypothesis
The objectives of this study were to describe the inpatient Medicine Critical Care patient population experiencing readmission to Boston Children’s Hospital. Our primary hypothesis was that patients with chronic care conditions and those with technology assistance discharged from medicine critical care had a high rate of readmission within 90 days.

Research Design/Methods Used in the Investigation
Medicine Critical Care is comprised of a Medicine Intensive Care Unit and an Intermediate Care Unit with a total of 2,052 admissions in 2012. All patients discharged home or transferred to an outside hospital from the Medicine Critical Care units from January 1 to April 15, 2012 were screened for this study. Chronic diagnosis prevalence (i.e., technology assistance and medical consultants prior to index admission) and reasons for hospitalization were assessed. Demographic and clinical data was collected retrospectively. Admission and discharge data, including medical consultations and presence of invasive technologies, were obtained from medical chart review. Children were considered to have a chronic care condition if they had ≥ 3 medical consultations prior to index
admission. Children met technology assistance criteria if they had a respiratory technology requirement such as tracheostomy or requirement for noninvasive positive pressure or continuous positive airway pressure, need for feeding technology such as via a nasogastric, nasoduodenal, gastrostomy or jejunotomy tube, and/or a permanent central line.

**Results/Summary of the Investigation**

From January 1, 2012 to April 15, 2013, 383 patients were discharged directly home or transferred to an outside hospital. One hundred ninety-five patients (50.9% [n=195/383]) met chronic care condition criteria prior to index admission. A total of 199 patients (52.0% [n=199/383]) were discharged with supports meeting the technology assistance criteria. One hundred and one patients (26.4% [n=101/383]) experienced at least one readmission within ninety days of the index discharge event. Ninety-day readmission rates were higher for patients meeting complex chronic condition criteria (42.6% [n=83/195] versus 9.6% [n=18/188]) and for patients meeting technology assistance criteria (42.2% [n=84/199] versus 9.2% [n=17/184]).

**Interpretation/Conclusion of the Investigation**

Patients with complex chronic conditions and/or technology assistance discharged from the Medicine Critical Care units at Boston Children’s Hospital experience higher readmission rates than patients not meeting these criteria. Further research is needed to explore additional factors that may influence readmission rates in these cohorts. Research findings may result in the development of a strategy to identify and manage patients at high- and low-risk for early readmission. Reducing the rates of early readmission will ideally lead to improved overall care by improving transitions to the medical home, and may reduce overall health care costs.
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SECTION 1: INTRODUCTION

Nationally, there is increasing focus on hospital readmission rates as an indicator of quality of care. Thirty-day readmission rates range from approximately 5% for pediatric hospital discharges overall (1) to up to 25% for children with complex care needs (2). For children with complex chronic conditions, dependence on medical technology has been significantly associated with increased readmission rates (3–6). Insurance status and race have also been associated with increased readmission rates (3). Patients with the highest readmission frequency are often admitted with respiratory diagnoses, which have been noted to be the primary cause of readmission for patients with complex medical needs (3).

Although a large proportion of patient readmissions occur in the intensive care setting, there is limited information describing risk factors for readmission (2). Risk factors for readmission are also not well understood in patients discharged from a children’s hospital intensive care setting (7). In 2013, as a quality measure, Boston Children’s Hospital (BCH) assessed patient readmission to an ICU within 24 hours of discharge from an ICU. Unfortunately, data collected within this restrictive time period was likely not accurately accounting for failures of care coordination that result in readmissions beyond this time period.

Existing BCH Medicine Critical Care (MCC) quality improvement data from January 1, 2012 to April 15, 2012 shows that 47.6% of patients admitted to an MCC unit were discharged directly home or transferred to an outside hospital (OSH). Many of the patients discharged directly from an MCC unit were dependent on a support technology, a characteristic that often prevents their transfer to the general pediatric wards prior to discharge. In 2013, it was yet unclear which factors contributed to the risk of readmission in BCH patients discharged home from an MCC unit.
This project aimed to provide an understanding of the rate and associated risk factors for readmission within 90 days of discharge for patients directly discharged from the BCH MCC, which includes two units, the Intermediate Care Program (ICP) and Medicine Intensive Care Unit (MICU). Understanding the characteristics of patients experiencing frequent readmission may lead to targeted quality improvement initiatives to ensure patients are discharged safely.(8)
SECTION 2: STUDENT ROLE

In June 2013, I created a REDCap database using the variable list outlined in Appendix B - Data Variables. Upon IRB approval, I populated the database with patient cohort information. Data collection took place from June through the end of 2013. Following data collection, I processed the data and performed the initial statistical analysis. My goal was to have all relevant data processed by the start of August 2014, which I was able to achieve.

Within the MCC, there exists a robust and multidisciplinary safety and quality program, which meets monthly and has numerous safety and quality initiatives. In addition to working with my primary mentor, I collaborated with Dr. Christiana Russ and Dr. Danielle DeCourcey to understand factors that may be contributing to patient readmissions. This collaboration included visiting patients on the floor and in the Emergency Room. Data collection and analysis took place in a semi-private cubicle space within the Division's main office at Boston Children's Hospital in Boston, MA.

By the start of this project I had access to all necessary data collection resources, including access to PowerChart, Cerner and REDCap. Jamin Alexander, Research Manager for the Division of MCC, assisted me to secure access to the aforementioned computing tools. Funding for living expenses as well as transportation and other logistics was sought from the Scholars in Medicine office and the Division.

The first challenge I encountered was completing and validating the REDCap database. Successful completion of this phase of the project was dependent on a BCH staff member who structured and approved all REDCap projects, meaning it took some time before I could use the database tool. Another obstacle that I encountered was finding the “technology at discharge” data in the medical chart. There was no standard location in the medical record for this information and I had to create a protocol to ensure consistent data acquisition across patient interactions. Despite these challenges, data was collected in a systematized fashion to reduce the likelihood acquisition error or bias.
SECTION 3: METHODS

Data Source: BCH uses an electronic medical record (EMR) for all medical related documentation. Data was extracted manually from the EMR. I collected admission and discharge data including duration of admission, diagnosis at discharge, and presence of medical technologies, such as gastrostomy, tracheostomy, cerebrospinal fluid (CSF) ventricular shunt, and permanent indwelling catheter. Concurrently, data for the same patient, as referenced by EMR number, was extracted from the Pediatric Health Information System (PHIS). See Appendix B - Data Variables for a complete list of variables that were collected.

Aim 1

Study Design: Retrospective cohort study of all patients admitted or transferred to the Boston Children’s Hospital Intermediate Care Program (ICP) or Medicine Intensive Care Unit (MICU) from January 1 – December 31, 2012.

Study Population: Study inclusion criteria were patients with (1) at least one health encounter with BCH during their life; and (2) one or more admission to the MCC during the study period; and (3) was discharged home or to a long-term care facility from the MCC, i.e. “discharged directly.” For each patient, only the first MCC discharge within the study period, the “index discharge,” and those that occurred within 90 days of the index discharge were included for analysis.

The following patients were excluded from this study: 1) patients transferred to a BCH general inpatient ward or another ICU; 2) patients who died during the index hospitalization; 3) patients with a scheduled or elective readmission within 90 days of discharge from an index admission. Patients were followed across multiple admissions to BCH using a unique patient identifier.
Exposure Ascertainment: All information on exposures was obtained from the EMR and from the Pediatric Health Information System (PHIS). Demographic characteristics including age, sex, race/ethnicity (Caucasian non-Hispanic, Black non-Hispanic, Hispanic, Asian, Other), interpreter use, and insurance type (public, private, self-pay) were collected in addition to the primary exposures, diagnoses characteristics, and technology assistance at the time of index discharge. Index admission length of stay was also assessed.

Diagnosis characteristics collected included the number of diagnoses encountered by each patient during an admission and the name of each diagnosis, recorded as individual International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) diagnosis codes. We categorized individual diagnosis codes into two categories, based on criteria outlined in previous studies: Feudtner et al (2000)'s Complex Chronic Conditions (CCC) and technology assistance.(1,9) A commonly accepted definition of a CCC is presented in Appendix A - Definitions.

Technology assistance at index discharge was defined as a medical device used to maintain a patient’s health status.(4) Examples of technologies include gastrostomy, tracheostomy, cerebrospinal fluid ventricular shunt, and permanent indwelling catheter.(2)

Data were recorded electronically at the time of EMR and PHIS review using REDCap, a free, secure, web-based application designed to support data capture for research studies.

Outcome Ascertainment: Outcome information was also obtained from patient EMR and PHIS. The primary outcome of interest was whether the patient was readmitted to the MCC within 90 days of index admission. The duration of readmission and location of discharge will also be extracted from the medical chart. We also collected the primary diagnosis and procedure ICD-9-CM code for each readmission as an indicator of the primary reason for readmission. Outcomes were assessed and recorded electronically at the time of chart review using a REDCap database.
**Statistical Analysis:** For our primary analysis, we assessed the cumulative readmission rates occurring each day following an index admission up to 90 days after discharge home from a BCH MCC unit for the following four-mutually exclusive groups: a) patient discharged from the MCC with technology assistance and a complex chronic condition, b) patient discharged from the MCC without technology assistance, with a complex chronic condition, c) patient discharged from the MCC without these characteristics, and d) for a baseline reference, patients not discharged from an intensive care unit at BCH who do not have these characteristics.

We determined if there was any associated higher readmission rate between patient groups. The overall direct discharge rate for the BCH MCC was calculated as total direct discharges over total discharges.
**Aim 2**

**Study Design:** Retrospective cohort study of all patients admitted or transferred to the Boston Children’s Hospital Intermediate Care Program (ICP) or Medicine Intensive Care Unit (MICU) from January 1 – December 31, 2012.

**Study Population:** Study inclusion criteria were patients with (1) at least one health encounter with BCH during their life; and (2) one or more admission to the MCC during the study period; (3) was discharged home or to a long-term care facility from the MCC, i.e. “discharged directly;“ and (4) had a Complex Chronic Condition. For each patient, only the first MCC discharge within the study period, the “index discharge,” and those that occur within 90 days of the index discharge were included for analysis.

The following patients were excluded from this study: 1) patients transferred to a BCH general inpatient ward or another ICU; 2) patients who died during the index hospitalization; 3) patients with a scheduled or elective readmission within 90 days of discharge from an index admission. Patients were followed across multiple admissions to BCH using a unique patient identifier.

**Exposure Ascertainment:** All information on exposures was obtained from the EMR and PHIS. Demographic characteristics including age, sex, race/ethnicity (Caucasian non-Hispanic, Black non-Hispanic, Hispanic, Asian, Other), interpreter use, and insurance type (public, private, self-pay) were collected in addition to the primary exposures, diagnoses characteristics and technology assistance at the time of index discharge. Index admission length of stay was also assessed.

**Outcome Ascertainment:** Outcome information was also obtained from patient EMR and PHIS. The primary outcome of interest was whether the patient was readmitted to the MCC within 90 days of index admission. The duration of readmission and location of discharge was also extracted from the medical chart. We also collected the primary diagnosis and procedure ICD-9-CM code for each
readmission as an indicator of the primary reason for readmission. Outcomes were assessed and recorded electronically at the time of chart review using a REDCap database.

**Statistical Analysis:** For our primary analysis, we assessed the cumulative readmission rates occurring each day following an index admission up to 90 days after discharge home from a BCH MCC unit for the following five-mutually exclusive groups: a) patient discharged from the MCC with respiratory technology assistance and a complex chronic condition, b) patient discharged from the MCC with feeding technology assistance and a complex chronic condition, c) patient discharged from the MCC with CSF technology assistance and a complex chronic condition, d) patient discharged from the MCC with central venous vascular access technology assistance and a complex chronic condition, and e) for a baseline reference, patient discharged from the MCC without technology assistance, with a complex chronic condition.

I next determined if there was an associated higher readmission rate between patient groups. Multivariable analysis was used to adjust for confounding variables listed in *Appendix C - Confounding Variable*, though the full analysis is not yet complete and thus not included in this report.

**Power and Sample Size:** Aimed to compare patient characteristics (race/ethnicity, insurance type, sex, and diagnosis clinical categories (CCC and/or technology assistance) among each unit using chi-square tests. With a Type I error of 0.05, Type II error of 0.10, we anticipated being able to detect a 20% difference in readmission rate, compared to the literature reported 30-day readmission rate of 25.4% for children with complex care needs, by sampling 128 patient charts. Thus, 128 patients are required to have a 90% chance of detecting, as significant at the 5% level, a decrease in the primary outcome measure from 25.4% in the control group (literature) to 5.4% in the experimental cohort. Three times as many charts, 383 in total, were reviewed to allow for future development and validation of a readmission prediction model using a consistent patient cohort.
SECTION 4: RESULTS

In this cohort, 195 patients (50.9% [n=195/383]) met CCC criteria of having at least 3 consults in the 6 months prior to index admission. A total of 199 patients (52.0% [n=199/383]) were discharged with technology assistance criteria (Figure 1). One hundred and one patients (26.4% [n=101/383]) experienced at least one readmission within ninety days of an index discharge event. Ninety-day readmission rates were higher for patients who either met criteria for CCC or technology assistance (39.9% [n=95/238] versus 4.1% [n=6/145]) (Figure 4).

Ninety-day readmission rates were also higher for patients meeting CCC criteria (42.6% [n=83/195] versus 9.6% [n=18/188] not meeting criteria) (Figure 2) and technology assistance criteria (42.2% [n=84/199] versus 9.2% [n=17/184] not meeting criteria) (Figure 3). Patients discharged with a permanent central line were more likely to experience readmission within 90 days (RR 2.23, 95% CI: 1.42 – 3.49, P = 0.0005) (Figure 5). Patients discharged with a respiratory technology were more likely to experience readmission within 90 days (RR 3.38, 95% CI: 2.36 – 4.85, P < 0.0001) (Figure 6). Patients discharged with feeding technologies were more likely to experience readmission within 90 days (RR 3.39, 95% CI: 2.34 – 4.91, P < 0.0001) (Figure 7). Patients requiring interpreter services at the time of discharge were more likely to experience readmission within 90 days (RR 1.96, 95% CI: 1.29 – 2.99, P = 0.0016) (Figure 8). Patients meeting both CCC and technology assistance criteria were 11.15 times more likely to experience readmission within 90 days (RR 11.15, 95% CI: 5.00 – 24.86, P < 0.0001) (Figure 10).
SECTION 5: DISCUSSION, LIMITATIONS, CONCLUSIONS, AND SUGGESTIONS FOR FUTURE WORK

Discussion

Prevention of hospital readmissions is a current, national quality improvement focus and considerable resources have been devoted to the reduction of excess readmissions within 90 days of discharge. Before this study, the MCC department at BCH was uncertain which factors contributed to the risk of readmission in patients discharged from an ICU.

This study found that patients discharged home from a BCH Medicine Critical Care unit with technology assistance (i.e. gastrostomy, tracheostomy, cerebrospinal fluid ventricular shunt, or central venous vascular access) and with a complex chronic condition experience a higher readmission rate compared to patients with a complex chronic condition in isolation, or patients meeting neither criterion at discharge. Interestingly patients discharged home from the MCC with respiratory assistance and a complex chronic condition experienced similar rates of readmission compared to patients with feeding technologies, but higher readmission rates compared to patients requiring another technology support at discharge (i.e., cerebrospinal fluid (CSF) ventricular shunt, and central venous vascular access) and a complex chronic condition. These findings are likely explained by the correlation between the need for respiratory and feeding assistance and the underlying presence of chronic disease states. The need for interpreter services at discharge also increases the risk of readmission within 90 days. The association between need for interpreter and higher readmission rates could be due to a family’s lack of understanding with post-discharge instructions or troubleshooting techniques (i.e., how to replace a G-tube or tracheostomy device), cultural differences in the threshold for when to seek medical care, or due to challenges in communicating concerns or needs over the phone. More work is needed to elucidate the root cause of this likely preventable source of readmissions.
Our study identified unique risk factors that may be amenable to intervention to improve the quality of care delivered and to reduce unnecessary, costly readmissions. Full analysis of collected data, together with multivariable analysis, will help inform the design of a prediction model for preventing unnecessary readmissions following discharge from BCH MCC units.

**Limitations**

Our research approach was limited for several reasons: 1) patients may be lost to follow-up; 2) we relied on the accuracy of demographic data collection including self-reporting of race/ethnicity, address, and insurance status; 3) we relied on the accuracy of patient notes indicating technology use at time of discharge; 4) the generalizability of results are limited to these two MCC units, since subjects, treatment and discharge protocols, and outcomes often differ greatly across other units and hospitals.

Despite these limitations, collecting data and understanding the characteristics of a patient population was a crucial step for this quality improvement effort. In the future, the department hopes to use the data to develop and validate a prediction model to estimate the probability of readmission based on patients’ demographic and medical treatment characteristics.

**Conclusions**

- Patients with chronic care conditions and technology assistance, especially respiratory and feeding support, at the time of discharge from the MCC experienced higher readmission rates than patients not meeting those criteria.
- The need for an interpreter itself is associated with higher readmission rates within 90 days.
Suggestions for Future Work

• Perform multivariate analysis to identify critical variables that could inform the development of a clinical prediction model.

• Prospectively identify and stratify patients at risk for readmission prior to index discharge.

• Provide interventions, as appropriate, for patients with risk factors for readmission, including:
  o Increased level of outpatient care
  o Earlier scheduled outpatient follow-ups
  o Coordinated nurse calls and home visits
  o Early involvement of interpreter services, including at home visits

• Evaluate interpreter effectiveness and provide unit specific cross-cultural training for all employees engaged in direct patient care.
SECTION 6: ACKNOWLEDGEMENTS

I would like to thank the following individuals for their support, patience, and encouragement throughout this project. Thank you for helping to make my transition from Seattle, WA to Boston, MA a wonderful experience.

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  - Barbara Sweeney
  - Devin Cromartie
  - Stephen Allsop

- **Boston Children’s Hospital Medicine Critical Care**
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  - Christiana Russ, MD
  - Danielle DeCourcey, MD
  - Michael Agus, MD
  - Susan Steele-Harrington
  - Jamin Alexander
  - Melanie Silverman
  - Cristina Palladino
  - Alexandra Oldershaw
  - Kerry Coughlin-Wells
  - Carmen Soto
  - Gabriella Howard
  - Melissa Traore
  - Josh Bartlett
REFERENCES


TABLES AND FIGURES

Figure 1: Cohort Stratification

Total pt. discharged from MCC = 383

195 (50.9%) met CCC criteria
≥ 3 consults in 6 mo. prior

199 (52.0%) met Tech. Assistance criteria
Central Lines, Resp., Feed., Other tech.

Complex Chronic Condition (CCC)
16.4%
n=39/238

CCC and Technology Assistance
65.5%
n=156/238

Tech. Assist.
18.1%
n=43/238

Meet CCC criteria
Meet Tech. Assis. criteria

Figure 2: 90 Day Readmission Rate: Complex Chronic Condition

90 Day Readmission Rate
Complex Chronic Condition

Total Patients Discharged from MCC (n=383)

Discharged with Complex Chronic Condition (n=195)

- Readmitted within 90 Days (n=83) 42.6%
- Not Readmitted within 90 Days (n=112) 57.4%

Discharged without Complex Chronic Condition (n=188)

- Readmitted within 90 Days (n=18) 9.6%
- Not Readmitted within 90 Days (n=170) 90.4%

Relative risk: 4.45
95% CI: 2.78 to 7.10, P < 0.0001
**Figure 3:** 90 Day Readmission Rate: Technology Assistance

90 Day Readmission Rate
Technology Assistance

- **Total Patients Discharged from MCC** (n=383)
- **Discharged with Technology Assistance** (n=199)
  - Readmitted within 90 Days (n=84) - 42.2%
  - Not Readmitted within 90 Days (n=115) - 57.8%
- **Discharged without Technology Assistance** (n=184)
  - Readmitted within 90 Days (n=17) - 9.2%
  - Not Readmitted within 90 Days (n=167) - 90.8%

**Relative risk:** 4.57
95% CI: 2.82 to 7.39, P < 0.0001

**Figure 4:** 90 Day Readmission Rate: CCC and/or Technology Assistance

90 Day Readmission Rate
and/or CCC or Technology Assistance

- **Total Patients Discharged from MCC** (n=383)
- **Discharged with Technology Assistance or CCC** (n=238)
  - Readmitted within 90 Days (n=95) - 39.9%
  - Not Readmitted within 90 Days (n=143) - 60.1%
- **Discharged without Technology Assistance or CCC** (n=145)
  - Readmitted within 90 Days (n=6) - 4.1%
  - Not Readmitted within 90 Days (n=139) - 95.9%

**Relative risk:** 9.65
95% CI: 4.34 to 21.44, P < 0.0001
Figure 5: 90 Day Readmission Rate: Central Lines Present at Discharge

**90 Day Readmission Rate**
Central Lines

<table>
<thead>
<tr>
<th>Readmitted</th>
<th>Not Readmitted</th>
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<tr>
<td>55.6%</td>
<td>24.9%</td>
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</tbody>
</table>

Relative risk: 2.23
95% CI: 1.42 to 3.49, P = 0.0005

Central Line Present at Discharge

Figure 6: 90 Day Readmission Rate: Respiratory Technologies Present at Discharge

**90 Day Readmission Rate**
Respiratory Technologies

<table>
<thead>
<tr>
<th>Readmitted</th>
<th>Not Readmitted</th>
</tr>
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<tbody>
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<td>46.9%</td>
<td>13.9%</td>
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</tbody>
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Relative risk: 3.38
95% CI: 2.36 to 4.85, P < 0.0001

Respiratory Technologies at Discharge
**Figure 7:** 90 Day Readmission Rate: Feeding Technologies Present at Discharge

90 Day Readmission Rate
Feeding Technologies

Relative risk: 3.39
95% CI: 2.34 to 4.91, P < 0.0001

- Readmitted: 45.8%
- Not Readmitted: 13.5%

Feeding Technologies at Discharge

---

**Figure 8:** 90 Day Readmission Rate: Interpreter Needed During Index Admission

90 Day Readmission Rate
Interpreter Need

Relative risk: 1.96
95% CI: 1.29 to 2.99, P = 0.0016

- Readmitted: 48.3%
- Not Readmitted: 24.6%

Interpreter Needed During Index Admission
Figure 10: 90 Day Readmission Rate: CCC or Technology Assistance – Expanded Flow Chart

90 Day Readmission Rate
CCC or Technology Assistance

Expanded Flow Chart

Total Patients Discharged from MCC (n=383)

Discharged with CCC and with Technology Assistance (n=156)
- Readmitted within 90 Days (n=72) - 46.2%
- Not Readmitted within 90 Days (n=84) - 53.8%

Discharged with CCC and without Technology Assistance (n=39)
- Readmitted within 90 Days (n=11) - 28.2%
- Not Readmitted within 90 Days (n=28) - 71.8%

Discharged without CCC and with Technology Assistance (n=43)
- Readmitted within 90 Days (n=12) - 27.9%
- Not Readmitted within 90 Days (n=31) - 72.1%

Discharged without CCC and without Technology Assistance (n=145)
- Readmitted within 90 Days (n=6) - 4.1%
- Not Readmitted within 90 Days (n=139) - 95.9%

Meet CCC criteria
Meet Tech. Assis. criteria
APPENDIX A – GLOSSARY OF ABBREVIATIONS

BCH: Boston Children’s Hospital

Complex chronic condition (CCC): Any medical condition that can be reasonably expected to last at least 12 months (unless death intervenes) and to involve either several different organ systems or 1 organ system severely enough to require specialized pediatric care and probably some periods of hospitalization in a tertiary care center.

The following table categorizes CCCs and their corresponding Four-Digit ICD-9 code:

Table 1: Categories of CCCs and Specific ICD-9 Codes (3)

<table>
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<tr>
<th>CCC Categories</th>
<th>Subcategories</th>
<th>ICD-9 Codes</th>
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<tbody>
<tr>
<td>Neuromuscular (NM)</td>
<td>Brain and spinal cord malformations</td>
<td>740.0–742.9</td>
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<tr>
<td></td>
<td>Mental retardation</td>
<td>318.0–319.0</td>
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<tr>
<td></td>
<td>Central nervous system degeneration and disease</td>
<td>330.0–337.9</td>
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<td></td>
<td>Infantile cerebral palsy</td>
<td>343.0–343.9</td>
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<tr>
<td></td>
<td>Epilepsy</td>
<td>345.0–345.9</td>
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<td></td>
<td>Muscular dystrophies and myopathies</td>
<td>359.0–359.3</td>
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<tr>
<td>Cardiovascular (CV)</td>
<td>Heart and great vessel malformations</td>
<td>745.0–747.4</td>
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<td></td>
<td>Cardiomyopathies</td>
<td>425.0–425.4, 429.1</td>
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<tr>
<td></td>
<td>Conduction disorders and dysrhythmias</td>
<td>426.0–427.4, 427.6–427.9</td>
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<tr>
<td>Respiratory</td>
<td>Respiratory malformations</td>
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<td>Chronic respiratory disease</td>
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<td></td>
<td>Cystic fibrosis</td>
<td>277</td>
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<tr>
<td>Renal</td>
<td>Congenital anomalies</td>
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<td>Chronic renal failure</td>
<td>585</td>
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<td>Gastrointestinal (GI)</td>
<td>Congenital anomalies</td>
<td>750.3, 751.1–751.3, 751.6–751.9</td>
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<td></td>
<td>Chronic liver disease and cirrhosis</td>
<td>571.4–571.9</td>
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<td></td>
<td>Inflammatory bowel disease</td>
<td>555.0–556.9</td>
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<tr>
<td>Hematology and immunodeficiency</td>
<td>Sickle cell disease</td>
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<td>Category</td>
<td>ICD-9-CM Codes</td>
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<td>Hereditary immunodeficiency</td>
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<td>Human immunodeficiency virus disease</td>
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<td>Metabolic</td>
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<td>Amino acid metabolism</td>
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<td>Lipid metabolism</td>
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<td>Storage disorders</td>
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<td>Other metabolic disorders</td>
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<td>Other congenital or genetic defect</td>
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<td>Chromosomal anomalies</td>
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<tr>
<td>Bone and joint anomalies</td>
<td>259.4, 737.3, 756.0–756.5</td>
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<tr>
<td>Diaphragm and abdominal wall</td>
<td>553.3, 756.6–756.7</td>
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<td>Other congenital anomalies</td>
<td>759.7–759.9</td>
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<tr>
<td>Malignancy</td>
<td>140.0–239.9</td>
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**CSF:** Cerebrospinal fluid

**EMR:** Electronic medical record - refers to the systematized collection of patient and population electronically-stored health information in a digital format. These records can be shared across different health care settings.

**HMS:** Harvard Medical School - graduate medical school of Harvard University. It is located in the Longwood Medical Area in Boston, Massachusetts.

**ICP:** Intermediate care program - The ICP is a 10-bed unit at BCH that cares for patients who are require more intensive nursing than can be provided on the floors.

**ICD-9-CM:** International Classification of Diseases, Ninth Revision, Clinical Modification - Code Set is used to classify diseases and a wide variety of signs, symptoms, abnormal findings, complaints.

**MCC:** Division of Medicine Critical Care units – Unit of the Boston Children’s Hospital in Boston, MA.
**MICU:** Medicine intensive care unit - at BCH is a 16-bed facility dedicated to the care of children with a wide range of critical illness diagnoses including respiratory failure (severe breathing problems), sepsis (serious infection), nutritional failure, poisoning, congenital anomalies and life-threatening complications of metabolic diseases and endocrine disorders.

**ORMA:** Office of Recruitment and Minority Affairs - recruits and provides supportive services to students underrepresented in medicine and dentistry and the economically disadvantaged. ORMA fosters an inclusive and respective environment that is supportive to lesbian, gay, bisexual, transgender students, faculty, and staff.

**OSH:** Outside hospital

**PHIS:** Pediatric Health Information System - a comparative pediatric database, includes clinical and resource utilization data for inpatient, ambulatory surgery, emergency department and observation unit patient encounters for more than 45 children's hospitals.

**Index Discharge:** The first unique patient discharge during the defined time period. Readmissions taking place 90 days after the index discharge will not be considered as a new index admission.

**Readmission:** Any unscheduled readmission to BCH up to 90 days from the index discharge, defined as follows:

a) Between 0 and 30 days of discharge
b) Between 31 and 60 days of discharge
c) Between 61 and 90 days of discharge
d) Within 90 days of discharge
**Technology assistance:** medical technology used to maintain a patient's health status, such as gastrostomy, tracheostomy, cerebrospinal fluid ventricular shunt, permanent indwelling catheter, and pacemaker.

Dependence of the following technologies were considered: outpatient requirement for CPAP, BiPAP, tracheostomy, or invasive home ventilation via tracheostomy, requirement for home gastrostomy tube (G-tube) feeds, gastrojejunal feeds (GJ), jejunal feeds (J-tube), nasogastric (NG) or nasojejugal (NJ) feeds.
APPENDIX B – DATA VARIABLES

1. Admission variables
   • Date of index admission
   • Date of index discharge
   • Admission location
     i. Home (even if via OSH)
     ii. Long-term care facility
     iii. Unknown
   • Interpreter needed for communication
     i. Yes
     ii. No
     iii. Unknown

2. Predictor variables
   • Age at index admission (DOB)
   • Sex
     i. Male
     ii. Female
   • Zip code
   • Race/ethnicity
     i. White, non-Hispanic
     ii. Black, non-Hispanic
     iii. Hispanic
     iv. Asian
     v. Other
     vi. Unknown
   • Insurance
i. Public
ii. Private/health maintenance organization
iii. Self-pay
iv. Other/Unknown

Technology Check-list

- Technologies on discharge (If yes: Is this a new technology at index admission?)
  ii. Central Catheters (type/brand of catheter used)
    i. Broviac
    ii. Port-a-catheter
    iii. PICC
    iv. Suprapubic
  iii. Feeding tubes (location of feeding tube along gastrointestinal tract)
    i. G tube
    ii. GJ tube
    iii. J tube
    iv. NG tube
    v. NJ tube
  iv. Respiratory (type of support being offered by respiratory technology)
    i. BiPAP
    ii. CPAP
    iii. Oxygen
    iv. Tracheostomy
    v. Tracheostomy w/ ventilation
  v. CSF Shunts
    i. VP Shunt
  vi. Other
3. **Discharge variables**

- Discharge disposition of index admission
  - i. Home
  - ii. Long-term care facility
  - iii. Outside hospital (OSH)
  - iv. Unknown

- Diagnosis on discharge of index admission — *Individual Discharge diagnoses are to be collected from the MD Discharge summary associated with the index encounter.*

- Mortality since Index Admission
  - i. Yes
    - ii. Hospital
    - iii. Home
    - iv. Unknown
  - ii. No

4. **Readmission Data**

- Was the patient readmitted to BCH within 90 days of index discharge?

→ If yes:

- Date of readmission # 1: __/__/____
- Date of discharge of readmission # 1: __/__/____
- Admission Location:
  - o Home (even if via OSH)
  - o Long-term care facility

- Diagnosis on readmission — *Individual Discharge diagnoses are to be collected from the MD Discharge summary associated with the index encounter.*
• Was there a new technology introduced in this readmission?  o No
  o Yes (branch to Technologies on discharge)

• Was there another readmission within 90 days of index discharge?  o No
  o Yes (branch to Readmission Data and collect data for subsequent admission)
APPENDIX C – CONFOUNDING VARIABLES

• Patient lifestyle
  i. Smoking
  ii. Drinking alcohol
  iii. Diet

• Family exposures
  i. Smoking
  ii. Diet