Accuracy of Malignant Hyperthermia Diagnoses in Hospital Discharge Records

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ABSTRACT

Background: In 1997, the International Classification of Diseases (ICD), 9th Revision Clinical Modification (ICD-9) coding system introduced the code for malignant hyperthermia (MH) (995.86). The aim of this study was to estimate the accuracy of coding for MH in hospital discharge records.

Methods: An expert panel of anesthesiologists reviewed medical records for patients with a discharge diagnosis of MH based on ICD-9 or ICD-10 codes from January 1, 2006 to December 31, 2008 at six tertiary care medical centers in North America. All cases were categorized as possible, probable, or fulminant MH, history of MH (family or personal) or other.

Results: A total of 47 medical records with MH diagnoses were reviewed; 68.1% had a documented surgical procedure and general anesthesia, and 23.4% (95% CI, 12.3–38.0%) had a possible, probable, or fulminant MH event. Dantrolene was given in 81% of the MH events. All patients judged to have an incident MH event survived to discharge. Family and personal history of MH accounted for 46.8% of cases. High fever without evidence of MH during admission accounted for 23.4%, and the reason for MH coding was unclear in 6.4% of cases.

Conclusions: Approximately one quarter of ICD-9 or ICD-10 coded MH diagnoses in hospital discharge records refer to incident MH episodes and an additional 47% to MH susceptibility (including personal history or family history). Information such as surgical procedure, anesthesia billing data, and dantrolene administration may aid in identifying incident MH cases among those with an ICD-9 or ICD-10 coded MH diagnosis in their hospital discharge records. (Anesthesiology 2015; 122:55-63)

Malgnant hyperthermia (MH) is a rare pharmacogenetic disorder of skeletal muscle metabolism. When a susceptible patient is exposed to a triggering agent (halogenated volatile anesthetic agent and/or succinylcholine) or event (such as elevated environmental heat along with exercise), a potentially fatal hypermetabolic reaction can occur. In 1997, the International Classification of Diseases (ICD), 9th Revision Clinical Modification coding system (ICD-9) added a code for “malignant hyperthermia: malignant hyperpyrexia due to anesthesia” (995.86). The availability of a special ICD code for MH has made it possible to conduct epidemiological research related to MH, including use of the code to evaluate MH prevalence, trends in MH occurrence, and coexisting diseases.4–6

However, the validity of the findings from studies based on ICD-coded data has been a serious concern. ICD codes are prone to error at several different levels including but not limited to physician, coding, and sequencing errors.5,6 Physician errors occur when a diagnosis is omitted from the record, made incorrectly, or improperly recorded using the wrong terminology. Coding errors can then occur when data abstractors, usually nonmedical personnel, misinterpret or incompletely review the chart and make incorrect decisions about which diagnoses to code.6 Sequencing errors are defined as improper assignment of a primary diagnosis versus a secondary diagnosis.5

Studies on the accuracy of ICD coded diagnoses vary widely in their findings due to the fact that each diagnosis and procedure is prone to its own unique rate and type of error.7

What We Already Know about This Topic

• The accuracy of International Classification of Diseases (ICD) coding for the purpose of registry research has been questioned in several fields.

• An ICD code for malignant hyperthermia was created in the 9th edition, but accuracy in its use has not been assessed.

What This Article Tells Us That Is New

• In review by an expert panel of ICD coding for malignant hyperthermia over a 3-year period, approximately 70% of coded cases were considered to be malignant hyperthermia susceptible.

• The most common reason for inaccurate coding was high fever unrelated to anesthesia.

Preliminary results were presented at the American Society of Anesthesiologists annual meeting, Washington, D.C., October 16, 2012, and at the International Anesthesia Research Society annual meeting, Montreal, Quebec, Canada, May 17–20, 2014.

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of errors. Factors influencing the accuracy of ICD-coded diagnoses include disease type, current state of medical knowledge and technology, clinical acumen, participation of various practitioners from patient to administrative personnel, and implementation of coding practices. Codes are most likely to be accurate when the disease is clearly defined with observable signs and symptoms, physician experts record the diagnosis in the chart, experienced coders with access to all patient data assign the code, and the code is not new. One study of 7,050 Medicare discharges from a national sampling of U.S. hospitals found that while the overall accuracy was 78.2%, it varied widely across different conditions. The positive predictive value in this study was highest for hip fractures (94%) and lowest for peripheral vascular disease (50%).

We conducted a critical review of a sample of hospitalizations containing the ICD code for MH at discharge to estimate the accuracy of coding, identify common errors, and develop strategies to improve the identification of incident MH episodes using ICD and other administrative data. The medical records reviewed in this study were for the 3-yr period from 2006 to 2008, the most recent years for which electronic medical records were available at all the study sites when the study was initiated in 2009.

Materials and Methods

This study meets the criteria for the Protection of Human Subjects exemption 4 (research involving preexisting data) of the U.S. Code of Federal Regulations (45 CFR 46.101). A formal application was prepared and submitted to each of the site institutional review boards (IRB) (Columbia University Medical Center Institutional Review Board, New York, New York; Saint Barnabas Medical Center Institutional Review Board, Livingston, New Jersey; Northwestern University Institutional Review Board, Chicago, Illinois; The Children’s Hospital of Philadelphia Institutional Review Board, Philadelphia, Pennsylvania; New York University Langone Medical Center/School of Medicine Institutional Review Board, New York, New York; University Health Network Research Ethics Board, Toronto, Ontario, Canada), and the study was either deemed exempt from full review by the IRB chair or approved after review based on local IRB policies. Written consent was waived by the IRB at all sites.

Design and Setting

For this multicenter study, hospital billing records with a primary or secondary diagnosis of MH (ICD-9 995.86 or ICD-10 T88.3) were identified at six academic medical centers (Columbia University Medical Center and Morgan Stanley Children’s Hospital, New York, New York; Saint Barnabas Medical Center, Livingston, New Jersey; Northwestern Memorial Hospital, Chicago, Illinois; Children’s Hospital of Philadelphia, Philadelphia, Pennsylvania; New York University Medical Center, New York, New York; University Health Network, Toronto, Ontario, Canada).

Study Population and Data Collection

The electronic databases from the participating hospitals were searched to identify patients with the discharge diagnosis of MH (ICD-9 995.86 or ICD-10 T88.3) for a 3-yr period, between January 1, 2006 and December 31, 2008. For each identified hospitalization, the medical record was reviewed including all notes, labs, and all available clinical data from both paper and electronic sources. Other hospitalizations for the same patient were not included in the review.

The chart reviews were conducted by an expert panel consisting of five anesthesiologists who are MH Hotline consultants and have been trained in human subjects protection and the Health Insurance Portability and Accountability Act (Teeda Pinyavat, Henry Rosenberg, Cynthia A. Wong, Sheila Riazi, Lena S. Sun). The records were anonymized by a nonpanelist coinvestigator or research coordinator trained in privacy policies and practices prior to review by the expert panel. Two panelists independently reviewed each record and completed a standard data abstraction form individually (appendix).

If, in the judgment of the panelist, an adverse metabolic reaction occurred, the MH clinical grading scale (CGS) was calculated. Although the CGS does rely on an anesthesiologist’s judgment, it provides a validated means to quantify and standardize the diagnosis. In addition to the CGS, the likelihood of MH was classified as possible, probable or fulminant based on the expert panelist’s opinion. When there was discrepancy between the two reviews, a third panelist was assigned to reconcile the differences on site with the two first panelists present to answer questions. When differences did occur they were usually easily reconciled when information missed by one panelist was found by another. There were no charts for which an agreement could not be made on a final CGS score and assignment of MH probability by three panelists.

Statistical Analysis

Proportions and confidence intervals (95%) were calculated using Stata Version 11.2 (StataCorp LP, College Station, TX).

Results

Demographics

A total of 47 patients were discharged with a diagnosis of MH as indicated by ICD-9 code 995.86 or ICD-10 code T88.3 from the six participating hospitals between January 1, 2006 and December 31, 2008. Medical records for all 47 patients were reviewed. Of these 47 patients, 10 (21%) were children (age 17 yr or less) and 23 (49%) were male. The mean age was 40 yr and the median age was 36 yr. Thirty-two of the patients (68.1%) were admitted for or underwent a surgical procedure with general anesthesia during the hospitalization.
MH Codes and Clinical MH Cases

Eleven of the 47 patients had an incident of possible, probable, or fulminant MH event triggered by anesthesia during the index hospitalization (table 1). Therefore, the positive predictive value for incident MH when MH was coded as a primary or secondary discharge diagnosis was 23.4% (95% CI (12.3–38.0%). MH was coded as the primary diagnosis in one case. This patient was transferred from an outside hospital for MH management.

The age range of the 11 patients with an incident of possible, probable, or fulminant MH was 4–77 yr. The mean age was 33 yr and 66% were male. All patients had a surgical procedure during the admission except for one who was transferred from an ambulatory surgical center for MH management after liposuction. Five of the 11 cases were emergent. Succinylcholine was administered in 6 of the 11 cases. In one patient, the sole triggering agent received was succinylcholine. The remaining 10 patients received volatile halogenated agents, most often sevoflurane or desflurane. The maximum temperature ranged from 36.3°C to 40.4°C with a mean of 38.7°C (temperature information was not available for two patients). All patients survived to discharge.

Nine patients received dantrolene. One patient who did not receive dantrolene was a 4-yr-old boy who had masseter spasm after succinylcholine. Volatile anesthetics were discontinued and the patient was observed without further treatment. The second patient who did not receive dantrolene was a 5-yr-old boy with congenital ptosis who had signs of hypermetabolism (temperature of 38.2°C, heart rate of 165 beats/min, and an end tidal carbon dioxide of 60 mm Hg) during an anesthetic that resolved after discontinuation of volatile anesthetic, cooling, and hyperventilation.

MH Codes and Personal or Family History

Twenty-two patients (46.8%) were coded due to a personal (n = 12) or family (n = 6) history of MH, or both (n = 4). In the cases of family history, all except one were in a first-degree relative.

MH Codes and Non-MH Cases

Eleven records were miscoded as MH due to a high fever unrelated to anesthesia (maximum temperature ranged from 40.5°C to 42.2°C with a mean of 41.5°C). The mean age was 40 yr; 36% were male, and 72% had no surgical procedure or anesthesia during admission. In-hospital all-cause mortality for these patients was 18%.

Dantrolene was administered in three cases determined not to be related to MH and miscoded due to fever. One patient was a 55-yr-old male with a history of traumatic brain injury admitted from a rehabilitation facility with fever and a diagnosis of urosepsis. Dantrolene was “given empirically” for his fever of 41.1°C and MH was listed on the differential diagnosis in an emergency department note. Another patient was a 91-yr-old female with heart failure, chronic obstructive pulmonary disease, and renal insufficiency admitted with pneumonia. She had received haloperidol, and dantrolene was given due to suspected neuroleptic malignant syndrome with a maximum temperature of 41.3°C. The third patient was a 2-yr-old female with severe pulmonary hypertension who became unstable after receiving epoprostenol. Upon arrival in the intensive care unit, dantrolene and antibiotics were given for a fever of 41.1°C.

The remaining three non-MH cases had no clear explanation for miscoding. Two were oncology patients. One was a 75-yr-old male with hairy cell leukemia admitted for osteomyelitis and possible infected spinal hardware with a maximum temperature of 37.5°C. The second patient was a 69-yr-old female with breast cancer admitted for breast lumpectomy and no recorded fever. The third patient was a 32-yr-old female with no recorded fever who had a respiratory arrest 2 h after a lumbar decompression and fusion possibly due to opioid overdose.

MH Codes for Surgical Cases and Patients Receiving Dantrolene

A total of 32 patients who underwent a surgical procedure with general anesthesia, 11 were judged to have a clinical MH event (34.3%) and 16 had personal or family history of MH (50%). A total of 12 patients who were given dantrolene, 9 (75%) had a clinical MH event, none had a history or family history of MH, and 3 (25%) had an event unrelated to MH. In patients who had surgery and dantrolene, 9 out of 10 had an incident MH event.

Discussion

Our results show that of 47 patients with ICD-9 or ICD-10 coded MH on hospital discharge, 23.4% had an incident MH episode and 46.8% a personal and/or family history of
MH. Taken together, approximately 70% of cases were MH susceptible. The most common reason for inaccurate coding was high fever unrelated to anesthesia. We were broad in our inclusion of all suspected cases, from possible to fulminant, as true positives for the ICD code. While this broad definition may have increased our estimate of coding accuracy, we believe most researchers using the ICD code to investigate MH are interested in any possible cases rather than being limited to biopsy-proven MH. Although we analyzed them separately, we did not consider the personal and/or family history cases as coded in error. In some ways, MH susceptibility can be viewed as a chronic disease. Having a positive history or family history has important clinical implications and the diagnosis should be carried through the medical record on each admission. However, because a different ICD diagnosis of MH susceptibility does not exist, the diagnosis of MH is assigned in these cases.

Our study found that a personal or family history of malignant hyperthermia is difficult to distinguish from an incident diagnosis using discharge diagnoses alone. Some databases such as Medicaid and Medicare databases, and individual state hospital discharge databases, contain a “present on admission” flag to identify a preexisting condition. In our previous study on MH prevalence in New York State between 2001 and 2005, 52% (38 of 73) of cases with the MH diagnosis were flagged as having the condition present on admission.7 We found in the current study that 47% of cases with the MH diagnosis were coded due to personal or family history of MH. The results and conclusions of previous studies of MH prevalence using administrative databases may be impacted by our finding that prevalence of MH susceptibility is more likely to be accurately captured by ICD code than MH incidence. The confusion in coding the patient as MH susceptible versus having had an acute MH event may also impact medical billing and reimbursement, arguably the most important use of ICD codes today.

Including only surgical admissions increased the positive predictive value of the MH code for incident MH from 23.4% to 34.4%. Most of the patients with a suspected MH event received dantrolene. Therefore, one way to improve specificity of searches for incident MH events using administrative databases might be to include information on whether a surgical procedure was performed and whether dantrolene was administered.

Many ICD coding accuracy studies use physician diagnosis in the medical record or expert coders reabstraction of the record as a gold standard.5,7,8,10 They address coding accuracy and assume physician accuracy. A definitive diagnosis of MH is often problematic to make over the course of one hospitalization. While muscle biopsy and caffeine-halothane contracture testing can be performed at special testing centers to confirm MH susceptibility, there is no test that can be applied acutely to distinguish MH from other causes of hypermetabolism or hyperthermia. Moreover, contracture tests are not reliable if performed in the first three months after an acute event and therefore these results are not available during the same hospital admission, if at all. Many studies in the United States and Europe have used the CGS as the clinical definition for MH.1,11,12 We chose the CGS and expert opinion as our standard for true MH occurrence. In choosing this external gold standard, we attempted to minimize the amount of physician error. For instance, in two of the three “non-MH” cases in which dantrolene was given, MH was perhaps on the treating physician’s differential diagnosis but was deemed highly unlikely by our expert panel. Validating the physicians’ notes in the instance of reported previous personal or family history of MH, however, was beyond the scope of the study.

Coding errors for MH accounted for approximately 32% of cases, most often involving patients with high fever. Because the introduction of the MH code occurred first in October 1997, familiarity with MH may be low among medical coders.11 We also found that it was fairly common for physicians to inappropriately use the term “malignant hyperthermia”—perhaps reflecting the ambiguity of the terminology that currently exists—to refer to this hypermetabolic syndrome that is neither malignant nor always hyperthermic. Patients with fever who were mistakenly coded with MH tended to have a higher maximum temperature than patients who had a true MH episode. They were sicker overall than patients who had a true MH episode with most patients having an American Society of Anesthesiologists Physical Status of 3 or greater and a high mortality rate. They were also unlikely to have had a surgical procedure or anesthesia or to have received dantrolene. Excluding patients with diagnoses associated with hyperthermia, such as sepsis and neuroleptic malignant syndrome, as Rosero et al.4 did in their study of MH using the Nationwide Inpatient Sample, would eliminate many of these coding errors.

Sequencing errors were studied widely when diagnosis-related groups became the basis for hospital reimbursement. The order of primary versus secondary diagnosis in these studies was found to be highly prone to error.5,10,13 The Institute of Medicine study found sequencing to be the number one reason for coding errors, leading to over 80% of errors made in coding ischemic heart disease, for example.10 To minimize the impact of type of error and find as many cases as possible for review, we included both primary and secondary diagnoses of MH. The primary diagnosis is often based on the admitting diagnosis and acute MH will usually not appear as the admitting diagnosis, with the exception of patient transfer for MH management. Including MH as only a primary diagnosis would have missed all but one admission in our study.

Limitations of our study include a small study sample and a limited number of institutions. Our study was also limited by the inability to identify cases in which the MH code was omitted. Therefore, we are unable to report a code...
specificity or sensitivity. Further studies of MH ICD code accuracy might be of interest based on a larger sample of hospitals, including both academic medical centers and ambulatory surgical centers. Comparing MH ICD coding accuracy in the United States and other countries would also be of interest.

To our knowledge, this is the first study to examine the ICD code for MH due to anesthesia. We estimate that the code has a positive predictive value of approximately 23.4% (95% CI, 12.3–38.0%) for incident MH, and 70.2% (95% CI, 55.1–82.7%) for MH susceptibility. The code is more likely to detect a history or family history of MH (47%) than an incident MH event. The remainder of the cases were miscoded, many due to high fever. Possible barriers unique to accuracy of ICD coding for MH include variable clinical presentation, lack of a pathognomonic test, rarity of the disease leading to inexperience among physicians and coders, and relative newness of the code.

Using the vast amount of data available through administrative databases is important in expanding our knowledge for rare diseases such as MH. It may be possible to improve accuracy in finding MH events, if additional information such as Current Procedural Terminology (CPT) billing codes or Clinical Classification Software (CCS) procedure codes are used to confirm that a surgical procedure took place, and anesthesia was given during the admission; pharmacy databases may be used to confirm that dantrolene was administered. Further study is required to find the best algorithm of codes to accurately capture incident MH cases in hospital discharge records. Educating physicians and medical coders about MH should also help increase coding accuracy.

Acknowledgments

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Competing Interests

Dr. Rosenberg received a one-time speaking fee from Eagle Pharmaceuticals (Woodcliff Lake, New Jersey), a company which manufactures Ryanodex, a concentrated formulation of dantrolene approved for the treatment of malignant hyperthermia. The other authors declare no competing interests.

Correspondence

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References

Appendix

### Malignant Hyperthermia Data Collection Form – Page 1/4

<table>
<thead>
<tr>
<th>Date recorded:</th>
<th>Recorded by:</th>
<th>Case #:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study Site:</td>
<td>Date of MH Event (MM/ YYYY): / (Day 0)</td>
<td></td>
</tr>
</tbody>
</table>

**Patient Demographic Information**

<table>
<thead>
<tr>
<th>Gender:</th>
<th>M</th>
<th>F</th>
<th>Date of Birth (MM/ YYYY):</th>
<th></th>
<th>State/Province of Residence:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weight:</td>
<td>kgs</td>
<td>Body Build: Normal</td>
<td>Muscular</td>
<td>Postpartum</td>
<td>Lean</td>
</tr>
<tr>
<td>Height:</td>
<td>ft</td>
<td>in</td>
<td>N/D</td>
<td>UNK</td>
<td>Other (specify):</td>
</tr>
<tr>
<td>Race:</td>
<td>Black</td>
<td>Hispanic</td>
<td>Asian/Pacific Islander</td>
<td>American Indian</td>
<td>White</td>
</tr>
<tr>
<td>Other (Specify):</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Medical History**

- MH (patient): Yes [ ] No [ ] UNK [ ]
- Family history of MH in 1st degree relative: Yes [ ] No [ ] UNK [ ]
- Family history of MH in relative other than 1st degree: Yes [ ] No [ ] UNK [ ]
- Masseter spasm: Yes [ ] No [ ] UNK [ ]
- Family history of intraoperative death NOT thought to be MH: Yes [ ] No [ ] UNK [ ]
- Heatstroke: Yes [ ] No [ ] UNK [ ]
- Family history of SIDS or cot death: Yes [ ] No [ ] UNK [ ]
- Family history of sudden death of unknown cause between 1.5-45 yr: Yes [ ] No [ ] UNK [ ]
- Diabetes: Yes [ ] No [ ] UNK [ ]
- Neurolept malignant syndrome: Yes [ ] No [ ] UNK [ ]
- Frequent muscle cramps: Yes [ ] No [ ] UNK [ ]
- Intolerance to heat: Yes [ ] No [ ] UNK [ ]
- Chronic muscle weakness: Yes [ ] No [ ] UNK [ ]
- Episodes of dark urine/ muscle pain: Yes [ ] No [ ] UNK [ ]
- Chronic muscle pain: Yes [ ] No [ ] UNK [ ]
- Exercise intolerance due to muscle pain/weakness/fever: Yes [ ] No [ ] UNK [ ]
- Idiopathic creatinine kinase elevation: Yes [ ] No [ ] UNK [ ]
- Myopathies (Specify): Yes [ ] No [ ] UNK [ ]

**Other pre-existing medical conditions:**

**Medications/therapies (not related to anesthesia):**

### Adverse Metabolic Reaction (AMR) to Anesthesia

<table>
<thead>
<tr>
<th>Type of Procedure:</th>
<th>Was it an emergency procedure?</th>
<th>Yes [ ] No [ ] UNK [ ]</th>
</tr>
</thead>
</table>

**Was the procedure performed inside a hospital?**

- Yes [ ] No [ ] UNK [ ]
- If no, where? ASC Other (specify:__________________________)

**Patient was an:**

- Inpatient [ ] Outpatient [ ] UNK [ ]

**Was any infection present at time of AMR?**

- Yes [ ] No [ ] UNK [ ]
- Specifying:__________________________

**After AMR was noted, procedure was:**

- deferred [ ] terminated before complete [ ] completed in spite of AMR [ ]
- N/A – pt already in recovery/ICU [ ]

**List all premedicants and anesthetic agents used before AMR occurred:**

**Induction Time:** : Morning : Day: 0 1 2 | Anesthes. End Time: : Afternoon: 0 1 2

**Case #:________ Reviewer’s Initials:________**
### Malignant Hyperthermia Data Collection Form – Page 2/4

**Adverse Metabolic Reaction (AMR) to Anesthesia continued**

<table>
<thead>
<tr>
<th>Induction Method:</th>
<th>❑ Inhalational</th>
<th>❑ Intravenous</th>
<th>❑ Other (specify):</th>
<th>❑ monitored anesth. care (local standby)</th>
<th>❑ regional anesth.</th>
<th>❑ regional plus general</th>
<th>❑ general anesth. w/o ET intubation</th>
<th>❑ general anesth. w/ ET intubation</th>
<th>❑ tourniquet use: (time 1st inflation: <em><strong>:</strong></em> Day: ___; final release: <em><strong>:</strong></em> Day: ___)</th>
</tr>
</thead>
</table>

**Signs Noted During Reaction**

<table>
<thead>
<tr>
<th>Time 1st AE noted:</th>
<th><em><strong>:</strong></em> Day: ☐ 0 ☑ 1 ☐ 2</th>
<th>Time 2nd AE noted:</th>
<th><em><strong>:</strong></em> Day: ☐ 0 ☑ 1 ☐ 2</th>
</tr>
</thead>
</table>

**Max. Temp. noted:** _____OC/OC °F Time: ___:___ Day: ☐ 0 ☑ 1 ☐ 2  
**Max. HR noted:** _____BPM Time: ___:___ Day: ☐ 0 ☑ 1 ☐ 2  
**Max. ETPCO₂ noted:** _____mmHg Time: ___:___ Day: ☐ 0 ☑ 1 ☐ 2

**Type of ventilation at time hypercarbia first observed:**  
❑ spontaneous  ❑ assisted  ❑ controlled  ❑ N/A  ❑ UNK

**Minute ventilation**  
(if known):

**Treatment Given**

❑ Volatile anesthetics discontinued: | ___:___ Day: ☐ 0 ☑ 1 ☐ 2 | ❑ Anesthesia circuit changed |

❑ Hyperventilation with 100% oxygen | ❑ Active cooling | ❑ Fluid loading | ❑ Furosemide |

❑ Mannitol | ❑ Bicarbonate | ❑ Glucose, insulin | ❑ Amrinone | ❑ Bretylum |

❑ Vasopressors | ❑ Lidocaine | ❑ Procaïnamide | ❑ CPR | ❑ Defibrillation |

❑ None of the above | ❑ Other (specify): |

**Was Danortole administered?**  
❑ Y ☑ N ☐ If yes, please complete the following:

**Initial dose (mg):**  
**Time of 1st dose:** ___:___ Day: ☐ 0 ☑ 1 ☐ 2  
**Time of last dose:** ___:___ Day: ☐ 0 ☑ 1 ☐ 2  
**Total dose (mg):**

**Check all signs that changed following dantrolene administration:**

❑ HR | ❑ ETPCO₂ | ❑ Temp | ❑ Muscle Rigidity |

**Min. Temp. noted:** _____OC/OC °F Time: ___:___ Day: ☐ 0 ☑ 1 ☐ 2  
**Min. HR noted:** _____BPM Time: ___:___ Day: ☐ 0 ☑ 1 ☐ 2  
**Min. ETPCO₂ noted:** _____mmHg Time: ___:___ Day: ☐ 0 ☑ 1 ☐ 2

**Check any observed dantrolene complications:**

❑ phlebitis  ❑ excessive secretions  ❑ GI upset  ❑ hyperkalemia  
❑ muscle weakness  ❑ respiratory failure  ❑ Other (specify): |

**List all anesthetic agents used after AMR occurred:**
### Appendix. (Continued)

<table>
<thead>
<tr>
<th>Laboratory Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Source</td>
</tr>
<tr>
<td>Time</td>
</tr>
<tr>
<td>Day</td>
</tr>
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<td>Rx</td>
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<td>K</td>
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<tr>
<td>AST</td>
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<tr>
<td>ALT</td>
</tr>
<tr>
<td>Creatinine</td>
</tr>
<tr>
<td>Myoglobin</td>
</tr>
</tbody>
</table>

#### Patient Outcome

Check the complications that occurred:
- ❑ cardiac dysfunction
- ❑ change in consciousness level/coma
- ❑ hepatic dysfunction
- ❑ disseminated intravascular coagulation
- ❑ pulmonary edema
- ❑ renal dysfunction
- ❑ compartment syndrome
- ❑ None
- ❑ Other (specify): ____________________________

Did patient survive initial reaction? ❑ Y ❑ N ❑ UNK

Did patient develop additional signs/symptoms after initial adequate treatment (recrudescence)?

| Time: | | |
| Day: | 0 | 1 | 2 |

Did patient survive recrudescence? ❑ Y ❑ N ❑ UNK ❑ UNK due to transfer to another hospital ❑ NA (no recrudescence)

Were any of the following tests performed?

| Muscle Biopsy | ❑ Y ❑ N ❑ UNK | Location: |
| Contracture Test | ❑ Y ❑ N ❑ UNK | Location: |
| DNA Test | ❑ Y ❑ N ❑ UNK | Location: |

If patient died, what was the primary cause of death?
- ❑ MH
- ❑ DIC
- ❑ renal failure
- ❑ Other: ____________________________
- ❑ UNK
- ❑ death > 1 month after MH episode

If patient died, was an autopsy performed?
- ❑ Y ❑ N ❑ UNK

Principal findings:

Was tissue from the deceased examined for a specific genetic defect?
- ❑ Y ❑ N ❑ UNK

Tissue type and findings:

Discharge Diagnoses:

Discharge Status: ❑ Discharged to home/Nursing Home ❑ Hospital Transfer ❑ Death ❑ UNK ❑ Other:

Case #_________ Reviewer's Initials ________
### Appendix. (Continued)

#### Malignant Hyperthermia Data Collection Form – Page 4/4

**Clinical Indicators and MH Raw Score**

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Order of occurrence*</th>
<th>Points†</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Process I: Rigidity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Generalized muscular rigidity (in absence of shivering due to hypothermia, or during or immediately following emergence from inhalational general anesthesia)</td>
<td>I</td>
<td></td>
</tr>
<tr>
<td>Masseter spasm shortly following succinylcholine administration</td>
<td>R</td>
<td></td>
</tr>
<tr>
<td><strong>Process II: Muscle Breakdown</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Elevated creatine kinase &gt;20,000 IU after anesthetic that included succinylcholine</td>
<td>I</td>
<td></td>
</tr>
<tr>
<td>Elevated creatine kinase &gt;10,000 IU after anesthetic without succinylcholine</td>
<td>R</td>
<td></td>
</tr>
<tr>
<td>Cola colored urine in perioperative period</td>
<td>I</td>
<td></td>
</tr>
<tr>
<td>Myoglobin in urine &gt;60 µg/L</td>
<td>R</td>
<td></td>
</tr>
<tr>
<td>Myoglobin in serum &gt;170 µg/L</td>
<td>I</td>
<td></td>
</tr>
<tr>
<td>Blood/plasma/serum K⁺ &gt;6 mEq/L (in absence of renal failure)</td>
<td>R</td>
<td></td>
</tr>
<tr>
<td><strong>Process III: Respiratory Acidosis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$P_{ET}CO_2 &gt; 55$ mmHg with appropriately controlled ventilation</td>
<td>I</td>
<td></td>
</tr>
<tr>
<td>Arterial $PaCO_2 &gt; 60$ mmHg with appropriately controlled ventilation</td>
<td>R</td>
<td></td>
</tr>
<tr>
<td>$P_{ET}CO_2 &gt; 60$ mmHg with spontaneous ventilation</td>
<td>I</td>
<td></td>
</tr>
<tr>
<td>Arterial $PaCO_2 &gt; 55$ mmHg with spontaneous ventilation</td>
<td>R</td>
<td></td>
</tr>
<tr>
<td>Inappropriate hypercarbia</td>
<td>I</td>
<td></td>
</tr>
<tr>
<td>Inappropriate tachypnea</td>
<td>R</td>
<td></td>
</tr>
<tr>
<td><strong>Process IV: Temperature Increase</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inappropriately rapid increase in temperature</td>
<td>I</td>
<td></td>
</tr>
<tr>
<td>Inappropriately increased temperature &gt;38.8°C (101.8°F) in the perioperative period</td>
<td>R</td>
<td></td>
</tr>
<tr>
<td><strong>Process V: Cardiac Involvement</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inappropriate sinus tachycardia</td>
<td>I</td>
<td></td>
</tr>
<tr>
<td>Ventricular tachycardia or ventricular fibrillation</td>
<td>R</td>
<td></td>
</tr>
<tr>
<td><strong>Other Indicators Not Part of a Single Process</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arterial base excess more negative than -8mEq/L</td>
<td>I</td>
<td></td>
</tr>
<tr>
<td>Arterial pH &lt;7.25</td>
<td>R</td>
<td></td>
</tr>
<tr>
<td>Rapid reversal of MH signs of metabolic and/or respiratory acidosis with IV dantrolene</td>
<td>I</td>
<td></td>
</tr>
<tr>
<td></td>
<td>R</td>
<td></td>
</tr>
</tbody>
</table>

**Total Score:**

* Number the signs of MH in the order they occurred; I=during initial rx, R=during recrudescence; use 0 if sign did not occur
† See Larach et al 1994. Count only the indicator with the highest points for Processes I-V

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**Review Panel's Clinical Impression**

- Patient experienced: ☐ AMR not related to MH ☐ Possible MH – may include masseter spasm
  - ☐ Probable MH ☐ Fulminant MH
  - ☐ Other (specify): ____________________________________________________________________________

- Were the patient and his/her family referred to an MH diagnostic center? ☐ Y ☐ N ☐ Q ☐ UNK

- If yes, name of Center: ____________________________________________________________

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**Case #________ Reviewer's Initials ____________**

AE = adverse event; ALT = alanine transaminase; AMR = adverse metabolic reaction; Anesth. = anesthetic; Art/Ven = arterial/venous; ASC = ambulatory surgery center; AST = aspartate transaminase; BE = base excess; BPM = beats per minute; CK = creatinine kinase; CPR = cardiopulmonary resuscitation; CPT = Current Procedural Terminology; DIC = disseminated intravascular coagulopathy; ET = endotracheal; ETCO₂ = end-tidal carbon dioxide; ETPCO₂ = end-tidal partial carbon dioxide concentration; F = female; FiO₂ = fraction of inspired oxygen; GI = gastrointestinal; HR = heart rate; I = initial reaction; ICU = intensive care unit; IRB = institutional review board; IV = intravenous; K = potassium; M = male; Max. = maximum; MH = malignant hyperthermia; Min. = minimum; MM/YYYY = month/year; N = no; N/A = not applicable; N/D = not determined; PaCO₂ = arterial carbon dioxide tension; P₂ = partial pressure of carbon dioxide; $P_{ET}CO_2$ = end-tidal pressure of carbon dioxide; pO₂ = partial pressure of oxygen; PPV = positive predictive value; pt = patients; R = recrudescence; Rx = reaction; SIDS = sudden infant death syndrome; Temp. = temperature; UNK = unknown; Y = yes; yr = years.

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Pinyavat et al.