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Clinical paper

Development of a data dictionary for the Strategies for Post Arrest Resuscitation Care (SPARC) network for post cardiac arrest research☆

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ABSTRACT

Background: The widely accepted Utstein style has standardized data collection and analysis in resuscitation and post resuscitation research. However, collection of many of these variables poses significant practical challenges. In addition, several important variables in post resuscitation research are missing.
Objective: Our aim was to develop a comprehensive data dictionary and web-based data collection tool as part of the Strategies for Post Arrest Resuscitation Care (SPARC) Network project, which implemented a knowledge translation program for post cardiac arrest therapeutic hypothermia in 37 Ontario hospitals.
Methods: A list of data variables was generated based on the current Utstein style, previous studies and expert opinion within our group of investigators. We developed a data dictionary by creating clear definitions and establishing abstraction instructions for each variable. The data dictionary was integrated into a web-based collection form allowing for interactive data entry. Two blinded investigators piloted the data collection tool, by performing a retrospective chart review.
Results: A total of 454 variables were included of which 400 were Utstein, 2 were adapted from existing studies and 52 were added to address missing elements. Kappa statistics for two outcome variables, survival to discharge and induction of therapeutic hypothermia were 0.86 and 0.64, respectively.
Conclusion: This is the first attempt in the literature to develop a data dictionary as part of a standardized, pragmatic data collection tool for post cardiac arrest research patients. In addition, our dataset defined important variables that were previously missing. This data collection tool can serve as a reference for future trials in post cardiac arrest care.

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1. Introduction

In 1991, a collaborative effort between the American Heart Association (AHA), European Resuscitation Council (ERC), Heart and Stroke Foundation of Canada and Australian Resuscitation Council published consensus guidelines for uniform reporting of data from out-of-hospital cardiac arrest patients termed the Utstein style.[1] The AHA Science Advisory and Coordinating Committee and the ERC Executive Committee extended the guidelines for reviewing, reporting, and conducting research to in-hospital resuscitation[2] and later to post resuscitation care research.[3] The Utstein style has standardized data collection and analysis, and is widely accepted by researchers in resuscitation. However, due to the large number of discrete variables, information management can be difficult particularly when data collection occurs at various hospitals by different collectors.

Information system management, including the use of a data dictionary, has been recognized as an important tool in data collection and maintenance of databases in clinical research.[4–10] A data dictionary is defined as a descriptive list of names/variables, definitions, and attributes of data elements to be collected in an information database.[11] It standardizes definitions and ensures the consistency of the database to improve data validity and reliability.

The Strategies for Post Arrest Resuscitation Care (SPARC) Network project implemented a knowledge translation (KT) program to improve the delivery of therapeutic hypothermia to post cardiac arrest patients treated at 43 hospitals within southern Ontario. Data collection for this project was planned to occur through retrospective patient chart review and entry of the data into a web-based case report form. The aim of this paper was to describe the development of a comprehensive data dictionary as part of a data collection tool for post cardiac arrest care.

We employed the Utstein standard[3] wherever possible but many of its defined variables posed significant practical challenges for charting and data collection. In addition, there were also sev-

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Table 1
Example of a data variable and its definition and abstraction instructions. A dropdown list of possible entry options can be entered on the web-based collection form.

Question label	Abstraction instructions	List items
Did the patient undergo induced therapeutic hypothermia within 6 h of ED arrival?	Definition: Cooling initiated within 6 h of arrival to hospital. Doctor's orders must be validated by nursing notes stating that cooling therapy was given, e.g. 2 L of cold saline, ice pack applied, cooling blanket applied, therapeutic hypothermia initiated Abstraction instructions: Find and retrieve this information from these sources in the following order: 1. Resuscitation flow sheet; 2. ED nursing record; 3. ICU nursing record; 4. ED physician order sheets; 5. ICU physician order sheets	0. No; 1. Yes

eral important variables for post resuscitation research that were missing in the Utstein standard.

2. Methods

The generation of data variables started with a review of the Utstein style guidelines[1,3] and of previous studies reporting data on post cardiac arrest therapeutic hypothermia[12,13] by the authors (SL, LJM, SCB). This was followed by input of expert opinion within our group of investigators, which consisted of cardiologists, emergency and critical care physicians. Data variables that were considered both important and pragmatic were included in our data dictionary. Primary and secondary outcomes of the SPARC Network project were defined *a priori* and also contributed to the inclusion of variables.

Each variable was then precisely defined while being cognizant of the possible use of different nomenclature at various hospitals (e.g. neuromuscular blocker vs. paralytic). Data abstraction instructions were then developed to aid data collectors in searching the patient chart for each variable. This included a hierarchical order of sources from which each variable were to be collected (e.g. emergency physician's note vs. intensive care unit nursing notes). These instructions aimed to standardize data collection in order to decrease biases within the data pool.

Data variables, definitions and abstraction instructions were integrated into a web-based collection form allowing for password protected, electronic access and interactive data entry. Data could be entered either directly or by scroll down options for many variables. Several measures were implemented to reduce the chance of error in data entry. "Visibility rules", a form of programmed logic embedded within the web-based case report form, allowed certain data entry options to be accessible only when data input to that point in the form met criteria for relevance. For example, the option for entering patient temperature data only became visible on the web data entry form after an affirmative answer to a question regarding the induction of therapeutic hypothermia. A series of automated error checks were also developed to prevent inappropriate data entries (e.g. indicating male gender and pregnancy in the same patient or the time of admission to the intensive care unit occurring before the time of arrival to the emergency department). Altogether, these measures aimed to minimize inappropriate data inputs prior to submission of the collection form to a centralized database.

To check for the feasibility and reliability of each data variable, two blinded reviewers (SL, SCB) piloted the data collection tool by performing a retrospective chart review. This data abstraction was approved by our institutional research ethics board. We employed a convenience sample of 6 out-of-hospital cardiac arrest patients with return of spontaneous circulation (ROSC). Instances of disagreement between investigators with respect to individual data points were examined for root cause of disagreement. Corrections and clarifications in the data variable definitions and data abstraction instructions were proposed and adopted by consensus based on the feasibility of identifying certain data points within the patient chart and issues identified by an analysis of disagreements between the two reviewers abstracting pilot data.

Data collectors were then recruited for the live project. We recruited from among a well-established network of nurse and paramedic data abstractors developed for other cardiac arrest studies administered by our research program. All data collectors were invited to attend a live instructional seminar either in person or via videoconference. The seminars reviewed the case report form, methods of data entry using the form, and detailed descriptions of each data variable required. Questions and concerns from the data abstractors were addressed prior to full implementation of the data collection tool. Each of the data abstractors had immediate access to research program personnel at all times during live data abstraction so that new questions could be addressed promptly.

The variability in data collection and thus accuracy of data analysis has recently received increased attention.[14,15] Variable definitions require further clarification to ensure consistent data collection. Interpretation of variable definitions and source materials by abstractors is a critical step in the acquisition of accurate data.[15] Two separate but similar quality assurance programs were developed to reduce variability and improve the reliability of our prehospital and in-hospital data collection. Our data management team randomly generated a number of completed cases from the previous month for duplicate re-abstraction. Members of SPARC who were blinded and not involved in the data collection for the particular site that related to the case performed the re-abstraction. Discrepancies and errors were corrected as well as analyzed to identify any information biases. These quality assurance programs helped identify systematic errors and improve the data collection process. Using data from 2009 to 2010, we calculated kappa statistics for two important variables, survival to discharge and induction of therapeutic hypothermia <6 h.

3. Results

A total of 454 data variables were included in our data dictionary (Appendix A), of which 400 variables were adapted from the Utstein style guidelines.[1,3] Although many variables from 2 randomized studies[12,13] were also adapted from the Utstein style, we included 2 additional variables specific to these studies. The remaining 52 variables were developed from expert opinion within our group of investigators and were based on primary and secondary outcomes of the SPARC Network project.

Many of the 52 variables were related to patient identifiers as part of database referencing and management. However, there were several new post resuscitation elements that were related to premorbid status, process of care and clinical outcomes. Several premorbid patient characteristics such as pregnancy, bleeding diathesis and prehospital anticoagulation use were included. These elements were considered important in the decision-making process to induce therapeutic hypothermia. In addition, several processes of care elements were included such as an existing cooling protocol and the location of cooling initiation. Although Langhelle et al.[3] mentioned the importance of recording patient

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outcomes including withdrawal of life-sustaining therapy, it was not an included variable in the Utstein template. These additions improved the face and content validity of the tool.

A clear definition and a set of data abstraction instructions including a hierarchical order of sources were developed for each data variable to aid data collectors in searching the patient chart for each variable (Table 1). Variable-specific definitions and abstraction instructions were readily available on the data collection form by *clicking* on a link next to each variable name. All data variables, definitions and abstraction instructions were integrated into a password-protected, web-based collection form allowing for interactive data entry. There were a total of 173 variables that allowed for discrete data responses by way of drop-down boxes. The remaining 281 variables allowed for direct, open-text or numerical data entry. Lastly, a series of automated error checks were developed to prevent inappropriate data entries. An error message would appear to inform each data collector to review specific errors prior to submission to a centralized database.

Depending on the complexity of each patient episode, the time required to complete the data collection form ranged from 15 min to 3 h. However, the vast majority of cases required approximately 1 h to complete. In addition, kappa statistics using 2009 to 2010 data for two important variables, survival to discharge and induction of therapeutic hypothermia <6 h, were 0.86 and 0.64, respectively.

4. Discussion

A comprehensive data dictionary consisting of 454 variables was developed as part of the SPARC network project. The variables were based on the Utstein standard,[1–3] previous studies[12,13] and expert opinion from cardiologists, emergency and critical care physicians, demonstrating face and content validity of the data collection tool. Using these defined variables in our data collection, our goal was to improve the analysis and reporting of our outcomes in post cardiac arrest care. Prior to its dissemination, two blinded investigators piloted the data collection tool. We also developed quality assurance programs whereby random cases were regularly re-abstracted by blinded SPARC members who were not involved in data collection at the respective hospital. These quality assurance programs helped identify sources of error and more importantly, any measurement or misclassification biases during data collection, and were corrected accordingly. We believe that our data dictionary and data collection tool will be important to the resuscitation science community as a pragmatic reference tool to help collect and report clinically important data for future trials in post resuscitation care.

Since the development of the Utstein standard for out-of-hospital resuscitation research, it has been extended to help standardize laboratory,[16] trauma,[17] paediatric trauma,[18] disaster medicine,[19] as well as post resuscitation research.[3] Although the adoption of the Utstein style has met with certain challenges,[20–22] its contributors recognized the value of standardized data variables. Collection of standardized variables enables meaningful comparisons and analyses within and between studies. The Utstein standard for cardiac arrest and post resuscitation research includes a large number of variables, however data collection of many of these variables pose several challenges.[20–22] These challenges include collecting and managing the large number of data variables as well as the use of different nomenclature by different countries and health care systems. In addition, as treatment of cardiac arrest patients becomes more sophisticated, several important variables are missing, including those important in post resuscitation care. To the best of our knowledge, this is the first attempt in the literature to develop a data dictionary as part of a standardized, pragmatic data collection tool for research in post cardiac arrest patients and to further define important variables in post resuscitation research.

Our dataset, developed for the SPARC Network knowledge translation project, was developed to capture the implementation of therapeutic hypothermia within a network of hospital emergency departments and intensive care units. As a result, there are important components of post resuscitation care that are not captured with this dataset. A universal dataset for the post cardiac arrest setting will need to accommodate the study of management strategies beyond therapeutic hypothermia, targeting clinical data relevant to specific components of post cardiac arrest syndrome.[23] These may include ventilatory parameters, hemodynamic data, cardiovascular interventions such as percutaneous coronary intervention, biochemical measurements (e.g. blood glucose), seizure monitoring and control measures, as well as neuroprognostic testing. Broad consultation with the scientific, clinical, regulatory and patient communities, in a process similar to the Utstein conference, is required to reexamine the standard data set for post resuscitation, which will maximize the face and content validity of post resuscitation research.

5. Conclusion

We have developed a data dictionary as part of a standardized data collection tool for research in therapeutic hypothermia for post cardiac arrest patients. This pragmatic data collection tool can help serve as a reference for future clinical trials in post cardiac arrest care. There is a need to reevaluate the current Utstein style list to enable comparable studies in post resuscitation research.

Conflict of interest statement

Dr. Steve Lin: None to declare. Dr. Laurie Morrison has no financial conflicts of interest related to the topic of this manuscript. She is a member of the Advanced Life Support Subcommittee of the American Heart Association. She is the Principle Investigator on unrestricted, peer-reviewed grants from the Heart and Stroke Foundation of Canada, the Canadian Institutes of Health Research, the Laerdal Foundation for Acute Medicine and the Ontario Ministry of Health and Long Term Care to study knowledge translation in post cardiac arrest care. She was a volunteer co-chair of the Advanced Life Support Task Force of the International Liaison Committee on Resuscitation which recently undertook a number of systematic reviews to form the basis of the 2010 Consensus on Science and Treatment Recommendations which included some aspects of post cardiac arrest care. Dr. Steven Brooks has no financial conflicts of interest to declare. He is a member of the American Heart Association Advanced Cardiac Life Support Committee and is an Investigator on several unrestricted, peer-reviewed grants from the Heart and Stroke Foundation of Canada, the Canadian Institutes of Health Research, the Laerdal Foundation for Acute Medicine and the Ontario Ministry of Health and Long Term Care to study knowledge translation in post cardiac arrest care.

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Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at doi:10.1016/j.resuscitation.2010.12.006

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