Title

Research Priorities for Data Collection and Management Within Global Acute and Emergency Care Systems

Authors

Reynolds, Teri A
Bisanzo, Mark
Dworkis, Daniel
et al.

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BREAKOUT SESSION

Research Priorities for Data Collection and Management Within Global Acute and Emergency Care Systems

Teri A. Reynolds, MD, MS, PhD, Mark Bisanzo, MD, DTMH, Daniel Dworkis, MD, PhD, Bhakti Hansoti, MBChB, MPH, Ziad Obermeyer, MD, MPhil, Phil Seidenberg, MD, Mark Hauswald, MS, MD, and Hani Mowafi, MD, MPH

Abstract

Barriers to global emergency care development include a critical lack of data in several areas, including limited documentation of the acute disease burden, lack of agreement on essential components of acute care systems, and a lack of consensus on key analytic elements, such as diagnostic classification schemes and regionally appropriate metrics for impact evaluation. These data gaps obscure the profound health effects of lack of emergency care access in low- and middle-income countries (LMICs). As part of the *Academic Emergency Medicine* consensus conference "Global Health and Emergency Care: A Research Agenda," a breakout group sought to develop a priority research agenda for data collection and management within global emergency care systems.

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The Disease Control Priorities in Developing Countries project estimates that 45% of deaths and 36% of disability-adjusted life-years in low- and middle-income countries (LMICs) could be addressed by the implementation of emergency care systems,[1] but this is only an indirect estimate of conditions judged likely to be amenable to emergency care. Little is known about the actual range and distribution of acute presentations or about the effects of acute care system development interventions in these regions.

Barriers to global emergency care dissemination include a critical lack of data in several areas: limited documentation of the acute disease burden, absence of descriptive or prescriptive accounts of essential components of acute care systems, and the lack of consensus on key analytic elements (such as diagnostic classification schemes to allow comparative analysis and regionally appropriate metrics to evaluate the effects of interventions).[2–5] These data gaps obscure the profound health effects of the lack of access to emergency care, and in

many countries, acute care system development is only slowly becoming a priority.

As part of the *Academic Emergency Medicine* consensus conference "Global Health and Emergency Care: A Research Agenda," the Data Collection and Management workgroup sought to develop a priority research agenda to address these gaps. Given the extensive representation of high-resource settings in existing literature on these topics, we focused our discussion on strategies of inquiry relevant to LMICs. This said, most of the discussion below is relevant to any area where dedicated emergency care system development is in early stages, and some aspects of the discussion apply globally.

PROVISIONAL CATEGORIES

Early in the meeting, the group identified a need for certain provisional categories to facilitate discussion. We accepted the characterization of an acute care visit as any *unscheduled visit for an acute complaint,* including complications of chronic diseases. More generally, we worked with a broad view of acute care, beyond specialty-defined emergency medicine, as the *provision of initial resuscitation, stabilization, and treatment to acutely ill and injured patients.*[6]

We developed research priorities within the framework of the data gaps mentioned above and derived the following related categories to organize the specific research questions: 1) burden of acute disease, 2) acute care in the global setting, 3) classification of acute care system interventions, and 4) metrics to evaluate acute care interventions. Each section in this article includes a brief description of the group's discussion around the topic, followed by a list of specific research questions that emerged.

BURDEN OF ACUTE DISEASE

Acute presentations are not well captured in existing data sets, and this creates an obstacle to quantifying both the need for and the effectiveness of emergency care in LMICs. While there exist sophisticated systems for capturing data on inpatient diagnoses in some LMICs,[7] the burden of disease requiring acute or emergency care is rarely represented as such.[8–10] Facility-based surveillance will miss people who are unable or choose not to seek care for acute conditions, and paper-based charts and poor record-keeping limit capture of data on those who do. In addition, in the absence of a formal prehospital system, most surveillance strategies will miss patients who die before arriving at a facility. Studies that compare police, hospital, and insurance records with other sources, for example, suggest that only a minority of injuries and traumatic deaths are documented in many official counts.[11–14] Beyond this, global funding initiatives and vertical disease-specific programs create a degree of acquisition bias, and current surveillance programs fail to include many acute conditions (or to capture data on acuity) or are based in facilities that miss a substantial portion of the acute disease burden.[15] Even when accurate data are collected on acute presentations,[16–18] diagnostic classification may not be standardized, rendering comparison difficult.

Specific Research Priorities
Characterize the range and distribution of acute disease:

- Conduct Delphi or other consensus process on case definitions for acute diseases and presentations.
- Review existing national surveillance systems, and develop a model to extract an estimate of acute disease burden from existing surveillance data sets.
- Conduct national and international comparisons of diagnostic and chief complaint patterns among centers providing acute care.
- Conduct comparative analysis of diagnoses associated with actual acute illness presentations and health priorities identified in national health plans.

Refine Data Acquisition
- Conduct qualitative research, including semistructured interviews with key informants, to identify barriers to collecting data on the acute disease burden.
- Review existing methods of diagnostic and chief complaint classification systems, with analysis of the effect of specific system characteristics on aggregate results.
- Conduct comparative analysis of a single existing data set classified by multiple systems to evaluate the effect of the classification system.
- Document, in a variety of settings, the minimum viable set of standardized diagnoses that allow capture of at least 80% of acute presentations.
- Field test the above to establish the logistically feasible size of a standardized diagnosis set.

ACUTE CARE IN THE GLOBAL SETTING

For many of the same reasons described in the previous section, much of the acute and emergency care delivered globally is not documented as such. A fundamental challenge is that acute care providers and settings vary greatly from region to region. Only a small fraction of the providers who deliver acute care in LMICs ever receive dedicated training on the management of critically ill patients, and facilities where acute care is delivered span a range of formal and informal centers with varying characteristics.[19–21]

While there have been systematic attempts to describe aspects of emergency care capacity in several regions,[22,23] identifying emergency or acute care facilities remains a challenge in many parts of the world. Acutely ill patients presenting to even a small district hospital in many parts of Africa, for example, may be evaluated in several different areas, based on a variety of presenting characteristics, including sex, age, HIV status, or perception of the chief complaint—an assessment that is often left to nonclinical personnel. Many care facilities have been designed around condition-specific funding streams and may lack dedicated space and personnel for the systematic triage and stabilization of acutely ill patients.

In addition, there is some evidence that patients in low-income countries will not present to formal health

care centers if they perceive the care offered in these settings to be poor,[24] and facility-based surveillance in these countries will likely underestimate the burden of acute disease even more severely than in higher resource settings.

Even where there are dedicated sites to care for acutely ill and injured patients, they may be staffed by rotating personnel who span many cadres and have a range of training backgrounds.[25] As a result, even targeting the appropriate personnel and technical level for acute and emergency care training initiatives can be a challenge.

Specific Research Priorities
- Establish where and by whom emergency care is provided, including community-based and other prehospital components.
- Use a Delphi or other consensus process to define what constitutes an episode of acute care and an acute care setting.
- Conduct qualitative research, including semistructured interviews with key informants, to document current understanding and functional definitions of an acute care provider.
- Conduct qualitative survey- and interview-based research to characterize the most common reasons for, and barriers to, seeking access to acute care.
- Develop a framework to characterize the state of development of acute care systems by nation or region.
- Conduct comparative analysis to establish the relative effect of resource level versus stage of emergency care system development on the distribution of diagnoses.

CLASSIFICATION OF ACUTE CARE SYSTEM INTERVENTIONS

Interventions to improve acute care delivery range from educational and other human capacity-building initiatives, to provision of equipment, medication, and other components of infrastructure.[26–29] Interventions may target individuals, communities, facilities, nations, or regions. The lack of a framework for categorizing acute care development initiatives inhibits both descriptive analysis and the coordination and integration of these efforts. While there is high-quality evidence for the effects of several specific emergent clinical interventions, there is almost no literature evaluating the effects of interventions for acute care *system* development.

Specific Research Priorities
- Development of a survey instrument to document the range of interventions designed to improve acute care systems, including classification by content type (education, physical infrastructure, equipment, etc.) and intervention target (patients, communities, providers, facilities, etc.).
- Conduct Delphi or other consensus process to identify most relevant data collection targets and strategies for different kinds of interventions.

- Develop (via Delphi or other consensus process) a general toolkit for acute care intervention development that assists in identifying milestones, goals, relationship to national health plans, key stakeholders, and terms for evaluation.
- Develop (via Delphi or other consensus process) a specific framework for the elaboration and evaluation of common categories of acute care initiatives that are likely to be repeated in the future, e.g., emergency medicine residency program development; short course training in trauma; and basic and advanced life support, introduction of ultrasound, or other diagnostic technologies.

METRICS TO EVALUATE ACUTE CARE INTERVENTIONS

While there are an increasing number of national and international initiatives aimed explicitly at the development of acute and emergency care capacity, little is known about what makes these programs effective. There is almost no literature with enough descriptive detail to facilitate replication, and effect is often described by the number of facilities visited or providers trained, rather than by measures of provider competence or health outcomes.

While existing data on fundamental metrics such as in-hospital mortality can provide the foundation for evaluating acute care improvements in limited-resource settings, developing relevant and useful metrics requires detailed knowledge of a particular health system. Dedicated emergency care units with resuscitation capacity may draw critically ill patients who would have previously died prior to arrival (or been logged as "brought dead" if they died while waiting for care) and may keep unstable patients in the unit longer prior to admission. Thus, the simple in-unit mortality rate of an effective dedicated emergency unit may actually increase as the interventions available and the quality of care increase. Even the use of seemingly straightforward acute care metrics may have unexpected pitfalls that derive from existing classification conventions. There are sites, for example, that classify all deaths within 24 hours of admission together with patients who are "brought dead," impeding the use of changes in "early" mortality as an outcome to evaluate the effect of acute care system interventions.

Specific Research Priorities
- Identify health metrics to estimate the burden of preventable disease due to lack of adequate acute care services.
- Identify the outcome measures that are important to evaluate interventions at various scales, as classified by target: individuals, communities, facilities, nations, or regions.
- Identify the outcome measures that are important to evaluate interventions as classified by type of metric: economic variables (e.g., classic cost-effectiveness analysis with cost per quality-adjusted life-year); utilization variables (e.g., description of changes in diagnostic and chief complaint case mix, serial changes in identified

barriers to accessing acute care); and behavioral variables (changes in patterns of seeking care).

- Analyze the relationship between proposed metrics and existing metrics from national health plans.
- Review acute care interventions that have successfully changed practice on local or national levels.
- Conduct specific econometric analysis on cost per quality-adjusted life-year for specific sentinel chief complaints and diagnoses in acute care settings.
- Develop advanced modeling to assess the financial and health effects of implementation of proposed acute care initiatives.

CONCLUSIONS

There are several aspects of data collection and management that substantially affect the development of emergency care systems in low- and middle-income countries. These range from documentation of the acute disease burden and identification of essential components of acute care systems to development of analytic schemes to allow comparison and evaluation of acute care initiatives. We have identified four priority areas for near-term research agendas, with specific objectives that might be pursued in parallel. We hope that this framework will serve as a starting point to coordinate collaborative trans-national efforts going forward.

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