

## BREAKOUT SESSION

# Making Recording and Analysis of Chief Complaint a Priority for Global Emergency Care Research in Low-income Countries

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### Abstract

The chief complaint is a patient's self-reported primary reason for presenting for medical care. The clinical utility and analytical importance of recording chief complaints have been widely accepted in highly developed emergency care systems, but this practice is far from universal in global emergency care, especially in limited-resource areas. It is precisely in these settings, however, that the use of chief complaints may have particular benefit. Chief complaints may be used to quantify, analyze, and plan for emergency care and provide valuable information on acute care needs where there are crucial data gaps. Globally, much work has been done to establish local practices around chief complaint collection and use, but no standards have been established and little work has been done to identify minimum effective sets of chief complaints that may be used in limited-resource settings. As part of the *Academic Emergency Medicine* consensus conference, "Global Health and Emergency Care: A Research Agenda," the breakout group on data management identified the lack of research on emergency chief complaints globally—especially in low-income countries where the highest proportion of the world's population resides—as a major gap in global emergency care research. This article reviews global research on emergency chief complaints in high-income countries with developed emergency care systems and sets forth an agenda for future research on chief complaints in limited-resource settings.

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**A**ny analysis of emergency care must take account of a fundamental aspect of the presentation itself: the chief complaint. Despite the fact that the chief complaint is "the patient's reason for seeking care or attention, expressed in terms as close as possible to those used by [the] patient or responsible

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informant,"<sup>1</sup> and "figures prominently in triage decision making, ... history taking, physical examination and diagnostic testing...."<sup>1</sup> it is infrequently captured as a primary data element to quantify, analyze, and plan for emergency care system development. Collecting data on patient chief complaints would enrich information on the epidemiology of emergency presentations and characterize emergency care resource needs in a way that other measures cannot.<sup>2</sup>

## PAST EXPERIENCE

The need for standardization of chief complaint data in emergency care settings is well recognized in high-income countries. In the United States, it was first put on the emergency medicine research agenda more than a decade ago, including at the *Academic Emergency Medicine* 2004 consensus conference "Informatics and Technology in Emergency Care,"<sup>3</sup> the Frontlines of Medicine Project, Data Elements for Emergency Department Systems,<sup>1</sup> the National Center for Health Statistics,<sup>4</sup> the National Syndromic Surveillance conferences,<sup>5</sup> the Canadian Association of Emergency Physicians, and the Victorian Emergency Minimum Dataset Overview.<sup>3</sup> Such efforts focused simultaneously on development of systems for clinical use and research of emergency care while maintaining a capability for syndromic surveillance.

Other efforts have been made by high-income countries with national health systems to establish mapping to standard medical nomenclatures. In Australia, analysts have standardized mapping chief complaints to the Systemized Nomenclature of Medical Disease (SNOMED)—an international standardized medical nomenclature—with a refinement for use in the Australian setting (SNOMED-AUS).<sup>6</sup> The Canadian Emergency Department Information System<sup>7</sup> working group developed a "standardized presenting complaint list" for emergency departments based on both locally derived complaint lists and acuity as determined by the Canadian Triage Assessment Scale (CTAS).<sup>7</sup> Further, efforts have been made in some high-income countries using retrospective analyses of presenting complaints to high-volume emergency care centers to create locally-derived minimum sets of chief complaints that may be used in restricted chief complaint entry systems—notably in Canada with the Canadian Emergency Department Diagnosis Shortlist,<sup>8</sup> the United States,<sup>9</sup> and most recently in Germany.<sup>10</sup>

While there are many reports from low-income countries on the local epidemiology of presentations to local emergency care centers,<sup>11–16</sup> none have derived minimum sets of chief complaints for use in limited-resource settings. No groups to date have established universally accepted global standards for chief complaint use. The systems that have been piloted in high-income countries have not yet been validated across national and cultural boundaries.

### The "Chief Complaint" as an Index of Emergency Medicine Care in Low-resource Settings

Limited data collection and analysis result in gaps in documentation of the burden of disease in low-resource

settings, especially the burden of acute care conditions.<sup>17</sup> This may be due to a variety of factors, including poor real-time data capture on emergency conditions, the lack of a single dedicated venue for caring for acute care cases, and very limited funding for acute care research in limited-resource settings. As such, understanding the emergency care needs in a country may require the use of proxy measures, such as the patient's chief complaint.

**Chief Complaints in Emergency Care.** While chief complaints have strengths and weaknesses for documenting disease burden, it can be argued that they have particular relevance to emergency care as a practice. Emergency care training is modeled around the management of cardinal presentations, and providers must often manage a constellation of signs and symptoms long before they can assign a diagnosis. The management of acute illness and injury can frequently be carried out almost entirely under a syndromic label, where the patient's chief complaint, along with cardinal findings on examination, may drive the course of care.

Further, in settings where prehospital care is available, the use of chief complaints provides a common language between prehospital providers, patients, and emergency care personnel. There have been significant recent advancements in prehospital information systems, such as the National Emergency Medical Services Information System version 3.<sup>18</sup> While originally developed as a U.S. data standard, it has been through Health Level Seven (HL7) International Standard Review and is now awaiting approval as an American National Standards Institute (ANSI) global standard (S. McHenry, personal communication).

**Chief Complaints in Low-resource Settings.** The use of chief complaints to quantify, analyze, and plan for emergency care in low-resource settings has several distinct advantages and disadvantages. Because the chief complaint is either directly or closely related to a patient's own words, its use as a unit of analysis allows for characterization of emergency care by the self-identified needs of patients. Some chief complaints are accurate by definition (e.g., shortness of breath), but others are not (e.g., hematemesis that turns out to be hemoptysis). In either case, chief complaints express a need that is voiced by a patient (or, at times, families, friends, and eyewitnesses) and represent perhaps the only place in the medical record where patients alone are the source of the data.

Consistently recording and analyzing chief complaints as part of the emergency medical record will bolster other initiatives to strengthen emergency care in limited-resource settings. For example, the routine recording and analysis of presenting vital signs for all patients in conjunction with chief complaints can help refine triage in low-resource settings. The evolution of emergency care has mirrored a transformation of triage from a tool of military medicine to one of clinical relevance for civilian emergency care settings. Within this context, chief complaints figure prominently, with certain instances representing potentially high-risk encounters in need of more urgent assessment and treatment (e.g., chest pain, severe shortness of breath).

Analyzing emergency presentations by chief complaint may allow health administrators to plan resource allocation for emergency services even in the setting where advanced diagnostics may not be available. Identifying the basic resources needed to treat a patient who presents with shortness of breath (e.g., an oximeter, radiograph, and supplemental oxygen) may be possible even if the exact etiology of the patient's dyspnea is not known. When used in combination with other key emergency care data (like provisional diagnosis or regional burden of disease) such resources can be further refined (e.g., to institute treatment for resistant TB in settings where TB and HIV are highly prevalent).

In limited-resource settings, as in high-resource settings, chief complaints are the backbone of syndromic surveillance.<sup>2,19–22</sup> Their recording and regular analysis can provide vital sentinel surveillance of index conditions, as well as information on trends regarding prevalent conditions, in settings where the capacity for definitive diagnosis is limited.

### Capturing Chief Complaints

The chief complaint is one of the first pieces of data gathered in any patient encounter in any setting, and unlike provisional or final diagnosis, it does not require interpretation by a highly trained medical provider. In settings where trained providers are a scarce resource, the chief complaint can be reliably recorded by a nurse's aide or even an administrative worker, like a registration clerk, thus freeing up medical personnel for diagnosis and treatment of registered patients.

There are various methods of capturing chief complaints at the initial emergency care encounter. The most basic method is also the most common and involves capturing the chief complaint as closely as possible in the patient's own words in a free-text string. Such a method is compatible with the paper-based information systems present in many limited-resource settings. This method captures, perhaps with the highest fidelity, the patient's articulation of his or her chief complaint. However, the variability introduced in how one patient describes his or her condition versus another poses challenges for researchers and policy-makers who seek to aggregate complaints into categories. To make use of these data, either manual or machine-based interpretation of chief complaints into standard categories is necessary. Various algorithms have been devised to map free-text strings to standard medical nomenclature,<sup>23–27</sup> as well as to numerous medical languages, including the Unified Medical Language System (UMLS),<sup>28</sup> the International Classification of Disease (ICD),<sup>29</sup> SNOMED-CT (Clinical Terms),<sup>30</sup> the Reason for Visit Classification system (RVC),<sup>31</sup> and other systems derived for different national health systems.

Another system involves creating a restricted set of chief complaints from which to choose to classify a patient's presentation. Such a method has the benefit of reducing at the outset the variability in how similar chief complaints are designated. It also obviates the need for expensive information systems or resource-intensive manual classification of chief complaints. This method does move away from the purely patient-centered chief complaint and introduces a risk of

misclassification and perhaps the need for additional training.

### Challenges With the Classification of Chief Complaints

There are additional layers of complexity introduced with chief complaint classification in multilingual settings, as the expression of chief complaint may vary between languages and cultures<sup>32</sup> or where lack of familiarity with the health care encounter can limit a patient's ability to articulate the problem to a provider. There is a need for harmonization of chief complaint concepts across cultural divides to conduct regional and global emergency care research.

The use of any restricted entry system requires the derivation of a robust set of standardized chief complaints, and little research has been done to identify what constitutes a "robust" set in specific limited-resource settings. In high-resource settings, there is a strong emphasis placed on the ability of any system to capture *all* chief complaints, but this may not be essential. The ability to capture a large enough percentage of chief complaints to define the local epidemiology of emergency presentations and to plan for the delivery of emergency care would be a major advancement to the current state of affairs in most parts of the world. While there has been some research in minimum data sets for emergency chief complaints, such research has primarily taken place in high-income countries like Canada and Germany and has yet to be conducted in limited-resource settings. In addition, there has not yet been research on how to define a threshold, or saturation point, for the number of presentations necessary (in absolute terms or as a percentage of presentations) to accurately characterize the epidemiology of emergency chief complaints.

In addition, the vast majority of emergency care settings around the world still use analog paper records. The lack of digital health information systems in low-resource settings necessitates the use of expensive and time-consuming manual reclassification of chief complaints after the time of initial presentation. While the use of paper records does not preclude the use of a restricted set of chief complaints, the possibility of introduction of narrative data "in the margins" of paper records would require at least manual spot review of records to ensure fidelity and accuracy of coding. Even the use of machine-based methods, where available, requires development of natural language processing algorithms in local languages that may be beyond the information technology capacities of low-resource countries.

Further, the use of chief complaint as a proxy measure will not obviate the need for recording and refining other parameters like provisional or final diagnosis. There is a loss of granularity with chief complaints that has important consequences for researchers and decision-makers alike. While there may be similar training for providers to approach all causes of shortness of breath, the distinction between congestive heart failure and pneumonia will be important for anyone making pharmaceutical procurement decisions, for example.

Finally, emergency chief complaints can only describe the epidemiology of presentations to acute care settings and are limited in their ability to describe the overall

epidemiology in a given community. By definition, they are skewed to populations that have symptoms for which care is culturally sought from “mainstream” medical providers, those that have access to health facilities, and those with resources to pay for care at an emergency care facility. To estimate the proportion of emergencies represented by chief complaints recorded at acute care facilities, population-based research is needed. This has been done for some acute presentations, like maternal mortality,<sup>33–35</sup> but to our knowledge, has not been widely used to assess the prevalence of emergency conditions more broadly in low-resource communities around the world.

### Moving Forward: Chief Complaints as Part of a Global EM Research Agenda

There is a dearth of data on emergency care in limited-resource settings, despite the fact that the majority of the world’s population resides in such settings. These settings also represent the regions of the greatest population growth in the future.<sup>36</sup> Rapid urbanization will ensure that ever-greater percentages of the population in low-income countries will reside near formal health care centers and seek episodic care.<sup>36</sup> The expansion of emergency care services, the further development of emergency medicine as a recognized discipline globally, and this urbanization will make accurate characterization of the epidemiology of emergency care essential to any national health plan.

There are several approaches to address current knowledge gaps via research on chief complaints. First, more research needs to be done to establish chief complaint variation across a variety of care venues. Because such research may initially be conducted at high-volume tertiary care facilities, and a large percentage of the population may not live within range of these facilities, research needs to be conducted at district hospitals and health posts to assess for any differences between high-volume and low-volume centers

Second, retrospective and prospective analyses should be conducted to establish locally derived minimum sets of emergency chief complaints. Capturing every complaint may be beyond the capacity of many low-resource countries and beyond what is necessary to describe and plan for emergency care; therefore, research should establish the minimum number or percentage of presentations that can capture a majority of presenting chief complaints. The Canadian experience from the Canadian ED Diagnosis Shortlist resulted in a list of 837 chief complaints that covered 99% of all presenting complaints.<sup>8</sup> Aronsky et al.<sup>9</sup> produced a more streamlined list of 54 chief complaints with three free-text modifiers that similarly captured a large percentage of chief complaints at a U.S. emergency department. These sets may be used to aggregate and categorize patient presentations for analysis by researchers and policy-makers.

Third, collaborative consensus-based multinational research should be conducted to evaluate the feasibility of developing minimum sets that are generalizable across geographic and cultural boundaries. This can be further elaborated by subjecting these minimum sets of chief complaints to validation by cognitive testing on the selected terms or performing cultural review of these

minimum sets to assess how certain chief complaints may vary by sex, age, and culture. Such research would be invaluable in advancing knowledge of emergency care presentations globally as well as helping pave the way for regional and global emergency care research.

Fourth, evaluation of existing systems can ascertain their ability to capture chief complaints and to facilitate comparative analysis to other known data about a given setting (e.g., burden of certain disease). This analysis might bring together regional health experts via a Delphi process. Such analyses would initially be retrospective, but would require prospective application and field testing across a variety of emergency care venues.

Last, given that short-term resource constraints may preclude the development of prospective research into emergency chief complaints in many low-income countries, alternative research should be conducted to assess whether minimum sets of chief complaints can be extracted from existing sources. Examples of such available data sets may include but are not limited to minimum sets established in high-income countries, existing national ambulatory care data, and national or regional burden of disease estimates. Any such modeled minimum sets will need to be prospectively piloted to establish their validity in low-income countries.

### CONCLUSIONS

Chief complaints are an essential component of emergency care and are critical for research, training, and resource allocation. While the granularity of emergency conditions will never be fully captured by the use of chief complaint data (e.g., stopping at the level of “shortness of breath” rather than identifying etiology), chief complaint data are likely sufficient to describe a large percentage of emergency care resource and training needs. Although efforts have been made to establish standards for chief complaint nomenclature and minimum data sets in high-income countries, there is a paucity of such research in low-income countries where the majority of the world’s population lives and where the greatest growth in population growth is expected to occur. Future global emergency care research should include chief complaint as an essential parameter to describe the needs of populations in low-income countries.

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