

# MANAGEMENT OF KAWASAKI DISEASE IN TEXAS: POLICY IMPLICATIONS

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# INTRODUCTION

- Kawasaki Disease (KD): Clinical Description:
  - An acute febrile illness that often affects children under age 5 years old.
  - Can potentially affect the heart and its larger arteries.
  - Currently the leading cause of acquired cardiovascular disease in children in the U.S.
- KD cause is unknown, but if symptoms are recognized early, children with KD can fully recover in a few days.
- If untreated, KD can lead to an aneurism of the coronaries arteries, myocarditis, toxic shock, and sudden death.

# INTRODUCTION (cont.)

- Since KD is the leading cause of acquired heart disease for children in the U.S. and with sudden deaths resulting from coronary aneurysm and/or thrombosis, the societal benefit in reducing KD is apparent.
- The financial costs and benefits of more accurate KD diagnosis and treatment will be further quantifiable when accurate incidence is identified and addressed.
- Estimation of national and state incidence of KD has been difficult due to the sporadic reporting of cases to the CDC and all KD tracking and reporting is left to state agencies to enforce.

# INTRODUCTION (cont.)

- Only a fraction of the total cases are reported.
  - As is the case with any large passive surveillance system.
- Researchers have been forced to rely on hospital discharge data for records of KD surveillance and reporting.
  - Mild cases or outpatients are lost and not counted.



# INTRODUCTION (cont.)

## Centers for Disease Control and Prevention (CDC) & KD

- The CDC has maintained a “passive” or voluntary surveillance system for tracking KD in the U.S. since 1976.
- While the CDC offers a standardized case report form to collect information about KD patients’ age, gender, race, residence, clinical data, complications, and outcomes, many forms are not filed properly.
- In 1984, the CDC released a computerized database, and a passive reporting system for KD was implemented in 22 states, but poor compliance with reporting procedures has prevented an accurate estimate of the number of cases diagnosed each year.

# INTRODUCTION (cont.)

- The number of states reporting KD has declined from a high of 29 in 1994 to a low of 11 in 2002.
- “Active surveillance” would require formal protocol for recording observations of the disease and reporting all suspected cases of KD and the circumstances under which hospital admission occurred.
- Moreover, through active surveillance better estimates of KD incidence and rates of long-term complications can be made available to the medical community and the public.

# PURPOSE OF THE RESEARCH STUDY

- This research study's main objective was to identify the policy factors related to KD reporting, either via passive or active reporting, to the CDC.

# METHODOLOGY

- The literature review used in this study followed the normal methodologies of a systematic search and was limited to articles and databases published in the English language.
- All electronic articles came from
  1. Four electronic databases, including EBSCOHost, Medline, Springer, and Pub Med.
  2. Internet search engines, such as Google Scholar and Dogpile.
- Agency Websites:
  - Centers for Disease and Control (CDC).
  - American Heart Foundation (AHA).
  - Kawasaki Disease Foundation.
  - World Health Organization.

# METHODOLOGY (cont.)

- All articles referenced and researched for the literature review were published within the last 10 years (1999-2010).
- The majority of articles used were compiled through the following search terms:
  - “Kawasaki disease” OR “Kawasaki Syndrome” in conjunction with the Boolean “AND” with “policy,” “passive surveillance,” OR “public health,” OR “active surveillance.”

# RESULTS

## Surveillance of KD in San Diego County, California

- In 1994, San Diego, CA, implemented passive KD surveillance
- KD was reported through the recognition, identification, and reporting of each case by healthcare providers to the San Diego HHS (epidemiology).
- In 1997, in a retrospective review of hospital discharge data for San Diego County using the 1994-1995 data , the following were demonstrated:
  1. Only 2/3 of the eligible KD patients for county and state levels were reported.
  2. A COMPLETE FAILURE to report any KD cases to the CDC.

# RESULTS (cont.)

- From this study, we recommended the implementation of a sentinel hospital reporting system, or an **active surveillance system**, as an alternative to the national passive surveillance system for tracking patients diagnosed with KD.
- The issue of acquiring accurate KD data remains problematic.
- Active surveillance will require reporting, collecting, storing, tracking, and disseminating confidential data regarding KD patients from registries or centralized databases and intervention at the regulatory and legislative levels.

# RESULTS (cont.)

- Several policy issues are of concern to legislative bodies, public health professionals, and the public:
  - Patient privacy issues due to provisions of the Health Insurance Portability and Accountability Act of 1996 (HIPAA).
  - Perceptions of governmental intrusion.
  - Ethical issues such as the potential for stigmatization (i.e., threat to autonomy).



# RESULTS (cont.)

## The Flipside of *Active Surveillance*

- Costly
- Involves outreach, such as regular telephone calls or visits to laboratories, hospitals, and providers to stimulate reporting of specific diseases (CDC, 2007).
- Places intensive demands on resources
- Should be limited in use only to brief or sequential periods of time and for specific purposes, according to the CDC.

# DISCUSSION

- The Texas Birth Defects Registry is an excellent example of how legislation can be used to create a centralized state-wide registry, control its use, safeguard privacy, provide for appropriate oversight, and limit access to the information contained in the registry.
- A statewide KD registry could be created and maintained in like manner in a state of Texas' size.
- Another purpose for a KD registry could be to establish the etiology of KD.



# DISCUSSION (cont.)

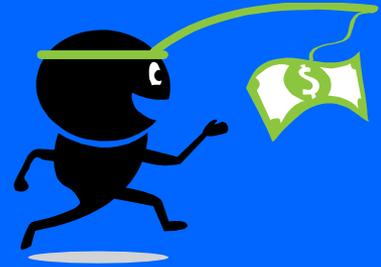


- Critical diseases likely to affect public health, like the swine (H1N1) flu, have been managed by the CDC with sentinel physicians and active reporting.
- KD is misdiagnosed 51% of the time, so monitoring its prevalence more accurately may lead to a more accurate diagnosis rate and less long term health and cardiac complications for children with KD.



# DISCUSSION (cont.)

- High cost in times of recession also plays a role in the failure to monitor KD.
- The central public health policy problem involving KD is the need for educating healthcare providers.
- For that goal is needed the acquisition of accurate and timely data on all suspected KD cases for purposes of early diagnosis, patient tracking, and determining the cause of the disease.



# CONCLUSION



In order for pediatricians, emergency room providers, and primary care physicians to stay abreast of the latest developments in pediatric medicine and infectious diseases,



(1) continuing medical education about KD and  
(2) better (or at the very least, more accurate) surveillance must be conducted across the nation.

Questions?

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