Critical Value Reporting: The Need To Develop Appropriate Communication Channels

Ken Obenson MD FRCPC
Saint John Regional Hospital NB
Dalhousie University

Critical values

May be defined as any result of a coronial postmortem examination (PME) that:
- PROMPTS expeditious testing/monitoring of the decedent's relatives
- MUST be rapidly communicated to the next of kin (NOK)

For example

Hypertrophic cardiomyopathy (HCM) in a 5-year-old girl
Inheritance: Autosomal dominant and may be familial

Is this a critical value?
Living relatives may be asymptomatic but carry the same gene. And therefore be at risk of sudden death themselves!!

Arrhythmogenic right ventricular dysplasia (ARVD)

In a 17 year old semi professional hockey player

Is it a critical value?

Inheritance: Autosomal dominant - 30 to 50% of victims will test positive for one of several mutations. Living relatives may asymptomatic and yet be at risk of sudden death themselves!!
How are the results communicated?

There should be a clearly defined mechanism to notify (NOK) and their family doctor (FD).

FDs role is to guide them as they seek medical advice on options for diagnosis or treatment.

In some parts of the world…

Such as NB, Canada forensic pathologists are not permitted under provincial law to make such disclosures to relatives or to the FD.

This can delay communication of critical values.

Privacy legislation in NB

Patient/decedent personal information

Right to Information and Protection of Privacy Act (RTIPPA).
RTIPPA

Under the act, “personal information about individuals held by public institutions is well protected and handled only in accordance with generally accepted privacy principles.”

The NB coroner’s office is part of the Department of Public Safety, and therefore subject to RTIPPA.

So what are the processes for notification in this situation?

A 23 year-old female with bilateral MAMMARY invasive carcinoma of no special type with metastases kept her disease private found dead in a hotel across state lines.

Why would it be a “critical” value?

Approximately 9% of breast cancers are associated with inherited gene mutations. Hereditary cancers tend to develop earlier and new (primary) tumors are more likely to be bilateral

What would you do or are permitted to do…?

Do nothing
Write a report
Call the Family doctor (FD)
Call 911
Call/email the chief coroner
Arrange a sit down with the family
Limitations of the Act

FORENSIC PATHOLOGIST IS NOT AUTHORIZED TO CONTACT FAMILY DIRECTLY

The FDs do not have an automatic right to know when a patient registered in their practice dies

FD does not have an automatic right to know the cause or manner of death.

ONLY The NOK can authorize the coroner to distribute copies of the postmortem report to the FD.

MAXIMIZING the forensic pathologists role

Forensic pathologist must transmit critical values through an intermediary - the coroner

PME report must be succinct and emphasize the importance to the family of following up with their FD

Follow up call to coroner should be part of SOP - document it

A 23 year old GSW victim with...

Colonic polypsis (familial adenomatous polyposis) FAP

Why is it a “critical” value? Genetic may be autosomal dominant or recessive

The incidence of malignancy in Familial Adenomatous Polyposis approaches 100%

Diagnosis is important to surviving family members who may carry the gene, regardless of the traumatic cause of death
LCHAD deficiency in a 12 month old male

Why is this a critical value?

Where a SIDS death has occurred, the autosomal recessive mode of inheritance indicates that...

- Another child in the same family could have the disease.
- A subsequent pregnancy could result in a child with the disease. The parents can receive appropriate genetic counseling.

“Not-so” critical values

- Ischemic coronary artery disease in a 75 year old male
- Enlarged yellow fatty liver with gallstones in a middle aged alcoholic male
- A surgically absent spleen in a 20 yo female s/p remote mva
- Unusually tall, with long limbs in 28 yo male in the absence of other stigmata of Marfans (“pigeon” chest, aortic dilation or dissection, mitral valve prolapse)

Why they ARE not LIKELY TO be deemed critical

- Is there a danger of sudden death from an inherited condition?
- Is there a danger that an infectious disease has been transmitted?
- Is there a potentially fatal environmental condition that would require monitoring/investigation?
In sum

Identify with “stakeholders” what critical values for your jurisdiction should be. Reach a consensus (ensures buy-in)

Discuss with stakeholders what the communication process should be- PREVENTS “we did not know” SCENARIOS….

Develop and update an SOP that includes notification protocols

Test them!!!

QUESTIONS

References


Government of New Brunswick. Making a request for information. https://www2.gnb.ca/content/gnb/en/departments/treasury_board/office_of_the_chief_information_officer/content/requisitions.html