

Autopsy and Verbal Autopsy: Seeking the Deadly Truth
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Introduction

This chapter will explore the topic of autopsy and the developing practice of verbal autopsy. First we highlight the historical perspective of the classic autopsy, current national initiatives and then the challenges facing the age-old practice . Next we turn to the global significance of accurate vital statistics, barriers to classic autopsy abroad, and then what the verbal autopsy has to offer in its place. By the end of this chapter, you should be able to consider the verbal autopsy as a valid and necessary approach for acquiring accurate cause-specific mortality data in developing countries. Possible utilization of the verbal autopsy in the developed world and maximizing the practice of classic autopsy will also be addressed at the end.

The Autopsy

The term “autopsy” means “to see for oneself”, and is also known as a “post-mortem examination, necropsy, or obduction”. It refers to a medical procedure performed by a specialized medical doctor called a pathologist. They can be performed for either legal or medical purposes. When the cause of death may be a criminal matter, a forensic autopsy may be performed to investigate and gather evidence. A clinical or academic autopsy is performed with the next of kin’s permission when cause of death is unclear or for research purposes.¹

Even though the concept and general practice of autopsy has been around for more than a millennium, Giovanni Morgagni, a physician and professor at the University of Padua, is credited for being the autopsy's "intellectual founder".² In his text, "The Seats and Causes of Disease Investigated by Anatomy" published in 1761, Morgagni describes 700 autopsies performed.² Many credit him for being one of the first to present the then new idea of disease as a traceable, logical entity instead of a result of "humors" or spirits.² Another important name in the history of autopsy is William Osler, a Canadian physician, who practiced and taught medicine in the United States in the late 1800's. Medical students today have him to thank for the current model of medical education where they enter their critical clinical training during the third year of medical school. The autopsy was placed at the center of this education. He performed greater than a thousand post-mortems and insisted that staff and students dedicate time to them as well.²

The power of autopsy was further exposed by Richard Clarke Cabot in the early 1910's. He reviewed thousands of autopsy records from patients at Massachusetts General Hospital and found the clinical diagnoses to be wrong about 40% of the time. The rates of autopsies being performed began to rise and by World War II they became part of standard medical school curriculum.² The autopsy is credited for the reduction in morbidity and mortality from certain medical conditions, like aortic dissections for example. Similarly they also "played central roles in diagnosing and spurring treatment for sudden infant death syndrome, Legionnaires' disease, toxic-shock syndrome, hantavirus, H.I.V., Ebola and other infectious diseases" and even assisted in making the association between lung cancer and smoking.²

In the history of medicine as well as in the current modern medical world, nothing else compares to the hospital autopsy for unveiling medical errors and oversights. Dr. Alan Schiller is chairman of pathology at Mount Sinai School of Medicine in New York. A contemporary champion of the low-tech hospital autopsy, he feels that it provides “a uniquely effective means of quality control and knowledge” even in today’s high-tech medical world.² Schiller says it is the most powerful tool in medicine, exposing “mistakes, bad habits, (it) evaluates diagnostic and treatment routines and detects new disease, (it) is responsible for most of our knowledge of anatomy and disease, and it remains vital”.²

In a 1998 article, Dr. George Lundberg, a pathologist and editor for The Journal of the American Medical Association (JAMA), published an article in 1998 reviewing discrepancies between clinical diagnoses and autopsy findings. He reported that numerous studies over the last century have found an undiagnosed cause of death in 25-40% of cases where autopsy was performed.² The findings were very similar to the first discrepancy studies in 1910; “low-tech autopsy trumps high-tech medicine...again and again”.² Medicine assumes that the information on death certificates is accurate and dependable. However the published medical literature reveals another truth. One study by Ravakhah looked at the accuracy of death certificates in reporting vital statistics with an emphasis on cardiac deaths. His investigation revealed frequent major discrepancies of commission and omission between death certificates and autopsy. The death certificate missed acute myocardial infarction in 25 of 52 autopsy-proven cases and conversely it wrongly asserted the presence of an acute myocardial infarction in 9/36 cases.³ A recent meta-analysis and review by Roulson et al claims that at least a third of

death certificates are likely to be incorrect and 50% of autopsies produce findings unsuspected before death.⁴

Despite its known power for truth, the autopsy has been neglected by the very institutions that originally brought it to the forefront of medical practice. In the 1960s, hospitals in the United States autopsied almost half of all deaths. Hospitals in the US now perform autopsies on fewer than 5% of hospital deaths.² When Dr. Lunberg talks to doctors' groups or health-care policy makers, they all generally agree that more autopsies need to be performed. However nobody seems to put that agreement into action; "the forces arrayed against the autopsy—regulatory, economic and cultural—seem to overcome any impulse to revive it".² The neglect of autopsy seems to be multi-factorial. First there are the many pathologists who don't like doing them. The procedure can take between 2-4 hours and takes away time spent on urgent analysis of samples taken from living patients. Careers and status are seldom advanced with the practice of autopsy and most hospitals don't pay extra for their special skill.²

Money is the hospital's excuse for decreasing the number of autopsies performed. Insurance usually doesn't cover the estimated \$2,000-4,000 ticket price and most families can't afford to pay it themselves after funeral and medical bills.² From about the 1950s to the 1970s, the Joint Commission on Accreditation of Healthcare Organization (JACHO) held a 20% quota rate for all hospitals to maintain as the necessary minimal for acceptable quality control. Some feel that the commission was pressured by hospitals to get rid of this quota since they were trying to meet higher and higher costs of medical care for the living.² By 1971 the quota was removed. Others argue that hospitals DO have the money to perform more autopsies but that they just don't want to allocate their

resources to something they don't value as much as buying the newest MRI machine or laser surgical equipment.² Medicare actually does include an autopsy allowance in the lump sum it pays hospitals for each patient. Three-quarters of hospitalized deaths are Medicare patients, easily financing double-digit autopsy rates if they so chose.²

“Lundberg and others have urged the Department of Health and Human Services to make Medicare payments contingent on hospitals' meeting a certain autopsy rate. But the agency shows no interest in doing so.”²

Vital Statistics and Barriers to Autopsy

Why is it important to know the “true” cause of death? Besides the obvious reasons of family closure and the necessary quality control for medical error and improvement, there is a broader public health issue related to the information autopsy provides. Vital Statistics refer to the “information maintained by a government, recording the birth and death of individuals within that government's jurisdiction. These data are used by public health programs to evaluate how effective are their programs and are the cornerstone to public health systems today”.⁵ The National Center for Health Statistics (NCHS), a division of the Centers for Disease Control and Prevention (CDC), is the agency responsible for overseeing this system in the United States.

In 2001 the NCHS along with The Autopsy Committee of the College of American Pathologists published a series of articles entitled, “The Autopsy, Medicine, and Mortality Statistics”.⁶ They highlight that accurate reporting of cause of death is vital to the continued development of quality medical care and effective public health programs; “Death certificate information is a major source of statistical data to identify

public health problems, to monitor progress in public health, to allocate research funds, and to conduct scientific research".⁶ Multiple studies show the need for improving our national mortality data derived from death certificates.⁶ Despite modern medical marvels being developed every day, nothing can validate or correct the death certificate like the autopsy.

Barriers to obtaining higher rates of autopsy have briefly been mentioned in an earlier section. They include JACOH's elimination of autopsy requirements for hospital accreditation in the early 1970s and that the expense of performing the autopsy is often not reimbursed by third-party payers. Other reasons cited include the cumbersome process for obtaining consent to the procedures. The next of kin must be approached by the involved physician during an obvious difficult time. For the last 30 years or so, physicians have not had active education on both the practice of and the family communication aspect of autopsy. One study showed that even when physicians claimed they would approach a family with an autopsy request, over 70% of them did not when the situation arose.² Another barrier cited is that the overall decline in autopsy rate is due to physicians believing that the autopsy has lost its value.⁶ More and more physicians are instead relying on the radiologist's dictation from the latest imaging studies, finding undeserved reassurance in the newest and most expensive medical technologies.⁶

International Public Health Implications

The need for accurate death certificates is magnified globally. Only about one-third of all deaths are registered with a full set of basic information like age, sex, and cause and the vast majority of these registered deaths are in developed countries.⁷

Scarce information about cause-specific mortality is available for the countries with the highest burden of disease. Demographic surveillance sites are the primary source for cause of death information in the developing world and have been shown to be unreliable at best.⁷ General Jong-Wook Lee, director of the World Health Organization (WHO) addressed his staff in 2003 about the urgency of this problem: “To make people count, we first need to be able to count people”.⁷

A “gathering storm” is brewing the longer this critical data is left undiscovered; “the crisis is being precipitated by the rapid escalation in national data demands and in reporting requirements for international initiatives, many of which require summary measures of survival and/or cause-specific mortality as indicators of program impact.”⁷ The existing systems in place for recording deaths globally include vital registration and demographic surveillance. Vital registration does not have sufficient coverage to provide accurate data and since it is mostly government-sponsored, many citizens of developing nations fail to report births and deaths either out of physical location barriers or out of fear and/or severe mistrust of the system. Demographic surveillance is where all deaths are reported on a regular basis throughout the year (often once every two weeks) and are commonly used to evaluate the impact of new health interventions before introduction to wider populations.⁸ It is expensive to set up and maintain, only exists in a limited number of countries, and cause-specific mortality cannot be generalized to wider populations.⁸

The clinical autopsy is usually an unrealistic option for most deaths occurring in the developing world. In the United States the average doctor-patient ratio is 1:390 whereas in sub-Saharan Africa it is 1:50,000.⁹ The 2006 World Health Report estimates

that there are currently 57 countries with critical shortages equivalent to a global deficit of 2.4 million doctors, nurses, and midwives. Surprisingly these deficits are more than likely to be found in countries housing a very large number of unemployed health professionals.⁹ “Poverty, imperfect private labor markets, lack of public funds, bureaucratic red tape and political interference produce this paradox of shortages in the midst of underutilized talent.”⁹ It is highly likely that many people living in developing countries could spend their entire life without ever seeing a doctor and would never expect to be formally evaluated by one in death.¹⁰

The Verbal Autopsy

To address the growing need for acquiring accurate vital statistics in the global world, the technique of verbal autopsy has been developed and investigated as a reliable method for the “community diagnosis” of major causes of death.⁸ Verbal autopsy has been utilized into routine functions of local health authorities and has demonstrated production of valid estimates of cause-specific mortality in many settings.⁸ Verbal autopsy is a method of finding out the cause of death based on an interview with next of kin or other available caregivers. The interview focuses not only on demographic data, but asks about symptoms experienced before death and the specific circumstances surrounding death. The survey is carried out by trained personnel and usually doctors review the forms and assign a specific cause of death using standardized ICD codes.

In developing countries the verbal autopsy can be a vital substitute for the clinical autopsy. It can provide data on mortality by cause, evaluate health interventions, identify health-seeking behavior and health service provision, and facilitate research into factors

associated with case-specific mortality.⁸ An initiative co-sponsored by the WHO from 1992-2004 implemented and validated the process of verbal autopsy first in Tanzania and then in China, India, Malawi, Ethiopia, and Cameroon; “Experiences from India, China, and Tanzania have shown how, in just a few steps, information generated through community-based mortality surveillance using verbal autopsy can generate statistics that influence policy, practice, monitoring, and evaluation”.⁸ The technique has been used for obtaining both child and adult mortality information. For the next decade the WHO and the United Nations Children’s Fund have ordered for the expanded use of the verbal autopsy to monitor child mortality specifically.⁷

The procedure for verbal autopsy can be broken down into 4 steps: 1) The event of death is registered using community reporters, 2) Trained interviewers visit households of the deceased within specified time periods after death and conduct structured verbal autopsy interviews with family members and care-givers of the deceased, 3) Causes of death are assigned and coded. Physician certifiers assign a specific cause of death and write the death certificate after full review of the interview forms and according to the internationally agreed format, 4) Cause specific mortality data can then be tabulated. These data “are fed into routine reporting, planning, and monitoring documents and...allow not only assessment of current cause structure of mortality, but also an analysis of trends”.⁸

The actual forms themselves were developed with flexibility and adaptability in mind. Keeping in mind cost implications, all forms fit on two pages. Both medically and non-medically trained interviewers with differing levels of literacy were considered when creating the forms. And finally all forms follow a similar structure:⁸

- * Demographic information, including place of death
- * Cause of death from the perspective of the respondent
- * Short narrative history
- * Symptom duration checklist
- * Utilization of health services in period before death
- * Any medical evidence available at the household

Figure 1: Part of a Verbal Autopsy Form ~WHO Standard Verbal Autopsy Method

Symptom Review:

8.17 During the illness that led to death, did he/she have a bulging fontanelle?

- 1. Yes
- 2. No
- 3. Don't know

8.18 During the illness that led to death, did he/she have "tetanus" (local words)?

- 1. Yes
- 2. No
- 3. Don't know

Note: When preparing the country-specific questionnaire include local terms for tetanus here.

8.19 During the illness that led to death, did he/she have yellow eyes?

- 1. Yes
- 2. No
- 3. Don't know

8.20 During the illness that led to death, did he/she have redness or drainage from the umbilical cord stump?

- 1. Yes
- 2. No
- 3. Don't know

8.21 During the illness that led to death, did he/she have areas of skin that were red and hot?

- 1. Yes
- 2. No
- 3. Don't know

8.22 During the illness that led to death, did he/she have a skin rash with bumps containing pus?

- 1. Yes
- 2. No
- 3. Don't know

8.23 During the illness that led to death, did he/she have a fever?

1. Yes 2. No 3. Don't know
(If "No" or "Don't know", go to question 8.24)
8.23.1 (If fever ask): How many days did the fever last? __ __ days

Figure 2: Part of a Verbal Autopsy Form ~WHO Standard Verbal Autopsy Method

Treatment and Records:

I would now like to ask a few questions about any drugs _____ may have received during the illness that led to death.

10.1 Did _____ receive any of the following?

10.1.1 Antibiotics

- 1. Yes
- 2. No
- 3. Don't know

10.1.2 Chloroquine

- 1. Yes
- 2. No
- 3. Don't know

10.1.3 Aspirin

- 1. Yes
- 2. No
- 3. Don't know

10.2 Do you have any health records that belonged to _____?

- 1. Yes 2. No 3. Don't know

(If "No" or Don't know", go to question 10.5)

10.2.1 (If yes ask): Can I see the health records?

- 1. Yes 2. No 3. Don't know

(If "No" or Don't know", go to question 10.5)

If respondent allows you to see the health records, transcribe all the entries within the 12 months before the child died.

10.3 Weights (most recent two)

10.3.1 Record the dates of the most recent weight two weights

- 1. __/__/__ (dd/mm/yy)
- 2. __/__/__ (dd/mm/yy)

10.3.2 Record the most recent two weights . .

- 1. kg __. __
- 2. kg __. __

10.4 Medical notes

10.4.1 Record the date of the last note. . . __/__/__ (dd/mm/yy)

10.4.2 Transcribe the note _____

{To view a complete form, see “A Standard Verbal Autopsy Method for Investigating Causes of Death in Infants and Children”: World Health Organization, Johns Hopkins School of Hygiene & Public Health, London School of Hygiene & Tropical Medicine. (WHO/CDS/CSR/ISR/99.4). Geneva: WHO, 1999 (Anker, M; Black, RE; Coldham, C; Kalter, HD; Quigley, MA; Ross, D; Snow, RW.) }

There are several assumptions for proper use of the verbal autopsy. 1) Each cause of death should have a set of observable features that can be recalled. 2) These features can be distinguished from one another. 3) Accuracy of the estimates will vary according to the population under study. 4) Cultural aspects influence accuracy.⁸ With regards to distinguishing specific disease symptoms, multiple validation studies have shown that verbal autopsy has different sensitivities and specificities when comparing different diagnoses. For example for acute diarrhea, sensitivity is close to 57% and specificity is about 95%. For malaria the sensitivity ranges from 24-55% and specificity from 48-93%.⁸ This can be explained by the fact that malaria is a constellation of very vague and nonspecific symptoms while diarrhea is easily determined to exist or not to exist with the interview. In other words, if a child did not die from malaria, by completing the verbal autopsy section on “malaria-symptoms” you have a chance of incorrectly identifying “malaria” as the cause of death due to the low specificity of this section. Whereas by completing the section on “diarrhea-symptoms”, you have a greater chance of correctly identifying those children that DID NOT die from diarrhea. See Table 1 below for an example of the sensitivity/specificity findings from Nicaragua for acute diarrhea.

**Table 1: Acute Diarrhea Neonates—Death and Survivors combined
Nicaragua**

Hospital Reference Diagnosis:

Caregiver’s history of liquid, watery, loose or soft stools for <14 days and either medically noted liquid/semi-liquid or watery stools or medically noted dehydration and no medically noted blood in stools.

	N1= 23	N2 = 314
Verbal autopsy algorithm	Sensitivity (N3)	Specificity (N4)
Acute diarrhea		
1. Frequent liquid/watery/loose or soft stools <14 days and no blood in stools	52% (21)	96% (270)
2. Local term for diarrhoea <14 days and no blood in stools	57% (21)	95% (266)
3. Frequent liquid/watery/or loose or soft stools or local term for diarrhoea for <14 days and no blood in stools	57% (21)	94% (270)

Notes:

N1 = Number of cases with a positive hospital diagnosis, and a caregiver interview.

N2 = Number of cases with a negative hospital diagnosis, and a caregiver interview.

N3 = Number of cases with a positive hospital diagnosis for whom sufficient caregiver interview data are available to make a verbal autopsy diagnosis.

N4 = Number of cases with a negative hospital diagnosis for whom sufficient caregiver interview data are available to make a verbal autopsy diagnosis.

~Taken from World Health Organization, Johns Hopkins School of Hygiene & Public Health, London School of Hygiene & Tropical Medicine. [A Standard Verbal Autopsy Method for Investigating Causes of Death in Infants and Children](#) (WHO/CDS/CSR/ISR/99.4). Geneva: WHO, 1999 (Anker, M; Black, RE; Coldham, C; Kalter, HD; Quigley, MA; Ross, D; Snow, RW.)

Table 2: Suitability of Diagnoses for Verbal Autopsy

Good:

Neonatal Tetanus
Measles
Malnutrition
Accidents

Less Satisfactory:

Acute Respiratory Illness
Diarrhea

Unsatisfactory:

Malaria

Validation studies are key to determining how well a set of verbal autopsy questions and algorithms identify a particular cause of death. One of the best and most utilized validation mechanisms is to compare the verbal autopsy results with a facility-assigned cause of death when it exists.⁸ This is the closest thing to the gold-standard clinical autopsy procedure practiced in developed countries. These validation studies have their own limitations though. First the people who are coming to the hospital and interfacing with the medical system may not represent the population as a whole based on their health-seeking behaviors. Second, after a death occurs the medical staff will usually discuss the possible diagnosis with the family members before the verbal autopsy can be conducted.⁸ “None the less, from a practical point of view, hospital validation studies are the only feasible way to validate a verbal autopsy questionnaire.”⁸

The danger of misclassification is an important limitation of verbal autopsy that needs to be considered. Just as isolated medical diagnoses can be invalid without the accompanying clinical autopsy in the developed world, the risk of assigning cause of death incorrectly based on the verbal autopsy is a reality that must be considered. Levels of cause-specific mortality fractions are affected by verbal autopsy misclassification as well as “changes in cause-specific mortality fractions over time and differences in cause-specific mortality fractions between two population groups”.⁸ The verbal autopsy method can underestimate the difference between two cause-specific mortality estimates due to imperfect specificity.¹¹ Large sample sizes might be required to overcome this problem.

Conclusion

By examining the history and current practice of clinical autopsy and the newer instatement of verbal autopsy, we see how important it is to correctly identify cause of death. Just as every birth deserves to be counted, so too every death deserves to be properly acknowledged. This chapter provided data and examples of how improper data collection on cause of death can have economic, political, and social ramifications. The challenge then is to improve collection of vital statistics both here at home and abroad. To improve the quality of death statistics nationally, a broad systems approach should be considered. It would require possible redistribution of hospital funds, creation of autopsy incentives, refocus of medical education, and increasing public education. Verbal autopsy is an excellent tool internationally, especially for developing nations with limited resources. Further validation studies and continued survey quality improvement should be pursued. International support for the verbal autopsy procedure should be encouraged and local ministries of health need to facilitate proper implementation procedures.

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