Autopsy acceptance rate and reasons for decline in Mulago Hospital, Kampala, Uganda

Janneke A. Cox[1], Robert L. Lukande[2], Alice Kateregga[3], Harriet Mayanja-Kizza[3], Yukari C. Manabe[4] and Robert Colebunders[1,5]

1 Department of Clinical Sciences, Institute of Tropical Medicine, Antwerp, Belgium
2 Department of Pathology, Makerere University, Kampala, Uganda
3 Mulago Hospital, Department of Internal Medicine, Kampala, Uganda
4 Infectious Diseases Institute, Makerere College of Health Sciences, Kampala, Uganda
5 Department of Epidemiology and Social Medicine, University of Antwerp, Antwerp, Belgium

Summary

OBJECTIVE   To determine the autopsy acceptance rate and reasons for decline at Mulago Hospital, Kampala, Uganda.

METHODS   The next of kin of patients who died in a combined infectious diseases and gastro-enterology ward of Mulago Hospital were approached to answer a questionnaire concerning characteristics of their deceased relative. During the interview their consent was asked to perform a complete autopsy. If autopsy was declined, the next of kin were asked to provide their reason for the decline.

RESULTS   Permission to perform an autopsy was requested in 158 (54%) of the 290 deaths that occurred during the study period. In 60 (38%) cases autopsy was accepted. Fifty-nine autopsies were performed. For 82% of refusals a reason was listed; mainly 'not wanting to delay the burial' (58%), 'no use to know the cause of death' (16%) and 'being satisfied with the clinical cause of death' (10%).

CONCLUSION   The autopsy rate achieved under study conditions was 38% compared to rates of 5% in Mulago Hospital over the past decade. Timely request and rapid performance of autopsies appear to be important determinants of autopsy acceptance. A motivated team of pathologists and clinicians is required to increase autopsy acceptance.

keywords   autopsy, post-mortem, acceptance, sub-Saharan Africa, Uganda

Introduction

Autopsy rates have been declining worldwide due to advances in diagnostic techniques, administrative and legislative difficulties and negative publicity on tissue retention among others (Burton & Underwood 2007). In sub-Saharan Africa (SSA), additional factors play a role such as the limited number of pathology services, lack of trained personnel and insufficient resources (Nelson & Kalengayi 1994; Cox et al. 2010).

Nonetheless, reliable information on causes of death is essential to inform health policy and allocate the scarce health resources in resource-limited settings. Verbal autopsies have been used as an alternative to determine cause of death in SSA (WHO, 2007; van Eijk et al. 2008). Verbal autopsy results show good concordance with clinical cause of death (Setel et al. 2006; Lopman et al. 2010). However, the accuracy of clinical diagnosis in SAA is limited by the lack of diagnostic tools and the high HIV

prevalence (Rana et al. 2000; Martinson et al. 2007). Also, in the United Kingdom, primary clinical diagnosis changed in 70% of HIV positive patients after a post-mortem examination was carried out (Beadsworth et al. 2009). Therefore systematic post-mortem examination remains an important tool to acquire reliable information on causes of death. We conducted a pilot study to evaluate the feasibility of a systematic autopsy study in Mulago Hospital in Kampala, Uganda. In this article, we describe the autopsy acceptance rate and reasons for decline provided by the next of kin.

Methods

Setting

Mulago Hospital in Kampala is the largest public hospital in Uganda, one of the two national referral hospitals and a university teaching centre. Over the last 10 years,

approximately 6800 people have died annually in Mulago Hospital including maternal and child mortality. The autopsy rate in Mulago Hospital over the past decade has been stable at 5% based on data from the mortuary. The study was conducted on a combined infectious diseases and gastro-enterology ward. The study team comprised clinical doctors related to the study ward and pathologists.

Study design

The study consisted of collection of clinical information by interviewing the next of kin using a standardised questionnaire and by reviewing the medical chart of the deceased to collect missing information and additional clinical information, e.g. CD4 count and clinical cause of death. For all patients who died on the study ward, the next of kin was asked for consent to respond to the questionnaire concerning characteristics of their deceased relative and to review the medical chart. After informed consent was obtained, either the ward doctor or a study team doctor asked permission for an autopsy. If an autopsy was declined, the next of kin was asked to provide the reason for the decline.

Relatives had to be at least 18 years old to consent. Both verbal and written information about the research and the autopsy procedure was provided in English and Luganda, the main local language. If needed, a translator was asked to assist. If an autopsy was performed the body was embalmed free of charge afterwards. Patients who died without next of kin to request consent from were not included in our study. Inclusion took place on weekdays during the period May–September 2009.

Autopsies

If consent was given, the study team would make the necessary arrangements for the autopsy to be performed as soon as possible, always within 12 h after obtaining consent. Complete autopsies (macro-and microscopic examination of all thoracic and abdominal organs and the cerebrum) were performed.

Ethical considerations

The study received ethical approval from the Makerere University Research and Ethics Committee, the Mulago Internal Review Board and the Infectious Diseases Institute Scientific Review Committee. The study received final approval and registration by the Uganda National Council of Science and Technology (ADM 154/212/01).

Data analysis

Data were analysed using STATA version 11.0 (Stata Corp., College Station, TX, USA).

Results

During the study period 290 patients died. The mean age of all deceased was 37 years (range 13–88 years) and 134 (46%) were female. A total of 158 families (54%) were included in the study and asked for permission for an autopsy to be performed. 60 (38%, 95% CI 30–46%) families consented. Overall, for 21% (60/290) of deaths that occurred during the study period an autopsy was accepted. Patient characteristics between patients with relatives who accepted an autopsy and patients with relatives who declined (Table 1) did not differ significantly. Spouses and parents consented to 23% (95% CI 7–38%) of autopsy requests, as did 43% (95% CI 34–52%) of children, siblings or other relatives (e.g. uncles, grandchildren or in-laws). There was a trend for a higher acceptance rate if autopsy was requested on the day of death (42%) rather than later (26%), but this difference was not statistically significant. Fifty-nine autopsies were performed. One autopsy was not performed because of communication errors between the study team and the mortuary personnel (the body was embalmed before autopsy could take place).

A reason for refusal was given by 79 (81%) of the 98 family members who declined an autopsy. The most frequent reason was 'not wanting to delay the burial' (59%). Other common reasons were 'not useful to know

Table 1 Patient and next of kin characteristics for accepted and declined autopsies

	Accepted autopsies (95% CI*)	Declined autopsies (95% CI)
Patient		
Age (years)	40 (36–43)	40 (36–43)
Gender (% female)	45 (32–58)	41 (31–51)
Living inside Kampala (%)	51 (37–65)	55 (45–65)
Employed (%)	47 (33–60)	47 (37–57)
HIV positive (%)	65 (53–77)	67 (58–77)
Next of kin		
Living in the same house as the deceased (%)	36 (23–49)	35 (25–45)

*Confidence interval.

the cause of death' (16%) and 'being satisfied with the clinical cause of death' (10%). Cultural and religious reasons were mentioned in 6% and 1% of cases, respectively. Other reasons were 'no approval from the father' (2%), 'the wish of the deceased expressed during life not to be autopsied' (1%) and 'the inability of the available relatives to decide' (1%).

Discussion

In this study 38% of the next of kin approved a post-mortem examination. This is a substantial increase over the 5% autopsy rate in Mulago Hospital during the last decade. A marked increase in autopsy acceptance rates in a study setting has been reported previously. In a Zambian paediatric autopsy study, the consent rate for autopsies increased from 10 to 25% during the study period (Lishimpi *et al.* 2001). There are several reasons for increasing consent rates in study settings, such as more frequent requests by clinicians, improved logistics that accelerate the autopsy procedure and the reporting afterwards and/or incentives offered to family members.

Two studies evaluated autopsy request behaviour among medical doctors in Nigeria. The main reasons for not requesting autopsies were 'not being in direct control of the patient', 'difficulty in getting consent from the relatives', 'administrative problems in requesting autopsy' and 'not being able to obtain the pathology report in time or not at all '(Ekanem & Gerry 2007; Oluwasola *et al.* 2009).

The importance of timely performance of the autopsy is indicated by 59% of next of kin giving 'not wanting to delay the burial' as reason for declining the request. There was also a trend for increased acceptance of autopsy when the request occurred on the day of death. This is consistent with other studies from SSA which report 'concern about delaying the funeral' and 'transport arrangements that were already made' as the second most mentioned reason to decline an autopsy (Lishimpi *et al.* 2001; Oluwasola *et al.* 2009). If a person in Uganda dies, the burial usually takes place in the home village. The body is usually transported in a hired vehicle that has to be paid per time unit. Therefore, when the transport arrives at the hospital the body has to be released without further delay. Funeral activities can last several days to weeks. During this period visitors will come to the family home to mourn and have to be fed and housed. This can be costly and, therefore, is another reason to execute the burial as soon as possible. Muslims bury deceased family members within 24 h after death for religious reasons.

Improved logistics and more common requests for autopsy are probably the main factors explaining these comparatively high acceptance rates. We offered free

embalming of the body after the autopsy. This was explained to the next of kin prior to the post-mortem examination and may have influenced their decision. We did not, however, ask whether it did. To our knowledge, there are no published studies that have measured the impact of incentives such as embalming on the acceptance rate of autopsies.

To increase autopsy rates, autopsies should be requested as soon as possible after death. The administrative procedure at the mortuary should be straightforward and communication between clinicians and the pathologists, including the reporting of autopsy results, should be clear, timely and relevant.

In our study relatives may have mentioned only acceptable and desirable reasons for decline. Within Ugandan society, stories about withholding organs after autopsy for sale and manufacture of medicines exist, but are not openly discussed. In Zambia, 8.6% of paediatric autopsy requests were declined because of the belief that ancestral spirits prohibit mutilation of the body and that possible retaliation would take place, making all women of the family infertile. The belief that organs would be sold for transplantation was another reason for decline in 0.7% (Lishimpi *et al.* 2001). 'Cultural belief' in our study was not specified further. It is likely that cultural and traditional beliefs co-exist and contribute to the family decision-making process regarding post-mortem examination.

Religious reasons were only mentioned once in our study. In Islam post mortem examinations are prohibited (Sheikh 1998). In Uganda 12% of the population are Muslim by self report (Uganda Bureau of Statistics 2002). We did not collect information on the religion of all deceased, but we elicit the religion of those who underwent autopsy. Six (10%) of the 59 autopsy cases were Muslims, suggesting that autopsies are acceptable for Ugandan Muslims. Moreover, as mentioned earlier, timely burial is very important for Muslims and those who gave time constraints as their reason for decline might have been influenced by religious considerations.

Our study had several limitations. We included only 54% of all deaths that occurred on the study ward during the study period. This was partly due to the study design in which we only included patients during weekdays. Because of our limited research budget and therefore small study team, consent of next of kin was only requested during working hours of each day. The study took place in a tertiary referral hospital, which has a different patient population and a different death rate than most other hospitals. This could have influenced acceptance rates. We consider the improved logistics and the increased request rate in our study important factors in the rise of acceptance, although we were unable to measure this in

our study and could compare them only to historical rates. Lastly, the demographic data collected from both deceased and next of kin were rather limited. The similarity in, e.g. employment of the deceased (Table 1) might suggest a similarity in educational level or social status, but the data are too limited to justify further interpretation.

Although this pilot study was not designed as an in-depth evaluation of the dynamics of requests and acceptance of autopsy, our results show that with a motivated team and good collaboration between clinical and pathology departments, acceptance rates of almost 40% can be reached through timely request and performance of the autopsies.

Acknowledgements

References

Beadsworth MB, Cohen D, Ratcliffe L *et al.* (2009) Autopsies in HIV: still identifying missed diagnoses. *International Journal of STD & AIDS* **20**, 84–86.

Burton JL & Underwood J (2007) Clinical, educational, and epidemiological value of autopsy. *Lancet* **369**, 1471–1480.

Cox JA, Lukande RL, Lucas S, Nelson AM, van Marck E & Colebunders R (2010) Autopsy causes of death in HIV-positive individuals in Sub-Saharan Africa and correlation with clinical diagnoses. *AIDS Reviews* **12**, 183–194.

van Eijk AM, Adazu K, Ofware P, Vulule J, Hamel M & Slutsker L (2008) Causes of deaths using verbal autopsy among adolescents and adults in rural western Kenya. *Tropical Medicine & International Health* **13**, 1314–1324.

Ekanem VJ & Gerry IE (2007) Attitude of Nigerian resident doctors towards clinical autopsy. *The Nigerian Postgraduate Medical Journal* **14**, 8–11.

Lishimpi K, Chintu C, Lucas S *et al.* (2001) Necropsies in African children: consent dilemmas for parents and guardians. *Archives of Disease in Childhood* **84**, 463–467.

Lopman B, Cook A, Smith J *et al.* (2010) Verbal autopsy can consistently measure AIDS mortality: a validation study in Tanzania and Zimbabwe. *Journal of Epidemiology and Community Health* **64**, 330–334.

Martinson NA, Karstaedt A, Venter WD *et al.* (2007) Causes of death in hospitalized adults with a premortem diagnosis of tuberculosis: an autopsy study. *AIDS* **21**, 2043–2050.

Nelson AM & Kalengayi MR (1994) The pathology of AIDS in Africa. In: *AIDS in Africa* (eds SM Max Essex, PJ Kanki & MR Kalengayi) Raven Press, Ltd, New York, pp. 283–323.

Oluwasola OA, Fawole OI, Otegbayo AJ, Ogun GO, Adebamowo CA & Bamigboye AE (2009) The autopsy: knowledge, attitude, and perceptions of doctors and relatives of the deceased. *Archives of Pathology & Laboratory Medicine* **133**, 78–82.

Rana FS, Hawken MP, Mwachari C *et al.* (2000) Autopsy study of HIV-1-positive and HIV-1-negative adult medical patients in Nairobi, Kenya. *Journal of Acquired Immune Deficiency Syndromes* **24**, 23–29.

Setel PW, Rao C, Hemed Y *et al.* (2006) Core verbal autopsy procedures with comparative validation results from two countries. *PLoS Medicines* **3**, e268.

Sheikh A (1998) Death and dying – a Muslim perspective. *Journal of the Royal Society of Medicine* **91**, 138–140.

Uganda Bureau of Statistics (2002) *The 2002 Uganda Population and Housing Census, Population Composition, October 2006.* http://www.ubos.org/index.php. (accessed 5 May 2011).

World Health Organization (2007) *Verbal Autopsy Standard. Ascertaining and Attributing Cause of Death*, Geneva.

Corresponding Author Robert Colebunders, Institute of Tropical Medicine, Nationalestraat 155, 2000 Antwerpen, Belgium. Tel.: +32 32476666; E-mail: bcoleb@itg.be