BHIVA
British HIV Association

2022 Spring Conference

Wed 20th - Fri 22nd April
Manchester Central, Manchester
Death certification – facts and practicalities

Professor Sebastian Lucas
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Death certification – facts and practicalities

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Conflict of Interest

In relation to this presentation I declare that I have no conflict of interest.
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• What and why death certification?
  • Since 1836, a legal requirement for a statement on why a person died
  • Required to register a death
  • National system of Registration of Births & Deaths
  • Relatives receive from the Registrar a document enabling them to dispose of a body
    • Burial
    • Cremation – 1894-1902
    • Expatriation
Death certificate

To be completed by a registered medical practitioner
To ‘the best of their knowledge and belief’
   ie absolute certainty is not expected
Doctor must have seen the deceased <15 days before death

Has to be a ‘natural cause of death’
The Registrar may bounce a draft certificate back to the coroner
Format (WHO – ICD terminology)

1a. Event/disease...
1b. Due to....
1c. Due to...
2. Contributory event/disease, eg why died **when** they did
Acceptable by the Registrar?

- Male 32yr
- Renal failure
- Biopsy: HIV-associated nephropathy?
- HIV test +ve
- Dies

- “1a chronic renal failure”
- Should not have been accepted: mode of death without an underlying stated pathology is not acceptable
Acceptable by the Registrar?

- Male 32yr
- Renal failure
- Biopsy: HIV-associated nephropathy?
- HIV test +ve
- Dies

- 1a chronic renal failure
- 1b. HIV disease
- Would be fine
Acceptable by the Registrar?

- Male 32yr
- Recent diagnosis of HIV
- Lays down in front of a train
- ie suicide

- Not a natural cause of death
- Has to be reported to a coroner
Unnatural death?

- Trauma & self harm (suicide)
- Poisoning and drug toxicity – medical, illicit & alcohol
- Mishap in health care – medical & surgical
- Death in state custody
- Neglect – self- or health care-related
- Death related to employment
Algorithm of what happens after a death

Cause of death **known** and **natural** → write death certificate

Cause of death **unknown** and/or **un-natural** → refer to Coroner

- negotiate, you write the DC
- Coroner commissions an autopsy [relatives cannot prevent]
Autopsy – pathologist writes the death certificate
+/- an inquest

At inquest, the wording may be changed
Two events have changed things:

Harold Shipman

COVID-19
• Shipman forced increased scrutiny into all deaths

Developed into the NHS programs of:
• Accountability
• Learning from deaths
• Duty of candour over medical errors
• *Numerous recent reports of institutional failings*

• Coroner & Justice Act 2009 introduced Medical Examiners
• Medical Examiners
  • Qualified >5 years, any speciality
  • Employed by Trusts, but function independently
  • Review – in real time – all deaths that have not gone directly to a coroner

• MEs are rolled out across nearly acute hospital Trusts
• To be introduced into General Practice for community deaths in future
  • Health & Care Bill, clause 143
• Medical Examiners’ remit

• Consider the draft death certificate
• Should the death be referred to the coroner
• Are there clinical governance concerns over the death

• MEs will obviate the need for cremation certification checks
• Medical Examiners’ process

• Proportionate review of the medical records
• Interaction with the treating doctors
• Interaction with the family - do they have concerns

• End result: modify/improve the death certificate if necessary
• Medical Examiners’ impact – *still being evaluated*

• Fewer deaths in hospital referred to coroners
  • But they are more complicated
  • In ~10%, potential harm identified

• Changes in draft DCs:
  • >80% in minor wording
  • >30% major change in the cause of death

• Fewer litigation claims against hospitals
  • Families are told the truth
• COVID-19 impact since April 2020 (Chief Coroner guidance)?
  • Reduced proper scrutiny of deaths – BEING REVERSED

• Extended the qualification period: 2 now 4 weeks post-death - STAYS

• Any doctor could sign a death certificate – REVERSED TO DOCTOR WHO SAW THE DECEASED

• Digital death certification to be introduced
That concludes my formal presentation on death certification

Three practical points about the case and HIV disclosure:

• If relatives do not/would not wish ‘HIV/AIDS’ to appear on a death certificate, how do you square that with ‘to the best of your knowledge and belief’?

• If there is an autopsy and HIV is irrelevant to the cause of death, there is no need to mention it in the cause of death.

• If HIV is relevant to cause of death, it gets put in the cause of death in all coronial autopsies even if the relatives object; coroners are firm on this point — and so am I.
Thank you for listening
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Defining preventable & HIV-related deaths

Dr Sara Croxford
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Defining and monitoring preventable HIV-related mortality

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Project overview

- **Background**: Various organisations, projects and countries have targets of achieving zero HIV-related deaths but clear, detailed definitions are lacking.

**Aim**: to develop a consensus definition of preventable, HIV-related mortality for public health monitoring and identifying areas for intervention to improve patient care.

- Secondary purpose: provide guidance to clinicians completing death certificate details relating to cause of death and contributory factors, or when reviewing local data.
- Collaboration between UKHSA, BHIVA, EACS and Fast Track Cities London (funder).
Project components

- Rapid literature review scoping how preventable, HIV-related death is currently being defined
- Expert review of definition with wider stakeholder discussion
- Piloting of consensus definition against historical London HIV data
- Publication
Rapid literature review methods

- Systematic approach
- 2010 - March 2021
- Conference abstracts: 2016 - March 2021
- English language
- Measurable definition of mortality
- Studies of children excluded (<15 years old)
- **Search terms**: HIV/AIDS, mortality, preventable, HIV-related, AIDS-related

**Sources**
- Medline (academic database)
- NDLTD (theses)
- OATD (theses)
- WHO BASE
- ETHOS (theses)
- UnAIDS (FTC website)
- AIDS/IAS (conference abstracts)
Rapid literature review findings

Studies describing an **increased incidence** of a given condition or **increased risk of death** from a given condition among people with HIV compared to those without (n=181)

- WHO/BASE (n=283)
- Embase (n=10,529)
- Medline (n=5,968)
- Other sources (n=17)

Records after duplicates removed (n=10,385)

- Full-text articles assessed for eligibility (n=272)

Articles excluded after title/abstract screen (n=9,613)

Articles excluded after full text review (n=472)

Studies included in literature review (n=129)

No definition (n=90)

HIV-related
HIV/AIDS
AIDS-related
Rapid literature review summary

- Most studies used AIDS coding from either the ICD-10 codes or Causes of Death in HIV (CoDe) protocol to indicate “HIV-related” mortality.
- Few studies considered non-AIDS-related causes of HIV-associated mortality.
- No studies classifying suicide or substance misuse as “HIV-related”.
- A subset of studies described “HIV-related” conditions or lifestyle risk factors which they found were more common in people with HIV or from which people with HIV were more likely to die than those without HIV.
Expert review of draft definition

- Small group of experts sent draft definition for comment
- **June 18th 2021**: Findings of the literature review and draft definition presented at wider stakeholder group meeting

![Logos of various organizations]
General principles:

- Definition based on a ‘best-case scenario’ of having the necessary available data
- Some countries may need to adapt the definition depending on data collected
- Primary application - national surveillance data

Meeting format:

- Two breakout sessions: HIV-related causes of death and preventable HIV-related death
- Discussion and feedback
**Draft recommendations**

**Recommendation 1:** Deaths among people with HIV should be categorised as:

- HIV-related (including AIDS)
- Possibly HIV-related
- Not HIV-related
- Unknown cause of death

**Recommendation 2:** Deaths among people with HIV should, for surveillance purposes, initially be categorised based on information on the death certificate.

- WHO guidance when data systematically inadequate
- Where data routinely available, but cause is missing, cause of death should be recorded as unknown.

**Recommendation 3:** The definition applies to those people who have tested HIV positive.

- Diagnosis may be made post-mortem.
- In high prevalence countries with inadequate data on HIV status of cases, apply WHO tools.

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Flowchart 1: Determining whether a death can be considered HIV-related

**Recommendation 5:** Where one of the listed conditions caused by HIV immunodeficiency/pathophysiology is recorded as a primary or contributory cause of death = HIV-related.

**Recommendation 8:** Where HIV infection is listed as a primary cause or as contributing to the cause of death = possibly HIV-related.

Where mandatory to include HIV on the death certificate regardless of contribution to death when HIV is included in the direct sequence of causation.

**Recommendation 7:** Where the primary or contributory cause of death is listed as a virally driven, non-AIDS-related malignancy = HIV-related.

**Recommendation 9:** Where a non-AIDS infection is the primary or contributory cause of death with a CD4 count <200 cells/µL = possibly HIV-related.

**Recommendation 10:** Where cause of death is suicide, substance misuse or other co-morbidities including conditions occurring more frequently in people living with HIV = not HIV-related.

†Includes other co-morbidities including conditions occurring more frequently in people living with HIV, suicide, substance misuse, and mental illness.

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Flowchart 1: Preliminary UK data from 2019 on HIV-related mortality

Death to categorise N=644

Is cause of death known? NO

YES n=528

Are AIDS-defining illnesses listed as a primary or contributory cause of death? NO n=423

YES n=105

Is the cause of death a condition caused by HIV immunodeficiency/pathophysiology? NO n=4

YES

Is HIV infection listed as a primary or contributory cause of death? NO n=344

YES n=342

Is cause of death a non-AIDS infection and CD4 count <200 cells/µL? NO

YES n=2

Is HIV included in direct sequence of causation? NO

YES

Is it mandatory to list HIV as a cause of death for people with HIV? NO n=51

YES n=51

Cause of death is POSSIBLY HIV-RELATED†

Cause of death is NOT HIV-RELATED†
2019 data for UK: HIV-related death

N=644

Manual review

- Unknown cause: 18%
- Not HIV-related: 30%
- Possibly HIV-related: 32%
- HIV-related (AIDS): 16%
- HIV-related (non-AIDS): 4%
Flowchart 2: Determining whether an HIV-related death was preventable

1. **Cause of death is HIV-RELATED**
   - **Recommendation 10a:** Preventable=Where a person is diagnosed late (CD4<350 cells/µL) and:
     - Was an intervention or screening for a condition known to reduce the incidence of the HIV-related condition causing death not received?
     - Was the intervention/screening not available at the relevant time for this person in this country?
   - **Recommendation 12b:** Potentially preventable=Where the intervention/screening was not available at the relevant time (i.e. if policy or recommendation had reflected best practice or international guidelines).

2. **Cause of death is POSSIBLY HIV-RELATED**
   - **Recommendation 11:** Preventable=Where access, uptake or persistence of HIV/care and/or ART was inadequate.
   - **Recommendation 10b:** Potentially preventable=Where a person is diagnosed late (CD4<350 cells/µL) and dies more than 12 months after diagnosis due to an AIDS-related opportunistic infection or malignancy.
   - Need for clinical review.

3. **Was the patient diagnosed late within 12 months of death?**
   - YES
     - **Death was PREVENTABLE**
   - NO
     - **Investigation of clinical data**
       - YES
         - **Death was PREVENTABLY POTENTIAL**
       - NO
         - **Death was NOT PREVENTABLE**

- Not applicable
- Not received
- Not available
Flowchart 2: Determining whether an HIV-related death was preventable

Cause of death is HIV-RELATED (N=133)

- Was an AIDS-related condition or opportunistic infection listed as a primary or contributory cause of death? NO n=81
  - Treatment/care markers
    - Was ART commenced more than 3 months after diagnosis and within one year of death? n=8
    - Was viral load not effectively suppressed in the 3 years prior to death including people with periods of significant viraemia (>1000 copies/mL on 2 or more occasions) (excluding where ART stopped due to initiating palliative care)? n=43
    - Was the person not seen in HIV specialist care services or was not receiving/taking treatment in the 3 years prior to death? n=11
  - Interventions
    - Was an intervention or screening for a condition known to reduce the incidence of the HIV-related condition causing death not received? Not applicable
  - NO n=66

Cause of death is POSSIBLY HIV-RELATED (N=53)

- Was the patient diagnosed late within 12 months of death? YES n=58
  - Was the patient diagnosed late (CD4<350 cells/µL)?
    - YES n=26
      - Death was PREVENTABLE
    - NO n=32
      - Death was POTENTIALLY PREVENTABLE
  - NO n=47

- Investigation of clinical data
  - Not received n=?
  - Not available n=?

Death was NOT PREVENTABLE n=?
2019 data for UK: preventable HIV-related death

- **186** deaths among people with HIV either HIV-related or possibly HIV-related
- At least:
  - **88** deaths preventable
  - **32** potentially preventable

![Pie chart showing preventable, potentially preventable, and not preventable or unknown categories]
Further work

• Circulate draft definition publication to expert stakeholders
• Meet with FTC reps from cities across UK to promote definition
• Improve collection of data on the uptake of interventions and screening perhaps through the UK National HIV Mortality Review.
• Role of HIV Guidelines and Standards, and engagement in treatment and care services, on preventable non-HIV causes of and contributors to death
• Death certificate standardisation
Acknowledgements

**Funding:** London Fast Track Cities Initiative

**Experts:**
- Robert Miller
- Anastasia Pharris
- Frank Post
- Laura Waters
- Vanessa Apea
- David Chadwick
- Gillian Dean
- Sebastian Lucas
- Jens Lungren
- Esteban Martinez
- Justyna Kowalska
- Simon Collins
- John McSorely
- Juergen Rockstroh
- David Asboe
- Teymur Noori
- Elena Vovc
- Giorgi Kuchukhidze
- Nicole Seguy
- Deborah Gold
- Caroline Sabin
- Nikoloz Chkhartishvili
- Garry Brough
- Tresca Wilson
- Maka Gogia
- Marilena Korkodilos
- Jane Anderson
- Niall McDougall
- Callum Verran
- Jacqueline Lindo
- Anna Kafkalias
- Lucy Lynch
- Helen Corkin
- Sarah North

**Project team at FTCi:** Jess Drummond, Eleanor Johnston

**Project team at UKHSA:** Ann Sullivan, Sara Croxford, Veronique Martin, Valerie Delpech, Nicky Connor, Adamma Aghaizu, Amber Newbigging-Lister
Conditions caused by HIV immunodeficiency / pathophysiology

**Viruses**
- Adenovirus
- Herpes zoster
- J-C virus

**Fungi**
- Blastomyces dermatitidis
- Coccidioides immitis
- Cryptococcus neoformans
- Dermatophyte spp.
- Histoplasma capsulatum
- Histoplasma duboisi
- Paracoccidioides brasiliensis
- Penicillium marneffei
- Sporotrichum schenkii
- Trichosporonosis

**Parasites**
- Acanthamoeba spp
- Balamuthia spp.
- Entamoeba dispar
- Falciparum malaria in pregnant women
- Isospora belli
- Leishmania spp.
- Microsporidia
- Schistosoma spp.
- Strongyloides stercoralis
- Trypanosoma cruzi

**Bacteria**
- Bartonella spp
- Chlamydia trachomatis (LGV)
- Shigella enteritis
- Listeria
- Mycoplasma spp.
- Mycobacterium leprae
- Mycobacterium avium-intracellulare
- Other non-TB mycobacteria, except M. ulcerans
- BCG infection
- Neisseria gonorrhoea (disseminated)
- Nocardia spp.
- Non-typhoid Salmonella spp. Sepsis
- Pneumococcal infections
- Rhodococcus equi
- Staphylococcus aureus and E. coli sepsis
- Syphilis

**Other conditions**
- Vacuolar myelopathy of spinal cord
- Inflammatory demyelinating polyneuropathy
- HIV-associated myopathy
- HIV-associated dementia
- HIV-associated nephropathy (HIVAN)
- HIV enteritis
- Lymphoid interstitial pneumonia (LIP)

**Virally driven malignancies**

<table>
<thead>
<tr>
<th>Human herpes virus-8 (HHV-8)</th>
<th>Hepatitis B &amp; C viruses (HBV &amp; HCV)</th>
<th>Human T-lymphotropic virus (HTLV)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Castleman's Disease</td>
<td>Hepatocellular carcinoma</td>
<td>Adult T cell leukaemia/lymphoma</td>
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<tr>
<td>Primary effusion lymphoma</td>
<td></td>
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<tr>
<td>Human papillomavirus (HPV)</td>
<td>Epstein Barr virus (EBV)</td>
<td></td>
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<tr>
<td>Anal cancer</td>
<td>Hodgkin's Disease</td>
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<tr>
<td>Penile cancer</td>
<td>Nasopharyngeal carcinoma</td>
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<td>Vulval cancer</td>
<td>Laryngeal cancer</td>
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<tr>
<td>Vaginal cancer</td>
<td>Gastric cancer</td>
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<tr>
<td>Oropharyngeal cancer (HPV must be mentioned)</td>
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</tbody>
</table>

**Direct HIV-induced conditions**
- Cerebral vasculitis

**Other conditions**
- Exocrine pancreatic insufficiency
- Coagulopathy and venous thromboembolism (VTE)
- Idiopathic thrombocytopenia (ITP)
- Thrombotic thrombocytopenic purpura (TTP)
- Diffuse infiltrative lymphocytosis syndrome (DILS)
- Haemophagocytic lymphohistiocytosis (HLH) or macrophage activation syndrome
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