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No Embalming for French HIV+: Ultimate Discrimination or Educational Issue?

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Abstract

Our objective is to describe and analyze the reasons for preventing embalming processes for HIV+ individuals in France. Arguments from both embalmers and health authorities, and patients' relatives and associations are presented here after, with recent historical and ethical development data. Aesthetic-only cares have never been forbidden or restricted for any HIV+ patient. Invasive processes (i.e. embalming stricto sensu) could be authorized in the future, if performed in adequate conditions of practice. This position is a good step forward towards post-mortem equity for HIV+ patients. The right balance has to be found between absolute protection of professionals, and the respect due to the dead and their image through embalming and body conservation, visible by the family. Such topic and focus confirm that infectious disease is of primary importance for medical ethics. We lastly discuss the possibility that is this more of an educational issue (misunderstanding of the risks) in getting the ban legally changed.

Keywords: Bioethics; Infection hazards; Post-mortem conservation; Status of the cadaver; Stigma; education

Introduction

To date, according to the French legislation [1], all kinds of embalming are forbidden to all HIV+ patients. This interdiction is considered by many organizations as a terminal discrimination or stigmatization [2,3], or as a post-mortem continuation of intra-vitam ones. By "stigma" and "discrimination", we are referring to any negative attitude, prejudice, abuse, and maltreatment directed at HIV+ individuals. Consequences may range from poor treatment in healthcare (including post-mortem respect of the body, i.e. a kind of erosion of human rights) to psychological damage and/or social eviction [4-6]. As stated by the Secretary-General of the United Nations Ban Ki-Moon, "to greater or lesser degrees, almost everywhere in the world, discrimination remains a fact of daily life for people living with HIV. One-third of all countries has virtually no laws protecting their rights. Almost all countries allow at least some form of discrimination against women and children who contract the disease, against gay men, and against communities at risk" [7]. Stigma is a source of fear for patients, based on a kind of global paranoia of the rest of the population.

Indeed, for ethical reasons–mainly, equity toward death and the rituals, including the possibility of viewing an almost perfectly conserved body – the death of any HIV+ patients should be treated the same way as the one of any other individual [8-11], allowing relatives to mourn in the best conditions. Such principles seem to be affected by this French discriminatory legislation. An HIV+ dead body should be considered socially the same as any other dead body. Such administrative interdiction is perceived as an injustice. Patient organizations such as ACT-UP Paris are clearly asking why preventing HIV+ patients from getting such post-mortem conservation, as some embalmers do not work according to the highest standards given by the WHO [12]. The question generally is: how is it possible to impose an altered view of a dead body to families and relatives following a long agony – a position assimilated to moral violence?

Principle of embalming process

What is the cultural impact of families deciding to embalm or not? Previously, most of all deaths occurred at home or in private places rather than at hospital or nursing homes. Contact with the dead body is now minimalist, as it is not left anymore to the family to minister to the dead until the funerals. To date, embalming a body (which is not at all a regular procedure in many cultures) offers the possibility to a family or relatives to see the dead, to understand its death, to make a transition from its presence to its absence, etc. The viewing of a well-preserved dead body is clearly a custom with benefits to the family and friends of the deceased, as the signs of death are present but minored by the professional. It is a non-negligible part of mourning, by making the death psychologically real (the individual is really dead, not only gone away) and physically acceptable, as the image of the dead is not too much altered. Embalmed dead are indeed described by relatives as "peaceful", "looking human again".

The aim of the embalming process is so to maintain a relative physical (and thus, general) dignity for the dead. As a matter of fact, physical preservation and aesthetic values may be perceived as important for end-of-life individuals, especially those with chronic diseases [13].

Embalming consists of an injection of antiseptic substances (mainly formaldehyde) within both vascular and visceral cavities, in order to temporarily delay the decomposition and putrefaction process [14]. This act is invasive for the cadaver, as opposed to superficial care. Almost 200,000 body conservations are carried out every year in France; in Paris, 15% of all deaths are currently followed by an embalming [15]. Thirty percents of those embalmings are performed at the bed of the dead patient, or at home (in any case, technically not in an ideal place). To be useful, the embalming process has to be done within the four to five days following death, mainly around the 36th hour [15].

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International background

What about policies on embalming HIV+ cadavers in other European countries as well as other regions of the world? A comparison with other countries in the European Union (EU) would be interesting considering the tentative to uniform rules and regulations within the EU. Embalming is mainly practiced in England and France (almost 80% of all European embalming activities). Other neighbor countries (Germany, Spain, Ireland, Austria, Greece, Italy, Malta, Portugal, and Switzerland) do not currently practice post-mortem body conservation, which is limited to institutions in capitals, mainly for cultural/religious reasons; indeed, embalming by intra-corporeal injection of desiccative products is still not entirely accepted by local Christian authorities. Embalming is legally forbidden in Belgium, Holland, Luxembourg, Denmark, and Scandinavian countries, where only exceptional cases are allowed for repatriation of dead bodies to their original land; the reason for banning embalming is a practical one, i.e. infectious concerns and/or concerns about exposure to formaldehyde with sanitary risks for the practitioner and the direct environment of the cemetery after inhumation.

In France and England, intra-vascular injection of conservative agents such as formaldehyde is the most current conservation mode; other European countries use refrigeration, with carbonic ice or refrigerant beds. Embalming is less common in Japan and Australia. Fundamental Jewish laws, Islam, Buddhism, Hinduism, and Eastern Orthodoxy traditionally forbid embalming [16]. In Canada and England, embalming of HIV+ individuals is not forbidden and is subject to a special procedure [17,18], as fully described in Table 2.

French official position

In its recommendations dated 27th November 2009, the French High Council of Public Health expressly confirmed its previous position dating from 1998 [1], forbidding embalming for 13 diseases, HIV included (Table 1) [19]. Such interdictions have been defined according to the respect of sanitary security (particularly for post-mortem professionals and their relatives). Indeed, embalmers are probably the most exposed profession to infectious, chemical, and psychological hazards.

This administrative interdiction has generated some malpractices, perverting the system: as attested by professional embalmers' blogs and anonymous testimonies, some funeral practitioners are asking bribes from families to perform forbidden embalming on an HIV+ cadaver, or to buy a fake non-contagion certificate from a physician. Conversely, some embalmers, not understanding well the French sanitary recommendations, have refused to perform any post-mortem activity, but also non-invasive acts such as washing, dressing and make-up of bodies. This latter case may be perceived by families as an extreme discrimination, as the cadaver is not easily presentable to relatives.

Orthopox viruses
Cholera
Hemorrhagic fever
Plague
Anthrax
Rage
Tuberculosis (active or treated less than one month)
All kind or emergent infectious disease (SARS, avian flu, etc.)
Hepatitis B and C
Creutzfeldt-Jakob disease
HIV infection
All severe sepsis to streptococcus A
All severe sepsis according to the medical practitioner

Table 1: List of all pathologies excluding any embalming process in France [1,15].

Is not this situation a little bit hypocritical? Normally, because of the medical secret, embalmers do not have to know the cause of death [20]. They may then practice embalming on HIV+ subjects without knowing the viral status of the individual, or because the family does not mention this to the embalmer as they absolutely want invasive conservation acts. As a consequence, many HIV+ subjects are embalmed in France, even if this practice is legally forbidden.

Scientific justification

According to medical literature, the French High Council of Public Health legitimately considers the contamination risk equal for both living and dead bodies, not just from a purely theoretically aspect [19,21,22]. How long can HIV survive in the body after a person dies? Post-mortem studies have indeed brought to light the viability of HIV in biological liquids and tissues in various temperatures of conservation for up to three weeks after death [23,24]. Does this lifespan overlap with the time for embalming? We do not know yet.

Cases of professional contamination to hepatitis B virus, tuberculosis and chickenpox after an accident with needles, have been reported [25-28], but cases with HIV are discussed [29-31]. The risk especially occurs during the puncture process, due to the projection of some of the six to ten liters of biological fluids extracted from the body [19]. The theoretical risk of being infected with HIV is in any case much less important than during dissection, a practice far more invasive than embalming. Several studies have demonstrated that the risk is negligible; for example, Burton states that "HIV serophobia has been documented among staff working in mortuaries handling risk cases since the 1980's (…) although there is no evidence that HIV is readily acquired in the mortuary. Consequently, it is difficult to justify refusal to undertake necropsies on patients with such infections" [31].

In addition, it is essential to summarize the very important literature on needlestick injuries, especially compiled by the Centers for Disease Control (CDC) in Atlanta. According to CDC survey data, approximately 384,000 percutaneous injuries occur annually in US hospitals, with about 61 percent (236,000) resulting from hollow-bore needlestick injuries [32]. Most needlestick injuries occur after the device has been used (and therefore exposed to potentially contaminated blood) but before its disposal. Fifty percent of injuries occur between the time the procedure is completed and disposal of the device; 20 percent are associated with disposal of the device. Other injuries occur when the needle pierces the syringe cap as the syringe is recapped after use, when a body fluid is transferred from a syringe to a specimen container, and when used needles are not disposed of in puncture-resistant containers. Devices requiring disassembly are associated with higher rates of injury. As of December 1999, CDC had received reports of 56 documented and 136 possible cases of occupationally acquired HIV infection in the United States. Twenty-five of the 56 documented cases of HIV infection have progressed to AIDS. The average transmission rate of HIV infection following a needlestick injury from an infected patient is 0.3 percent.

It has been calculated that, on average, 99.7% of health care workers who are exposed to HIV will not be infected [31,33,34]. As far as pathologists, forensic practitioners and anatomists are concerned, there is only one well-documented case of body-opening-acquired

What precautions should I know when required to do embalming?	Funeral directors and mortuary attendants or any person assisting in post mortem procedures must wear gloves, masks, protective eyewear, gowns and waterproof aprons.
Consider all body fluids and tissues as potentially contaminated.	• Wear disposable pants and gowns and double gloves. Wear eye protection, mask and cap if there is the possibility of splashing blood or body fluids. • Identify body "Blood and Body Fluid Precautions". Keep identification with body. • Check body for intravenous lines, catheters or colostomy bags. Take extreme care to avoid accidental cuts or splashes before shrouding the body. • Place body in shroud and impervious body bag for transport. Do not open bag in transit. • Remove protective clothing. Double plastic bag for incineration.
What precautions should I take when embalming?	• Use disposable materials. • Remove all personal jewellery. Wear disposable pants and gowns or disposable jumpsuit with hood, double gloves, eye protection, mask and cap, shoe covers and plastic apron. • Have instruments, puncture-resistant containers, and individual items, such as eye caps and trocar buttons, readily available. Place needed amount of cosmetics on a paper towel or wax paper sheet. • Line garbage can with double plastic bags and place in work area. • Usa a medical grade disinfectant to disinfect all potentially contaminated objects and surfaces both during and after preparation. Discard left-over solution according to material safety data sheet (MSDS) directions. • Add a gallon of disinfectant solution to an enamel, porcelain or stainless steel bucket before embalming begins. Place bucket underneath drainage hose from embalming table. • Ventilate preparation room to control exposure to formaldehyde and other volatile airborne contaminants; the room should have a dedicated ventilation exhaust and fresh air supply. • Place body in casket immediately after restoration. Have head, arm and feet rests tightly encased in plastic. • Assign specific tasks with one person to do suturing. • Make arrangements for a person not involved in procedures to take telephone calls and answer door.
What precautions should I use during clean up and disposal?	• Consider all instruments and embalming table contaminated and potentially infectious. • Disinfect all working surfaces and restorative and embalming instruments. Wash embalming table, floors, walls and embalming machine with hot soapy water. Autoclave instruments if possible. • Place all disposable material in a tightly secured double plastic bag. Tag for incineration. Do not dispose with regular garbage. Wash hands with appropriate germicide.

Table 2: Precautions for HIV/AIDS individuals in morgues and during embalmings in Canada [17].

HIV infection: a pathologist, who had sustained a scalpel wound to the hand, first had a positive HIV test, but never developed AIDS nor has successful further attempt to isolate HIV [35].

The life cycle of HIV may explain such frequencies of post-mortem contaminations. HIV enters the body through open cuts, sores or breaks in the skin; through mucous membranes, such as those inside the anus or vagina; or through direct injection (including accidental ones in a context of professional activity). Excluding classical cases of sexual contact with an infected person, sharing needles, syringe or other injection equipment with someone who is infected, mother-to-child transmission, and transmission via donated blood or blood clotting factors, some healthcare professionals have been infected with HIV in the workplace, usually after being stuck with needles or sharp objects containing HIV-infected blood.

Is it legitimate to prevent families asking for such body conservation processes, based on the latest scientific knowledge and technologies? Probably not. Simple practical modifications or improvements would clearly increase the safety of all funeral practitioners during the embalming process: systematical vaccination against hepatitis B; strict respect of all universal precautions towards pathological hazards (wearing professional glasses, Kevlar with double latex gloves, FFP1-type masks instead of none or classical ones); avoiding embalming in another place than a technical and well-equipped location (hospital, morgue, funeral house or specialized laboratory). Lastly, an embalmer should remain absolutely free, for personal fear or other reasons, to refuse to perform any work on an infected cadaver, whatever the evoked reasons.

Ethical concerns?

A recent meeting, organized by the French Ministry of Health and involving administrative personals, physicians, embalmers and patient representatives, pointed out that aesthetic-only cures have never been forbidden or restricted for any HIV+ patient, and that invasive processes (i.e. embalming stricto sensu) could be authorized in the future, if performed in adequate conditions of practice [36]. This position, based on the most recent data about infectious hazards and medico-surgical practice [37-46], is a good step forward towards post-mortem equity for HIV+ patients. As for autopsies performed by pathologists and forensic practitioners, embalmers with immunosuppressive diseases, uncovered wounds, weeping skin lesions, and other dermatitides, should remain distant from those cadavers given the high risk of acquiring opportunistic pathogens [47,48]. Lastly, isolated rejection should be permitted to embalmers, based on personal fear, as this profession is a commercial one (and not a medical one, nor one participating in the public health general organization).

The right balance has to be found between absolute sanitary protection of professionals, and the respect due to the dead (and their image through embalming and body conservation, visible by the family), confirming that infectious disease is a topic of primary importance for medical ethics [49,50]. This fight against the discrimination attested by HIV+ patient organizations – based on the fear of the other, or fear of the dirty? – may then be understood only with a perspective of equity. But on the other hand, should embalming of HIV patients be restricted to government authorities or licensed embalmers?

Educational issue?

As a conclusion to this issue, can we make our point that "discrimination" has an ethical basis? HIV is one of several infectious diseases listed in the (Table 2). Why is HIV different than hepatitis B, for example? If HIV has a low or zero transmission rate in the setting of embalming, is this more of an educational issue in getting the ban legally changed?

The discrimination against HIV patients exists all over the world. Because of the lack of basic information many people tend to avoid interacting with HIV patients, and of course, are afraid of the transmission of HIV from embalmed bodies. On the other hand, the doctors, nurses, staffs in the hospitals as well as those embalmers also need to be well protected in order to reduce the risks for them to be

infected. While France allows embalming, many EU countries do not. Obviously, HIV-positive individuals die in those countries and are not embalmed. Have ethical concerns been raised in those countries because of the total ban on embalming? There are legitimate concerns about the risk of infectious disease transmission in embalmers (e.g., hepatitis B has been shown to have a higher prevalence in embalmers), so because HIV is on the exclusion list for embalming is the issue one more of education (i.e., use of universal precautions, education of the law as regards the low or non-existent transmission of HIV in this setting, etc) rather than an ethical one?

If, as we stated before, "the right balance has to be found between absolute sanitary protection of professionals, and the respect due to the dead", this could also be argued for other diseases listed in the Table 1. However, this is not an ethical argument but an educational issue. This balance between absolute protection of healthcare professionals and patients harboring infectious diseases is made every day in the hospital, but the lack of balance becomes an ethical issue when a healthcare worker refuses to treat an HIV patient in the normal course of their care because, for example, the life-style of the patient is not supported by the healthcare provider. Because France has listed HIV as one of several banned infectious diseases does not necessarily mean that it is on the list because of a breach of ethics, but one of education (misunderstanding of the risks) and work-place standards of care.

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