

# Ethical Issues in DNA Identification of Human Biological Material from Mass Disasters

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## Abbreviation:

ICRC: International Committee of the  
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## Abstract

Each mass disaster has its own characteristics and will involve a different approach, so the safeguarding and collection of forensic evidence have to be considered as part of the field response procedure. DNA typing has played a more prominent role in the identification of human remains, and particularly so for highly decomposed and fragmented remains. Although the ultimate goal is to obtain the identification, the specific context of each application of human identity testing has its specific problems, ranging from technical approach, through statistical interpretation, to ethical issues. The preparedness plan of the forensic genetics laboratory needs to include policies for family notification, long-term sample storage, and data archiving. For this reason, DNA sample collection and a strategy for DNA-based victim identification needs to be part of the preparedness plan. In this paper, the authors seek to define three of these ethical aspects: (1) the humanitarian importance of identification; (2) resource allocation in the victims' DNA identification; and (3) the secondary use for research of the samples initially collected for identification purposes. DNA analysis for the purpose of identifying victims of mass disasters has complex implications that demand much more rigorous examination than they have received until now.

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## Introduction

A disaster is defined by the World Health Organization (WHO) as "a sudden ecological phenomenon of sufficient magnitude to require external assistance." This definition underlines that mass disasters imply the inability to provide adequate assistance to all persons involved, independently from the absolute number of victims.<sup>1</sup>

A mass disaster is an unexpected event that causes serious injury and death to a number of people, and each incident has its own characteristics and will involve a different approach.

Depending on the nature of the event, the safeguarding and collection of information and biological specimens, which are useful for identification of the victims, will also have to be considered as part of the response procedure.<sup>2</sup>

Various characteristics or traits are used to assist in the identification of human remains, including but not limited to skeletal features (sex, age, stature, and ancestry); dental comparisons; fingerprints; distinguishing marks (tattoos and scars); medical devices and implants; other unique features; DNA profiles; and, sometimes, personal items.

Victim identification is difficult but is essential to satisfy humanitarian considerations and legal and administrative aspects: to notify the legal next of kin, resolve estate issues and criminal/civil litigation, identify victim perpetrators, and issue death certificates. The procedure involves different disciplines to assist in the identification of the deceased following a mass disaster.

Traditional methods require both the recovery of largely intact bodies and the availability of premortem information. Because of their nature, many mass disasters will result in severe distortion of the victims' bodies, precluding the use of many traditional means of identification.

DNA typing techniques are available to aid identification.<sup>3,4</sup> DNA typing has played a more prominent role in the identification of human remains, and particularly so for highly decomposed and fragmented remains. For cases involving mass fatalities and/or highly fragmented remains, DNA provides an essential component of the identification process.

DNA analysis can: (1) identify the victims, (2) associate fragmented remains, and (3) assist in ongoing medical and legal investigations.

According to the International Society for Forensic Genetics (ISFG) Recommendation,<sup>5</sup> “The preparedness plan of the forensic genetics laboratory needs to include policies for family notification, long-term sample disposition, and data archiving. For this reason, DNA sample collection and a strategy for DNA-based victim identification need to be part of the preparedness plan.”

Human identification based on DNA technology may be achieved through different strategies. The DNA profiles from recovered mass-disaster remains can be compared with the DNA profiles from reference samples such as known personal effects of the victims. When direct DNA comparisons are not possible, reference samples provided by family members can be used for indirect identification using kinship analysis.<sup>6</sup> The new DNA techniques not only aid the individual identification of disaster victims but also can allow the reassembly of heavily fragmented remains that could not be reassembled by any other means.

For these reasons, forensic DNA profiling is increasingly becoming an important tool in the individual identification in the aftermath of mass disasters. Therefore, DNA sample collection and a strategy for DNA-based victim identification need to be part of the preparedness plan, including policies for family notification, long-term sample disposition, and data archiving.

The DNA identification process following mass fatalities raises specific problems ranging from technical approach (including intensive labor and costly analysis), through interpretation of DNA profiling results, to ethical issues.

There has been very little systematic effort to identify and analyze the major ethical and policy challenges associated with this new use of genetic technology. This report seeks to define some of these ethical aspects: the humanitarian importance of identification, resource allocations in DNA identification of victims, and the secondary use for research of the samples initially collected for identification purposes.

## Report

### *The Humanitarian Importance of Identification*

Forensic identification of victims is essential for humanitarian reasons. In fact, one of the purposes of the forensic investigation on human remains is to identify them and, if possible, return them to their families. This objective helps family members by ascertaining the fate of their relative and allowing the remains to be handled in a culturally appropriate manner, thus enabling the families of the missing to accept their loss. Without proper identification, there could be social or administrative difficulties for families and, above all, it would be impossible to conduct burials in accord with traditional religious customs. Furthermore, identification represents an important step in the rebuilding of societies affected by mass fatalities, helping the return to normalcy for families and communities. So every effort should be made to identify as many human remains as possible to avoid increasing emotional suffering for families.

### *Resource Allocations in DNA Identification of Victims*

Physicians make many decisions every day involving the prioritization of resources. Given that physicians are experienced

at making these types of resource decisions, they often are made without much thought to underlying ethical considerations. In disaster situations, the consequences of decisions about the allocation of medical resources are magnified because physicians have to accomplish the “greatest good for the greatest number.” So it is important to provide physicians with a framework of ethical and operational principles upon which interventions provided have to be adapted to demand and available resources, considering that priorities and approaches differ from those in daily practice.<sup>7</sup>

In a forensic genetics context during a mass-disaster situation, the typical questions emerging in the decision-making process related to resource allocation in managing victims’ identification could be:

- Is it sufficient to identify all victims, or would it be necessary to attempt a complete reassociation of all recovered body parts?
- Does each family need to be informed about their relative’s identification as early as possible, or when all samples are completely reassociated?
- Will all fragments, only fragments meeting a certain size, or only anatomically recognizable fragments require testing?

Although the decisions on these matters are in the hands of the local authority in charge of the operation, the forensic geneticist should be ready to assist in such a decision-making processes.

The realistic possibility of obtaining identifications should outweigh the cost and complexity of a strategy using DNA analysis. However, there should be an “exit strategy” through which the identification process can be brought to a close when the cost and complexity outweigh the social benefit. Even if DNA analysis could lead to certain identifications, other identification approaches—for example, initial anthropological screening—may be useful to eliminate the need for expensive and repeated analysis.

This cost savings in the victim identification process also can be reached through an overall coordinating body that would be in charge of managing the victim-identification process. In the absence of such a coordinating body, how those steps (ie, the procedures for identification) are taken and by whom should be stipulated in advance according to competencies. Important considerations include: (1) any issues relating to the ownership, transport, and final distribution of the remains (repatriation), and (2) data generated on human remains and samples. In the case of multinational disasters, these issues should be handled in accordance with government rules that apply to the place where the mass disaster occurred, and can include eventual financial support or close cooperation from other involved governments.<sup>8</sup>

### *Using Samples Collected for Identification in Research*

Regarding the use of samples collected for identification purposes for the secondary purpose of research, a brief preface is useful. Generally, legislation that deals specifically with the issues arising from technological advances has not kept up with the rapid advance of DNA analysis in both forensic and medical applications. The authors have considered as reference for the discussion of this aspect the document entitled *Missing People*,

*DNA Analysis and Identification of Human Remains—A Guide to Best Practice in Armed Conflicts and Other Situations of Armed Violence*, published in 2009 by the International Committee of the Red Cross (ICRC). The publication contains a set of principles specifically related to the use of biological samples and the resulting DNA profiles in managing identification in mass disasters.<sup>9</sup> Relative to the secondary use of biological material collected after a mass disaster, the most appropriate aspects outlined in the document are the following:

- The collection, use, and disclosure of DNA profiles are subject to the rules relative to the protection of personal data;
- DNA samples may be collected and analyzed only for a clearly identified and specific purpose;
- DNA samples may be taken and analyzed only with the informed consent of the individual, except where an overriding public interest dictates otherwise. An overriding public interest should be limited to criminal investigations or public security and, in case of death, to the identification of remains. The specific purpose should be only direct individual identification;
- DNA information that is collected may be used and disclosed only for the purpose identified at the time of collection, or beforehand;
- DNA samples and profiles should be destroyed or deleted after they have served the purpose for which they were collected, unless required for related purposes; and
- Once the victim's identification has been completed, what type of research is ethically permissible on samples collected for identification and, above all, is the research ethically justifiable?

The types of research proposed by Knoppers, et al<sup>10</sup> for the DNA biobanks of victims of mass disasters fall into three major categories:

- Forensic research to develop improved methods of identification;
- Disease-related research, such as susceptibility to toxic substances or physical agents involved in mass disasters; and
- Epidemiological studies of diversity.

There is an increasing necessity to address ethical issues surrounding secondary use of samples following mass disasters, and to provide guidance to researchers and research ethics boards.<sup>10,11</sup>

Ethical considerations discussed generally in respect to secondary uses in other fields (routine medical activities or research), especially on vulnerable individuals, should be applied also to the secondary use of collected biological materials from mass disasters. It is widely held that the interests and rights of a person do not expire at death. In the context of mass disasters, deceased persons should be considered "vulnerable" individuals because they cannot protect their own best interests. Once samples collected for identification are used for secondary purposes, deceased persons become "subjects" involved in the research, so the protection of their rights should be guaranteed and respected by all persons involved, from family members to researchers.

According to ICRC guidelines, "when relatives are asked to donate reference samples, the reason for collecting the biological

material should be explained to the consenting individual: the persons should be able to understand how the collection will affect them." In these cases the information that has to be provided to victims' relatives regards:

- Why the samples have been collected and how the identification process will work;
- The practicalities of participating in the program and the benefits that they are likely to receive from participation;
- How data relating to them will be managed and used, and that the principles of data protection will be respected; and
- How they will receive information during the identification process.<sup>9</sup>

The request for consent for future uses of the reference samples in such situations may be difficult and can present ethical problems, because many factors may play a considerable role in the supposed family members' decision-making process. In fact, in relation to the impact of mass fatality on the relatives of the deceased, different physical and mental symptoms can emerge as pain, anxiety, and depression related to the traumatic nature of the whole situation, so these affections could vitiate the consent that they would give.

The ICRC guidelines point out the possibility that DNA samples and data should be destroyed unless required for related use, and that the emerging questions are: (1) which kind of related uses may be considered in this field, and (2) who will determine the "related uses" of the samples.

Regarding these questions, in conformity with the position of ICRC described above, the improved methods of DNA identification seem to be the only type not contrary to the original consent given by the relatives with the purpose of identification; samples should be anonymized and there should be ethical approval of the research project.

Another aspect related to the secondary use for research of the samples is the return of results; that responsibility becomes a duty for the researchers. In fact, it seems difficult to manage any incidental findings that reveal concrete consequences to the survivors' health.

In this context it is difficult to deal with particular situations, for example, the discovery of a misattributed paternity during research on reference samples. Considering that the identification is possible and the first purpose of the consent has been achieved, it could become a duty for the researcher to reveal the incidental finding. Nevertheless, it should be kept in mind that daily family life already has been affected by the mass disaster, and additional traumatic information as well as unjustified privacy violation should be avoided.

## Discussion

DNA identification techniques are widely used in the setting of mass disasters. From an ethical point of view, identifying victims is important for humanitarian reasons, ranging from the necessity of families to face the consequences of their loss to the respect for religious burial customs. In disaster situations, ethical and practical frameworks should be given to the personnel involved, with the purpose of operating the best possible allocation in light of available resources, considering that priorities and approaches differ from those usually involved in daily medical decision-making processes. The forensic genetics laboratory should be part

of this preparedness plan, and laboratory personnel should be aware that the resource allocation may be different from routine practices. There is an increasing necessity to address ethical issues surrounding the secondary use of samples following mass disasters, and to provide guidance to researchers and research ethics boards. The use of samples collected for victim identification in mass disasters should be allowed only for secondary research improving the primary purpose of the personal identification.

### Conclusion

A combination of humanitarian attention, improvement of identification technologies, harmonization of preparedness strategies and, above all, ethical reflection should be required when faced with the management of victims' identification in mass disasters, both in policy making and in practice. Indeed, DNA analysis for the purpose of identifying victims of mass disasters has complex ethical implications that demand much more rigorous analysis than they have received until now.

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