

Transcript of the episode of Privacy Studies Podcast: The New Frontiers of Postmortem Privacy: Negotiating the Research Ethics of Human Remains in the Era of the Third Science Revolution in Archaeology – Presentation by Professor Liv Nilsson Stutz and Dr. Rita Peyroteo Stjerna (Linnæus University, Sweden)

Hello, my name is Felicia Fricke and I am Natacha Klein Käfer, and you are listening to the Privacy Studies Podcast.

This season of the Privacy Studies Podcast follows the discussions of the symposium *PRIVACY AND DEATH: Past and Present*, which took place at the University of Copenhagen and online between October 12th and 13th, 2023. This event aimed to bring to the fore the discussions of what kind of privacy, if any, we have given to our dead in different cultural and historical contexts. We will hear presentations by historians, archaeologists, sociologists, and other experts.

Transcriptions of the episodes can be found on the Centre for Privacy Studies' website.

In today's episode, we will hear from Professor Liv Nilsson Stutz and Dr. Rita Peyroteo Stjerna from Linnæus University in Sweden. Their presentation is entitled 'The New Frontiers of Postmortem Privacy: Negotiating the Research Ethics of Human Remains in the Era of the Third Science Revolution in Archaeology'.

Rita and I are currently working on a research project on research ethics entitled 'Ethical Entanglements: the Care for Human Remains in Museums and Research' and the topic of death and postmortem privacy is a small part of this project, but we feel like it's also kind of fundamental in many ways to the questions that we're asking.

In our paper today, we will focus specifically on the challenges that emerge from the development of new research methods in bioarchaeology and how they relate to these issues.

So in the past 20 years, we have witnessed an impressive development in laboratory methods to investigate archaeological human remains. This development has been referred to as the Third Science Revolution, and it has had a fundamental impact on bioarchaeology by unlocking previously unknown information lodged in human biomaterials. But while it has had these fundamental implications for research, very little has actually been said about how it relates to the concepts such as privacy, dignity, and ethics, and how this information can be shared and used. A lot of the information now accessible addresses aspects of an individual's life that could be considered private. All human remains, and by that we in our project refer to all preserved materials that originate from the human body, including bones, pre-mains, organic tissue, potted specimen, nails, hair, body fluids, including human remains that are part of other objects and that originate somehow from a historic context, which sets them apart from medical context, which will then be more structured by medical ethics. These remains are not neutral objects, but they can be conceived of, and this is a fundamental model for our project, as moving on a spectrum between being objects of science and lived lives. Where on the spectrum we perceive them to be positioned depends on a range of factors including how much we know about them, their provenance, but also their character and degree of preservation. So, for example, we're more likely to see the lived lives in the potted conjoined twins in the central picture compared to the cremated remains or the hair jewelry. And that also includes, of course, bloodstains on the shirt.

With the new methodologies, however, new categories of human remains previously overlooked in the debates about ethics have become sources for this type of information. The new technologies

allow us to see more of the humanity in previously overlooked samples. For example, these bloodstains, a single tooth, or a cup of hair. We have unlocked a new level of insight into the past, moving them from being objects of science or even throwaways of science toward the end of the scale that designates this lived life. And with these new opportunities comes responsibilities and new ethical dilemmas. Research ethics tend to be based on research on living subjects and they're often built around the concepts of informed consent, but for individuals that have been dead for hundreds of years, consent can no longer be obtained and very rarely inferred. Other laws, regulations, and recommendations are vague about how we should handle this number. And in fact, many best practices in some parts of the scientific practice, such as open access, are in direct conflict with protecting the privacy information of the dead. So in this paper, we will address these issues through two concrete examples that allow us to highlight the ethical challenges relating to potentially sensitive information recovered from all human remains, and then move into a study of original data collection.

The rapid development of biomolecular archaeology has aggravated the number of already existing challenges and underlined the ethical entanglements of research using human remains in a highly unregulated field. However, some of the existing challenges in the field are actually prior and independent from biomolecular archaeology. For example, the microscopic observation of human forms can reveal diseases, pathologies, and the health status of an individual. These osteobiographies can potentially expose private health issues such as syphilis, tuberculosis, with varying degrees of social stigma. With new research methods becoming more powerful, issues regarding the privacy of the dead are being pushed towards new frontiers of post-mortem privacy with research revealing potentially sensitive information. That is the case of ancient DNA research, which can reveal not only a range of individual information, but also aspects that are intrinsic to the family tree including relationships. The power of DNA actually lies on this. It goes beyond the individual. While DNA is arguably the most powerful methodology in the biomolecular toolkit, other methods, such as stabilisator analysis, when used in combination, are also powerful as well. Stabilisator analysis of human remains measures carbon, nitrogen, oxygen, strontium, and so forth, and in some contexts can expose potentially sensitive information digging deep into issues of migration, social inequality, or taboos associated with age and gender. To illustrate the connections between post-mortem privacy and ancient DNA we'll briefly present two case studies. The first is the recent publication of the analysis of several samples of Beethoven's hair and the second explores the controversy behind the potential study of DNA in the early 2000s of Queen Christina of Sweden.

So our first example in the study is that of the hair attributed to Ludwig van Beethoven that was published in *Current Biology* earlier this year. Beethoven is a historic person with a well-known identity and living descendants and since he is one of the most influential composers of Western classical music he and his life, professional and private, is of great public interest. But does that mean that he has no right to privacy? I think that the distinction here to be made is between laws and rules that regulate privacy of people in their private lives and what we can do in science and then make available as open access. The study was based on the analysis of eight blocks of hair required for both public and private collections, and the first research question pertained to the authenticity of these samples, and the study could confirm that five of them were authentic, so three collectors must have been very disappointed. At first glance, hair doesn't seem to be a controversial category of human remains. We shed it daily, we cut it, discard it repeatedly over our lifetime, and many would not consider it to be truly part of the body, not like bones, skin, and organs. Nevertheless, a lot of information is stored in every single strand of hair, and while we cannot practically protect these strands of hair from

spreading, we may want to consider how we can handle this information as part of our research ethics, and how we protect the individual whose body it originated from. Beethoven was a sick man. He suffered from hearing loss, abdominal pain, diarrhea, and jaundice. Significant research has already been carried out as regards to his health and it was based on historic sources such as his autopsy reports, his diaries, conversation books, and accounts from the time of his death. His body has been exhumed twice in this study. Despite these efforts, there hasn't been any conclusive diagnosis, and although cirrhosis has been presented as likely, historical documents indicate that Beethoven did not only consent but actually requested that following his death his disease may be described and made public. This information is included in the paper as a little bit of a consent. The question is thus not whether he would consent at all, but perhaps to what extent he could imagine what might become public knowledge. What could this study add to the already rich record? Was it simply like a desire of scientific accuracy that motivated this study or was it perhaps because we can? It should be added here that the method that was applied to extract DNA from hair that is no longer contained like a hair sack is new and quite exciting so it was kind of a cool case. The analysis sequenced two-thirds of Beethoven's genome and when analyzing it, they could conclude that he was genetically predisposed to liver disease. They could also conclude that he suffered from Hepatitis B, at least in the months leading up to his death, and the study confirms that this condition likely was caused by his well-known enthusiasm for alcohol. The study also offered up a bonus. The team performed an ancestry analysis, and the point of this exercise was to determine the location of Beethoven's ancestors. Interesting research, by the way. And they compared his genome to two groups of genealogically documented living relatives. And the study revealed an extra-marital paternity event in Beethoven's direct paternal ancestry, possibly an event in his immediate paternal level, meaning an extra-marital affair. While Beethoven may have been comfortable having his dead body examined after death to determine what in his lifetime was a mysterious illness, he may not have been ready to consent to studies that revealed his substance abuse and perhaps especially not a case of an extra-marital affair in his immediate family history.

The second case study takes us to Sweden to Queen Christina, who lived between 1626 and 1689. As the heir to the throne Queen Christina received an education usually reserved for men. Also, she didn't follow the stereotypical ideals of the time for how a woman should behave. And questions have long been raised about the queen's gender. Christina refused to be crowned using the queen's crown, which has been remade for her and instead insisted to be crowned with the king's crown her ancestor, King Eric XIV. Before her coronation, she made it clear that she never intended to be married, saying: were it in my power to marry, I would willingly do so. But I say this explicitly that it is impossible for me to marry such is the nature of the matter. I cannot give my reasons, but my heart is not in it. I have prayed diligently to God but in vain.

When Christina was buried in Rome, the grave was reopened in 1965 and the Swedish physician who was present at the reopening secretly collected pieces of fabric from the queen's crown. Allegedly, DNA from this material has been extracted and it's stored in Uppsala in Sweden. Some years ago, a journalist contacted the researcher with access to this DNA. The journalist's question, and again interesting that the journalists are taking initiative here, was if the rumors of the queen's gender identity could be settled through genetic analysis and thus the idea of genetically testing for a disorder of sex development was raised. Technically this is actually very challenging to test and we are not really sure if we can be confident about the authenticity of the DNA of this extraction, if it's the queen's Christina DNA. But the issues here were not just technical. Importantly, the researcher in charge of

this legacy raised concerns. If one should even attempt to acquire such personal genetic information considering that in the case of living persons the genetic information is protected by law. As Marlene Masterton, here the cover the PhD dissertation 'Duties to Past Persons' from 2010, she asks does Queen Christina have a posthumous interest in protecting her privacy? Or put it in another way, can personal information continue to be of sensitive nature and therefore require ethical reflection before exposing and even after that person died a long time ago?

As Masterton argues, while Queen Christina can no longer maintain her own identity, we maintain it by our research into her life. Based on Queen Christina's case and others, Masterton proposed three duties to past persons:

The duty for truthfulness, the duty of recognition, and the duty to respect of privacy.

Of course, Beethoven and Queen Christina are both well-known individuals and any privacy they may have held in life are arguably already breached by studies of their letters, diaries and so forth. But these kinds of studies still invite us to critically ask, what are the ethical boundaries when it comes to extracting and sharing potentially private information of past people without informed consent? Additionally, what can we learn from cases of famous people that is applicable as we develop our professional ethics with regards to human remains in general?

In parallel to this, we are running a study to identify attitudes, rationales, arguments and concerns, underlying practices and decision making from a research point of view to bring forward the researchers' perspectives and identify the views of those who are actually in the field of biomolecular archaeology. To do this, I have conducted more than 30 interviews with researchers and technical staff carrying out biomolecular research on human remains from archaeological, ethnographic and medical anthropological collections. We are interviewing colleagues at all career stages, and due to the nature of type of research: multidisciplinary and very international, this study includes people from multiple nationalities and diverse backgrounds in reaching in this way the results of this project.

When asked about post-mortem privacy, and these are some of our preliminary results, some topics emerge. Researchers tend to find the post-mortem privacy of the dead an intriguing question.

Most have not thought about it, although when they are asked they find it an interesting question, but one that is difficult to answer. Most are unsure where they stand but highlight that, while we should be careful, it would be a shame not to investigate populations because of privacy reasons. Researchers also question if this is actually a problem. They mention if it's old, more than 150 years or so, depending on heritage loss, it's something to not worry about since most of these people are anonymous and the results are often kept at the general level. One of the researchers even mentioned that nowadays there is so much data available for everyone that having a strong value available, it's not going to be so bad.

Another common thread projects the privacy of the dead in relation to the living. Post-mortem privacy is currently perceived in connection to living persons, and there's not much thought about the dead individuals per se. In general, researchers feel a lot more comfortable researching old remains because they cannot be connected to modern populations and it is understood that it may be sensitive to some people, but here again the focus is, the concerns are with the living. One final thread that we would like to highlight is the concept of common heritage that is being highlighted by researchers. Once the

material is collected for example, when it's excavated, we're already interfering with the dead, and this is protected by heritage law. Because sampling is destructive, we should generate as much data as possible and making it open access is part of that, highlighting the idea of common heritage.

When researchers are asked about historical individuals and very briefly, and hear about the Beethoven paper, and what researchers think about it, on one hand, they highlight this research is not scientifically interesting, comparing it to celebrity journalism, and that even in today's society, these people are not afforded the same level of protection as a private individual. One researcher summarized this quite well, I think, and I quote: it is always interesting to read about scandals and gossip about historical celebrities, but there is no scientific relevance, it's just a story, there is no scientific value. We researchers do it and abuse it because we can, it's just a hard line to draw.

On the other hand, some researchers point out, if we study the anonymous why shouldn't we study the historically known? What would be the reasons to make such a distinction? The value of stories, and it's been highlighted already here today, is often mentioned, and that this can also be exciting research. And I quote: you are telling their story. It's good to have these stories. It can also be useful to give this person the right story, using the data to give a more accurate story.

So, to conclude, we argue that new methods present new challenges for how we think about private information in the past and our research ethics with regards to making this information public. And also recognizing the existence here of multiple ethics that will need to be somehow negotiated. While we don't have any answers yet, we conclude that with a fast development in this field it will be imperative that the researchers involved in these fields themselves engage with the development of their professional ethics and go beyond best practices, protocols, and reflect in a deeper way on these complex ethics. And here, the interview research can be a first step. It's useful to collect qualitative data, but more for us because we get the data, but an additional step perhaps even more significant bonus output of this work is that it engages the researchers. It provides time for reflection, raises awareness about issues that have not been addressed before, and as one interviewee said, quote:

I think it's good this project exists because it raises a lot of questions, and that would be very helpful.

Thank you.

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Thank you so much for listening.