

## Zefinha – the name of abandonment

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**Abstract** *Zefinha has been living in a forensic hospital for the last 39 years. She is the longest female inhabitant surviving under compulsory psychiatric treatment in Brazil. This paper discusses how the ethical rule of anonymity might be revised in research concerning a unique case involving severe violations of human rights. My argument is that there are cases in which disclosing the names of research participants protects their interests and rights.*

**Key words** *Anonymity, Confidentiality, Research ethics, Forensic hospital, Insanity*

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## The crowd

I coordinated the first census of custody and psychiatric treatment hospitals in Brazil, also known as forensic hospitals. In 2011, 3,989 individuals lived in 26 such institutions that are neither asylums nor prisons<sup>1</sup>. Some individuals are temporary inhabitants: they are in forensic hospitals for evaluations of insanity, since outbreaks or strange behavior generally inspire the suspicion of insanity in prison. Other individuals stay longer because they were given a compulsory treatment order. The duration of treatment is from one to three renewable years, but is generally extended into the indefinite future. There are individuals who unknowingly became permanent inhabitants upon arrival, because they never received a psychiatric discharge order or termination of their sentence. The census identified 18 individuals committed to institutions for more than 30 years, which is the maximum duration of punitive detention for individuals charged with crimes of insanity determined by the Brazilian Supreme Court<sup>2</sup>. Since there are no life sentences in Brazil, the question arises whether there is permanent psychiatric imprisonment for mentally ill offenders.

The census study was reviewed by an ethics committee and approved according to the principles for the protection of human subjects. The directors of each forensic hospital were considered the gatekeepers of information and authorized the archival research. During the fieldwork stage of the study, a set of additional information was collected and formed different archival fonds about mentally ill offenders in the country – one of them comprised the individuals committed for the longest time in each forensic hospital. There are 25 men and one woman whose documents were retrieved to form a new catalogue of information<sup>3</sup>: the *corpus* of the longest inhabitants of forensic hospitals in the country, the abandoned inhabitants.

To form the archival fonds, the project underwent another ethical review through which the copying of specific dossiers was approved. The administration of each establishment authorized them to be digitalized, and the research team began to reflect on the significance of certain legal and ethical tools to access and disclose official information. It is known that ethical review committees employ a hegemonic biomedical model, which is not very sympathetic to the particularities of research studies in the humanities, especially those in anthropology, history, or human

rights<sup>4,5</sup>. However, the duty of anonymity is a shared principle across disciplinary boundaries: the differences between fields lie in what should be disguised in order to prevent the identification of individuals.

My objective is to dispute the duty of anonymity as a common and absolute presupposition of ethics in social research. I argue that there are cases in which the ethical responsibility of the researcher is to disclose the name of the research subjects. I begin by clarifying how the *corpus* of the abandoned inhabitants was formed and, in particular, by explaining the access to the archive and the type of documents researched. Then, I analyze the implications of anonymity for this group, using as normative reference the Brazilian Law of Archives<sup>6</sup>, the Brazilian Law of Access to Information<sup>7</sup>, and the Brazilian CNS (National Council of Health) Resolution 466/2012<sup>8</sup>. I will focus my argument on Zefinha, the woman abandoned for the longest period of time in a forensic hospital in Brazil<sup>9</sup>.

## Dossier

For the census, forensic hospital inhabitants were not interviewed. The study, which consisted of document analysis, was the first population count in the 90-year history of these institutions in Brazil. The first forensic hospital was founded in Rio de Janeiro in 1921, and the size of the population of mentally ill offenders in these establishments remained unknown since then. We visited every forensic hospital in the country and opened the dossier of each inhabitant, whether they were committed for a psychiatric evaluation, detained for compulsory treatment, or already in the process of being released. In each forensic hospital, we recovered the dossier of the individual committed for the longest period. The dossier of an inhabitant of a forensic hospital is a specific unit of archival documentation, a hybrid piece that attends to two orders of knowledge and power, the penal and the psychiatric. It is a collection of documents that describes and justifies the necessity of confinement.

The *corpus* of the longest inhabitants in these institutions in the country was catalogued according to two criteria: the duration of confinement and the restriction of one individual per forensic hospital. Depending on the date on which the institution was founded, the longest inhabitant could be considered a novice when compared to the permanence of abandoned inhabitants in

other institutions. Given that 23% of the forensic hospitals were founded in the 2000s, there is a significant disparity<sup>1</sup>: the longest inhabitant in the country had been committed for 47 years, while the individual committed for the longest period in another institution had been confined for eight years at the time of data collection.

We digitalized the dossiers to form the *corpus* of the abandoned inhabitants in Brazil's forensic hospitals. Zefinha was the only woman in a group of 26 abandoned inhabitants. She had been living in custody for 39 years at the time we gathered the data—two years in a common prison and 37 years in the Judicial Psychiatric Center Pedro Marinho (*Centro Psiquiátrico Judiciário Pedro Marinho*), in Alagoas state<sup>9</sup>. Her status is doubly shocking: she has been confined for more time than the acceptable duration for just punishment, and the only woman still enduring confinement among those committed for the longest period of time. While still a young woman, she committed a crime that appears under different classifications in her archival records: bodily harm, attempted homicide, or, in her own words, “a little poke”. Whether she committed bodily harm, attempted homicide or a small puncture wound, Zefinha was described as a normal woman according to the psychiatric assessment conducted upon her arrival at the forensic hospital. Almost four decades later, her psychiatric history is one of morbidity, illness, and dependency. The conclusion of the most recent psychiatric assessment is that Zefinha can no longer be released from confinement because she does not know how to live free. The file described her as a “paranoid schizophrenic,” but only in old age did she become a woman dependent on the care of others for a life outside of custody.

In order to recover Zefinha's history, we returned to the forensic hospital in Alagoas after another ethics committee review and with authorization from the director of the institution. I personally spoke with Zefinha, but her state of mental suffering rendered impossible a fully informed encounter. Zefinha was consulted regarding her interest to speak with me. She accepted and agreed to have the encounter recorded and photographed. The director of the hospital signed a permission form for the interview, reviewed the research instrument, and affirmed the informed consent form for the interview, which came to terms with the alleged centrality of the informed consent as a key component of research ethics. Zefinha's dossier is 85 pages long and comprised of police reports, photographs, medical reports, accusations and court sentences

collected from the 39 year period of her confinement. There are no details concerning medical privacy, given that there are two types of archive for each inhabitant: the dossiers, or case files, and the medical files. In addition to the dossier, we recovered a copy of the court case files, after receiving authorization from the judge responsible for the case. The dossier, court case files, conversation and photographs comprised the *corpus* of Zefinha's confinement.

## Responsibility

Documents and archives were brought together through two separate legislations in Brazil's political history: The Law of Archives<sup>6</sup> and the Law of Access to Information<sup>7</sup>. The Law of Archives defines the distinction between a public and a private archive as well as management procedures. To understand the concern behind its creation and successive revisions, Georgete Rodrigues<sup>10</sup> covered the tense path of Brazil's history that led to the overlapping of secret and memory for the access to official information. By regulating access to information produced by the State or by organizations financed by public authority, the Law of Access to Information revoked a set of precepts in the Law of Archives, in particular, those concerning forms of access and disclosure of information.

The two laws transit through a vast vocabulary that combines archival science with government bureaucracy—information, document and archive are three concepts with definitions worth scrutinizing. Information is material, regardless if it consists of personal information or public accounts. It corresponds to the form of communication that drives state bureaucracy. Documents are the units of discursive record and may consist of words on paper or numbers in an electronic message. Finally, an archive is a collection of documents: the set of information concerning a common theme produced by an institution is described as an archive. It is in this manner that phrases such as “judicial archive,” “police archive,” “medical archive,” and “educational archive” are formed—as many phrases as there are life-governing entities through which the state bureaucracy is put into motion. If, on the one hand, the Law of Archives was oriented toward the past, on the other hand, the Law of Access to Information is timeless—past and present are both covered by the regulated right of access to information.

For academic research, access to information is still administered by the CNS Resolution 466/2012<sup>8</sup>, which regulates procedures and practices to be followed by researchers. The information in the documents, according to the terms of the Law of Access to Information, is transformed into “research findings” in the language of the Resolution. “Research findings” is a broad concept that covers a creative diversity of disciplinary methods and fields: from laboratories to interviews, from photographs to clinical trials. To establish a dialogue between the Law of Archives and the Law of Access to Information, on one side, and the CNS Resolution 466<sup>8</sup>, on the other, one possible metaphor would be to understand information as a raw record produced by state bureaucracy, and the research findings as what is created by “cooking” the information. In Zefinha’s story, the pages and images are the information, and the academic analysis is the research findings.

The Law of Access to Information articulates who should submit to its regime of rules concerning disclosure and treatment of information: “Article 1. This law stipulates the procedures to be observed by the *Union, States, Federal District and Municipalities*, with the objective to guarantee access to information stipulated in proposition XXXIII of Article 5, proposition II of § 3 of article 37, and in § 2 of article 216 of the Federal Constitution”<sup>7</sup> (without italics in the original). In legal terms, academic researchers are “solicitors of information,” and not directly linked to control measures—except in an expanded hermeneutic of the demonstrative pronoun “those,” in Section V, the theme of which is the regulation of the treatment of personal information: “Article 31 [...] § 2 Those who obtain access to information that concerns this article will be held responsible in the case of *undue* use” (without italics in the original)<sup>7</sup>.

The dossiers could be considered current personal documents in the terms of the Law of Archives, but not secretive in the terms of the Law of Access to Information<sup>6,7</sup>. There is identifiable personal information and, according to the sensitivity classification of the documents proposed by the Law of Access to Information, excessive caution could lead to understanding them as documents of restricted access, particularly because of the vulnerability status of the documented individual. However, given that compulsory psychiatric treatment is a confinement penalty, I will risk arguing that transparency concerning punitive acts by the State should be more important

than secrecy measures when it comes to access to personal information.

The medical information about Zefinha in the dossier is what was provided to the justice system to justify the permanence of her confinement for compulsory psychiatric treatment. In other words, these medical reports have the status of expert authority for the justice system. Copies of the evaluations are also included in the court case files, but they are not documents that describe the state of Zefinha’s health for her daily care routine. The psychiatric reports describe signs and symptoms of mental illness, in which the investigative concern is dangerousness. It is in this way that psychiatric reports are expert reports or, in the terms of Michel Foucault<sup>13</sup>, ubu- esque writings, texts of a pathetic duality of powers, that of punishment and that of the classification of insanity as a justification for involuntary commitment.

A researcher is not an agent of the State who produces bureaucratic information to govern laws, policies or norms. In the terms of the CNS Resolution 466<sup>8</sup>, researchers are excavators of findings. The information contained in archival documents is transformed into artifacts for academic argumentation. The raw data offered by the guardians of the archives do not constitute “research findings,” since a basic epistemological principle of the scientific concern is that of the denaturalization of the current discourse. The information is a rudimentary element, and only an intellectual reflection will transform it into an argument. Following the CNS Resolution 466<sup>8</sup>, the “final report” is the name of the metamorphosis of information into an argument.

But how do the Law of Archives, Law of Access to Information and CNS Resolution 466<sup>8</sup> relate to the history of Zefinha? There was no formal appeal to the Law of Access to Information for the census study or to form the *corpus* about Zefinha. The guardians of the dossier and the court case files authorized the study. But if the assumption of a broad hermeneutic of “those” in Section V § 2 in the Law of Access to Information<sup>7</sup> is reasonable, there would be responsibilities in the dissemination of identifiable personal information. It is necessary that the text produced not be an *undue* use of personal information. In this moment, by writing about personal information, I provoke the meaning of responsibility by disclosing the name of the woman abandoned for the longest period of time in a forensic hospital in Brazil.

The responsibility mentioned by the Law of Access to Information is of a punitive character,

so much so that it appears in the passive voice, with the expectation of a subject for the verb in the future tense, “will be held responsible.” The vocabulary of responsibility is in turn connected to a hegemonic rationality of the secret that colonizes not only policies on archives and access to information, but also the CNS Resolution 466<sup>8</sup>. The researcher will be summoned to take responsibility if the disclosure of information implies risks to the individual. The qualifier “undue” is ambiguous in the law given the absence of specification, and attempts to describe the moral or juridical content of obligatory responsibility in this legal context are directed toward the agents of the State responsible for the treatment of information, and only residually toward the users of information.

The CNS Resolution 466<sup>8</sup> is clearer and more ambitious regarding the subject of responsibility. Item III, “On the ethical aspects of research involving human subjects,” asserts that

[...] research studies in any area of knowledge involving human beings should observe the following requirements: [...] i) foresee procedures that ensure confidentiality and privacy, protection of the image and non-stigmatization of the research participants, guaranteeing that information not be utilized that places people and/or communities in harm, including in terms of self-esteem, prestige and/or economic-financial aspects<sup>2</sup>.

Confidentiality becomes a requirement of the Resolution in order to qualify the ethical character of a study. I assume confidentiality to be one of the central dimensions of responsibility in the use of personal information, and I also argue that there are paradoxes in the presumption of confidentiality as absolute ethical protection. It is worth remembering that the Brazilian Code of Ethics of the Anthropologist determines that “constituted as rights of the anthropologists and researchers are: [...] 3. The right to preserve confidential information”<sup>14</sup>. In contrast to professional codes in the biomedical field, in which regulation is oriented towards professional practices, not those of research, there is no requirement of confidentiality.

### Confidentiality

I do not propose imploding the meaning of confidentiality or privacy for biomedical research or for other forms of social research. There are groups or methodologies in which confidentiali-

ty of information is essential to guarantee fundamental rights, as was the case when I interviewed women for a study on abortion<sup>10</sup>. Yet, although they are ambiguous qualifiers, I assume there to be *due* and *undue* uses of personal information—*undue* use could be the result of the obligation of confidentiality without consideration of the political and ethical implications for the group studied.

Concepts such as confidentiality, privacy, intimacy, secrecy, secret, honor or image overlap with the normative, ethical and methodological literature on how personal or institutional information should be presented without harm to the research participants<sup>15-21</sup>. On one side, there are liberal values that recognize the centrality of the individual, her interests and rights. On the other side, there are utilitarian principles that consider the benefits and risks of the use of personal information. The confusion between concepts is not irrelevant to reflect on the “convention of confidentiality”<sup>15</sup> or, as Jan Nesper<sup>20</sup> prefers, the hidden meanings of the “black box”.

Confidentiality can be described as a methodological arrangement that conceals information to impede the identification of the individual, and anonymity is one of its primary tools. Confidentiality presupposes the delusion of a form of reasoning that pursues the discourse of truth: we do not construct fiction, but write with the status of science<sup>15</sup>. As researchers, we place into doubt the absolute truth, but depend on the accuracy and veracity of the “research findings” in order to make the text credible<sup>11</sup>. Through anonymization, we describe people and locations as expressions of reality, but present them under a textual cloak: Zefinha would have to be another person in order not to be identified. However, we would have to change not only her name, but also the duration and location of her confinement, her crime and diagnosis. The concealment required for a narrative of a unique case amplifies the cloak of secrecy that transformed the young Zefinha into an aged woman, insane and too dangerous for social cohabitation. I argue that the use of confidentiality in this case is *undue*, not simply because of the impossibility of de-identifying Zefinha, but for political and ethical reasons.

Anonymity is a barrier to the identification of an individual. The question is: why would admitting the identification of Zefinha be an *undue* use of her personal information? The barrier of a name as an instrument of ethical protection presupposes an individual that possesses secrets,



as well as an interest in preserving secrets of intimacy or privacy. Due to a paradox of the archive, as Jacques Derrida<sup>22</sup> notes, “the secret is the very ash of the archive,” or, the true secrets about Zefinha are not in the documents that we recovered to report her story of abandonment. There are traces of precarity in her life, such as delays in evaluation, use of electric shocks or poor medical assistance. Power is represented institutionally, and the duality of penal and psychiatric powers is produced through the doctors and judges who sign the written decisions of confinement—and those two groups of individuals were made anonymous in the recovery of the story of Zefinha’s abandonment. The anonymity of the authors of the documents was not conducted as a strategy to protect the liberal values inscribed in legal norms, but to concentrate efforts on the person who needs to be named in order to be recognized as the subject of the testimony.

There are studies in which to uncover forms of power it is necessary to name their victims. Zefinha is a victim of the ubiquitous penal and psychiatric duality of powers of criminal insanity. By identifying her, I abdicate from the sovereign authority of interpretation—other researchers can review my research *corpus* and contest my thesis concerning abandonment. I therefore take the risk of declaring two false presuppositions in the obligation of confidentiality by anonymizing Zefinha: the assumption that disclosing her name would cause her harm and the notion that identifying her would violate her intimate life. The anonymity of the woman abandoned for the longest period of time in a forensic hospital in Brazil would not protect the woman who lives forgotten, but the powers that permitted her existence as such.

## Zefinha

I argue that disclosing Zefinha’s name as well as those of other abandoned inhabitants in forensic hospitals is an act of responsibility in research. Why do I have to disclose her name? Because she cannot be another person, only herself. Not only because of the truth of the archive, but because of the truth of the history. The *corpus* of the longest abandoned inhabitants requires testimony, and it is not just any testimony: it is one of the truth of abandonment. My writings on Zefinha are like the announcement of a secret: she had been living in confinement for 39 years by the time we conducted the study. The name, location and

details of the history of the woman abandoned for the longest period of time are necessary to demonstrate the gravity of the injustice, but also to permit those who should be held responsible by the State for the consequences of the testimony to present their reasons. To make Zefinha anonymous would be to hide her once again, behind a false veil of “protection of intimacy, private life, honor or image,” the liberal morality on which the Law of Access to Information is sustained in order to conceal personal information<sup>7</sup>.

Zefinha has lived a life without intimacy. She sleeps in a cell, eats what is offered to her, and dresses herself with clothes imposed by the institution’s administration. Her sole form of resistance is to like the color blue in a space where the official color is red. There is no private life in a totalitarian institution, even more so when its inhabitant is a woman, old and insane. Honor and image are values that presuppose the existence of an independent individual with the right to exist in the world<sup>15</sup>. I believe that the meaning of “image” for the Law of Access to Information is not that of the “face,” as Judith Butler<sup>23</sup> proposed concerning mutual recognition, but a figurative use that refers to the sovereign liberal morality of the narrative about oneself—the disclosure of identifiable personal information could threaten the “image” that each individual possesses. But what is Zefinha’s self-image? And, were this image to be known, in what way might the disclosure of her name disturb or compromise her intimacy?

My argument opposes the presupposition of the CNS Resolution 466<sup>8</sup>: disclosing Zefinha’s name is to demand that her face be recognized, to identify her as the woman abandoned for the longest period of time in a forensic hospital in Brazil. Zefinha’s image is all that remains for her—her existence as a dependent old woman abandoned in a prison hospital. Poor, old, illiterate and from the northeast of Brazil (one of the poorest regions of the country), Zefinha no longer has any connections or biographies outside of the forensic hospital. She has lived as an anonymous and forgotten woman in a regime of confinement. To disclose her story is therefore a form of recognizing her existence as someone whose rights were significantly violated. The responsibility that I would like to assume by disclosing Zefinha’s name is that I willingly testify to the history of a woman abandoned because of mental illness.

To maintain Zefinha’s identity as anonymous would be to return her to the multitude of in-

sane offenders that inhabit forensic hospitals. She would be one of the 291 women, and not, sadly, the longest confined of them all. Given the singularity of the drama, anonymization as a practice of secrecy and regime of confidentiality would require not only changing Zefinha's name—but to refer to her as Josefa da Silva would denounce the previous precarious regimes that favored her long confinement. In the forensic hospital of Alagoas, there are only two women diagnosed with schizophrenia, and one of them was accused of homicide. According to the census, 82 women had the same diagnosis as Zefinha, seven of whom were in custody for a crime of physical harm. In other words, Zefinha could be one of seven women if de-identified. Nonetheless, a grave misunderstanding would result from the obligation of confidentiality—none of the other six women had been confined for more than a decade. The longest confined would disappear even within the small group of seven with a similar past of suffering and crime. Zefinha would no longer be herself in what is most significant to the story: the long permanence of her confinement.

The multitude of inhabitants in forensic hospitals is comprised of 3,989 men and women, with 2,956 under compulsory psychiatric treatment and 1,033 under provisional internment<sup>1</sup>. By counting them, we demonstrated that the State is unaware of the reason for the confinement of half of the population in custody: there are individuals with delayed psychiatric evaluations, others without a proper court decision, or even reports indicating that they are no longer dangerous, attesting to the possibility of living outside of confinement.

Nonetheless, the regime of compulsory treatment is maintained. The numbers demonstrated that there is no causal relation between psychiatric diagnosis and gravity of the penal infraction—individuals with different psychiatric classifications commit the same infractions. Through numbers we speak of the multitude, using rhetorical and statistical resources to demonstrate the cruelty of the system: one in every four inhabitants should already have been released from within the walls of the forensic hospital, and 952 of them have been confined for longer than had they were sentenced to prison.

Another form of presenting what the numbers denounce is to narrate stories with names and faces. The crowd cries out for help, but singularity respects the forgotten biographies. I presented this in the documentary *The House of the Dead*, in which Bubu, Jaime, Antônio and Almerindo provoke the injustices of confinement for crimes and insanity<sup>24</sup>. If there is uneasiness in images of vulnerable men, the power of watching resides in perturbing through exhibition. The regimes of precarious lives lay bare there—those men are black, poor, undereducated, and abandoned by the imprisonment of mental illness. To see them is a form of presenting the reality that is hidden in the numbers of the anonymous crowd described as insane perpetrators. While in the film the appeal to art protects me from the inquiry of disclosing the names of forensic hospital's inhabitants, I cannot invoke the same aesthetic and ethical tranquility as I write the story of Zefinha, the name of the woman who was abandoned.

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