THE ARCHITECTURE OF A CONSTITUTIONAL CASE IN THREE ACTS – ANENCEPHALY AT THE BRAZILIAN SUPREME COURT

// A ARQUITETURA DE UMA AÇÃO EM TRÊS ATOS – ANENCEFALIA NO STF

Debora Diniz

>> ABSTRACT // RESUMO

This paper describes the analytical and political course of the anencephaly case that reached the Brazilian Supreme Court. My aim is to demonstrate how that case was comprised of a distinct combination of political, juridical and academic actions. Presented as a documentary and biographical narrative, I reconstruct the trajectory of the anencephaly case in three historical acts (murmurs, announcement and spectacle) that precede the final scene of judgment by the Supreme Court in April 2012. // Este artigo descreve o percurso político e argumentativo que acompanhou a Ação de Descumprimento de Preceito Fundamental n. 54/2004 no Supremo Tribunal Federal. Meu objetivo é demonstrar como o sucesso da ADPF resultou de ações políticas, jurídicas e acadêmicas coordenadas. Por meio de um relato documental e biográfico, reconstruo o percurso da ação em três atos históricos (murmúrio, anúncio e espetáculo) que antecederam a cena do julgamento final, em abril de 2012.

>> KEYWORDS // PALAVRAS-CHAVE

Abortion; Anencephaly; Therapeutic Anticipation of Delivery; ADPF 54; Brazilian Supreme Court. // Aborto; Anencefalia; Antecipação Terapêutica do Parto; ADPF 54; Supremo Tribunal Federal.

>> ABOUT THE AUTHOR // SOBRE O AUTORE

Professor at the University of Brasília and researcher at Anis – Institute of Bioethics, Human Rights and Gender. The translation was done by Maria-Fatima dos Santos and review by Sinara Gumieri. // Professora da Universidade de Brasília e pesquisadora da Anis – Instituto de Bioética, Direitos Humanos e Gênero. Tradução foi realizada por Maria-Fátima dos Santos e revisada por Sinara Gumieri

>> ABOUT THIS ARTICLE // SOBRE ESTE ARTIGO

This text is written in the first person. However, the story is made of a multitude of characters and discourses, sometimes in conflict, sometimes in agreement with one another. This was the course of the anencephaly case since the moment I became a part of it in the middle of the 1990s. Some of my key partners have been cited here as sources, but they were also the first to read this manuscript. I sincerely thank them for all of their generosity in revising dates, facts and credits: Fabiana Paranhos (co-author of the *Habeas Corpus* 84.025-6/STF); Thomaz Rafael Gollop (physician, author of dozens of expert medical reports during the litigation process regarding anencephaly in São Paulo in the 1990s); and Diaulas Ribeiro (legal prosecutor and founder of the first coordinated system between the Public Ministry and SUS for therapeutic anticipation of delivery, without any judiciary intervention). I am entirely responsible for the choices made in this text and I apologize for any unjust omissions that certainly occurred in my reduction of a history of 24 years since the first sentence into only a few pages. This story

is dedicated to physician Jorge Andalaft Neto, who passed away before having the opportunity to see the conclusion of a cause that he so profoundly believed to be just. // Este é um texto contado em primeira pessoa. A história, porém, é feita por uma multiplicidade de personagens e discursos – ora em conflito, ora em sintonia. Assim foi o percurso da ação de anencefalia desde o momento em que passei a fazer parte dele, em meados dos anos 1990. Alguns dos parceiros-chave foram aqui citados como fontes, mas também foram os primeiros a ler este manuscrito. A eles, agradeço a generosidade com que revisaram datas, fatos e créditos: Fabiana Paranhos (coautora do Habeas Corpus 84.025-6/STF); Thomaz Rafael Gollop (médico, autor de dezenas de laudos médicos para a judicialização da anencefalia em São Paulo nos anos 1990); e Diaulas Ribeiro (promotor de justiça e criador do primeiro sistema coordenado entre o Ministério Público e o SUS para a antecipação terapêutica do parto, sem intervenção do Poder Judiciário). Sou inteiramente responsável pelas escolhas aqui feitas e peço desculpas pelas omissões injustas que certamente realizei ao reduzir uma história de vinte e quatro anos desde a primeira sentença em poucas páginas. Esta história é dedicada ao médico Jorge Andalaft Neto, que faleceu sem ter conhecido o desfecho da causa que tanto acreditou ser justa.

THE ARCHITECTURE OF A CONSTITUTIONAL CASE IN THREE ACTS – ANENCEPHALY AT THE BRAZILIAN SUPREME COURT

ACT 1
MURMURS

Continuity and its rupture mark the history of judicial action. There is a sense of archaeological discovery when evidence serves as a breaking point. The jurisprudential history prior to the case of anencephaly that reached the Federal Supreme Court of Brazil had its own particular moment of rupture. In 1989, Judge Jurandir Rodrigues Brito of Ariquemes, a municipality of the state of Rondônia, is said to have issued the first court order in favor of a woman interrupting a pregnancy with a fetus diagnosed with anencephaly.[1,2] Those who reject narratives that point to particular moments of rupture and prefer not to nominate specific individual protagonists of a cause for change recognize that the 1980s was an effervescent period – fetal diagnoses through imagery techniques had gained popularity, without which anencephaly could only be identified after birth. With such technology, jurisprudence would naturally have to follow from the new ability to make diagnoses during the gestation period, which is exactly what happened in the 1980s.[3] In this other narrative, Ariquemes would no longer have been the rupture point, but merely a statistical example.

It was necessary for doctors and women to go from the clinics to the local courts in order to set the judicial system in motion. We do not know how many women received a diagnosis of fetal anencephaly in the two decades leading to the arrival of the case at the Supreme Court.[4] Nor do we know how many sought alternatives to the lottery of the courts, and even less, how many were heard and forgotten by the courts. The gestation period was much shorter than the time it took to work through the medical and legal machinery: it could be days or years between the moment of diagnosis, filing a lawsuit and receiving a court decision. At the beginning of the 2000s, the universe of 3,000 cases was considered the official number that had reached the judiciary, but even the authors of the estimation were conscious of the limits of any population projection.[5] There were silent and repeated ruptures for the case to reach the Supreme Court – first, in the clinics between women and their physicians, and then in the courthouses between women and judges.

If the court order of Rondônia was actually the precursor to what became a national story, it is a sign of how change was inspired at the margins. It was not a revolutionary action, but an existential and unique one of women, physicians and judges. It was through the unique experience of living a duplicity of place, embodied in each woman in a singular form, that the diagnosis of anencephaly migrated from the clinics to the courts.[6] The marginal and tentative gesture of each decision is marked by the text that characterizes the different moments of the history of anencephaly in Brazil – from eugenic abortion at the beginning of the 1990s, to selective abortion at the end of the century and therapeutic anticipation

of delivery after 2004.[7] The first decisions repeated themselves both in form and content: expert medical reports, ultrasound images and short sentences. Some judges expressed their uneasiness, laid bare their religious beliefs or metaphysical convictions about the beginning of life, launching themselves as an element of women's existential conflict.[8]

The analysis of a few dozen court orders in the 1990s would suggest a circulation of success stories: Rondônia disappeared from the scene and São Paulo became the focus of cases and strategy.[9] However, the people who put the law in motion were not the judges or the courts, but the geneticists or specialists of fetal medicine – a select group of professionals that confronted what became known as "the unsteadiness between scientific advancement and the law."[10] This language, however, was insufficient and a form of betrayal for both physicians and legal actors. The use of the concept "eugenic abortion" brought with it an unacceptable historical shadow and would provoke uproars in the chapters to follow of the political course of action in the Supreme Court. If, for fetal and genetic medicine, "eugenics" could be a revived term with the Human Genome Project, and if for criminal law it was already a prevalent term in teaching manuals, it was not as such that the concept was received by the defenders of the "slippery slope" argument immediately after the proposition of an Allegation of Disobedience of Fundamental Precept (ADPF).[11]

The hypothesis of the "slippery slope" in bioethics has its juridical equivalent in criminology in the "broken windows" theory.[12] The metaphors of the slope or window are geographies of fear promoted by changes in the moral sphere – authorizing abortion in the case of anencephaly would be to launch down a slope without any brakes. In other words, other pathological or aesthetic conditions could be converted from undesirable to morally incompatible with notions of the good life. The slippery slope correctly denounced the risk of unjust discrimination, but also incited the moral panic that the case would be an entrance for the decriminalization of abortion. It was in this way that the eugenics hypothesis accompanied the history of anencephaly in the courts – from Rondônia to the Supreme Court. However, doctors and judges were concerned with the limits of the argumentative innovation. They were frightened by the growing movement of people with deficiencies that related to the debate and became intimidated with what became the primary religious argument against the action in the final years of the legal process in the Supreme Court:[13] authorizing abortion of fetuses with anencephaly would be a eugenic act of the Brazilian State.[14]

The *reductio ad Nazium* fallacy is part of the common rhetoric of resistance to the advance of genetic testing and medical procedures that interrupt gestation. In countries where abortion is legalized, or where selective abortion in cases of malformation is authorized in a state of exception from penalization of abortion, the discussion about the limits between the acceptable and unacceptable in the reproductive field gained importance by the end of the 1990s. This was also a period of strong consolidation of research on disabilities, particularly in the United States and United Kingdom.[15] Intellectuals and political activists, many of them

with physical impairments, advanced to amplify the political agenda about forms of oppression against the body – racism and sexism expressed mechanisms of segregation by skin color or sex, but something similar occurred with disabilities.[16] The social model of disability was the one that best represented the attempt to approximate disabilities to other forms of discrimination, with an intense critique of the medicalizing and individualizing rhetoric about physical impairments.

The first judicial actions regarding anencephaly in the country did not directly dialogue with such rich re-description of the body as a destination of nature, but the academic world recognized early on the necessity to confront the dual agenda. In 2003, one of the thematic sections of *Physis: Revista de Saúde Coletiva* (*Journal of Collective Health*) translated one of the most unsettling critiques against selective abortion with the secular position of human rights. Adrienne Asch, a blind feminist academic, argued that selective abortion was not only an intimate reproductive practice of each woman, but also a political text: a woman, in deciding to interrupt her pregnancy for reasons related to fetal health, would send a negative message to individuals with disabilities.[17,18] The text was fictional, but would have repercussions for the discrimination experienced by people with physical impairments – the stigma of feeling like an undesirable subject within the social world would be reaffirmed by the new medical techniques to diagnose fetal malformation. The hypothesis of Asch's "manifest argument" regarding selective abortion was the subject of several critiques, particularly in relation to its speculative nature on how people with disabilities relate themselves to the intimate and private decisions of women, but mostly by putting on women a responsibility for discrimination against subjects that interact in the world, in contrast to abortion, which would involve developing cells.[19]

In this way, much earlier than Brazil's ratification of the Convention on the Rights of Persons with Disabilities in 2008, the theme of physical impairments and disability discrimination accompanied the academic construction regarding the judicialization of anencephaly. In fact, I believe that it was this initial dual sensibility – of women's reproductive rights and the rights of people with disabilities – that resulted in the decision to have ADPF 54 focus on one unique fetal malformation. The case did not concern malformations incompatible with life, about which there were numerous legal precedents by the time it arrived at the Supreme Court.[20] Anencephaly was the fetal malformation with the most registered number of cases recovered from empirical studies, but it did not encapsulate the entire diagnostic field confronted by physicians and women in the clinic room. The decision to concentrate the case on anencephaly followed a medical rationality, but was also guided by the moral sensibility of the theme of abortion in the Brazilian political scene. This overlap between medical rationality and moral sensibility facilitated the construction of a juridical argument that therapeutic anticipation of delivery in the case of anencephaly would not be abortion as outlined in the Criminal Code – in the words of Alberto Silva Franco, "this is a case of pure atypia."[21]

The medical rationale was favorable to the action: it was concerned with malformation incompatible with life; the diagnostic report was made by imagery, a technology already available in public health services in Brazil; and there was no dissent in the medical literature about the irreversible character of anencephaly.[22] This certainty was reflected in the public hearings where medical and scientific associations attested to the impossibility of survival of an anencephalic fetus outside of the uterus.[23] In times of argumentation by imagery, the ultrasound image of an anencephalic fetus with a flattened cranium and the absence of a brain was a superlative form of evidence of the diagnosis: it complicated any attempt to relate anencephaly to other forms of physical singularity or disability. Disability calls for the right to exist in the world free of barriers or constraints; anencephaly is a physiological limitation prior to being any act of symbolic discrimination against the body. There is a medical consensus that the fetus will not survive after birth, and there are high rates of intrauterine death, or death during the delivery process.[24,25] In medical terms sensitive to the fight of the disabled, anencephaly is not described as a disability, but a fetal malformation incompatible with life.

However, there were also moral reasons related to what anencephaly symbolized in the collective conscience about how a human life is constructed – the brain is a fundamental organ for *humanness,* understood here as a shared culture between members of the specie.[26] People with or without physical impairments share this humanness, be it through cultural forms of sociability, or ethical relations of care and interdependency. But, without a brain, there is no survival; there is no means to claim humanness simply by belonging to the specie of *Homo sapiens*. For this reason, the discussion did not concern notions of the perfect body or the limits of desirable forms of individual uniqueness, but rather the impossibility of survival without the organ of humanness. At least in the initial stage of the legal filing of the case in the Supreme Court, the philosophical digressions, particularly the utilitarian tensions,[27] were reduced – only in one intermediary stage of this historic process did discussions about the status of the person emerge as a reasonable argument for justifying or completely rejecting the medical and moral choice about anencephaly.

The murmurs in the clinic and courts gained institutionalization with the first public assistance program for women pregnant with fetuses incompatible with life. Pró-Vida, the Office of Criminal Justice for the Defense of Health Service Users, of the Federal District's Public Prosecutor's Office (MPDFT), specialized in medical and bioethics law. The leading prosecutor at the time, Diaulas Costa Ribeiro, precociously identified anencephaly as a central question for physicians and judges. The instability of the case-by-case decisions were just as unsettling for physicians as they were for women. The remedy was a conduct agreement in the year 2000 between the Maternity Hospital of Brasília (HMIB), the reference center for maternal and fetal health in the Federal District, and Prosecution Office Pró-Vida – decisions of the MPDFT declared that there was no penal infraction in the medical act of selective interruption of gestation

of anencephalic fetuses. The protocol for authorization sought guidance from the customs of previous cases in other courts: expert medical reports, ultrasound images and the voice of the government authority, in this case, the MPDFT. The initiative of the Federal District became a national reference and some states sought to replicate it.

The decisions of the MPDFT inaugurated a new juridical and medical reality, or at least a distinct split from a story that had persisted for over a decade since the sentence of Ariquemes. Authorized by the hospital and the women, I accompanied the ultrasound and diagnostic medical exam sessions.[28] These pregnant women came from health centers in the periphery regions with previous diagnoses of fetal malformation, but the HMIB was the reference center for the procedure of interruption of gestation. I accompanied dozens of women who silently heard the sentence of the nature of the fetus, and alone or with their families chose an anticipated delivery. Informed by the medical and judicial course, the vast majority of them preferred the abortion to giving birth. It was in hearing the decision process of the women that the expression "therapeutic anticipation of delivery" was created.[29] As much in the hospital as in the prosecutor's office, the women would not refer to the medical procedure as "abortion," as described by religious morality or by the penal and medical rhetoric. They said "I want to take it out; I want to end this; I want to anticipate the delivery."

Listening to them attentively was the end point of what I consider to be the first act of the itinerary of the anencephaly case before its arrival at the Supreme Court. For the women, abortion of a fetus with anencephaly did not fit into the current vocabulary of reproductive practices. They saw themselves in the middle of a new existential dilemma – the diagnosis of anencephaly was made while the gestation was still in its initial stages, but at a point by which women had already assumed the reproductive process as part of their bodies and family histories, and they socially already felt like future mothers. The ultrasound that showed the future child as stillborn symbolically put them in a dilemma of "cradle and coffin." Without any political impetus to confront the punitive law, the women refused to describe their decisions as "abortion." It was an intimate act of resistance. They wanted to anticipate the delivery of a fetus that would inevitably be prematurely registered as a certified death.

It was in this way that the decisions of the MPDFT came to adopt the concept of "therapeutic anticipation of delivery" and that physicians of the HMIB came to describe the medical procedure, its risks and its possibilities as "ATP" (*antecipação terapêutica do parto*). The new name not only revived the judicialization or clinical practice, but also offered comfort to women, physicians and judges. "ATP" was not a euphemism for escaping the penal difficulties of abortion. If a euphemism is to be understood in reference to its official dictionary definition, "an act of softening the expression of an idea by substituting the proper term or expression for a more pleasant, more agreeable term,"[30]ATP was more than an agreeable term; it was a moral challenge - there is no nature in vocabulary. Words are part of an established moral lexicon, and the question of anencephaly

refused to be described by the effective order: "eugenic abortion," "interruption of gestation," or, simply "abortion", were insufficient to describe the experience of the early pain and grief lived by these mothers. They anticipated the delivery of a fetus without a brain that would not survive outside of the uterus. They no longer embodied the duplicity of place of the beginning of reproductive life.

ACT 2
ANNOUNCEMENT

The second act was short and marked by juridical moments: the first *habeas corpus* concerning anencephaly to reach the Supreme Court and the months following the legal proposition of ADPF 54. This is the most biographic act of the narrative, where my own academic and activist history may be confused with the action of the non-governmental organization that brought both cases to the Supreme Court, Anis – Institute of Bioethics, Human Rights and Gender. Anis, in partnership with Themis – Legal Advisory and Gender Studies, and Agende – Actions in Gender, Citizenship and Development, was the coauthor of *Habeas Corpus* 84.025 and participated in the filing of ADPF 54 with the National Confederation of Health Workers (CNTS). In this act of the story, anencephaly was no longer simply an issue reserved for women and their doctors, or for the few courts that received their requests – it became part of the national scene, with a public announcement that a difficult case had arrived at the Brazilian Supreme Court.

In November 2013, Anis was sought by prosecutor Soraya Taveira Gaya of Teresópolis, a city in the interior of Rio de Janeiro, who had participated in an abortion case of an anencephalic fetus. A man had entered her office and asked "Have you heard of anencephaly?". The truth is that she, like other legal professionals, had never encountered a case like this.[31] That man was Petrônio Oliveira Júnior, husband of Gabriela Cordeiro dos Santos, who was four months pregnant with a fetus with anencephaly.[32] The prosecutor was convinced that Gabriela had the right to have an abortion, but the judge of the District Court of Teresópolis dismissed the request. The prosecutor and public defender of the case sought the State Court of Rio de Janeiro to strike down the decision of the District Court of Teresópolis. Magistrate judge Giselda Leitão authorized the procedure. On November 21, three people presented themselves in defense of the interests of the fetus and positioned themselves against Gabriela: after reading about the decision in the press, two catholic attorneys of Rio de Janeiro and a curate from the interior of Goiás contested the decision.

Gabriela's story did not merely go through moral abstraction and the juridical machinery, but moved from Rio de Janeiro to Brasília. The case reached the Superior Court of Justice and a *habeas corpus* request was ruled in favor of the fetus on February 17, 2004. The *habeas corpus* not only invaded Gabriela's privacy, but also made the debate more nebulous – how could the ethical and juridical reasonableness of a *habeas corpus* in favor of a fetus be sustained? Sadly, however, the opinion of Justice

Laurita Vaz, who led the ruling, cited the then Prosecutor General Claudio Fonteles: "if the fetus is physically deformed, no matter how ugly it might appear, this will never impede that reception, affection and love flow to that life, which exists, and as long as it exists, can receive such affection. This, thanks to God, is beyond science."[33]

At that point, Anis' action was academic more than judicial. But the Supreme Court's decision of the *habeas corpus* in favor of the fetus opened a dangerous and unstable argumentative precedent for the second historical act still in construction. Fabiana Paranhos, Samantha Buglione and I drafted *Habeas Corpus* 84.025/2004 for the Supreme Court in favor of Gabriela. I travelled to Teresópolis to present our initiative to Gabriela. She had been four months pregnant when the case was initiated at the local court, but when we found her, her pregnancy had already concluded after eight months, with a premature delivery and death certification. Gabriela knew her daughter, Maria Vida, for seven minutes. But her life had suffered an upheaval since the legal filing with the prosecutor's office. In an interview with *Época* magazine, the first news report to identify anencephaly as a promising question in the national political debate, Gabriela described how she had been threatened by representatives of the Catholic Church not to abort – "they gave her a rosary and a shirt with the words: 'I love life.' They told her that her body was an ICU (intensive care unit) for the fetus and that as long as the girl remained in her womb, even without a brain, she would be fine."[34]

With a copy of the death certificate of Maria Vida, I returned to Brasília on the same day that the court convened to pronounce its ruling of *Habeas Corpus* 84.025. The presiding justice was Joaquim Barbosa and there were already two opinions in favor of Gabriela's request for an abortion, from Justices Joaquim Barbosa and Celso de Mello, both of which were included in the legal report.[35] As a public act of confession, I share the uneasiness that we experienced in that moment – would we leave the vote to follow its course and perhaps achieve a favorable outcome for a concrete case, or should we inform the court of the "loss of purpose"? We decided in favor of political transparency: since Gabriela was not a case, but an actual woman, her story should be understood by itself, not as a means for further gain. The death certificate of Maria Vida was received and the case was dismissed.[36] We began to feel a combination of restlessness and distress. For the first time, we thought of the Supreme Court as a space for solving what the judge in Ariquemes first initiated individually in the superposition between hospitals and courts.

The most difficult step was reaching the Supreme Court. We could wait for another concrete case to appear, but there were many difficulties in pursuing that path, the most important of which was that the gestation period was shorter than that of the judicial case. Gabriela was a concrete example of the slowness of the system and the temporal limits of what the judicial system would consider an "object" for litigation. Of all of the previous judicial cases of anencephaly or other fetal malformations, Gabriela was the first case to reach the superior courts. Additionally, there was a *habeas corpus* decision in favor of a fetus issued by the Superior

Court of Justice; in other words, a superior court considered it possible to attribute the right to "come and go" to a combination of developing cells. We were convinced of the legitimacy and adequacy of the anthropologic, ethical and juridical argument that therapeutic anticipation of delivery is not abortion. However, we needed a strategy to reach the Supreme Court and a legal framework to be able to speak to it. Just as importantly, we needed a constitutional translator that the Supreme Court would recognize as legitimate for a thesis so unsettling to the legal and moral order.

In March 2004, Anis and Pró-Vida organized a meeting with juridical specialists in Brasília. The idea of an ADPF was announced for the first time – Regional Prosecutor of the Republic Daniel Sarmento not only designed the legal strategy to reach the Supreme Court but also proposed the individual who might represent it: the then constitutional attorney Luis Roberto Barroso, now justice of the Supreme Court. That same month, I went to the office of Professor Barroso to present the idea, the argument and to request *pro bono* legal assistance.[37] His reception was immediate, but there was one prerequisite: it was necessary to have an entity with juridical legitimacy to be the author of the proceeding. Anis would not be recognized as such; we had to go through the nine institutions recognized as legitimate by the Federal Constitution.[38] I recall the moment when I received the printed sheet: on it were the entities already accepted until then by the Supreme Court in judicial review cases. "Who knows if one of them would take on the anencephaly case proposed by Anis?" Professor Barroso asked me.

Reminiscent of the anguish of this period, the first entity on the list was the Brazilian Association of Shopping Centers (Abrasce). The list reflected a logic of property rights laws defending entities that reached the Supreme Court, rather than entities that advocated for fundamental rights for a cause like the one we sought to propose. But there on the list was the National Confederation of Health Workers' (CNTS), a union association created on December 21, 1991, that consisted of more than one million members.[39,40] Health workers was a broad and generic concept for what in the past had been described as the proletarians of health – nurse technicians, x-ray technicians, hygiene and cleaning assistants, laundry assistants, employees from medical cooperatives, lab technicians and assistants, gurney pushers, ambulance drivers, nurse assistants or administrative technicians of health institutions, SUS workers, medical and dental assistants, domestic medical attendants or health center workers, among others. Just outside of Professor Barroso's office, I called one of the board members of the CNTS, José Caetano Rodrigues, and proposed a meeting to discuss a possible legal action of interest to the health workers. The subject of abortion was not mentioned during the call.

The following week, we left the meeting with the board of the CNTS with an agreement: yes, the association would participate, but it was necessary to converse with the regional federations – we would form a political caravan with the local entities so that the action would be constructed in partnership with the bases of the union association. Again, in addition to the participation of dozens of partners of Anis throughout the country,

Daniel Sarmento and Dafne Horovitz were fundamental to the local conversations about the legal and medical details of the action. As in any union movement, the construction was participatory – we presented the proposal, but listened to the positions and uncertainties of the members. In all of the regions, the thesis that "therapeutic anticipation of delivery is not abortion" was accepted, and it was assumed that the commitment of the action would protect health professionals from the risk of punishment for the prohibited practice of abortion. In less than three months, the CNTS signed the initial petition, designed by Professor Barroso's team. ADPF 54 was presented to the Supreme Court on June 17, 2004. The CNTS was the author of the proposal and Anis requested participation as *amicus curiae*. The participation of Anis was never denied, in contrast to other requests rejected by the reporting justice, which occurred in the case of the National Council of Brazilian Bishops (CNBB).

Until the proposal of ADPF 54, few journalists had turned their heads to what was happening in the courts or hospitals concerning anencephaly. Eliane Brum, Laura Capriglione and Simone Iwasso were the sole voices in the national press.[41] The issue mostly circulated through murmurs. However, there was a drastic change on the first day of July 2004: the reporting justice granted a preliminary injunction in favor of the request. It was a new juridical split not only in the cause, but in the constitutional system: an injunction about abortion, whose instrument was a constitutional argument. There was tremendous and wide coverage by the national press of the issue: "Supreme Court liberates abortion of fetus without brain" (*Folha de S. Paulo*, July 2, 2004); "In favor of abortion – and of life" (*Veja*, July 14, 2004); "Injunction authorizes abortion in case of anencephaly" (*O Estado de S. Paulo*, July 2, 2004); "Supreme Court authorizes interruption of gestation of fetus without brain" (*O Globo*, July 2, 2004); "The end of torture in the courts" (*Época*, February 5, 2004).[42] Social and religious organizations that opposed the cause also mobilized with similar intensity. It was a difficult case for the Brazilian juridical ethos, perhaps an index of the position the Supreme Court would take on issues of fundamental rights.

The day following the release of the preliminary injunction was a recess for the court, a silence justified by the court calendar, but strategic for a change in the geography of power – it enabled the Ministry of Health to regulate what the Court had just authorized. The Ministry of Health announced that SUS had the means to realize the diagnosis from images, in contrast to what the press had speculated about the inefficiency of the system to respond to the court's decision.[43] Another fundamental step would be achieved by the Federal Council of Medicine (CFM) with Resolution 1.752/2004, a text that regulated the removal of organs of anencephalic fetuses for transplants.[44] In one sense, the resolution suggested a conservative form of resistance to the juridical debate, the medical possibility of maintaining the gestation for organ donation, but the delicacy of the message was also of another sort. An anencephalic was a "cerebral stillborn" and the alternative medical procedure to delivery for the donation of organs was "therapeutic anticipation of delivery." If until that

moment therapeutic anticipation of delivery was a legal neologism, the voice of the CFM gave it medical legitimacy, even before gaining recognition in gynecological or obstetric manuals.

Similarly, the participation of women's movements and in particular the National Feminist Network for Health and Sexual and Reproductive Rights, an entity with national influence that assembles movements of women, feminists and anti-racism, was fundamental for the political articulation with civil society groups. The notion that "requiring a woman to stay pregnant against her will with an anencephalic fetus would be an act of torture of the State" gained force among feminist voices.[45] Representative of this expansive movement of social articulation was the campaign initiated by Cepia– Citizenship, Studies, Research, Information and Action, a feminist organization based in São Paulo, and by the National Council on Women's Rights. They distributed the campaign message outdoors throughout metropolitan areas with the image of a woman experiencing severe suffering during delivery. The physicians wore black clothes and gloves. The air was of solemn bereavement. The sayings were as telling as the image: "when the delivery is of an anencephalic, the result is not a birth certificate. It is a death certificate."[46]

October 20, 2004 was the date set by the Supreme Court to analyze the merit of the case. According to procedural rationale, but also a strategic one on the part of those against the case, the agenda suffered a reversal during the session – the question would no longer be about the thesis launched at the beginning, but about the pertinence of maintaining an injunction if not even the juridical instrument used (ADPF) had been an object of evaluation by the court. In a tense trial and with ramifications for broad questions of Brazilian democracy, such as the secular character of the State, the injunction of anencephaly was repealed.[47] There was no decision on the merit of the case, but a seven-year pause for it to go through a slow process: ruling of the suitability of the ADPF, other correlated cases, such as the case of stem cells in ADI 3410/2005, public hearings and questions of merit. In the text that summarized the repeal of the injunction, the then president of the court, Justice Nelson Jobim, determined that "the Court, also by majority vote, revoked the granted injunction in the part where it recognized the constitutional right of the pregnant woman to undergo therapeutic *operation* of delivery of anencephalic fetuses."[48] "Abortion," "therapeutic anticipation of delivery," or "therapeutic operation of delivery": the terms pointed to the moral and juridical confusion of the scene, but also gave back to women the task of individual resistance until the court would consider the case as one of fundamental rights.

ACT 3
SPECTACLE

The repeal of the injunction reinvented juridical and political instability: physicians and judges distant from the workings of the Supreme Court were not certain what the court had decided. It was as if the news had

circulated in fragments: the symbolic normative power of the Supreme Court weakly became communicated to judges and defenders in each Brazilian city. Even less was it communicated to hospitals. This is exactly what happened with Severina Leôncio da Silva, a poor, 26 year-old illiterate farmer, whose life was definitively marked by the procedural controversy of the court. On the same afternoon that the court repealed the injunction, Severina was waiting in a public hospital in Recife for an anticipation of delivery. That night, physicians at the hospital watched the news of the repeal of injunction on the broadcasted news, and convinced that "there was no way the judge would allow it any more,"[49] sent Severina back home to where she lived in Chã-Grande, a small town in Pernambuco. Severina gave her name and biography to what was before a juridical argument. The abstraction of the court gained body and suffering inside the womb of Severina, already four months pregnant.

During the trial that revoked the injunction, Justice Cezar Peluzo, who came to preside the final decision seven years later, was uneasy not knowing the women whom this abstract case concerned and speculated that "suffering in itself is not something that degrades human dignity; it is an inherent element of human life."[50] Provoked by Peluzo's question of "who are these women?" Anis sought out the stories of these women in the public health system in Brazil. Our intention was to recount the experiences of the women protected by the injunction, those who believed that involuntary suffering did not dignify their lives; on the contrary, it was an avoidable torment. We encountered 58 women and presented four of them in the documentary *Who Are They*?[51] Severina, however, was a separate and unique story of this history. She demonstrated how the necessities of existence were weakened by unjust acts of the State.

Érica, Dulcinéia, Camila and Michele were some of the women the court had protected by granting the injunction: their stories were shown in the film and replicated by the press at several moments throughout the process of the case.[52] In revoking the injunction, the court understood the impetus of the reporting justice did not represent the collective thought, at least in that historical moment. Severina was a woman who would embody the consequences of the hypothesis of legal prudence of the court and of the auto-imposed request for a pause. For this reason, we followed her story from the day she learned that the country had a Supreme Court until the day that same court closed the case in 2012. The first chapter of this journey became the documentary *Severina's Story*,[53] launched on October 5, 2005, 12 months after the repeal of the injunction.[54] The delicacy of the story and the co-direction of Eliane Brum made it so that the film gained prominence on stages beyond the academic or juridical realm; most importantly, it assumed the force of an empirical counter-argument to the little reasonability of the juridical rationale of the court. The case of anencephaly was the pain of Severina and not the speculations of life, death or dignity proposed by the justices.

There were years of waiting. We do not have a clear hypothesis for why the Supreme Court drew out the final trial for so long. The movements were slow and the arrival of ADI 3.510/2005 about the law of bio-security

postulated an emergency for our academic and political action. In March of 2005, the then General Prosecutor Cláudio Fonteles filed ADI 3.510 contesting the use of frozen embryos obtained by assisted reproduction techniques for the ends of stem cell research. The central thesis of the case was that "life happens in and starting from fertilization;"[55] research that violated this magical beginning of life would threaten constitutional principles, particularly the right to life. It is possible to understand the controversy presented by the ADI on two levels: first, it raised the reality of the moral uneasiness of those who sustained the ontology of life in the act of fertilization, and for that reason the dispute would be genuine; the second had more profound ambitions, for if the court observed the thesis of the ADI that "life begins with fertilization," frozen fertilized cells consisted of inviolable beings. The second level pointed not only to research with embryonic stem cells, but also abortion, anencephaly and the legal provisions of the Penal Code.

The public hearings for the case of anencephaly were the first to be summoned in the history of the Supreme Court, but those of the ADI concerning stem cells were the first to be realized in 2007. Anis participated as *amicus curiae* in the case and I was its representative during the hearings. The thesis of Anis was simple, but had a dual aim regarding the case of bio-security: the Supreme Court did not have to confront the question of the beginning of life to judge the constitutionality of research with supernumerary frozen embryos unviable for reproduction; in addition, the question of the beginning of life was not juridical or scientific, but religious.[56] The beginning of life is a question of unease of infinite regression – there are fragments of human life in frozen embryos, in strands of hair or in dead bodies. The massive public support in favor of embryonic stem cell research anticipated what would happen in the anencephaly action. There was no opposition in the national media; in fact, the spotlight on the court permitted a final vote of 6 to 5 (between votes for partial provision and dismissal). In both the public hearings on stem cells and the trial, public figures and associations of people with disabilities gave a face to what appeared to be a dispute of science and morality.[57] But the court also gained greater visibility as an emergency space of new interpretations of fundamental rights. An agenda of questions like those of bioethics had arrived at the court; the difficulties and fascinations moved justices, academics, media and civil society.

The ADI was defeated in 2008, the same year that the public hearings for anencephaly were summoned. It was four days of listening to scientific entities, and religious and civil society organizations, in addition to a few individual specialists. Anis was one of the civil society groups invited to the public hearings, in addition to the Feminist Network for Health and Catholics for Choice. The representative of the Feminist Network for Health conceded part of her allotted time for oral exposition to the couple Michele Gomes de Almeida and Ailton Almeida. Michele, in contrast to Severina, interrupted her gestation of an anencephalic fetus during the time in which the preliminary injunction was valid and appeared in the auditorium with the two daughters she had after the abortion. Michele

played a national role, during different stages of the case and even before it, as a concrete voice for the decriminalization of abortion in cases of fetal malformation incompatible with life.[58] Michele did not speak of juridical theses our scientific certainties; she simply told her story. She was a woman who wanted to be a mother, Evangelical, married and with daughters, but found herself in front of a diagnosis of anencephaly during her first gestation. She had the abortion and then became pregnant again. She was a common woman, but one who depended on the Supreme Court to have her abortion legally. She had a select audience: first the reporting justice, then the national media.

The spectacle of the third act moved in cycles of intense repercussion and periods of silence. Between public hearings and the final session of the case, two more years passed – an interim animated with discussion by the case of same-sex unions, in which Anis was also *amicus curiae*. In what would be the final session, Justice Cezar Peluso presided the merit vote for ADPF 54. In the first row of the assembly, the eyes of the president looked toward those of Severina, the farmer who disbelieved in the thesis that involuntary suffering would dignify a woman. With her husband, Rosivaldo, and her son, Walmir, Severina left Chã-Grande for Brasília. She would no longer be the face of the documentary, but a voice of the body that went through courts and hospitals eight years before. Severina presented herself to the reporting justice of the action, someone she had also only known through the film that told her story to the nation.

The court was no longer the same one that had repealed the injunction seven years earlier: other members, a favorable public opinion, a certain pride in being a more progressive space than the National Congress in questions of individual freedoms, in particular reproductive rights. The vote was 8 to 2, and there were more ample pronouncements than what the specificity of the case demanded. Some justices proclaimed the urgency of the court to confront the question of abortion as a problem of public health and women's rights, a thesis also sustained by Professor Barroso in what was one of his ultimate scenes on the platform before being nominated as a justice of the Supreme Court. In that moment of the spectacle, the participation of Anis was discrete – the farmer Severina and Professor Barroso served as the two necessary voices at the close of what was described as an event initiated by the rupture of the uneasy judge of Ariquemes twenty-three years earlier. But perhaps the action was the beginning of a new rupture, a movement that makes the instant of new jurisprudence a permanent game between the before and after of history.

>> ENDNOTES

[1] Gollop, 2003.

[2] "Abortion," "interruption of gestation" and "therapeutic anticipation of delivery" will all be used in the text as synonyms, although they each mark different historical moments in the case of anencephaly in Brazil.

[3] In São Paulo, the ultrasound was introduced in 1975. The diagnosis of fetal anomalies was achieved with acuity by the 1980s.

[4] "Federal Supreme Court," "Supreme Court" and "court" will all be used as synonyms.

[5] Frigério, 2003.

[6] Alberto Silva Franco, inspired by Damião Cunha, describes the dilemma of abortion as one of duplicity of place (2005: 165).

[7] Diniz/Ribeiro, 2003.

[8] Diniz, 2003.

[9] Gollop, 2003.

[10] Gollop, 1995.

[11] Buchanan *et al*., 2000; Hungria, 1979. Nelson Hungria speaks of "eugenic abortion."

[12] Kelling/Wilson, 1982.

[13] "People with disabilities," "disabled people" or simply "disabled" will be used synonymously. My political and esthetic preference is to use "disabled person" or "disabled," but the interference of the juridical language adopted by the Convention on the Rights of Persons with Disabilities in Brazil inaugurated a new discursive path in the portuguese language (Diniz, 2012).

[14] That was the thesis sustained by the memorandum of the Union of Catholic Jurists in São Paulo and the Union of Catholic Jurists in Rio de Janeiro, signed by their directors and attorneys at the time, among them Ives Gandra da Silva Martins. This memorandum does not comprise part of the documentary archive of the Supreme Court case, since the presiding justice of ADPF 54, Marco Aurélio Mello, did not accept the participation of those entities as *amici curiae*. The memorandum, however, can still be found in secondary electronic sources linked to the Catholic Church. Justice Cezar Peluso alludes to the logic of "social exclusion through corporal deformities in the fetus" in the vote for the repeal of the preliminary injunction in 2004 (Brasil, 2004b: s/p).

[15] Hughes/Paterson, 1997; Oliver/Barnes, 1998; Barnes, 1999; Thomas, 1999; Kittay, 1999; Francis/Silvers, 2000.

[16] Diniz, 2012; Diniz, 2013.

[17] Parens/Asch, 1999.

[18] Parens and Asch sustain that "prenatal tests to select against disabling traits express a hurtful attitude about and send a hurtful message to people who live with those same traits" (1999: S2).

[19] Barros, 2003.

[20] Frigério *et al*., 2001.

[21] Franco, 2005: 167.

[22] World Health Organization, 2003.

[23] Brasil, 2008.

[24] Aurélio, 2013.

[25] The rare cases of survival are for short durations of time, generally hours or a few days. The cases of children taken to the public hearing sessions or to the judgment of ADPF 54 were not of anencephaly, but other malformations of neural tube defects. Despite being grave, they were medical conditions compatible with life after delivery (Agência Estado, 2008).

[26] Diniz, 1997.

[27] Singer, 1993.

[28] In anthropological terms, I realized an ethnography of the service. Every Thursday, I accompanied the clinic of fetal medicine of the HMIB. Dr. Avelar de Holanda Barbosa, the hospital director at the time, was one of the great supporters of therapeutic anticipation of delivery in cases of anencephaly.

[29] Diniz/Ribeiro, 2003.

[30] Ferreira, 1986.

[31] Brum, 2004: 70.

[32] The medical narrative describes gestation by weeks. The women, however, describe it in months. For this reason, I opted to maintain Gabriela's narrative description of her body.

[33] Brasil, 2004d.

[34] Brum, 2004: 70-71.

[35] HC 84.025 was ruled by the Supreme Court on March 4, 2004, with the following composition: Maurício Corrêa (president), Sepúlveda Pertence, Celso de Mello, Marco Aurélio, Nelson Jobim, Ellen Gracie, Gilmar Mendes, Cezar Peluso, Carlos Britto and Joaquim Barbosa (presiding justice). The trial counted with the presence of the then Prosecutor General, Cláudio Fonteles. In the words of the presiding justice, "the consequence of all of that is that the woman was obligated to bare, to carry that undesired pregnancy for two months by the force of those mismatched and, from my perspective, completely irregular judicial decisions" (Brasil, 2004c: 2).

[36] Another highlight of the trial was the debate among the justices during the voting and the loss of purpose. The U.S. case of *Roe v. Wade* was cited, as well as other important authors in the debate about rights in Brazil and other countries, such as Ronald Dworkin, Nelson Hungria and Daniel Sarmento.

[37] Also present in this meeting were attorney Samantha Buglione, representative of Themis – Legal Advisory and Gender Studies, and physician Dafne Horovitz, then president of the Brazilian Society of Clinical Genetics.

[38] Article 103 of the Federal Constitution determined nine active legitimate entities for the proposal of actions of concentrated judicial review: the President of the Republic; the Federal Senate; the Chamber of Deputies; state Legislative Assemblies or the Legislative Chamber of the Federal District; state or Federal District governors; the General Prosecutor of the Republic; the Federal Bar Association of Brazil; a political party with representation in the National Congress; a union association or class entity of national scope.

[39] The CNTS represents over 50 unions of health professionals throughout the country. There are 8 federations and 190 associated unions.

[40] In August 2009, The Brazilian Society for Scientific Development (SBPC) sent a letter to the Supreme Court with 27 more entities supporting the therapeutic anticipation of delivery in cases of anencephaly. The document is available at: http://www.observatoriodegenero.gov.br/menu/noticias/sbpc-envia-ao-supremo-documento-favoravel-a-antecipacao-do-parto-em-casos-de-anencefalia/.

[41] Among others, Simone Iwasso wrote for the newspaper *O Estado de S. Paulo* the article *72% defend abortion of anencephalic fetus*, on October 26, 2008 (http://www.estadao.com.br/noticias/vidae,72-defendem-aborto-de-feto-anencefalo,267088,0.htm); Eliane Brum wrote for *Época* magazine the article *War of embryos*, on March 15, 2004; and Laura Capriglione wrote for the newspaper *Folha de S.Paulo*, the article *67% Defend right to stop pregnancy in SP*, on October 21, 2004 (http://www1.folha.uol.com.br/fsp/cotidian/ff2110200406.htm).

[42] The journalist Marisa Sanematsu (2005), of the Patrícia Galvão Institute, published an analysis of the press coverage of the injunction.

[43] Biancarelli, 2004.

[44] CFM, 2004. That resolution was repealed by Resolution CFM 1.949/2010.

[45] Sociologist Maria José Rosado Nunes (2008), director of the organization Catholics for Choice, described the research results and sentiments about the issue of anencephaly in an ample perspective of human rights: "This is the sentiment of the Brazilian population previously recorded in research: forcing a woman to maintain her pregnancy is torture. If by her own choice she decides to maintain her pregnancy, she can, and in that case her sentiment would certainly be another than if she maintained her pregnancy due to an imposition."

[46] Cepia/CNDM, 2009.

[47] When the injunction was repealed, the opinion of Justice Marco Aurélio invoked the secularity of the State: "we still have in our plenary room a Christ, but for a long time there has been a separation of church and state. I believe that in the present case there are technical and constitutional parameters, that are not fundamentalist, moral or religious ones about this subject" (Transcription of the opinion of Justice Marco Aurélio in the plenary session of October 20, 2004).

[48] Brasil, 2004a.

[49] Diniz/Brum, 2005.

[50] Peluzo, 2004: 4; Diniz/Vélez, 2007.

[51] Diniz, 2006. The film is available at: http://www.youtube.com/watch?v=pM1aCmkTn9g&feature=share&list=UUbnXcxzeZIZrJ2GVOfvXH3g.

[52] An example was the report in the magazine *IstoÉ: Life after the abortion,* about the characters in the film, published in July 2011 (Azevedo, 2011).

[53] Diniz/Brum, 2005.

[54] The film is available at: http://www.youtube.com/watch?v=65Ab38kWFhE. Severina's story gained three narrative levels: screenplay of the directors, the xylograph images of J. Borges and the music of *repentista* artist Mocinha de Passira. After that film, the production company ImagensLivres became an institutional arm of political action for Anis through its use of imagery. *Severina's Story* won 17 awards, was translated to seven languages and circulated throughout academic conferences, classrooms and public television channels. Just as important as its artistic repercussion was the construction of a new architecture for difficult cases – the combination of academic research, juridical rationality and the language of images facilitates the juridical dialogue as much as the dialogue of the public opinion.

[55] Brasil, 2005: 10.

[56] The elaborate memorial delivered by Anis is available at: http://redir.stf.jus.br/estfvisualizadorpub/jsp/consultarprocessoeletronico/ConsultarProcessoEletronico.jsf?seqobjetoincidente=2299631.

[57] One of the most active organizations in the field of human rights defense for those with disabilities is the School of People, led by Cláudia Werneck. During the time of the public hearings, her action was fundamental to the process of clarification about anencephaly, where there is no compatibility with life, and disabilities, where one fights for the right to be and live in the world.

[58] Michele and Ailton were heard at the Supreme Court public hearings. They directly addressed the justices and spoke with the then Minister of Health, José Gomes Temporão. The entities against ADPF 54 used a similar strategy, bringing mothers and children with other anomalies to sensitize the court and public opinion. Recently, Michele and Ailton

were also protagonists in one of the editions of the television program *Na Moral*, of Rede Globo, presented by Pedro Bial. The program, dedicated to the theme of legal abortion, was aired on August 2013. Michele was pregnant with her third daughter.

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