DOI: 10.1590/1807-57622016.0334

Aisengart Menezes RA, Luna N. Pregnancy and maternal brain death: decisions on the fetal life. Interface (Botucatu).

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This paper presents cases of brain death of pregnant women in different countries, that were published in the press, aiming to reflect about the decision making process on the prolongation of somatic support of vital functions of the women, in order to keep fetal development until they reach viability. Based on the analysis of the positioning of the different social actors involved, such as family, medical staff, religious authorities and Justice officials among others, this paper reveals the values that are present in each context and situation.

Keywords: Brain death. Pregnancy. Fetus. Vital support. Decisions.

Introduction

In the second decade of the 20th century there has been an increase in the number of news articles in the media about pregnant women with brain death. This scenario demands a decision to be made: whether or not to maintain the pregnant

woman's vital functions in order to allow fetal development. Diverse social actors position themselves: family members, religious authorities and justice officials, among others. In this article, we present cases published in different countries with the controversies surrounding the possible decisions on maintaining a pregnant woman's life. Based on this data, we undertook an anthropological analysis of the values that emerge in the case reports, looking at the impasses and decisions made.

The case of a 27-year-old woman who was 22 weeks pregnant is described by Margaret Lock[1] in her study about brain death and organ transplant. The 1983 case was published in 1988 in an article by Field et al.[2] The pregnant woman was admitted to a United States hospital with vomiting and disorientation. Her clinical examinations yielded normal results, except for an increase in medullary pressure. She suffered heart failure, was reanimated and transferred to the intensive care unit with respiratory support. After two days the brain death diagnosis was confirmed, while fetal functions remained normal. In accordance with the husband and father's wishes, the medical staff provided cardiorespiratory support, aiming to provide the conditions for the fetus to reach viability, which would be followed by intervention and birth. In the 28th week of pregnancy, on the 62nd day after admission, an infection led to a caesarian. The baby, a boy, was born with low weight and was taken to the neonatal intensive care unit; at three months he was transferred to another hospital where he developed well. After the caesarian, the equipment was switched off and the mother's (second) death was declared.

According to Lock[1], the Field et al.[2] medical article makes no mention of the ethical discussion on the intensive care unit staff's feelings about caring for the body of a woman with brain death and for her fetus. There is also no reference to the husband and father's participation. Finally, emphasis is placed on the ambiguity created by the choice of maintaining a "living corpse" [1] in a hybrid state for over two months. Still according to Lock[1], in medical articles on the theme, the focus shifts from the ethical debate to the prescription of the ways of controlling and caring for fetal development.

The article by Lock[1] raises a question: as the technology is available for somatic support of the brain-dead pregnant woman's vital functions, it is a matter of making this procedure routine and regulating it. The case occurred in 1983. Since then, diagnostic and treatment resources have developed, new laws and regulations have been created, new sensibilities and subjectivities have emerged out of each case. The debates remain, with the participation of diverse social actors.

As a rule, the dissemination of news on the theme mobilizes communities and sparks positionings in society. In face of each circumstance, the debate often becomes polarized: on the one hand, defense of the fetus's right to life; on the other hand, the woman's right to autonomy. The possibility of maintaining fetal life in cases of maternal brain death generates a specific problem. If, in cases of voluntary abortion, the ethical debate contrasts women's autonomy in reproductive decisions with the fetus's right to life, these positions assume a distinct configuration when maternal brain death is involved. The fetus can only survive and develop if the mother's vital functions are preserved, which is only possible with the support of equipment and therapeutic resources.

Technology and new possibilities for the management of life limits:

In the second half of the 20th century equipment is created and technology developed which make it possible to preserve life, such as the artificial respirator, hemodialysis and others. To these are added treatments that prolong life in cases of degenerative illnesses such as cancer and auto-immune and neurological diseases.

In contrast to the death management model considered inhuman, cold and technologized, which Philippe Ariès[3] described as the modern death model, new proposals emerge for end of life care and deliberations. Innovative discourses are presented defining new dilemmas concerning the different forms of life management, care and the dying process. "Death with dignity", "dysthanasia", "therapeutic doggedness", "orthothanasia", and "good enough death" [4], among other expressions, are used both by advocates of life maintenance and by militants for the right to free

will over one's own life and death. At times there is polysemy of some expressions such as "good death"[4] or "death with dignity" [4]. For some, this can only be achieved via palliative care, while for others, only through individual action leading to the end of life – assisted suicide or euthanasia[5].

Since the end of the 20th century a debate has existed in the West centering on the right not to suffer[6] [7]. This debate is inserted in two movements: the first, concerns over the genocide of World War II; the second, the consequences of the new technologies directed at creating, prolonging and maintaining life[7]. The first movement encompasses the formulation of human rights and bioethical guidelines for research *on* and *with* human beings. The moral principles and values that rule human conduct are continually questioned. To Giorgio Agamben[8], it is a discussion about the differences between biological body and political body, naked life and dignified life or, in his terminology, between "zoé" and "bios".

The 20th century witnessed the large-scale development of technology directed at life, through new resources. Different deliberations have become possible through use of this equipment. New categories and concepts (brain death, life with dignity, donation and transplant of body tissues and organs) have led to the creation of new laws and regulations in each context[5].

The possibility of prolonging somatic support of a pregnant woman's vital functions in order for the fetus to reach viability for birth is analogous to the organ maintenance, for donation purposes, of people whose brain death has been declared. Similarly to the debates, in different countries and contexts, surrounding the preservation of vital functions for organ removal and donation, when a pregnant woman suffers brain death, questionings emerge around the dignity (or not) of maintaining a (pregnant woman's) vegetative life in favor of fetal life. Lock's[1] pioneering research reveals the difference in values and acceptance of brain death and organ donation and transplant in the United States and Japan. Among the Americans, the concept and diagnosis of brain death are accepted by society in general, while for the Japanese there has been broad social rejection of the possibility of removing organs for donation and transplant.

Different meanings are attributed to the term dignity, especially with respect to the end of life and the dying process. According to the preeminent value in each context, it is possible to classify a dignified or non-dignified condition. In this sense, for those who consider life to be a supreme value and advocate maintenance of a pregnant woman's vital functions in order to preserve fetal life, it would be a dignified condition for the woman, since it would have a dignified purpose.

We are here presupposing that the demarcation of the frontiers between life and death involves cultural, social, religious and political factors relative to person management. The most diverging concepts about the meaning of personhood and a person's statutes and rights must be considered in order to understand aspects of the controversy around deliberations on life's beginning and end.

Life and death are structuring concepts in every culture's shared values that make it possible to access the existing concepts of personhood[9]. Every social group creates its definition of a person as a social agent[10,11,12]. Every culture demarks when a person is recognized socially. Historically, in the West, life and death have been the objects of religious definitions guided by Judeo-Christian tradition[12]. With the processes of secularization[13] and increasing medicalization[14] they have moved from the religious sphere to that of science in the context of life and death. Generalized belief in reason as an objective reading of nature has become prevalent in the West[15]. As to a pregnant woman's autonomy in relation to the right of fetal life, distinct possibilities present themselves.

From the second half of the 20th century the theme of rights has acquired preeminence and centrality. The uses of the body, of corporal substances, the prolongation of terminal patients' lives, pregnancy interruption and organ donation have become part of the rights debate[16]. Two positions stand out: the position of lay society and that of religious authorities. The proposals for legalizing abortion, euthanasia and assisted suicide have been responsible for the polarization between the right of individual free will – whether the pregnant woman's or the terminal patient's – and the sanctification of life[17].

The debate about the embryo statute[18,19] involves judicial, ethical and religious disputes. Anthropological studies on the limits of life point to differences and similarities in the personhood statute for the embryo and the terminal patient, especially when brain death is diagnosed. The fetus and the terminal patient possess the same characteristic: both are situated in a provisional time[20], although there is a difference. In the beginning of life there is recognition of a person's social condition, while at the end a transformation occurs and the living being enters another category.

In order to maintain a brain-dead pregnant woman's vital functions, knowledge, technology and health care professionals qualified to deal with life support equipment are required. In a survey about the theme, we found biomedical articles, presented below, which tackle dilemmas and positionings regarding the possible decisions and their consequences. The survey was carried out on the internet via the Google search engine to find media articles on the theme after 2014, up to April 2015, and scientific articles, based on the following words: pregnancy, brain death, and decisions on fetal life, considering the Portuguese and English versions. Media articles relative to twelve cases of pregnant women with brain death were found. From these cases, we selected three for analysis, as the positionings of the family members and medical staff and the judicial decision were different in each case, which allowed deeper reflection on the decision-making process. It is worth mentioning that the articles published in biomedical journals and from the justice and law fields were all found using Google, as we did not search scientific bases. As the possibility of maintaining a pregnant woman's life with the purpose of preserving fetal life is recent, due to the development of technological resources, the number of articles in the biomedical area is restricted: only four. The search was carried out in 2014 and 2015.

Biomedicine and ethical questions

In 2004 an article was published about the brain death of a woman in the 13th week of pregnancy[21]. It focuses on the decision to prolong somatic support of the mother's vital functions in order to reach fetal viability. The fetal heartbeats stopped

on the eighth day after maternal brain death. The authors consider mother and fetus to be two distinct organisms. Although there is no minimum limit for pregnancy time, the maintenance of maternal somatic functions depends on time to reach fetal viability, with the ideal being 32 weeks. The article cites the maximum prolongation of 107 days, after which birth occurred. In this case 133 days would be needed to reach viability. The authors believe prolongation to be ethical only when there is hope of success. The text mentions the mother's right to autonomy, but the focus is on the attribution of primacy to the life of the mother or the fetus. Family members' opinions must also be considered. The authors point out three perspectives: 1. to consider the mother as an autonomous subject, respecting her expressed wishes; 2. the perception of the woman as an incubator, with no autonomous rights, emphasizing fetal rights; 3. to consider the woman as a voluntary organ donor, according to a previously expressed opinion.

In legal terms, European legislation varies as to the concession of rights to the fetus[20]. In Ireland, the fetus has the right to life from conception, but in other countries a 13-week fetus has no legal rights. In Ireland, even with legal support to the fetus, the imperative of maintaining maternal somatic support is fulfilled when birth is probable.

To João Paulo de Souza et al.[22], brain death in pregnancy is rare and demands a decision. Depending on the time of pregnancy, measures should be taken for homeostasis of the woman's body after brain death, aiming to maintain fetal life until viability. The text presents a case in Brazil: a 40-year-old woman suffered intracranial brain hemorrhage in the 25th week of pregnancy. Having been diagnosed with brain death, the patient began to receive respiratory and nutritional support and vasoactive drugs, hormones, temperature control and interventions to prolong pregnancy. The decisions were made in consensus with family members. The woman's conditions remained stable for 25 support days, but after alterations in the conditions of the fetus, the medical staff decided to perform a caesarian. The boy was placed in the neonatal intensive care unit and was discharged with no after-effects after 40 days.

The article by Anita Catlin and Deborah Volat[23] focuses on nursing practice in maternal brain death. The question is whether to maintain (or not) life support for the pregnant woman for another 5 months for the sake of fetal development. The text reflects on the decision-making process. Using examples, the authors analyze ethical dilemmas concerning the woman, the fetus, the family members and the nursing staff. It is necessary to define what life and death is in order to assess the mother. The authors cite the Kantian imperative – not to use a person as a means – in contrast to Mill's utilitarian thought, which aims to maximize happiness for the greatest number of people. It is asked whether the woman's signature on an end-of-life directive, refusing heroic measures, should be ignored. The text questions whether the completion of an organ donation form means acceptance of life-sustaining measures. Is it possible to compare the pregnant woman's brain death with a decision to donate organs? Questions are raised, such as who should decide and what are the deliberations when there is a conflict of interest. As for ethical dilemmas, it is asked whether the fetus can be considered alive when the mother has suffered brain death. The article presents a concern with leading the fetus to a condition of viability for birth, as if it were an individual with a right to treatment. These questions are posed: should weeks or months be spent to save the fetus's life? Would this care be an experimental treatment, without the consent of the woman or the fetus? Finally, the authors state that the cases reflect the religious environment of the country in which the study was conducted.

Majid Esmaeilzadeh et al.[24] present a systematic review carried out on the Medline, Embase and Central bases about cases of brain-dead pregnant women with prolonged somatic support. As explained above, this article was found with an internet search. Thirty cases were found from 1982 to 2010. The average time of pregnancy at brain death diagnosis was 22 weeks, and the time of pregnancy to birth, 29.5 weeks. Twelve viable children were born and survived. The authors stated that it is possible to sustain the somatic functions of the brain dead pregnant woman for a long period. No limit is defined for the minimum time of pregnancy after which medical efforts can lead a fetus to development. The decision must be for each case, according to

maternal stability and fetal growth. The article lists the medical support procedures and presents obstetric, fetal and neonatal considerations, as well as those concerning organ donation. As for ethical questions, some professionals do not agree with the maintenance of a woman's body after death to be used as a recipient for the fetus. The opposing position is to consider the woman as a cadaverous incubator with no autonomous rights, attributing preeminence to fetal rights. Other authors compare the prolongation of maternal life to an organ transplant in which the fetus would be the recipient. The article concludes that the decision must be made by specialists, in conjunction with the pregnant woman's family members.

The possibility of extending life in brain death cases presents a specific problem when the subject is a pregnant woman. In cases of maternal brain death, the fetus only has a chance of becoming viable if measures are taken to maintain the mother's vital functions.

In the Pontifical Academies for Life page on the Vatican portal[25], the brain death theme is mentioned in documents about euthanasia and death with dignity. In the Key to Bioethics[26] manual the discussion about the right to life is presented in topics linked to protecting the embryo from conception, covering assisted reproduction, embryo use in stem cell research, pre-implantation genetic diagnosis, pre-natal diagnosis, cloning and abortion. The debate on death with dignity emerges in the discussion of euthanasia and organ donation. Despite mention of the brain death concept, there is no reference to maternal brain death and pregnancy continuation. The manual condemns any form of abortion and embryo manipulation except to extend its life. It is categorical with respect to informed consent for organ donation, opposing end-of-life directives such as contracts for life support interruption in case of irreversible coma. The text rejects any action modality to reduce the terminal patient's life at his or his family's request.

The isolated guidelines lead to two contradictory movements in relation to the pregnant woman's brain death: 1. to respect the absence of authorization for organ donation, which means not using life support resources; 2. to maintain the pregnant woman's vital functions, based on the presupposition that the fetus has the right to life

from conception, to make fetal development possible. Our hypothesis is that the Vatican assumes the last interpretation, based on the example of an anencephalic fetus, where the magisterium advocates that pregnancy be maintained until the end in order to give an unviable being the right to life.

The controversy around the brain-dead pregnant woman's right to autonomy and her fetus's right to life is a dispute over rights, within the individualistic configuration of modern Western values. The fetus and the brain-dead pregnant woman are considered individuals: "the moral, independent, autonomous and, consequently, essentially non-social being, which guides our modern values and occupies first place in our modern ideology of mankind and society[11]." Equality and liberty are fundamental traits of the individualistic configuration of values, a characteristic of modern Western societies. The autonomy ideal imposes itself on the model of the person as individual: "the rational being, the normative subject of institutions", "as the values of equality and liberty witness[27]." This individual is the subject of rights[26] from the normative point of view.

The cases: dilemmas on life continuity

From the cases reported in the media, we have chosen three: an Irish, a Canadian and an American case. We have described abortion legislation in their countries so as to reveal the contexts of the situations. The choice to focus on abortion and its regulations is based on the possibility of interpreting non-maintenance of the brain-dead pregnant woman's vital functions as an option equivalent to interrupting pregnancy with fetal death, as in abortion cases.

Ireland is a country with restrictive abortion legislation. The Irish constitution recognizes both the unborn child's right to life and the mother's right to life. A Supreme Court decision allows abortion in cases of risk to the mother's life. Travelling abroad to terminate pregnancy and to obtain information about the intervention is permitted[28]. The case in question did not contemplate abortion. A 16-week-pregnant woman was diagnosed with brain death. Her parents expressed the wish for the life

support equipment to be switched off. The doctors' refusal was based on the abortion legislation, which guaranteed the fetus's right to life. It was ultimately about allowing the fetus to develop after maternal brain death. The first news article stated that, if the case went to court, the state should "designate a lawyer to defend the fetus against its grandparents", who were pleading for life support to be removed from the pregnant woman[29]. The Supreme Court authorized the equipment to be switched off[30], considering it "a useless exercise" and "unimaginable anguish" for the father. The court judged that authorizing the removal of maternal life support would be "in the unborn child's interest" [30]. The case is reported in two newspapers. In the first, the pregnant woman's parents manifest themselves. In the second, the court's decision refers only to the father's suffering. Doctors used the abortion law to justify not interrupting the pregnant woman's life support, against her parents' expressed will. In this sense, the fetus has a right to life regardless of the mother's situation. The doctors' perspective reveals a hierarchizing of the rights of the pregnant woman and fetus. According to Dumont[27], the social principle of hierarchy implies reverse containment. Although the woman is the bearer of the fetus, by hierarchizing – or prioritizing the fetus's life – the latter starts to contain the woman.

The next news article shows how the case unfolded. The court's decision undoes the first containment, arguing that interruption of the pregnant woman's life support would be in the fetus's interest. The pregnancy was recent (16 weeks) when maternal brain death occurred. The second aspect concerns the family's wish to end the process. The clinical argument regarding pregnancy time considers that, the more advanced the pregnancy, the easier it is to maintain maternal support for fetal development to viability. Perhaps the family members had not grown attached to the fetus in its early stage. It was not yet considered a person, a loved grandson or son, while there was the certainty of the pregnant woman's death. When a woman can no longer answer or write a document, the declaration is the responsibility of close family members. Irish law treats the fetus simultaneously as the subject of rights and interests, including the court's decision to remove maternal life support under the argument that this would also be in the fetus's interests. According to Agamben [8], the

law considered the fetus as “bios”, or life worthy of being a political subject. It would be in its interest for maternal life support to be interrupted, thus stopping its development and preventing it from becoming “zoe”, or naked life[8].

Canada does not have restrictive abortion legislation. Intervention was decriminalized in 1988, is treated as a medical procedure and regulated by province laws and medical norms. Unlike Ireland, there is no legal pro-life environment to influence medical and family decisions. Despite this context, there was a public reaction to the decision, on behalf of Robyn Benson’s husband and doctors, of not terminating the pregnant woman’s life support. She was diagnosed with brain death after a hemorrhage, and the medical staff found the fetus to be developing normally. The intention was to allow it to reach 34 weeks. An internet community raised approximately 150 thousand Canadian dollars, a sign of the mobilization sparked by the case[31]. The brain death occurred in December 2013, when the woman was 22 weeks pregnant. Iver was born prematurely by caesarian on February 2014, at 28 weeks. The case became known because the father reported the experience in a blog and on Facebook, making an appeal to raise funds to be able to take a few months’ unpaid leave to care for his son[32].

This case occurred in a different judicial environment from the first. No reference is made to laws defending the fetus’s right to life. The pregnancy was more advanced. The news articles discuss the possibility of birth with no complications. The fetus’s normal development motivated the medical staff and husband to decide to maintain life support. In contrast to the case before, there was no mention of family conflict, but rather an agreement between medical staff and husband. The pregnant woman’s interests are not referred to. Life support maintenance for the woman to serve as an incubator for fetal development is not described as loss of dignity. She is treated as a subject that serves as a means for others and not for herself, contradicting the Kafkian imperative of not using a person as a means to an end[23]. Thus, the woman is contained by the fetus she bears, in a hierarchizing process[27]. The woman, in Agamben’s[8] typology, reflects “zoe”, naked life, the biological body, while the fetus represents “bios”, or qualified life.

This development is the opposite of what happened in Ireland and also in the other case, in Texas, United States. Following a 1973 Supreme Court decision, abortion is legal in the United States[27]. Despite the decision, Texas is one of the states with the most restrictions for the procedure, through regulatory tactics[34], and has a strong anti-abortion movement[34]. This is the context of the case of Marlise Muñoz, who suffered pulmonary embolism and was diagnosed with brain death in the 14th week of pregnancy. Her family learned that she was receiving life support in hospital. The medical decision was based on a state law prohibiting suspension of somatic support in pregnant women. The husband was opposed, as Marlise had previously expressed the wish not to be kept alive by machines[35]. He went to court, arguing that, apart from the need to respect Marlise's will, the law prescribed life support maintenance for pregnant women in a coma, and not with brain death. The fetus was not considered viable after 22 weeks of pregnancy; images of its lower limbs displayed deformities. The judge ordered the equipment to be switched off, supposing that Marlise would have opted for an abortion due to fetal damage[36].

Marlise Munõz was the only pregnant woman who had previously declared her will. The fetal malformation was a factor offsetting Texas's pro-life state law. The family considered it inhumane to prolong the fetus's development. Texas law hierarchizes in favor of the fetus; it is not possible to turn off the pregnant woman's life support equipment. From the three cases, for the first time the pregnant woman was treated as an individual subject of laws[26], whose will is valid after her death. The woman's autonomy as a subject prevailed over the law protecting the fetus in the final decision. Based on Agamben[8]'s typology, the medical staff considered the woman to be "zoe", naked life, defending the fetus as "bios", in its dignity as a political subject. The family's perspective stood out in considering the woman as an autonomous subject, "bios", political body. This positioning was followed by the judicial decision.

Final considerations

The three cases display a defense of the "sanctity" of life, according to Dworkin[16]'s conception, both from those who value fetal development and from those social actors who prioritize the autonomy of the brain-dead pregnant women. When reflecting on life's extremes (abortion and euthanasia) and the different possibilities for decisions, this author tackles the "sanctity of life" and dignity – defined as respect for "the value inherent in our own lives." To him, "dignity [...] lies at the core of both arguments" – in favor or against abortion and euthanasia. Also according to Dworkin[16], in the debate over the different possibilities for managing the limits of life, another category presents itself: individual freedom, a preeminent value in modern Western cosmology[6]. It is what Luiz Fernando Duarte[6] describes as general ideological characteristics of "modern Western culture"[6], with the following structuring values: "ethical individualism", "hedonism", "naturalism" and "corporal rationalization" [6]. The first expression, ethical individualism, emphasizes the primacy of personal choice, of presumed individual freedom. To Duarte[6], the ethical qualifier refers to the Weberian tradition and its emphasis on linking modern rationality to the world's disenchantment. The second theme – hedonism – signifies the privilege of finding pleasure in the world. Naturalism concerns the importance of the nature category in modern cosmology. On the moral terrain there is a connection with a "natural" state, a "natural law" characteristic of human societies[6].

From this perspective, it is possible to reflect on the tensions revealed in the cases studied. On the one hand, life as a fundamental value in our culture, belonging to the holistic[27]dimension, of totality, of a transcendent plane that encompasses the individual and is also connected to the view of nature[6]. To prolong fetal development in a brain-dead pregnant woman is contradictory to the woman's death (according to the brain death definition) and to nature, in its appeal to life support technology, but emphasizes the life of the fetus. In terms of the individualistic notion of personhood, it signifies to consider the fetus a subject and the woman a means of supporting the development of the former. On the other hand, to invoke the woman's right to autonomy, even when dead, is to emphasize her condition as an individual, in contrast to the fetus's right to life. These values relative to life and nature are intimately

connected and interwoven with the dignity category, as respect for life's inherent value[16]. As for freedom, according to Dworkin[16], freedom of conscience presupposes personal responsibility of reflection, according to the ethical individualism dimension described by Duarte[6]. Cases where the person cannot reflect on their own life and freedom, such as dementia and brain death, present complex dilemmas; who can/should answer for decisions? Each situation must be analyzed.

In face of the creation and development of each new technology or therapeutic resource for creating or maintaining/extending life, new formulations emerge relative to regulation, professional conduct of health care professional and scientists, criteria, prognostics or diagnostics, and possibilities for controlling life/pain/suffering conditions, among others – in law, medicine and in society in the broad sense. In the case of a pregnant woman's brain death, an equation of difficult solution is formed, where the exaltation of life as a supreme value and individual freedom occupy relevant positions. All the situations and cases discussed here reveal a crucial value in our contemporary Western society; life. However, as biomedicine increasingly succeeds in producing life in innovative ways; and, also, in maintaining a fetus's life under conditions previously unimaginable, as is the case of maternal brain death, ethical dilemmas emerge, leading to a demand for reflection, not only by specialists, but also society in general.

In each situation, different social actors occupy a central place in the decision-making process. When examining the aspects involved in each context, we seek to reflect not only on the positioning of the social actors, but also on their political positions, for we start from the assumption that life and death do not constitute notions defined by science. These categories are political concepts, which acquire meaning only while a medical and/or judicial decision is valid.

Collaborators

Both authors participated equally in the survey of media articles and bibliographical research, data analysis, writing of the article and, also, the revision and creation of the text's final draft.

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Translated by Ana de Andrada