Gestational and neonatal loss, a suffering as any other[a]

Perda gestacional e neonatal, um sofrimento como outro qualquer

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ABSTRACT

We investigated 63 narratives of mothers published in the book *Histórias de amor na perda gestacional e neonatal* (Love stories in gestational and neonatal loss). We aim to show that these mothers' fighting strategies are similar to those of other social identity movements. In common, the idea that contingent suffering allows the construction of identity. In the case of mothers with gestational and neonatal loss, in addition to the death of their babies, there is suffering caused by those who do not give the dead child the status of *Person*, not recognizing the pain of loss. In contrast, mothers publicly testify to their child's existence, claim the condition of mothers, and fight for public policies that minimize the harm caused by those who do not consider their suffering.

Keywords: Mourning, gestational and neonatal loss, ultrasonography, suffering

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RESUMO

Investigamos 63 narrativas de mães publicadas no livro *Histórias de amor na perda gestacional e neonatal*. Nosso objetivo é mostrar que as estratégias de luta dessas mães são similares às de outros movimentos sociais identitários. Em comum, a ideia de que um sofrimento contingente permite a construção de identidade. No caso das mães de perda gestacional e neonatal, além da morte de seus bebês, há um sofrimento causado por aqueles que não atribuem ao filho morto o status de *Pessoa*, não reconhecendo a dor da perda. Em contrapartida, as mães vêm a público testemunhar a existência do filho, reivindicar a condição de mães e lutar por políticas públicas que minimizem os danos causados por aqueles que não consideram seu sofrimento.

Palavras-chave: Luto, perda gestacional e neonatal, ultrassonografia, sofrimento

DOI:http://dx.doi.org/10.11606/issn.1982-8160.v13i2p91-112

INTEREST IN NARRATIVES OF GESTATIONAL AND NEONATAL LOSS

AMONG THE MANY websites, blogs and internet profiles devoted to mourning, countless are intended solely for the narrative of mothers who lost their children during pregnancy or shortly after birth. Given this event, we must ask: what would be the singularity of this kind of mourning that requires exclusive spaces for its discursivization? In other words, how are reports of gestational and neonatal loss different from other mourning narratives?

The analysis showed that, while other mourners mourn the death of an estimated person, those who suffer gestational or neonatal loss not only mourn the death of a loved one, they also lament the non-recognition of the loss. They argue that, beyond the unbearable pain of a child's death, there is avoidable suffering linked to the responsibility of different actors. For example, doctors make them suffer when they name the stillborn baby as a simple *embryo*, a *mere fetus*. Hospitals and maternity wards are denounced for their *cold* and *inhuman* attitude of placing mothers who have lost their children in the same ward as those whose births have been successful. Relatives and friends, when they suggest that a woman who has lost a baby get pregnant again, are judged as insensitive for supposing that another child is able to take the place of the deceased. All of this is because, often, a pre or post term baby is not given the status of a *Person*. Without acknowledging the existence of these short-lived beings, consequently, the pain of loss is not recognized, which is the main complaint of those whose babies died prematurely. The following examples from the book *Love Stories in Gestational and Neonatal Loss* (Lupi, Lupi, Camargo, & Couri, n.d.) illustrate this double loss:

> I am speaking here of the recognition of the existence of the pain, the MOURNING, or, in that case, it would be better placed as its absence. The absence of the right to mourning in cases of gestational loss encourages and aggravates psychological cruelties. (Lupi et al., n.d., Chap. 13, para. 4)

> People do not give us permission to feel pain; but I don't need anyone's approval for that… The mere fact of not having seen [my baby] does not take the legitimacy of his presence among us. People are embarrassed to talk about my son, and the act of not talking about him is interpreted as if he didn't exist. Denying his existence also denies the pain of his loss. But it's still here and there, around the corners of the house. It's part of me, it's something I have to carry, to live with. (Lupi et al., n.d., Chap. 28, para. 8)

If, on the one hand, the grieving narrative of parents who suffered gestational and neonatal loss differs from that of the other bereaved, on the other hand, we maintain that it reproduces the trajectory of so many other identity groups, namely: 1) publicly witnessing biased attitudes on the part of those who do not recognize the victim's suffering or consider that it was not so serious; and 2) demanding compensation for the damage through raising awareness of society and developing public policies that guarantee them rights.

To highlight this fact, we analyzed the narratives published in the above-mentioned book, organized by the group *Do luto a luta* (From mourning to fight), which also runs the eponymous website (https://dolutoalutaapoioaperdagestacional.wordpress.com/), where there are hundreds of reports on the topic and which has thousands of followers.

The relevance of studying such narratives is also because they illustrate four important changes from modernity to contemporaneity, which will be discussed below. These are the conditions for the possibility of the appearance of these reports in the discursive order: 1) the return of death to the public space; 2) the transformation of the mother/baby status; 3) the rise of self-help as a therapeutic discourse; and 4) the moral appreciation of suffering.

THE RETURN OF DEATH TO PUBLIC SPACE

Researchers from different fields of knowledge show that, from the 19th to the 20th century, death and related processes were systematically silenced, interdicted, repressed and pushed behind the scenes of social life (Ariès, 2014; Freud, 2009; Elias, 2001).

As the authors mentioned above, when reflecting on the emergence of biopower, Foucault (2006) also highlights the phenomenon of death concealment in modernity. According to him, in a society in which political power assumes the task of managing life, "death is power's limit, the moment that escapes it; death becomes the most secret aspect of existence, the most 'private'" (p. 151). According to the French philosopher, the worry of turning away from death is less linked to a new anguish that makes it unbearable than to the fact that it is located outside the domain of biopower mechanisms. Foucault (1999) shows that, by intervening mainly to prolong life, this type of power seeks to "control its accidents, its eventualities, its deficiencies" (p. 295). In his words, death represents the "limit", the "end of power", it is "outside" power.

Technical-scientific knowledge plays a crucial role in this scenario by proposing ways to decrease the chances of future illness and premature death. Unable to act on the irrefutable reality of death, the control society acts on

mortality. It identifies the probable causes of illness and death and, from there, guides ways of acting in the present in order to postpone the end of life and prevent disease. Thus, the real is replaced by the virtual. Approaching death as mere virtuality is a way of emptying man's fundamental anxiety in the face of finitude. In this process, anguish, whose object is opaque and undetermined, is replaced by fear, whose causes are identifiable and, for that reason, can be dealt with.

Current discourse propagates both the idea that it is never too early to start taking care of yourself, and that it is never too late to do anything. In the face of terminal illness, things change, because there is nothing more to do to prevent death. In these cases, palliative care (PC), designed to take care of patients considered to be out of therapeutic action, provides a *good death*. However, in a complex mix of life and death politics, PCs are nonetheless operating from a kind of *life optimization* when they aim for terminally ill patients to enjoy quality of life, dignity, autonomy and happiness to their last moments.

The question of the autonomy of the dying in the PC implies managing the circumstances of their death and mastering themselves. It is a kind of compensation for the impossibility of controlling the world, in this case, the imminent death. It is no coincidence that the palliative speech is mixed with that of self-help. Because of all this, PC are nonetheless, although quite different from "modern death" (Ariès, 2014), a domestication of death, a true pedagogy of dying.

Palliative ideas encourage the dying subject to think and talk about death. Nowadays, it is not uncommon to find reports of terminally and chronically ill patients on the internet. These people come to the public to talk about coping with the disease, treatment, moments of joy and depression, how they have redefined their lives and so many other things that affect them. In a society that has grown accustomed to extolling a healthy body and happiness, it is strangely surprising that such reports attract the interest of so many, retaining followers who often *like*, for example, a post about a chemotherapy session.

These reports reveal the strength of biographical narratives in the contemporary context, marked by individualism, in which the exposure of intimacy is understood as a therapeutic act (Lerner & Vaz, 2017). Nowadays, the psychotherapeutic clinic has been insufficient to overcome suffering. Only those who have experienced similar pain are believed to be empathetic, to welcome the outburst, understand what is being reported, and share experiences. Thus, sharing similar stories of suffering makes it possible to build a group identity. A group that grows and strengthens as more people want to share their story with the intention that it can serve as inspiration and hope for those

who still suffer. In a movement of contagion and mirroring, the narratives of pain and suffering are succeeding and accumulating. It is in this scenario that not only the reports of chronic and terminally ill patients, but also those of the bereaved, gain visibility where the narratives of gestational and neonatal loss are located.

Even when one thinks about the discursivization of death in the public space, the discussion about the profile of the dead in social networks occupies a prominent position. The controversy revolves around maintaining or deleting such profiles and who would have access to online data to accomplish this task. In fact, there is a whole digital market focused on *postmortem*. For example, relatives and friends of the deceased can leave messages, testimonials, and share photos in online cemeteries and memorials. Applications enable anyone to program in life so that their circle of family and acquaintances receives posthumous publications. There are services that allow you to designate heirs who will be responsible for the fate of a deceased's digital assets. All these events give visibility to a new discursivization of death in the contemporary.

THE TRANSFORMATION OF THE MOTHER/BABY STATUS

The testimonies about gestational and neonatal loss also express a recent and profound change in the experience of motherhood. By the late 1960s, there was a unity between mother and fetus; symptoms of this unit were the fact that the pregnant woman was the social object of care and the invisibility of the child until birth (Armstrong, 2003, p. 13). The 1960s and 1970s brought with them the spread of the birth control pill and the legalization of abortion in several countries. Then the separation between the pregnant woman and her baby became conceivable, even because there is a possibility of conflict of interest: for a variety of reasons (professional fulfillment, hedonism, material difficulties, etc.), a pregnant woman may not want to be mother now or always; The fetus, in turn, strives to persevere in being.

Ultrasound devices, designed to enable non-invasively diagnosing diseases in fetuses, were also invented in the 1960s and 1970s. In fact, the first device was designed and used in Germany in 1966; in Brazil, the first device was used in 1973 in Recife; in 1974 there were only six in operation (Santos & Amaral, 2012, pp. 44-45). For someone born in Brazil more than forty years ago, chances are high, therefore, that they were invisible to their parents until they were born.

Improved image resolution (2D images were created in 1970 and 3D images, which depend on software data reconstitution, emerged in the 1990s) and widespread use of ultrasound equipment has another function: make the baby's existence sensitive before birth (Armstrong, 2003, p. 21). The availability of images guarantees their existence prior to birth or, more precisely, at the exit of the womb, since childbirth now seems more a change of environment than a movement of becoming, of arising. This *previous existence* is recognized in the legislation of several countries through the obligation of civil registration for babies who died from the 22nd week; the World Health Organization (WHO), in turn, has counted the number of babies who died in the womb and not just those who died soon after birth — the annual report (WHO, 2016) has the suggestive title of "making every baby count".

Existence before childbirth changes the object of social concern: the embryo is now the vulnerable to be cared for. The mother's place is immediately transformed; from object of care, it becomes potential aggressor. It can be said that the morality of contemporary Western cultures combines relativism and consequentialism. Many accept the reasoning that if an individual, group, or society believe that doing X is right, then it is right for them to do X. Since *X* is often a pleasure practice, this gentle relativism accommodates and encourages contemporary hedonism. At the same time, these cultures only indicate or demand limits to pleasure practices if they increase the chance of harm. They indicate when the damage is done to individuals themselves: it is up to someone to decide whether or not to continue smoking, even knowing that the habit increases the chances of a series of diseases. And they forbid when it is another whose risk is magnified by the pleasure practices of a given individual. To stick to the example of smoking, smoking in closed public places, which affects others, has been banned in virtually every country in the world for the past thirty years.

The pregnant woman is in the position of endangering the life of another — the most vulnerable and dependent conceivable — by her pleasure practices. The counterpart of the mother's extreme responsibility for caring for the vulnerable resident in her womb is constant distress. Medical knowledge ensures that even a slight oversight can have serious consequences. An example is the evolution of Fetal Alcohol Syndrome, not by chance formulated in the early 1970s, when a potential conflict between the mother and her baby began to be believed. Initially, the syndrome indicated only one effect, the birth of children with severe neurological problems, and restricted the cause to excessive alcohol use (Armstrong, 2003, p. 4). More than forty years after the initial diagnosis, both the effect and the cause widen. Doctors now believe that alcohol use generates a

spectrum of neurological problems ranging from deadly neurological deformity to poor school performance (Belluck, 2018). Regarding the cause, there is no longer the threshold indicated by the terms *excessive drinking* or *alcoholism*; even a simple glass of wine drunk at a party can cause both poor performance and deadly deformity.

THE MORAL VALORIZATION OF SUFFERING

Another reason to study the fetal and neonatal loss discourses is that the groups of bereaved parents also present themselves as a social and therapeutic movement. By the way they express and legitimize their claims, the groups organized around this loss are yet another movement to propose that the greatest contemporary form of avoidable suffering is that of suffering caused by lack of recognition, that is, caused by prejudice.

The list of social movements based on the denunciation of prejudice is long and includes some that have profoundly affected our politics and morality: Holocaust victims, victims of hate crimes, victims of domestic violence, harassment and rape, victims of crime, AIDS patients, etc. In all of them, prejudice would cause, at least in part, suffering, and, therefore, these movements propose the need for moral change.

They assume two ways in which prejudice causes suffering. Directly, when prejudice created violence, as in the case of victims of the Holocaust or hate crimes or, from the point of view of conservative morality, victims of crime insofar as compassionate prejudice, which is moved by alleged *bandit* tribulations, would have prevented the adoption of *truly* effective public security policies, specifically intimidating policing and stringent punishments such as the reduction in criminal majority and the return of the death penalty. Not all identity movements can propose that prejudice directly causes suffering, as was the case with AIDS patients in the 1980s and 1990s, since illness and death were caused by a nonhuman agent. But the indirect form is shared by all these movements, regardless of their place in the usual ideological arc. Prejudice is a cause when it is not recognized that there was suffering and trauma.

By the postulation of unrecognized suffering, there are complaints about a society that does not want to listen to Holocaust victims, saying that the survivors, having endured the extreme violence of the concentration camps, continued to suffer from the lack of social recognition of the trauma and for the lack of interest in listening to their testimonies (Leys, 2007). Or, there is the mobilization against the budget cut made by the Reagan administration

in the 1980s for AIDS research: the gay movement denounced that the cut was based on prejudice (Gould, 2009). Because of the mobilization of various feminist movements, the additional suffering imposed by the prejudice against victims of domestic violence and rape has been widely criticized since the 1970s: the chauvinism of society and the police and judiciary tended to minimize suffering and blame the victim for what they experienced (Cole, 2007; Weed, 1996). Still related to feminist movements, there is the effort to establish the scientific validity of the diagnosis of postpartum depression, with the refusal of validity attributed to sexism that destines women to motherhood (Taylor, 1996). We have, in several countries of the world, the struggle of movements of race, gender and sexuality for the recognition of the category of hate crimes, which would require a more severe punishment; prejudice would prevent criminal rigor and thus presumably would prevent the reduction of this type of crime (Jacobs & Potter, 1998). A final example is the movements of victims of crime, which make demands easily appropriated by conservative groups and parties; in this case, they propose that compassionate prejudice in favor of criminals causes victims to be victimized again by a criminal system that leaves no room for their suffering in either trial or punishment (Elias, 1993; Weed, 1996). From this perspective, police officers would also be a victim, as their ability to fight criminals who threaten them and their citizens is limited by human rights defenders (Simon, 2007).

In addition to the identification between the idea of contingent suffering, which is within the reach of individual and collective human action, and the idea of second victimization due to the lack of recognition, these movements also have the common characteristic of witnessing as a form of mobilization. An individual narrates to others the suffering they have experienced, articulating it at the same time with the suffering experienced by other individuals in the same group, and indicates as cause of all of them the prevailing immorality in society — in this case, some prejudice. Testimony has at least two goals. One is to urge other members of the victimized group to also narrate the sufferings they have experienced, reinforcing the mobilization by the intense commitment of those who become narrators, in a dynamic of imitation that tends to be explosive, quickly gaining a large number of testimonies, and then, also quickly, cooling its intensity. Another objective is to invite to solidarity those who do not belong to the group but do not want to cause suffering; the invitation, therefore, takes the form of an intimation to discover prejudice in the one who was invited. By denouncing immorality, even when it has the form of moralism, personal becomes political.

There is another feature that brings these movements together: they all originated in the United States, even the Holocaust Victims Movement, which became Americanized in the 1970s through a shift in emphasis (Leys, 2007, p. 61). In the 1960s, the political and clinical problem was the survivor's fault; in the 1970s, the issue becomes the difficulty of witnessing in a society that does not want to remember. Because of this fundamental relation with American culture, the origin of these identity movements can be traced back to the mobilization of Presbyterians and Evangelicals for temperance and against slavery, both in the 1830s (Young, 2002). Starting from the belief in American exceptionalism that God would have made a special alliance with its inhabitants, these movements assumed that individual sins caused social ills: they threatened to attract divine wrath and the breaking of the alliance. In this way, they set out to seek the conversion of sinners based on the evangelical experience of awakening. A sinner performs his conversion in public, which immediately encouraged the conversion of others. In the case of temperance, a drinker, perhaps still drunk, watching a march, performs his conversion in a public square, and narrates how he had sinned before and now discovered faith; his example is followed by several. Individuals were connected to the collective in the form of the individual responsibility: it is their immorality (their racism or their intoxication) that threatens the common good. In contemporary victim movements, on the contrary, it is the immorality of others that causes various sufferings to members of a group that is conceived as stigmatized. From then on, a sufferer mobilizes against this immorality, assumes and takes pride in the identity that made her a victim of prejudice, bears witness to her suffering, and thus again connects the individual and the collective, the suffering and the immorality, promoting the mobilization of others.

Couples and women who experienced gestational or neonatal loss could relatively easily assimilate their experience with the idea of second victimization and use testimony as a form of mobilization. Self-help groups linked to loss appear to have emerged in Brazil only at the 21st century, when the repertoire of identity movements was stabilized and available. In general, these groups will propose that prejudice precludes giving sufferers the identity of parents who have lost their children — and this is because their children died in the womb or soon after childbirth. As summarized by Erika Pallotino (n.d.), one of the psychologists who signs one of the texts in the book *Love Stories in Gestational and Neonatal Loss*, prejudice causes suffering for not allowing grief; thus parents lose the loss.

THE RISE OF SELF-HELP AS THERAPEUTIC DISCOURSE

The fourth reason for studying these discourses is that they express a change in therapeutic practices. If apprehension compares different therapeutic schools, change is the transition from psychoanalysis to self-help. If apprehension focuses on the evolution of a therapeutic school, restricting us to psychoanalysis, change is the transition from the clinic of desire to the clinic of trauma.

The resumption of the relationship between female condition and motherhood indicates how a clinic of desire could operate in the face of the suffering of a gestational loss. There were, of course, other changes in motherhood beyond the existence of the baby before birth and the imposition of extreme responsibility on the pregnant woman. For those that would be relevant to the clinic of desire, it is known that fewer and fewer women recognize in their motherhood the purpose of their lives, that, in many countries the first maternity is postponed and the average number of children per woman continues to decrease. These trends suggest that having a child is an option and potentially conflicts with professional dreams and the desire to enjoy life while it is possible.

Believing in the conflict between desire and social norms and supposing that guilt haunts those who come to his office, a psychoanalyst of the clinic of desire, in the face of the discourse of suffering of a mother lamenting an involuntary abortion, would suspect the internalization of the social norm forcing motherhood and the desire not to be a mother, now or never. The profound sadness over the loss could then be anguish at the realization of the unconscious desire to *kill* her child, a far more troubling fantasy since a medical discourse is at the disposal of her consciousness that estimates as potentially momentous every daily act of a pregnant woman: perhaps you aborted because you ate this, or drank that, or did not exercise, etc. Treatment would include taking responsibility for the desire not to be only a mother and questioning the internalized social morality that placed motherhood as the patient's destiny.

In structural terms, three characteristics are relevant. First, the psychoanalyst would take the patient's discourse as a symptom because, as a matter of principle, he does not believe in self to self-transparency: it does not matter whether she really wanted to be a mother. Secondly, what causes suffering is not the trauma of a *mere* abortion, but the fulfillment of an unconscious desire. Finally, and perhaps most importantly, from the patient's assumption of self-deception, the psychoanalyst knows more than the sufferer about what she experiences, whether or not she has gone through the traumatic experience. By the way

the causality of suffering is constructed, it is not the authority of experience that guarantees the understanding and position of who can help a sufferer; it is rather the acquisition of theoretical and practical knowledge about self-deception and rationalization strategies.

Later it will be seen that, in the trauma clinic and especially in self-help, these three structural characteristics are transformed. The sufferer's speech is no longer considered a symptom. In fact, by not interpreting, the suspicion is over and discourse is taken in its referential relation, which indicates events in the world, instead of inadvertently revealing, as it once was, an unconscious desire in its origin. As a second change, what makes you suffer is actually what happened. The expert's greatest function is merely to endorse that events of such kinds cause suffering. Interpretation no longer has a therapeutic function, because what causes suffering is not the self-deception caused by the patient's inability to take responsibility for their desire, but the event. Thirdly, therefore, the discourse that helps one sufferer is that of another surviving sufferer who has experienced trauma.

The hierarchical verticality assumed in the direction of consciousness conducted by experts in the forms of self-deception is replaced by the horizontality of the testimonies of all who undergo trauma. The recognition of oneself in the discourse of suffering of the other would be therapeutic because it reinforces the existence of suffering denied by the prejudiced others and because it indicates the possibility of surviving for those who are immersed in unbearable pain that seems insurmountable. In short, discourse has a referential relationship and is supposed to be transparent to itself; the function of the expert is not to suspect (Fassin & Rechtman, 2007, p. 89) and to interpret, but to argue that this type of event causes suffering, placing themselves beside victims of prejudice; finally, the authority of experience overcomes *formal knowledge*. It helps those who have suffered and not those who have graduated theoretically and practically in the study of self-deception.

Having exposed the conditions of possibility for the emergence of the narrative of gestational and neonatal loss in the public space, we turn our attention to its discursive function, its textual form and its argumentative chain.

THE REASONS FOR NARRATING THE GESTATIONAL AND NEONATAL LOSS

The relation between writing and grief is old. Talking about the death of a loved one has a strong therapeutic character, fulfilling the function of *relieving*, *alleviating* and *reducing* pain. In a self-reflective movement, the reports of

fathers and mothers who lost their children prematurely clearly point out the importance of writing for the process of overcoming grief.

> And two days after our farewell, I decided to write. Write to myself. To him. For me. For him. . . . Writing was the healthiest solution you could choose. (Lupi et al., n.d., Chap. 3, para. 9 and para. 10)

> Writing about one's emotions is also valid, because we organize ideas and bring clarity to the changes and adaptations we need to make within ourselves. (Lupi et al., n.d., Chap. 22, para. 12)

While previously mourning journals used to remain restricted to private space, in the age of increasing self-exposure and hyperconnectivity practices, this type of writing is born for public space, specifically the internet, given the potential of websites, blogs and social networks to promote the meeting between people with similar life stories.

From the exposure of suffering, there is the desire to form a community. Only those who have experienced similar pain are believed to be empathetic, to welcome the outburst, understand what is being reported, and share experiences. Sharing similar stories of suffering builds a group identity; a group that grows and strengthens as one who can overcome grief is grateful and wishes that their own story can also serve as inspiration and hope for those who still suffer. This movement of solidarity with another sufferer resignifies the loss of the dead child, as the mourners find themselves in the mission of helping others. This reveals the self-help character of this discourse.

> Desperately seeking support from someone who understood me, I searched the internet for help… and I heard reports of mothers feeling that same emptiness, that same pain I was feeling. (Lupi et al., n.d., Cap. 24, para. 5)

> I decided to write after three years of his departure, because my heart warns that I can and should be useful. I don't want to take the pain away from a mother who loses her child, I just want to show ways that each one, in their moment, can feel better or less alone in this pain, and also help each other. (Lupi et al., n.d., Chap. 11, para. 1)

Couples and women who experienced gestational or neonatal loss could relatively easily assimilate their experience with the idea of second victimization

and use testimony as a form of mobilization. In general, these groups will propose that prejudice precludes giving sufferers the identity of parents who have lost their children. The prejudice is in not recognizing the suffering or evaluating that it was not so serious, considering that the baby still dead in the belly or soon after birth is not recognized as a *person* either. In order to change this situation, the mourners seek to make society aware of the problem and fight for the development of public policies that guarantee them rights, such as paternity leave. In this context, these mourners quickly become militants of the cause, making it a battle flag.

> Two weeks after giving birth, I was in the personal department where I worked, trying to sort out the license issue. They gave me a fortnight, but I didn't feel ready to take care of children again. Finally, they fired me and I went to court. The same thing happened with my master's degree: they did not extend my deadline, and I had to finish my dissertation. I worked out my grief, fighting. For the system, it didn't matter what I was going through, but what the rules said. There was no sensitivity, and I felt I had no choice but to go from mourning to fighting. (Lupi et al., n.d., Chap. 48, para. 11 and 12)

> A month after the loss of Antonio Henrique, I called State Representative Marcelo Freixo and asked him to hold a public hearing at the Rio de Janeiro State Legislative Assembly (Alerj) to give visibility to this matter... the public hearing was held on October 15, International Gestational Loss Awareness Day... On that same date, the deputies who called the public hearing presented a draft Constitutional Amendment (PEC 16/15) on maternity and paternity leave in case of gestational and neonatal losses and, as important as, in case of premature birth. This proposal was approved on December 21, with 56 votes in favor: a true Christmas present. (Lupi et al., M., n.d., Chap. 38, para. 21, 22 and 25)

THE MOURNING MOTHER'S JOURNEY

The narrative for gestational and neonatal loss is built from four primordial events around which secondary, anterior and posterior events are structured: pregnancy, death, grief and overcoming. These events are narrated from a linear chronology from pregnancy to overcoming mourning (Figure 1), never in reverse order. We discuss each of these narrative segments in order to show their main textual characteristics and discursive functions.

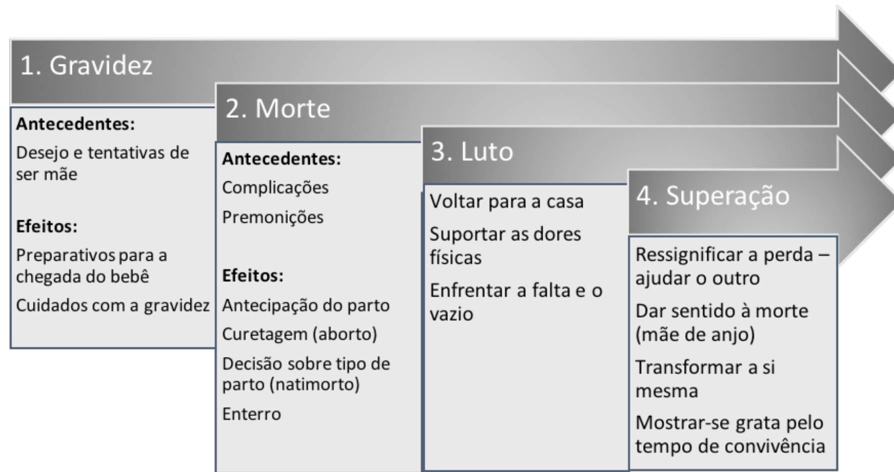

Figure 1. The mourning Mother's Journey
Source: Elaborated by the authors.

The *ethos* of the wishing and caring mother

The analyzed narratives emphasize how much the lost child was dreamed, idealized, which attests to the strong psychic investment in the existence of the baby, even before conception. In cases of planned pregnancy, the alignment between desire and the moment considered most conducive to pregnancy becomes evident. In cases of unplanned pregnancy, the idea of a child's arrival is soon accepted as a source of happiness. Even in situations where difficulties with getting pregnant and/or taking pregnancy to term are reported, the desire to become pregnant and to be a mother prevails.

> I had always wanted to have a daughter, and she would be called Mariana! Mariana existed before she existed physically. She lived in my dreams, in my plans. When I got pregnant and knew it would be a girl, I named her Mariana — finally the dream would come true! (Lupi et al., n.d., Chap. 55, para. 2)

> Mother! Now what?! I found myself being a mom! I, who had never seen myself in this role, just discovered myself as a… Mother! After the initial shock, the feeling was of surrender. I plunged headlong into the world of motherhood, me, who had never thought of being a mother! I wanted a lot from there, I went and didn't look back. There, only the unwillingness to be a mother remained. I was a mother from the first moment. (Lupi et al., n.d., Chap. 10, para. 2)

> My fight started at age 25, when, after two years of trying to get pregnant, I had an abortion at home without even knowing I was pregnant! From then on, there were many visits to the doctor, many tests and the diagnosis was discouraging: to be a mother, I depended on a miracle, because my husband had grade three varicocele and oligospermia, and I, anovulation micropolycystic ovaries. But the miracle happened: In March 2006, I discovered that I was pregnant with my Prince David. At twenty weeks I was diagnosed with preeclampsia and Hellp syndrome and at 26 weeks I had to have an emergency caesarean section. My angel lived for four days and went to heaven. (Lupi et al., n.d., Chap. 34, para. 1, 2 and 3)

On the rare occasion that mothers who have lost a baby prematurely blame themselves, this judgment is immediately denounced as a mistake, since the mother already suffers from the loss and should not suffer from the guilt. When the mother insinuates any attitude that may have contributed to the baby's death, it is soon understood that this occurred unintentionally, and she asks the dead child for forgiveness.

> Everyone talked to me if it was a crime to have lost a baby… And then our guilt only increases. Those who have experienced this know that feelings of guilt, rage, anger and sadness mingle and take time to pass. (Lupi et al., n.d., Chap. 8, para. 4)

> Mothers and fathers who lose a baby so prematurely tend to find themselves guilty, but I decided not to do so because it would only make things worse. I am sure that I did everything within my power and gave myself the right not to carry a blame that does not belong to me. (Lupi et al., n.d., Chap. 22, para. 10)

> I wanted to see him, I could say goodbye, smell him, and apologized if I had somehow failed. (Lupi et al., n.d., Chap. 2, para. 10)

The absence of any hesitation about the desire to be a mother or the desire to carry on an unexpected or difficult pregnancy is a significant datum in itself. How to think discursively this *unsaid*? What would prevent women from sustaining another, less affirmative and more oscillating discourse? What is at stake so that other subject positions do not appear on the discursive surface? In the case of narratives in which the mother explains her religious background, it is easier to understand non-hesitation, since interrupting a motherhood is a prohibition. In other situations, we believe that this occurs less due to an explicit censorship exerted by the website than a *constitutive silence*, necessary to build the identity of mothers of gestational or neonatal loss.

The central role of ultrasound

In the past, the signs of a pregnancy necessarily passed through the perception of the pregnant woman. Nowadays, ultrasound has overridden the woman's body awareness. Often women find themselves pregnant only after an ultrasound. It is also through ultrasound that mothers can hear the heart and view an image of their babies. Ultrasound plays an important role throughout the prenatal period. Linked to risk culture, its ultimate goal is to track the baby's evolution and detect anomalies. In this context, it is easy to understand why pregnant women not only submit, but also want the monitoring and surveillance of ultrasound, which makes their bodies transparent. It is through routine or emergency obstetric ultrasound that the mother knows of a pregnancy complication or receives the bad news that the baby is dead.

Importantly, when a problem in pregnancy is detected, whether or not through the use of ultrasound, pregnant women claim to follow medical advice to preserve the proper progress of pregnancy and, if necessary, make sacrifices in the name of the health of the baby. Once again the *ethos* of a wishing and caring mother is stressed.

> On January 7, 2015, worried that the baby had been quiet since the day before, I entered the hospital for an ultrasound. I felt very good and would not have sought care had it not been solely because of decreased gestational movement. (Lupi et al., n.d., Chap. 22, para. 3)

> When I was sixteen weeks old, I went for an ultrasound to confirm the sex of the baby. The doctor who attended me, a friend of mine, spent a long time looking at the computer screen while doing the exam. I thought it was because she couldn't see the sex. It was then that she told me that the baby's heart was not beating. My world collapsed! (Lupi et al., n.d., Chap. 7, para. 3)

The loss and the mourning

As pointed out earlier, after proof of the death of the baby, mothers of gestational loss report that they are under a lot of psychological pressure and embarrassment to share the same space with mothers of full-term babies. Following the report comes another very painful moment: the birth of a lifeless baby. Another situation described as remarkable and unforgettable is having the child in their arms, alive or dead. A feature of this moment is to emphasize the

child's beauty and resemblance to the father or mother. In the case of preterm mothers, after the baby's death, it is often emphasized how much they fought for life, as if they were *warriors*.

> I needed to go into labor and try a normal birth because I was at risk of infection... After much insistence from the doctor and my mother, I agreed to have the IV put on to attempt normal delivery; but when the pain began, I called the doctor and said stop, because I would not go through all that suffering so as not to have the best reward, which was to have my son in my arms alive. (Lupi et al., n.d., Chap. 45, para. 8)

> The angel nurse, who accompanied me that night, told me that I could stay with her as long as I wanted. How long? Can it be forever? A lot of people found it morbid that I stayed with her. I didn't. It was my daughter and our chance to say goodbye. (Lupi et al., n.d., Chap. 51, para. 25 and 26)

> Holding her in my arms was the best feeling I ever experienced. See her little fingers, perfect little body... modestly, my face! With generous and attentive eyes like her father's. (Lupi et al., n.d., Chap. 37, para. 8)

The temporality of grief is narrated as intense suffering. Immediately comes the difficulty of burying the baby, the physical pains of recovering from childbirth and the psychological distress of the child not occupying the house that was so prepared for his/her presence. After this initial moment, the most constant references are to the state of prolonged sadness that sets in and the belief that it is impossible to overcome it.

> Burying my daughter was the worst pain I've ever felt. Getting home, just the two of us, without her in my belly accompanying me or without her in our arms, and still see that beautiful room, all decorated, tidy, dedicated to her, we smell the baby between the clothes, was the second worst pain. The memory of the pain is reflected in the body, the recovery of the cesarean section, the breast milk that was ready to feed her... (Lupi et al., n.d., Chap. 43, para. 8 and 9)

> What to do to live again? Would we ever be happy again? I thought that would never happen again in our lives; no matter how hard we tried, we were immersed in an abyss and had the conviction that we would be there forever. (Lupi et al., n.d., Chap. 14, para. 13)

In the end, grief is overcome, it is ephemeral. The strength that fathers and mothers say they find to go through this phase comes from the passage of the baby in their lives, a quick but intense passage that can transform and strengthen them. Just for that they are very grateful. They feel privileged to have been the fathers and mothers of these short-lived beings. Many give a religious meaning to the loss. No wonder the children are named *angels*, *little stars* that populate the sky. There is always the discovery of a purpose for suffering, meaning is attributed to chance. Survivors often find themselves on a mission to help others and improve themselves.

> Her passage here on Earth was quick, but I am happy and thankful for her coming, for choosing us as parents, for making me a mother, for emanating the pure and beautiful love she passed on, and for making us better people. (Lupi et al., n.d., Chap. 43, para. 12)

> God didn't leave me. He chose me to be the mother of an angel who had a beautiful and important mission that for some reason I will never know. And I feel honored for that. (Lupi et al., n.d., Chap. 3, para. 14)

Importantly, while overcoming grief is possible, the identity of a mother who has lost her child never is. Indeed, far from wanting to overcome this condition, it is claimed that this is a permanent, irrevocable identity. The complaint is that common sense rejects the title of mother to the bereaved woman for gestational or neonatal loss. Contrary to this understanding, women are categorical in self-attributing the identity of mother. At this point in the narrative, the name of the dead child is often mentioned as a way of singularizing the existence of that being. References to the absence of the child as well as to the incompleteness of the family are recurrent. By indicating the absence, a kind of ghostly presence of the departed person is indicated.

> I will always feel amputated, crippled. When I have other children, I will always know that my family is not complete — the presence of my firstborn will always be missing. My happiness will never be complete, but it exists and I try to enjoy every moment life gives us. (Lupi et al., C., n.d., Chap. 6, para. 16)

> I am so happy to have Pedro Lucas and Clarissa in my arms, but Maria Fernanda's place is here in my heart, and no one will ever occupy it. (Lupi et al., n.d. Chap. 27, para. 11)

> I was not a mother, I AM a mother. I am the mother of Otto, the mother of that beloved and dearly awaited baby, with immeasurable love. I am the mother of a child who has not lived here, nor distributed her laughter in the corners of the house, but has warmed my heart in such a way that I will never be the same person, never feel alone again. (Lupi et al., n.d., Chap. 28, para. 8)

EXPOSURE OF SUFFERING GUARANTEES IDENTITY

The two-way street between overcoming grief and maintaining the identity of a mother who lost a child in her belly or shortly after birth is exemplarily illustrated in the photo campaign created by the team *From mourning to fighting* to sensitize society about gestational and neonatal loss. In the #maisamorporfavor (more love please) campaign, parents, mothers, and their grown-up children appear smiling posing next to a baby's ultrasound (Figure 2). This kind of record reminds us of the scene in which family members pose together for a photo. But the gesture of showing off a baby's ultrasound is odd.

Figure 2. Photos of the campaign #maisamorporfavor

The words of the posters allow us to infer that the ultrasound of the baby fulfills the role of embodying the child who is no longer here. The very presence of ultrasound within the photographic image is also evidence of an absence and its relation to death. Thus, ultrasound restores some materiality to the *lost object*, attesting that that baby, often not recognized as a *Person*, existed. It is a trace, a trail, a proof of the existence of the one who is gone.

Besides the function of attesting to truths (*the baby existed*, *the baby is dead*), this photo campaign fables a new existence for the baby, or at least resumes its promise of existence. In the fable created by the image, past, present, and future are entangled in each other. It is as if the images whisper: *Look what could have been! Look what was dreamed*. Dreamed not exactly like that, but almost. The dream was of the existence of the baby in the family. In the face of this impossibility, memory and fabulation remain.

The images from this photographic campaign still refer us to the *memories photographs*, very common in the nineteenth century, when the family posed for the camera next to the image of a dear dead, portrayed while still alive. But there are also some differences. One of them concerns the materiality of the portrayed image. Whereas in memorial photographs the image representing the dead is a painting or photograph; in the photo campaign, the featured image is an obstetric ultrasound.

Another distinction concerns the countenance of the photographed. In the images of the past, expressions are always solemn, serious, sad. In our present, in spite of the fact that they are also remembering the death of a child, people are happy. Happiness depicted in smiles and in the setting of a verdant, sunny garden can be read as overcoming grief and resignification of loss.

The image of the mother carrying the ultrasound of her baby in her hand suggests that her identity as a mother does not die with the death of her child. More than that, this image seeks to make public this visible identity that cannot be seen with the naked eye, and only by making it public can the recognition of suffering be claimed. Thus, the movement of mothers of gestational and neonatal loss reproduces the trajectory of so many other identity groups: suffering is publicly witnessed and the damage repaired. This characteristic, common to the movements of women, black people, Indians, LGBT population, and so many other groups, including mothers of gestational and neonatal loss, leads us to affirm that, in contemporary times, contingent suffering, because caused by prejudice, is itself even an identity mark. M

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Article received on July 26, 2018 and approved on May 7, 2019.