

The experience of illness of women with endometriosis: narratives about institutional violence

Paulo Alexandre de Souza São Bento ¹
Martha Cristina Nunes Moreira ¹

Abstract *This paper conjures up the centrality of the relational category of gender to shed a light on women's life narratives with a chronic disease named endometriosis. It aims to discuss the meaning of the illness experience of women with endometriosis in the interface with institutional violence. Based on Bertaux reference, in the Narratives of Life method, twenty women participated in this research. They were invited from two virtual spaces of discussion and gatherings about living with endometriosis. Interviews were conducted in person in the States of Rio de Janeiro, São Paulo and Minas Gerais circuit. Authors sustained the theoretical approach and addressed the experience of chronic illness as a sociocultural phenomenon, metaphorical readings of the problem and criticism of institutional violence. The results identify situations of gender/institutional violence perpetrated in various women care settings. They are expressed through the trivialization of women's discourses; user-physician tensions, where the supposed lay knowledge appears as an insult to official biomedical knowledge and, mainly, the difficult access to services, leading women to a care pilgrimage and to submit themselves to care types not necessarily based on best practices.*

Key words *Endometriosis, Violence, Gender identity, Women health, Public health*

¹ Instituto Nacional de Saúde da Mulher, da Criança e do Adolescente Fernandes Figueira, Fundação Oswaldo Cruz. Av. Rui Barbosa 716, Flamengo. 22250-020 Rio de Janeiro RJ Brasil. saobento@iff.fiocruz.br

Introduction

Endometriosis is a progressive, sometimes incapacitating painful gynecological disease with abundant menstrual flow, characterized by the ectopic evidence of endometrial cells (tissue lining the uterus internally). Estimates point to 70 million women affected by the disease worldwide. It is one of the leading causes of hospitalization in industrialized countries. In Brazil, from 2009 to 2013, there were 71,818 admissions due to endometriosis¹. While it is a striking disease, access to services, diagnosis and treatment is scarce.

Two theoretical poles predominate² in endometriosis-related studies: (a) one reduces endometriosis to a clinical entity with symptomatology and treatment, prognosis and distribution in the female population³⁻⁵; (b) another gathers knowledge of the biopsychosocial field – with all the snags suggested by this expression – that attributes to women the responsibilities of their illness process⁶⁻⁸. Reductionist analyses on women, their bodies, decisions and ways of living predominate in both, compromising the prominence of female experience of this illness. Understood as *a modern woman's disease*, women with endometriosis feel guilty for ignoring what would *only* be expected from their bodies: marriage instead of work, children instead of career, private life rather than public life. Both discourses ontologize illness or body, corresponding to a supposed *female nature*.

Conversely – based on a larger survey² – we invoke the field of feminist epistemology in the centrality occupied by the relational category of gender, to shed light on the life narratives of women with a chronic disease, namely, endometriosis. Using the category of gender and recognizing women who organize themselves in groups on the internet, from life with endometriosis, we identified theoretical-conceptual links in the feminist epistemic perspective. The groups which (re) discuss the experience of falling ill with endometriosis are spaces of criticism and review of distorted knowledge about the problem, when they disregard women in the core of that experience⁹. According to their historical and cultural experiences, Rago¹⁰ affirms that women can produce a counter-discourse of rupture with the models and science operating hierarchical assumptions. Thus, we recall the marks of the social construction of differences between genders and reductionist readings within biomedicine^{11,12}.

One of the underpinning expressions of the realm of living, narratives of people with chron-

ic disease were enlightened by socio-anthropological lenses¹³⁻¹⁵. By positioning itself against an understanding that diseases have a fatalistic determinism, the first one¹³ explores the metaphorization of the disease, located here in the female body, and the second^{14,15} understands the situation of chronic illness in the places of social life and socialized experiences shared in virtual groups.

Regarding gender and institutional violence, Jewkes et al.¹⁶ state that the violence acceptance culture is associated with the discussion of *masculinity*. Masculinity spreads in different segments through institutions and supports, seeking to erect its supremacy. Authors¹⁶ analyze the logic of several oppositions homologous to male-female distinction and all the alternatives in which it is expressed, such as, dominant/dominated, active/passive, among others. In the case of violence perpetrated within hospital institutions, the rationale of opposition occurs on the dominant/strong/authoritarian side of science/health figure (represented by institutions and their professionals, *regardless of gender*), while on the other side lies a dominated/weak/submissive woman/patient¹⁷.

Institutional violence occurs in institutions providing public services (such as hospitals, health centers, schools, police stations and judiciary), perpetuated by stakeholders who should ensure a humanized, preventive and damage-reparative care¹⁸. The hospital routine can include neglect and disregard of users, thus failing to meet their basic needs; or involves unnecessary and/or undesirable procedures, turning to the technical aspect of care¹⁹.

This paper aimed to discuss the significance of the endometriosis experience of women who resort to health care services and is expressed as institutional violence.

In the first part, we address violence as the pilgrimage of women seeking access to diagnosis, treatment and care. Women stumble upon hostile settings and with diverse professionals, where violence appears in the swift and rather unclear care; in women's endless pilgrimage across several professionals, including health plans; in the high cost of private consultations and proposed treatments; in the disinformation/lack of knowledge on the part of professionals about the disease and its clinical management; and in the scarce access to specialized services in response to a growing demand.

In the second part, violence is discussed from the body axis versus disqualification. It is the fe-

male body's objectification at the service of hegemonic biomedical knowledge, where gender issues are concretely positioned in the clinical scene, starting with a strong/dominant pole – the health professional's scientific knowledge – to a fragile/dominated pole – knowledge derived from women living with endometriosis. This asymmetrical relationship of power is revealed by negligent care in pain management, the (evident or metaphorical) depreciation and invasion of women's bodies, disqualified complaints, the exposed intimacy in a setting where institutional violence is still little discussed, that is, in gynecology services.

Methodology

Bertaux²⁰ theoretically qualifies the *narratives of life*, and supports us in the focus of life with endometriosis, enlightened by women who had a space of support and information exchange in groups on the Internet.

The empirical universe contemplated the virtual access to two groups: *Endometriosis and I* and *Endometriosis and Infertility Carriers Support Group (GAPENDI)*, both moderated by women with endometriosis. After the presentation of the researcher and the objectives of the research in those spaces, invitations were made for individual interviews. When contemplating this shift from virtual to real, it is necessary to include two impressions of this universe connected to two points.

The first was to deconstruct the idea that the internet is a free, uncontrolled terrain. The researcher's stance was to recognize the group's goals and the role of mediators. Thus, we had to get the approval of those in charge to contact and invite participating women. The researcher was guided by a set of concerns that generated symbols of safety and control on their part. This respectful attitude was also necessary in building trust between researcher, moderators and guests. The researcher' and counselor's Lattes curricula link, an explanatory e-mail about the project of the thesis, with the institutional references, address, telephones and e-mails were provided.

Following authorization by moderators, women were invited through two different channels. In the *Endometriosis and I* group, the moderator sent an invitation to the participants and made a list of possible interested parties so that an official invitation would be sent later. In the *GAPENDI* group, moderators authorized a pub-

lic invitation within the group on *Facebook*®. Invitations were sent through the virtual channel, but following the method's classical prerogatives, interviews were performed in person and took place in the States of Minas Gerais, São Paulo and Rio de Janeiro. Meetings were held in the courtyard of the São Paulo Art Museum Assis Chateaubriand (MASP), food courts of shopping malls, public institution spaces, cafes and at women's own home.

The second sensitive issue addresses the fact that working with narratives means generating in the research participant *impossible and disruptive emotions*. This reminds us of Kristof and Wundunn²¹ who, by gathering various reports of violence against women in Asia, Africa and Latin America, recognize that "...we were invasive in asking women to describe intimate, frightening or stigmatizing experiences and, surprisingly, they agreed." In this research, in addition to agreeing, some women were eager to provide their verbal or non-verbal account. After all, there is a lot in what is unsaid²⁰ and narratives were intense in what was verbalized and in what was observed by the researcher; details were recorded in the field diary. Women were moved and affirmed the importance of being able to tell their stories to a qualified interlocutor who is willing to listen, allowing the organization of the experience through the narrative stirred by the gathering and research.

Interviews were transcribed and printed together with the field diary, whose collection totaled 392 pages, with 18h36m6s of recording and 23 field diary pages.

Regarding data analysis and interpretation, the material was read twice again, the first time to identify evidence that emerged from the narratives, and the second time around to organize this evidence into 19 total statements, duly systematized in a spreadsheet for the treatment of qualitative data²², identifying sample saturation in the ninth interview. Data recurrence was identified in the subsequent eleven interviews (the negative case survey). We proceeded with the diachronic structuring of stories, achieved a *plausible interpretation status* and we moved to a comparative and comprehensive analysis (the first governed by the comparative spirit and the second by creativity and rigor) – methodological steps as per Bertaux²⁰. The research was approved and both the voluntary status and anonymity of participants was guaranteed. They were labeled with a pseudonym, namely, the letter "P" as in *Phoenix*, with reference to the mythological bird

that gives the title to the thesis, followed by Arabic numeration.

It is important to affirm that the issue of institutional violence arose from the narratives of women who gather in groups, sharing the experience of living with endometriosis unexpectedly. The theoretical assumption of the research that gives rise to this paper was not to discuss the violence associated with the experience of living with a chronic disease that is essentially female. However, it was identified from the successive readings of material and recurrent analysis. The theme of violence became relevant in the narratives and, as a finding, was discoursed with the field of gender relational analysis, on the one hand, and disqualification of a disease whose experience refers to the female life private sphere. This realm of institutional violence in women health care relationships, from the perspective of life mediated by the chronic condition, worked as a lens to produce knowledge about the subject in the light of the feminist episteme.

Results and discussion

We addressed an axis of the intimate realm of the experience with endometriosis that concerns the dialogue between the treatment/pilgrimage symbols, named by one of the interviewed as *endometriosis kit*, uncovering the violence of unassured public service and the specific situations of institutional violence.

We avoided long narrative excerpts, valuing the short sentences and expressions, facilitating the dense critical analysis and avoiding the misunderstanding of a descriptive analysis based on the pure empirical data. The participants' profile appears in Chart 1 and it merely aims to characterize the deponents of the research. The item "income" refers to family income, "skin color" was self-declared and "delay" is a terminology that refers to the delay in obtaining the medical diagnosis since the appearance of the first signs and symptoms.

Violence expressed in the pilgrimage for health care

The relationship with the official health system – including physicians, other professionals and private clinics – in the search for care by women with endometriosis appears qualified by *criticism*, coexisting with an unresolved *tension* between two ends: exaltation or disqualification,

but essentially in one public, unassured access to treatment. This expression is accompanied by the establishment or not to accept complaints, with the support of information and the assurance of a dignified service: ... *there's a great expectation when you schedule an appointment. You cannot even sleep... and when you are in the consultation, you stand before a cold person* (P3); *I came home kind of desolate, because he did not touch me to examine me* (P20); ... *because a good doctor wants the patient to have quality of life after surgery, he doesn't want her to come back anymore!* (P13).

In this search for acceptance, recognition and resolution of their problems, participants qualify this trajectory in detail, which appears to be a *therapeutic pilgrimage*: women's migration to several gynecologists. While praising the competence of some (for recognizing their grievances, seeking rapid diagnosis and proper treatment), others are harshly criticized (trivializing complaints, ignorance, and even venal practice) - P4: ... *my complaint my whole life was colic, right?*; P6: ... *but all doctors have always said was that it is a super normal thing ... if the doctor says it is normal, then it is normal.*

There is a tension between recognition and disqualification of experience, which includes a shortage of specialists and services, with a restricted access sometimes to the private practice, a high cost of consultations and oppressive approach of some doctors, inducing them to pay for surgical treatments with the sale of their assets. P20 affirms: ... *X himself ... the price of the consultation is some five hundred reais; when you say that it is a consultation for endometriosis, it is six or seven hundred reais, you know? ... It has become a trade, you know? It's an absurd thirty-seven thousand, my friend, as if you sell a car.*

Women's trajectories and pilgrimages lead to the search for several specialists, since the disease can affect other organs, which is aggravated when, in supplementary care, the specialist following-up on women stops attending under the health plan: ... *it is an expensive disease ... the covenant does not favor you, you don't find a specialist* (P10); ... *you put your endometriosis kit, that bunch of resonance tests that you do every year and go to doctors* (P3).

Women with endometriosis learn to deal with these feelings of contempt or injustice, and seek their recognition. Le Breton²³ explores this pilgrimage for answers when analyzing pain from the lens of anthropology: *Thus, these patients run from a hospital service or from one doctor to another with their package of x-rays and medical*

Chart 1. Profile of women interviewed.

Participant	Age	Household Income	Schooling	Skin color	Children	Diagnostic delay
P1	39	12,000	PhD	White	1	5 years
P2	31	3,000	<i>Lato sensu</i>	Brown	No	16 years
P3	48	7,000	Complete Secondary school	White	3	3 years
P4	33	7,700	Complete Higher Education	White	No	14 years
P5	23	15,000	Incomplete Higher Education	White	No	4 years
P6	38	6,000	Complete Higher Education	White	No	23 years
P7	37	1,500	Complete Secondary School	White	No	8 years
P8	41	4,000	Complete Secondary school	Brown	1	9 years
P9	35	2,000	Incomplete Higher Education	White	1	16 years
P10	38	12,000	Complete Higher Education	White	No	2 years
P11	35	2,100	Complete Higher Education	White	No	13 years
P12	39	7,000	Complete Higher Education	White	3	24 years
P13	37	Not Reported	Complete Higher Education	White	No	10 years
P14	38	10,000	Complete Higher Education	White	2	5 years
P15	38	11,000	Complete Higher Education	White	No	15 years
P16	40	21,000	Master's Degree	White	1	26 years
P17	39	3,300	Incomplete Higher Education	Black	1	15 years
P18	35	6,000	Incomplete PhD	Brown	No	3 years
P19	21	12,000	Incomplete Higher Education	Brown	No	7 years
P20	34	5,000	<i>Lato sensu</i>	White	1	17 years

Source: own elaboration.

reports under their arm, without ever receiving the expected response²³.

The sometimes-unsuccessful search for specialists due to the low availability of professionals specialized in the treatment of endometriosis in public health services increases its value in the market, migrating from public health services and health plans, concentrating on private practice. P13 criticizes mercantilism, however, recognizes the devaluation of professionals by the plans:... *postdoctoral, doctorate ... and expensive endometriosis courses ... would you operate for two hundred and seventy-six reais? No one would... where are the five hundred and a few reais that I pay each month for the covenant?*

One of the respondents residing in the northern region (P8) found difficulties in her capital with unprepared and uninformed doctors, lack of specialists, physician-to-physician migration, long waiting time to get consultation and pain trivialization. Pilgrimage to the Southeast for

treatment, she was surprised to find a doctor with active listening in the public service - ... *I was attended by the obstetrician gynecologist who sat with me – and you look like her (the researcher) – she drew me on a paper and explained everything to me.* P11 diagnosed her endometriosis in Salvador, left rural Bahia and then migrated to São Paulo: ... *I went to the Hospital das Clínicas, I had to sleep in the queue ... I slept in the chair crying in pain ... Then my husband said that if it were necessary for us to move to São Paulo, there would be no problem with that.*

The pilgrimage that leads to migrations to seek health care still conjures up contents of violation in the access to the right to health. A pilgrimage for health, in pain and suffering characterizes structural violence. The expression “pilgrimage for reproductive health care”, in search for childbirth care, has already been referred to as one of the expressions of obstetric violence²⁴ and as a trait in general public health care²⁵. In

parallel, the experience of endometriosis sickness is made invisible and takes a back seat in public women health care.

An answer to symbolic violence may come in the struggle with the professional field and the official health system for the legitimacy of feelings, experience, and knowledge derived from it. We were not dealing with *passive respondents before pain*. Metaphors used emanated and assumed a *critical role*. Women master the terminology of technologies and medications; they mention various names, indications, contraindications and effects.

Endometriosis appears in the metaphorical form – *it is an excruciating pain, as if a sink plunger was attached to the vagina and sucked with all that pressure the uterus, the ovaries towards it* (P3); *The pain is as if you were pouring a lemon juice into a giant blooded wound, you can just imagine that burning sensation of some bruise and multiply that feeling by a million* (P* – *this deponent is known by this account and, therefore, it is not possible to identify it by its Arabic numerals*); *The belly is an open flesh, an open wound, a pain that the deponent feels the need to cry just by remembering it* (P16) – and in its scientific form, with the language of books and papers, using terms such as “*videolaparoscopy*” (P11); *Gestinol*® (P17); *Dyspareunia* (P13) etc. They are ways, in duplicate, of underpinning knowledge of the problem and looking for ways to make themselves understood and clarify their demands.

Seizing knowledge and scientific expressions is a way of empowering yourself to deliberate about decisions about your body, treatment and outcomes. The pilgrimage consists of seeking professionals, services and technologies that promote well-being, adequate and effective treatment. The adverse effects of medications can influence their replacement, seeking the best medicine and managing their possible dependencies. P17 affirms it is *God in heaven and medicine on Earth* – ... *I cannot see myself without Gestinol*®, *right? Well, it's part of my life, you get it? ... I'm really scared to stop taking the medicine and feel everything I felt before, to live what I've lived*.

The high cost of treatment and the few public places that meet this demand makes women value their financial independence: ... *it's an expensive disease ... It's not expensive, it's exorbitant, right?! (P1)*.

The number of specialists, exams and medications for treatment is high. In spite of medications, prices may vary up to 40%: ... *drugs are sold in pharmacies and drugstores and require a high*

*treatment cost for patients*²⁶. One of the reasons for not seeking medical consultation is the scarce availability of medical care and the unaffordable price of existing care, whether medication, diet, or transportation²⁷.

With the experience of the disease and what they investigate and share, women gain expertise and begin to develop sharp assessments and criteria to choose professionals, based on trust, establishment of a listening, acknowledging and curricular relationship. Rather than only becoming ill, they are evaluators of services provided, where this assessment gains strength in terms of relationships, references and indications, in a personal relationship circuit. When questioned about indicating a doctor, P13 reports that she accesses the professional's curriculum and evaluates disease relapses after surgeries. *I do not recommend a doctor with many surgery relapses*.

Violence and body: disqualifying women

Violence is evident in the way the woman's body is treated, objectified and in unequal power relations, in which hegemonic biomedical knowledge seeks to override women's knowledge. As in obstetrics, the other areas of women health care also include situations of verbal and physical abuse, neglect, invasive care and deprivation of care.

Pain management neglect and body undermining at the time of illness is another aspect of the violence experienced by these women. Trivialization of their suffering with pejorative classifications of their body that is reduced to disruptive and failing functioning machine, an object in a state of deterioration and reduced to the issues of a disqualified female gender: “*woman suffers*”, “*that's the way it is*”, “*it will pass after the wedding*”, “*women were born to endure pain*”, “*menstruation is not a disease, it is women's health*”, “*it's a fuss about nothing*”, “*don't be a wimp*” (P2; P11; P16 ; P17). A silent, unreported, legitimized and justified violence is perpetrated and disseminated by/ among health professionals.

Le Breton²³ asserts that individuals revolt against the lack of understanding or stand up against medical incompetence in outlining a diagnosis and treating what causes their suffering: *They claim a name for their illness, a relief for their suffering*. Doctors' distrust about pain experience, justified by the negative test result, leads women to additional pain; after all, if she suffers, it is because there is something: her speech cannot be denied or questioned.

Women are subjected to insidious or direct forms of silencing, humiliation, scare and invasion. These forms of violence occur because the doctor feels questioned in his *place of power*. In the clinical scene, women grab something that is part of the medical monopoly, the *production of diagnosis*, as well as, of course, nuances that can position these stakeholders in the scene according to gender hierarchies. When claiming to have endometriosis, a *self-diagnosis*, P11 was disgusted when the doctor disdained her speech by saying *I am the doctor here ... then shut up your mouth and make up another excuse, because you do not have endometriosis*. P1 recognizes professional qualities, but was startled by the approach in the consultation: *... a competent doctor, but he terrorized me*. P3 affirms *... the doctor does not explain, and they (women) sometimes leave with more doubts than they already had, because the doctor says, Listen, you're going to do it like this, and that's it. And I'm shocked*.

The generalization or use of stereotypes to anticipate how one will or will not behave in the face of pain already carries a violent attitude. Social and symbolic power discrepancies in the physician-patient interaction may refer to the social markers of different class, ethnicity, age or gender, greatly influencing any consultation²⁷.

Scientific expressions are associated with depreciative and violent metaphors related to women. The aforementioned neutrality of science is exposed when institutional violence is there in health care settings. Thus, women reported the horror of hearing expressions such as – *rotten, spoiled from within ... it was very ugly*(P8); *it's all spread out on the inside* (P9), *the damage is done* (P11) and *horrible on the inside* (P17).

In international studies, the subject of violence appears in professional care within formal settings. Whelan²⁸ says that women with endometriosis endure disqualification of their complaints and are faced with confused and ignorant clinicians. The lack of appreciation of speech, complaints and pain is a common phenomenon and is registered in research²⁹⁻³¹.

Health practice is a social practice that sometimes naturalizes and trivializes violence by reproducing within its core a new reading of society's values. Naturalization of violence may be justified by *necessary care* and *good care practices*. Thus, health professionals are agents of other forms of violence trivialization³².

Endometriosis refers to women's intimacy, causing a feeling of disease invasion by the disease, the diagnostic investigation and treatment

thereof. Women are subjected to handling parts of the body until then untouched by strangers. For some women: *... it was a place that nobody touched until then, right?* (P5); *... it is invasive ... you are invaded by examinations... in short, by other organs that are attacking...* (P3). P14 translates the difficulties of her illness, per se extremely invasive by the pulmonary foci, coupled with a physician's invasive therapeutic approach: *ah, if it's something, we have to remove the lung ... just like that, remove a lung, as if it were to remove a nail, right?* P17 describes the exposure of her intimacy to a group of young medical students: *I was lying down there in the bed, opened that way, each one came in, looked, most were boys ... I thought with myself: if they do all this and it solves my problem, then it is worth it*.

The "school vagina" picture and the meaning that it carries before the narratives of women is clear here. Diniz³³ affirms that this term was common in several states of the country thirty years ago and remains so in women's health care settings. It states that vagina of women who use public services – usually poor and black – is the teaching-learning locus of health students. The author argues women's bodies cannot be used for teaching purposes, in this trivial logic and denial of rights. Procedures and techniques require regulation of its use.

This invasion of women's bodies, which according to Diniz³³ is aimed at obstetric care, extends to other areas of women care – gynecology, for example – since as the author says it is based on the hard core of female gender identity development, that is, that women *should* suffer. Moreover, this shows that services and professionals are conniving with gender violence, consummated within institutional spheres, which imprison women as an object, objectifying their bodies in a utilitarian rationale.

If with experts difficulties are enormous, when women seek emergency professionals, the problem grows exponentially. Because of the frequent episodes of disabling pain and without an appointment, emergency rooms are widely visited. Narratives reveal harsh, biased, ignorant, and violent approaches. Neglected pain and judgment are common; women get tired of explaining what they have and what they are going through repeatedly. Professionals go so far as to mock the amount of times women seek the service, fake pain to get away from school/work. They conclude that women exaggerate: *So you only suffer because you are neglected by the doctor himself, right?* (P4); *... we listened to doctors' jokes... from*

the emergency room staff, that we always liked to be visiting them ... that we made a fuss about nothing just to skip class (P11).

Medicine isolates and *creates* disease or pain by classifying it and taking responsibility for them. Thus, the physician is qualified to decide and justify socially the suffering experienced: *The medical monopoly of telling the truth or the illusion of pain is cause for conflict with the patient, stupefied by the physician's indifference to what she feels and with the questioning of his statements*²³.

Chronic pain reveals the impotence of medicine in its understanding and treatment. Individuals are classified as “*functional patients*” and, while seen as such, are affected by medical failure. Pain has no tangible evidence and there is no other testimony of its existence but the word of the sufferer, for it is not the injury that the individual feels, but rather the human being in the singular. Pain denounces a dualism between the body, which is under medical jurisdiction and the rest – *The relatively common failure to identify the roots of pain in patients whose existence is paralyzed by pain is one of the perverse effects of a medical science totally centered in the body in their indices*²³. P20 recognizes the extent of her pain, as well as the impossibility of others understanding this realm. On pain, she affirms: *A pain of death and despair, and you don't know whether to scream, cry and roll on the ground, something that you don't wish for the worst enemy, a huge, unspeakable pain.*

Individual pains are diluted in the impossible recognition; few take the time to perform a good listening, to listen to it and, indeed, to inquire about her claims. Undermining women's grievances may be the frustration doctors feel while identifying their impotence in providing relief to women. As the main complaint, pain is not capable of providing any proof of its existence beyond what is felt by women, exposing them to being discredited, even accused by an organicist professional²³.

Institutional and gender violence is an issue that has been gaining prominence in the discussion on obstetric care, known as *obstetric violence*³⁴, combining the various forms of violence and injuries during professional care, abuse endured, excessive unnecessary interventions and deprivation of care based on good practice. Aguiar et al.³² argue that unequal power relationships between doctors and patients generate gender violence in women care, “... *whose occurrence is related to the conjugation of being women in addition to patients, annulling them as subjects*

of rights.” Negligence, physical and verbal abuse, as well as sexual violence are deemed gender violence.

In the unequal relationships between social subjects, violence is the result of a lack of power derived from the exercise of authority by a non-legitimized pole, in this case, women. It is non-power before a legitimized and, thus, sovereign authority that will use physical force and other rights violation's resources³². It is no wonder that doctors order women to silence before their official knowledge “... *I am the one who studied six years here (P11).*

According to medicine, physical changes objectively demonstrable in the body's structure or function are valuable to the medical definition of a problem. It is necessary to quantify the *normal* physiological measures, to identify somatic or biological references, to use tests and diagnostic technology to decipher a patient's speech. What escapes these limits transcends medical competence to seek resolutions – ... *factors such as personality, religious beliefs, culture and socioeconomic status of the patient are often considered irrelevant in the diagnosis or prescription of treatment*²⁷. In the illusion of treatment-related problems, patients need to receive it well indicated and this is ensured once it makes sense to them, especially when it involves physical sensations and side effects²⁷.

Conclusion

This paper provides an alert for the non-perpetuation of violent environments in women's care – whatever it may be, by giving it visibility and making it public. Women's health care spaces can still be places where *institutional* and *gender violence* occur.

Violence in discourses that reduce the female body to the ideal of *defective machine* that generates disorders *worthy* of oppressive metaphors, in which *adjustments* are suggested in the form of *difficult access* to health care, not necessarily based on *good practices*. Medications, conducts, health procedures, among others, to which women are submitted, must be questioned under the sieve of solid and recognized scientific evidence.

In collective health, we need to promote debates about *gender violence* in care for women with *endometriosis* in health care settings and ensure that topics are discussed in the academia with professionals in their training. Triggering discussions with women with endometriosis, un-

derstanding their health demands and recognizing their discourses are necessary counterpoints to a critique of the biomedical *establishment*. It is also necessary to think that analyses referred to endometriosis care can emerge in other situations of chronic illness where women are those who transform pain and suffering into a claim for dignified care, not subjected to any form of violence.

Collaborations

PAS São Bento worked on the design, research, methodology and final writing of the manuscript. MCN Moreira worked as counselor and on the final writing.

References

1. Filho ND, Myung LHJ, Caraça DB. Epidemiologia da endometriose. In: Trindade ES, Melo NR, organizadores. *Manual de endometriose*. Rio de Janeiro: Elsevier; 2014. Coleção Febrasgo. p. 11-23.
2. São Bento PAS. *Vozes de Fênix - narrativas de mulheres que se associam a partir da experiência com endometriose* [tese]. Rio de Janeiro: Instituto Nacional de Saúde da Mulher, da Criança e do Adolescente Fernandes Figueira; 2016.
3. Almeida Filho DP, Oliveira LJ, Amaral VF. Accuracy of laparoscopy for assessing patients with endometriosis. *Sao Paulo Med J* 2008; 126(6):305-308.
4. Bellelis P, Dias Júnior JA, Podgaec S, Baracat EC, Abrão MS. Aspectos epidemiológicos e clínicos da endometriose pélvica: uma série de casos. *Rev Assoc Med Bras* 2010; 56(4):467-471.
5. Podgaec S, Dias Junior JA, Chapron C, Oliveira RM, Baracat EC, Abrão MS. Th1 and Th2 immune responses related to pelvic endometriosis. *Rev Assoc Med Bras* 2010; 56(1):92-98.
6. Matta AZ, Muller MC. Endometriose: considerações teóricas para uma leitura junguiana. *Mudanças - Psicologia da Saude* 2004; 12(1):153-166.

7. Dahlke R, Dahlke M, Zahn V. *A saúde da mulher*. São Paulo: Cultrix; 2005.
8. Pereira HGS, Canella PR. Avaliação da satisfação sexual e fertilidade em mulheres com endometriose. *Femina* 2006; 34(3):175-182.
9. Cruz LA. Crítica epistemológica do feminismo. In: *III Jornada Internacional de Políticas Públicas. Universidade Federal do Maranhão. Programa de pós-graduação em políticas públicas. Questão social e desenvolvimento no Século XXI*; 2007; São Luís. p. 1-14.
10. Rago M. Epistemologia feminista, gênero e história. In: Pedro J, Grossi M, organizadores. *Masculino, feminino, plural*. Florianópolis: Ed. Mulheres; 1998. p. 1-17.
11. Martin E. The egg and the sperm: how science has constructed a romance based on stereotypical male-female roles. In: Keller, EF, Longino HE. *Feminism and science*. New York: Oxford University Press; 1996. p. 103-120.
12. Martin E. *A mulher no corpo: uma análise cultural da reprodução*. Rio de Janeiro: Garamond; 2006. Coleção sexualidade, gênero e sociedade.
13. Sontag S. *Doença como metáfora. AIDS e suas metáforas*. São Paulo: Companhia das Letras; 2007.
14. Herzlich C. Saúde e doença no início do Século XXI: entre a experiência privada e a esfera pública. *Physis* 2004; 14(2):383-394.
15. Adam P, Herzlich C. *Sociologia da doença e da medicina*. Bauru: EDUSC; 2001.
16. Jewkes R, Flood M, Lang J. From work with men and boys to changes of social norms and reduction of inequities in gender relations: a conceptual shift in prevention of violence against women and girls. *Lancet* 2015; 385(9977):1580-1589.
17. Oliveira PPM. Crises, valores e vivências da masculinidade. *Novos Estudos* 2000; 56:89-110.
18. Mury L. Violência institucional: caso de violação de direitos humanos na área da saúde materna e neonatal no Estado do Rio de Janeiro. In: Sydow E, Mendonça ML, organizadoras. *Direitos humanos no Brasil 2004. Relatório da Rede social de justiça e direitos humanos* [relatório na Internet] 2004 [acessado 2016 dez 2]; [cerca de 9 p.]. Disponível em: www.social.org.br/relatorio2004/relatorio019.htm
19. Santos AMR, Soares JCN, Nogueira LF, Araújo NA, Mesquita GV, Leal CFS. Violência institucional: vivências no cotidiano da equipe de enfermagem. *Rev Bras Enferm* 2011; 64(1):84-90.
20. Bertaux D. *Narrativas de vida: a pesquisa e seus métodos*. 2ª ed. São Paulo: Paulus, EDUFRRN; 2010.
21. Kristof ND, Wundunn S. *Metade do céu: transformando a opressão em oportunidades para as mulheres do mundo todo*. Osasco: Novo Século Editora; 2011.
22. Fontanella BJB, Luchesi BM, Saidel MGB, Ricas J, Turato ER, Melo DG. Amostragem em pesquisas qualitativas: proposta de procedimentos para constatar saturação teórica. *Cad Saude Publica* 2011; 27(2):389-394.
23. Le Breton D. *Antropologia da dor*. São Paulo: Fap-Unifesp; 2013.
24. Rodrigues DP, Alves VH, Penna LHG, Pereira AV, Branco MBLR, Silva LA. A peregrinação no período reprodutivo. Violência no campo obstétrico. *Esc Anna Nery* 2015; 19(4):614-620.
25. Oliveira LH, Mattos RA, Souza AIS. Cidadãos peregrinos: os “usuários” do SUS e os significados de sua demanda a prontos-socorros e hospitais no contexto de um processo de reorientação do modelo assistencial. *Cien Saude Colet* 2009; 14(5):1929-1938.
26. Agência Nacional de Vigilância Sanitária (Anvisa). Endometriose. *Saúde & Economia* 2014; 6(11):1-4.
27. Helman CG. *Saúde, cultura e doença*. 5ª Edição. Porto Alegre: Artmed Editora; 2009.
28. Whelan E. ‘No one agrees except for those of us who have it’: endometriosis patients as an epistemological community. *Social Health Illn* 2007; 29(7):957-982.
29. Cox H, Ski CF, Wood R, Sheahan M. Endometriosis, an unknown entity: the consumer’s perspective. *International Journal of Consumer Studies* 2003; 27(3):200-209.
30. Markovic M, Manderson L, Warren N. Endurance and contest: women’s narratives of endometriosis. *Health (London)* 2008; 12(3):349-367.
31. Cox H, Henderson L, Wood R, Cagliarini G. Learning to take charge: women’s experiences of living with endometriosis. *Complement Ther Nurs & Midwifery* 2003; 9(2):62-68.
32. Aguiar JM, D’Oliveira AFPL, Schraider LB. Violência institucional, autoridade médica e poder nas maternidades sob a ótica dos profissionais de saúde. *Cad Saude Publica* 2013; 29(11):2287-2296.
33. Diniz CSG. Superando a “vagina-escola”: inovações científicas e éticas no ensino de saúde das mulheres no século XXI. *Grupo de estudos de gênero e evidências, maternidade e saúde – GEMAS*. Faculdade de Saúde Pública, Universidade de São Paulo. 2015; Vídeo-aula. [acessado 2016 dez 3]. Disponível em: <http://iptv.usp.br/portal/transmission/iflalc%20M%20s%20informaci%20n:%20http://blogs.ifla.org/lac/video.action;jsessionid=AD75127C235D7A76FC94A8BD5A-4F6660?idItem=28224>
34. Tesser CD, Knobel R, Andrezzo HFA, Diniz CSG. Violência obstétrica e prevenção quaternária: o que é e o que fazer. *Rev Bras Med Fam Comunidade* 2015; 10(35):1-12.

Article submitted 03/12/2016

Approved 07/05/2017

Final version submitted 09/05/2017