

# RADIANT: UNDERSTANDING ENDOMETRIAL CANCER, VAGINAL BRACHYTHERAPY AND MOTHERHOOD THROUGH WORDS AND IMAGES

# RADIANTE: COMPREENDER O CÂNCER DO ENDOMÉTRIO, A BRAQUITERAPIA VAGINAL E A MATERNIDADE ATRAVÉS DE PALAVRAS E IMAGENS

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#### **ABSTRACT**

This article results from an anthropological analysis based on the experience of a Portuguese woman during diagnosis and treatment of an endometrial adenocarcinoma. Her embodied knowledge and narrative will raise our awareness of a specific set of health issues experienced by women with gynaecological malignancies, showing how perceptions of illness, treatment, corporeity, sexuality, womanhood, motherhood and resistance are intertwined. Her illness and her three-year old son emerge as two opposing elements in her story, conveying the notion of resistance through motherhood, using this bond against the forms of violence and suffering engendered by cancer and its treatment. Methodologically, this analysis blends oral narrative, anthropology and creative scientific illustration, that is, ethnographic drawing and painting enhanced by the use of metaphor and imagination. This hybrid and collaborative exercise implied a balanced mixture of speech, text and image, grounded in the words of Lua, the interviewee. Conceptually, it understands creative visual practices as ontological, epistemological and performative resources, enlarging the way social science can understand and act in matters of health and illness. Lua agreed to tell her story, but she decided to remain anonymous under a pseudonym, not finding a social opening for a woman's account of a diseased uterus and vaginal brachytherapy sessions. Responding to her unease, this illustrated analysis also intends to dismantle stereotypes entrenched in the ways we see and understand women, gynaecological malignancies and sexual organs, bringing into discussion a type of cancer that, although frequent, is absent from public discussion and collective imagery, being similarly disregarded by social science.

**KEYWORDS:** Endometrial cancer; Brachytherapy; Motherhood.

#### **RESUMO**

Este artigo resulta de uma análise antropológica centrada na experiência do diagnóstico e tratamento de um adenocarcinoma do endométrio vivida por uma mulher portuguesa. A dimensão incorporada do seu conhecimento e narrativa permite-nos compreender um conjunto específico de problemas enfrentados por mulheres com câncer ginecológico, mostrando como concepções de doença, tratamento, corporeidade, sexualidade, maternidade e resistência se interligam. A doença e o seu filho de três anos emergem como dois elementos opostos da história, veiculando a noção de uma resistência construída pela parentalidade, ou pela condição de mãe, usando-se esse vínculo contra as violências e sofrimentos produzidos pelo câncer e seu tratamento. Metodologicamente, esta análise combina narrativa oral, antropologia e ilustração científica criativa, ou seja, pintura e desenho etnográfico potenciados pelo uso da metáfora e da imaginação. Este exercício híbrido e colaborativo implicou uma mistura nivelada de fala, texto e imagem, partindo das palavras da mulher entrevistada. Conceptualmente, estas práticas visuais criativas são entendidas como recursos ontológicos, epistemológicos e performativos, ampliando a forma como a ciência social pode produzir conhecimento e ação em questões de saúde e doença. Lua aceitou contar a sua história preservando a sua identidade sob um pseudónimo, não encontrando abertura social para relatos sobre úteros cancerosos e sessões de braquiterapia vaginal. Respondendo ao seu desconforto, esta análise ilustrada



também pretende desmantelar estereótipos enraizados na forma como vemos e entendemos as mulheres, as doenças ginecológicas e os órgãos sexuais, trazendo para a discussão um tipo de câncer que, apesar de frequente, permanece ausente da discussão pública e da imagética coletiva, sendo igualmente descurado pela ciência social.

PALAVRAS-CHAVE: Câncer do endométrio; Braquiterapia; Maternidade

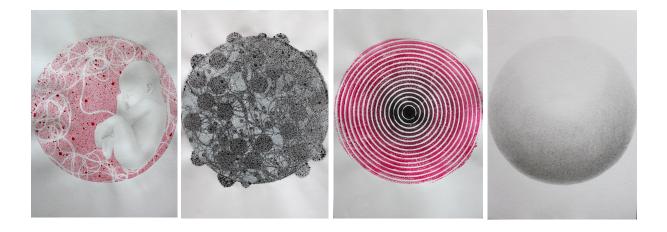


Fig. 1 Susana de Noronha & Lua (2019) All the strength [graphite and acrylic on paper, 21x29.7cm]

- Fig. 2 Susana de Noronha & Lua (2019) *I know it's malignant* [acrylic on paper, 21x29.7cm]
- Fig. 3 Susana de Noronha & Lua (2019) It got a little shorter and tighter [acrylic on paper, 21x29.7cm]
- Fig. 4 Susana de Noronha & Lua (2019) This thing inside the vagina [charcoal on paper, 21x29.7cm]

#### INTRODUCTION

"Occasionally, when I talked about it, people confused it with the one that is better known... not endometrial, but cervical cancer, which has nothing to do with it, nothing, zero!" (LUA, 2019). The endometrium, as the etymology of the word indicates, is the inner layer or lining of the uterus. Endometrial cancer is the sixth most commonly diagnosed cancer in women worldwide, with more that 300,000 new cases and 70,000 deaths each year (LORTET-TIEULENT et al, 2017). It is also the most common gynaecological malignant tumour in what statistical reports define as 'developed countries', and its incidence continues to increase (MORICE et al, 2015). Nevertheless, it is a word and a part of the female reproductive tract we rarely hear, speak or read about, removing its possible impact from our outer context of social interaction and collective knowledge (CARLISLE, 2014). This lack of focus of attention does not seem to be a problem within the field of biomedicine or oncology, with an extensive list of research literature on the diverse aspects of endometrial cancer, from risk factors to patients' follow up care. Nevertheless, oncology and nursing professionals



recognize a shortage of public information and educational materials on the risks and symptoms (SALANI et al, 2014), and a disconnection between women's embodied reasoning and medical knowledge, which prejudices the delivery of care, from diagnosis (COOK et al, 2018) to the post treatment phase (JONES et al, 2012). Female authors such as Dusenbery (2019) and Jackson (2019) unveil a more insidious scenario, fuelled by social prejudice and medical ignorance about women's bodies, conditions and particularities. Women's experiences, complaints and needs regarding pain, illness and suffering are too often neglected, distrusted and dismissed as exaggerated psychosomatic fabrications, resulting in misdiagnosis or in a delayed identification and treatment of their real problems (DUSENBERY, 2019 & JACKSON, 2019).

In social science literature, endometrial cancer, as a word and a possible locus of experience, is also subsumed under the broader category of gynaecological cancers. Even when we specify vulvar, vaginal, cervical, uterine and ovarian cancers, forming a cohesive five-part set of malignancies, in a sequential path through the external and internal female sex organs, this blurring of the words 'endometrial cancer' might still occur, since the subcategory 'uterine' also encompasses the endometrium. Although it is acknowledged that disproportionate predominance is given to cervical cancer, thus denying women with other gynaecological malignancies a public collective outlet for shared manifestation and expression of their experiences, stories and knowledge about the specificities of their illnesses and treatments (WRAY, 2007), nevertheless little has been done in sociological or anthropological research to change this situation. However, the existing literature on gynaecological cancers can guide us in understanding a specific set of common experiences endured by these different groups of patients and survivors.

Gathering the narratives of patients and their explanatory discourses across the risks factors and the aetiology of cancer, these malignancies are often contextualized as processes beyond the control or influence of their carriers, as unpredictable as unavoidable (MANDERSON, 2005). Concerning the onset of symptoms and the search for diagnosis, research also points to a frequent lack of agreement between patients and their doctors about the interpretation of their complaints, divided between what is defined as a regular occurrence



and an abnormal dysfunction, delaying the possibility of a timely identification of cancer (MARKOVIC, 2008). The experience of a gynaecological cancer, as in most accounts of malignancy, is also described as a biographical disruption, undoing a woman's life plan, forcing a reconfiguration of one's lifeworld (LARANJEIRA, 2014), an ontological adjustment to uncertainty. As for physical and subsequent relational consequences, vulvar, vaginal, cervical, uterine or ovarian cancers present an additional challenge to a woman's intimacy and sexuality, considering the specificities of their locus of manifestation and treatment (including open surgical procedures, pelvic radiotherapy and vaginal brachytherapy) (RAGNHILD, 2012 & WHITE, 2013). However, the effects of these forms of illness and treatment in a woman's or a couple's sexual dynamics are seldom tackled by social science (WHITE, 2013) a situation that can be explained by the silences engendered by social stigma, concealing and censoring sexual organs.

If vulvas and vaginas are excluded from the publicly acclaimed narratives where only cervical and ovarian malignancies are accepted as valid and dignified matters of concern, what can explain the absence of the uterus and its endometrium from our everyday conversations and scientific enquiries? Articles giving women's accounts of endometrial cancer may suggest one reason. Against the common backdrop in which cancer is understood as a matter of urgency, a lethal spreading reality with unexpected outcomes, from recurrence to metastization, clinicians frequently characterize endometrial malignancies as 'good' cancers with regard to their prognoses (SIDENIUS et al, 2019). Patients tend to embed this discourse in their own understandings, finding their personal experiences too modest and uninteresting to be considered worthy of sharing, devaluing and silencing their emotional, physical and psychological distress, accepting the idea of being 'lucky' (SIDENIUS et al, 2019b). However, my conversation with Lua, the woman who collaborated with the writing of this article, also revealed that we could not talk about an endometrial adenocarcinoma without speaking about the vulva, the vagina, the uterus, the ovaries and the Fallopian tubes. Her disease symptoms, her diagnosis, her hysterectomy, her bilateral adnexectomy and specially her vaginal brachytherapy sessions force us to confront her vulva and vagina. How can we then reach this diseased mucous membrane called endometrium? How can we grasp and



understand the violence, victories and losses of endometrial cancer experience and treatment? To put it bluntly, we can reach it through the vagina, but also with our mouths and tongues, by talking about it. Nevertheless, we cannot grasp this experience without talking about Lua's son, who throughout her narrative is the embodiment of her resistance and healing. The conversation from which this article was written and drawn took place between two women, a researcher and a cancer survivor, between embodied knowledge (CSORDAS, 1994) and speech, between anthropology and art, and between friends, knowing that endometrial cancer must not be kept hidden between the legs.

### 1. METHODOLOGIES BETWEEN WOMEN FRIENDS

Although it was motivated by a previous anthropological postdoctoral investigation focusing on the stories of Portuguese women with diverse cancer experiences, analysing how illness and resistance are experienced and conceptualized (NORONHA, 2019), this particular article is not part of a funded project. On the contrary, it results from a relationship, conversation and purpose growing beyond the guidelines and temporalities of my financial support<sup>1</sup>. Lua, a 47-year-old Portuguese woman, has no uterus, no ovaries and no Fallopian tubes. She underwent a total hysterectomy and an adnexectomy in 2008, at the age of 36, after being diagnosed with an endometrial adenocarcinoma. She is also a carrier of a genetic mutation known as the Lynch Syndrome or hereditary nonpolyposis colorectal cancer, a causal explanation for her adenocarcinoma and a risk factor that also threatens her future health.

The first time we spoke about her experience, she approached me and, lowering her voice, she reminisced about the harshness of her medical treatment, a process where vaginal brachytherapy and its cylindrical applicator emerged as her most violent embodied memories. Her words were whispered, kept private between the both of us, ensuring no one else was listening. Back then, in November 2015, I was already conducting research about malignancies experienced by women from my own relational circle, family and friends. Lua

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was not comfortable with the idea of exposing her name or experience, but I said I would always be open to hear her and write it all down if she ever felt the need to tell her story. I told her this because I realized that endometrial cancer and vaginal brachytherapy were loaded with stigma and emptied by silence, since until that moment I had never been confronted with a similar story. Years went by, and with occasional meetings and many written messages our friendship matured. In January 2019, I asked her if she was now willing to share her story and knowledge about her endometrial cancer experience. Following her positive answer, our meeting and conversation took place at the garden table of a café-bookstore on the first of April.

We might ask, what kind of relevance can these details have within the scope of an academic article about illness? They matter because the information and knowledge we gather in the process we call fieldwork are shaped by these relational intricacies. Lua found the comfort and confidence to tell me her story because, more than a researcher, I was a woman and a friend. She also trusted my ability to analyse and retell her story with what she calls "sensitivity and intelligence", using not only reason, but also a degree of care, emotion and affection, respecting her words, silences and decisions, but also our friendship. There, by her side, with a similar body, I was able to relate to the experience of losing one's womb, to the strangeness of an irradiated and shortened vagina, to the intrusive feeling of the wrinkled scar that crosses her abdomen. She knew I would not be repulsed by the description of her symptoms, of the large blood clots falling from her vagina into the hospital toilet - the sound of gravity, in both senses of the word. Having cancer, receiving radiation treatment, and firming her resistance and survival in her three-year-old son are beyond my experience as a childless woman with no cancerous diseases. But her embodied knowledge, her own words, along with anthropological reasoning and creative scientific illustration, will allow me/us to grasp and understand the connections between endometrial cancer, hysterectomy, adnexectomy, radiation, vaginal brachytherapy, motherhood, a child, and the ability to resist.

With a view to a reinforced understanding of gynaecological malignancies, this article underlines the embodied knowledge of a woman who experienced illness in the flesh, an endometrial cancer survivor. As an art-based exercise embedded in medical anthropology



(MATTINGLY & GARRO, 2001), this article also aims to dismantle social stereotypes associated with diseased female sexual organs, bringing a cancerous endometrium and an irradiated vagina into discussion. With the use of creative scientific illustration and ethnographic drawing, and by giving public form to her experience, I intend to fill a gap not only in the scientific understanding of women's cancers, but also in our collective knowledge and imagery, seeking to amplify our notions of womanhood, motherhood, corporeity, sexuality, illness, treatment and resistance. By illustrating this article, combining text and image, using visual and creative methodologies, I aim to make this easier: democratizing the science, producing a form of knowledge that, more than readable, is also graphic and visual, diversifying what anthropology can say, show, and do (BANKS, 2015 & SCHNEIDER, 2005), using art's ontological (NORONHA, 2009), heuristic, epistemological, and performative (GELL, 1998 & NORONHA, 2009) methodological properties.

As a collaborative exercise, the conversation with Lua was conducted at a place of her choice, establishing the rules of a dialogue in her own terms. It was a dialogue without a predefined questionnaire, allowing Lua to guide the plot and flow of her own story, bringing to the discussion whatever was regarded as relevant from her point of view. The three-hour conversation was audio recorded for subsequent transcription and analysis. Gradually hearing and writing down her words, silences, laughs and sounds of exclamation, allowed me to grasp and understand the most important characters and moments in her story, the losses and joys from diagnosis to recovery, from major events to the objects that fill the material surroundings of a cancer narrative. Reemphasizing the moments, persons and ideas underlined by Lua, combining speech and writing, her words and mine, this article is a balanced combination of both, demonstrating how her explanations drive my own reasoning and comments. In order to illustrate her story, transforming speech into drawings, I decided to focus on the most harsh and most redemptive realities of her experience, using her words and phrases as titles, and her guiding plot to create a meaningful sequence of images. Methodologically, however, the drawings and paintings go beyond what is conventionally understood as scientific illustration. By adding metaphor and imagination to the creative process, with the use of specific colours and shapes, I was able to materialize ideas and facts that otherwise would not be translatable



into conventional realistic illustration, aiming to broaden and facilitate the reader's and viewer's comprehension. Resulting from our shared reflections, the paintings and drawings are thus understood and presented as co-authored collaborative creations. The credits include my interlocutor's chosen pseudonym, Lua, reaffirming the undivided roles of the researcher and the interviewee in their conceptual formulation.

#### 2. MISDIAGNOSIS: WRITTEN IN BLOOD

I wasn't working at the time. I had taken a break from my professional activity. [...] I had two options, letting my boy be thrown into the hands of a nanny I didn't know... that was completely out of the question... or sending him to a very expensive kindergarten. [...] No, I will not work to spend a big part of my salary so that OTHER people can take care of MY son! [...] When I was going through these things... I wasn't looking for a job because I wasn't in a condition to do so. It made no difference at the professional level. (LUA, 2019)

Lua's story begins three years before her diagnosis. Rephrasing this statement, Lua looks back to the year of her son's birth in order to create a biographical preamble for her endometrial cancer story. When she became aware of her pregnancy, she stopped smoking, seeing this gesture as a way to create the most welcoming environment for her child from the inside out, from her lips and lungs to her womb and home. While her son grew in size and weight inside her uterus, she also took the decision to remain at home during the first years of his infancy. So she had her first and only child in 2005, choosing to 'rock the cradle': motherhood was to be her full time occupation. Lua and her son shared the same space seven days per week, twenty-four hours a day, building a stronger physical and emotional connection as time went by. Lua says her cancer did not have an impact at a professional level, but she was a full time stay-at-home mother and that job was to be severely interrupted by her illness and treatment. At the age of three, when Lua became ill, her son was already at preschool, unaware of his mother's debilitated health and impending hospitalization. The preamble to her narrative asserts the importance of her son for what was to come, his ascendency over cancer and his irreplaceable influence and participation as a constitutive part of her resistance and healing process.



It was diagnosed in 2007. I was 36 years old. I had been experiencing problems for almost two years, which I thought were related to a uterine fibroid that had been detected. However, I was bleeding a lot, and over time it got worse. I had several gynaecology appointments, but they let it go too far! At that time I trusted them, and maybe I should not have trusted my life in the hands of other people. [...] In the meantime, it started to assume very unpleasant proportions, because I got to a time... my period instead of lasting the usual four or five days, was the other way around. I was losing blood throughout the whole month except for four or five days. It was completely the reverse! (LUA, 2019)

In Lua's interpretation of her symptoms, we read an inversion of her menstrual cycle, a different temporal order and duration, but also a kind of antithesis of pregnancy, since her disease, instead of interrupting her menstrual blood, transformed it into a nearly permanent bleeding. But something was indeed growing inside her, in her uterus, in the wrong place, for over 24 months, assuming "unpleasant proportions". What was growing, though, was not a multiplication of normal life but abnormal cells of malignancy, decay and possible death. While undergoing what she understands as 'normal' routine medical exams, vaginal ultrasounds and pap smears, only adequate for cervical cancer, the doctors and laboratories were unable to correctly diagnose her disease. They identified a few ovarian polyps and cysts and a uterine fibroid, understanding her symptoms and discomforts as benign conditions, delaying a date for a possible surgery, scheduled for the year after, dangerously inattentive to the growing and almost continuous flow of her haemorrhage. She trusted her doctors, believing they would know the difference between a 'complicated' emergency and a minor or temporary occurrence.

I fell ill on November 2007. [...] I was so weak... obviously from so much blood loss. That day I went to the hospital... I think the first time was on my birthday. The coincidence, the irony of fate! [...] She (the doctor) examined me, made the tests and realized that I had very severe anaemia and told me 'look, you can't leave now [...] you have to stay here for a few days. [...] On one side, I was being intravenously medicated with iron... but I was losing it on the other. It was a vicious cycle! (LUA, 2019)

Lua understands her admission at the hospital as an ironic twist of fate. The day she left her mother's womb was the day she arrived at the emergency room, 36 years later, paralleling her own birth with the aggravated arrival of her illness, bleeding from her vagina, anaemic and depleted of haemoglobin. But her illness was not yet known, nor was it taken out of her



womb that day, because it still needed a name, a correct diagnosis and classification. Lua describes the intravenous administration of iron as an inconsequential and ineffective procedure, a waste of time and medication, since the causes of her blood loss were not being correctly addressed, examined or treated.

The blood clots were inside. I had ball-sized blood clots... I would feel them coming out, then they would get a little bit torn, because you have a big pad which they give you at the hospital, that I was constantly changing... I soaked the bed... this was really stressful for me. Meanwhile, whenever I was going to pee, I would hear a noise like... plop... in the toilet... and it was systematic. I was always asking please do you mind changing the sheets? (LUA, 2019)

The answer was written in blood, in her highly visible and audible symptoms, ball-sized blood clots, ignored for over two years, falling from her vagina to her underwear, sanitary pads, hospital bed sheets and toilets. But that abundant flow did not guarantee an increased attention from doctors or a more simplified access to the hospital's diagnostic or surgical procedures. Although soaking and staining her clothes, the blood clots were hidden from view, only visible to Lua and the hospital cleaning staff. Vaginal blood and bleeding is commonly a private matter kept between the legs and preferably inconspicuous to others. But Lua's blood was a sign and symptom of an underlying debilitating disease, and hence it needed to become a matter of conversation and shared observation.

One night, when the doctor on shift was visiting the rooms... I will never forget that sometimes my personality has some very good things. I am a person who's never content with insufficient information. Above all, I like to understand, especially when it comes to my health. I approached him and said, 'Doctor, I need to have a word with you! I have some very large blood clots and I need you to see them!' He answered... 'Oh, maybe not!' I will never forget what I answered back. I said, 'Maybe yes!' I grabbed him, took him, and said... look, here it is! He was astonished, because they were really large blood clots. He said 'we have to treat that! Tomorrow, you get your medical tests done and we have to operate as soon as possible!' [...] What triggered everything, what SAVED me, what made him immediately aware that emergency surgery was needed, what lead to the discovery that my haemoglobin was too low and that I needed a blood transfusion... was a simple phrase I said! (LUA, 2019)

It was Lua's personality and persuasiveness that saved her. She just had to open the toilet, 'grab' and get the doctor's attention and make her coagulating haemorrhage visible. The doctor was reluctant and even careless in his answer, but Lua was assertive and decisive in the events that lead to her correct and timely diagnosis. The medical procedures and



decisions that followed were a consequence of that precise moment, a direct result of her words and actions. The materiality of her body and blood and the voicing of her embodied certainties about her deteriorating situation exposed the indisputable facts of an urgent condition that needed an accurate and mindful medical approach.

I had the blood tests the next day. My anaemia was worse than they imagined. Haemoglobin has to start at 12 and I was at 6 point something, an absurdity. So, they decided to act very quickly and told me 'you need a blood transfusion!' I got very distressed, it was very complicated! We hear so many things! I wasn't thinking only about myself, because I was the mother of a three-year-old boy at that time, and all of this made my head spin. I was thinking... let's see if this goes well, because I have a child to raise! (LUA, 2019)

Confronted with the gravity of her situation, Lua shifted her attention from her body to her son's life, focusing on her responsibility as a parent and mother. Her body and survival were now the means to an end, accessories to her primary duty, her son's upbringing. Knowing her life was at stake, motherhood became the strongest motive to overcome anaemia and its inexplicable causes, the emergency excision surgery and any unwanted effects from the blood transfusion. She was prepared to lose her uterus, to receive blood that wasn't hers, but she would not permit any diminution in her parenting capacities.

#### 3. AN UNEXPECTED DIAGNOSIS BETWEEN SURGERIES

The surgery went wonderfully well! I woke up... the first one was a hysterectomy, to remove the uterus. There were no complications in the surgery itself, everything was all right. [...] Of course I was sad... we get very distressed... it makes us think that there is no use in thinking about having more children... this is so utterly serious that it can put an end to our lives. [...] I thought, okay, I have these scales... what do I have to do? I have to do everything, EVERYTHING, to be here and raise the child I already have. My dreams and my aspirations were set aside. (LUA, 2019)

For Lua, removing that organ, a part of her female reproductive tract, was also a subtraction in her "dreams and aspirations", an erasure of whom and what she was still planning to become and do. A surgery can be perfectly performed and nevertheless have negative effects on a woman's life plan. She could no longer increase her family, have a new pregnancy, give birth to a new baby. To define her resistance strategy, she used the metaphor of balance scales, placing the weight of losing her uterus in one plate, and her son on the



other. Her life needed calibration, a removal of certain personal expectations and the addition of 'everything' that could help in the preservation and nurturance of her family and small son.

When we have a surgery under these circumstances, there is usually a piece of what is taken out that goes for analysis. When the answer came back it was not very friendly. They realized that there was a huge chance that we were dealing with a very serious problem and they sent me to get a CAT scan... Right then, I realized that something wasn't right. [...] I had surgery on November 13 and this happened a few days later, the exact date I can't... I never thought it would be such bad news, because it's the kind that changes our lives forever. She (the doctor) said 'you have an adenocarcinoma of the endometrium, which is the lining of the uterus. We don't know if it is spreading or not.' (LUA, 2019)

Lua wanted to leave the hospital and go back home, to her 'son, husband and family', but her illness was more than anaemia caused by the haemorrhage of a uterine fibroid. The words 'adenocarcinoma of the endometrium', the lining of the uterus, an organ she no longer had inside of her, changed not only her understanding of how her body was working, but the way she conceptualized her life. She cannot remember the date, although she knows it was Sunday, the day everything changed, creating uncertainty over the years to come. The histological analysis of her tissues revealed the localized presence of cancer, while the medical imaging by computed tomography was meant to reveal its possible dissemination and extension in the rest of her body. The gravity of her condition could have been overwhelming, but the words 'fear' or 'despair' were never uttered by Lua. Once more she built her emotional and psychological resilience by focusing on the weight of motherhood and on the fragility of her son's infancy.

I remember being silent, absorbing the information. When the doctor said adenocarcinoma... I know it's malignant. She told me it was malignant. There are no half words, that's cancer, that's the word, cancer! [...] The first reaction I had, before thinking about myself, was to think of my son! I told the doctor 'I have a three-year-old son, what do you think, is it too complicated? Please tell me the truth, don't lie to me! [...] Once again, I thought of the person who at that moment was... my God, my son is obviously everything to me, but at that moment... a fragile three-year-old being! [...] At that moment I ceased to exist... my son needs me, he needs me to be there for him! [...] A tremendous, tremendous uncertainty! (LUA, 2019)

Adenocarcinoma is a long word and it takes time to absorb and envisage all the changes that it can carry. But Lua wasn't worrying about medical treatments or their side effects,



because her doubts and questions were entirely concentrated on the protection and needs of her son. Cancer would only be difficult if it shortened her possibilities of raising and educating her child. The consequences of a second operation, radiotherapy sessions or chemotherapy cycles did not cross her mind, only the stages of her son's life, from childhood to adolescence and adulthood.

I cried several times at night when I thought about my son. It was really very hard being away from him during hospitalization. Obviously, I love my husband, my parents, my brother, my family! But if I died, they would go on with their lives. But my son... it would be a loss that could leave very difficult marks to deal with as an adult. I did not want that! I held on to that idea right away... I have to fight obviously for myself, but also for my son! He will be THAT person who will give me all the strength in the World to carry on! I have to be alive to see him grow and to see him become a man of character! [...] The connection he and I have always had, is very strong... how can I explain it? A connection I never imagined having with anyone, because it's unconditional love. Unconditional love really exists! (LUA, 2019)

The lives and members of a family are obviously interconnected, through blood, affection, chance or choice, but for Lua one of these connections could not be broken or diminished without violent consequences. Her son was three years old, he had already learned to walk and talk, but he would still have to grow, not only in size but also in wisdom. In Lua's understanding, to become a man he needed a strong personality but also the presence of a mother, a 'fighter' that even sick or weak would keep him from harm. Cancer stood at the opposite side of this equation, damaging her body, distressing her life, separating her from her family and putting at risk her future participation in her son's life course.

Meanwhile, after three weeks, I was called for another surgery. It lasted several hours, and they removed everything... it went beautifully. [...] I think it was on December 10, 2007! The uterus had already been removed, so they took my ovaries, lymph nodes from the groin area, my fallopian tubes... everything that characterizes us as a woman. It was all taken out as a preventive measure, because if eventually there was any cell, something circulating, it was very important that it had no means to move throughout the rest of the body. [...] My essence remains. I am still a Woman with a big W! I can't create a life in my womb but I can be a Mother forever! (LUA, 2019)

Lua's womanhood was not dependent on a complete body, and her survival was less related with the changes experienced in her reproductive organs and more with the child that had been generated inside that emptied abdominal space. Lua is not characterized by a uterus, two ovaries, Fallopian tubes or by an indeterminate number of lymph nodes. Lua's identity is



a reflection of her son, defining herself as a woman who becomes complete and accomplished in his presence, performing the nurturing work of a mother. Her resistance as a patient depended on maintaining this link and relationship inside the hospital itself. However, though her family brought him to visit her while she was hospitalized, she realized that 'it was not the place for him', preferring to preserve him from an untimely experience of its harsh realities.

#### 4. RADIATION: FROM ABOVE AND BETWEEN THE LEGS

Meanwhile, what was I told? 'Now we'll try to understand, according to the results of the additional exams, whether to have chemotherapy or radiotherapy, which will be the best treatment.' The least of evils... they told me that, as a preventive measure, I was going to have radiotherapy at the IPO in Porto. [...] At that time they spoke about conventional radiotherapy, but then told me that I was going to have three brachytherapy sessions as well. I had no idea what brachytherapy was! (LUA, 2019)

Lua started her twenty-five radiotherapy sessions in February 2008. She arrived at the IPO in Porto with her husband, who accompanied her in every session and medical treatment. They were holding hands that first day, as two tears rolled down her cheeks, one from each eye. She was not alone, but under the linear accelerator there is no space for friends, family or affection. We can recognize in her falling tears the anxiety and questions that surrounded the radiotherapy sessions. She had no details of the procedures, no knowledge about the 'big machine' or the tattooed marks to align her skin under the radiation beam. She calls them her 'life markings' and 'lifelong tattoos', a triangular shape in the pelvic area, connecting 'the permanent little dots' that tell the story of her cancer treatment for 'the rest of her life'.

I started with the radiation. It doesn't hurt. It tires us, it does! Then, along the course of the sessions they warned me that I was going to suffer from diarrhoea. They said to apply *Biafine* to avoid burns. The only thing I have in my belly, which was due to the second surgery, not the first one, is a big scar that I have here in the lower abdomen, from side to side, that has nothing to compare with the mini scar from my son's birth, delivered by caesarean section! I had something minimal that you don't even see anymore. (LUA, 2019)

While pointing to the tattooed triangle in her abdomen, underlining that she was 'lucky' and 'blessed' enough for being undamaged by burn marks, she compares her only 'big scar', a result from her second surgery, to the 'mini scar' of her son's birth and C-section. The comparison between oncology treatment and parturition accentuates the opposite nature of her



illness and her son, the scarred line that separates her weaknesses from her strengths. While her son's birth is understood as an event with no physical or visibly violent consequences, her bilateral adnexectomy and ileo-pelvic lymphadenectomy, performed through a laparotomy, are described as indelible processes that changed her body from left to right, wrinkling her past, present and future. Her son's head or body weren't pulled from her vagina, they emerged from her belly with 'minimal' pain. Cancer and its treatment, nevertheless, required a kind of 'forced' entry into her vagina, irreversibly changing its size and shape, from length to width.

For me, emotionally, brachytherapy was the most difficult and most complicated treatment, what really disturbed me the most... during three consecutive Mondays! [...] I was in a room where even the staff could not enter without wearing a lead vest. They laid me on a table and... it has a kind of a penis shaped material... it's metal, a metallic thing that is placed inside your vagina so that you can receive internal radiation for twenty minutes. What disturbs you is that... we have the table, this thing inside the vagina, that is also fixed to the table... and you are there for 20 minutes. They tell you not to move and you think... okay, I won't move, but what if something happens? [...] The first thing you think about is, my God, if I fall I'll be torn apart! [...] In that situation my anxiety started to escalate and I had to do a tremendous mental exercise not to hyperventilate. It is not easy! You are already dealing with 'the thing' and you still have to cope with that tremendous anxiety of what else can go wrong... for twenty minutes... twenty, you know? Please! (LUA, 2019)

That first Monday Lua found herself in a different treatment unit, a different room where she knew no one. However, she had to trust the decisions and actions of others and to tolerate the invasiveness of the cylindrical vaginal brachytherapy applicators inserted by the gloved hands of strangers. Comparing the cylindrical instrument to a penis, Lua accentuates the violence of brachytherapy treatment to a woman's intimacy, as a metaphor of sexual intrusion in a moment of uncomfortable immobility and submission. The narrowness of the table beneath her aggravated her anxiety and feelings of insecurity, and instead of a sense of healing she felt an impending risk and possibility of being torn apart. Three Mondays of brachytherapy sessions left more marks on her body and memories than twenty-five days of 'conventional radiotherapy'. Over those Mondays, she spent 60 minutes with the cylindrical applicator inside her vagina, exposed not only to radiation but also to the many forms of violence that shaped those medical encounters.



Can you imagine what those three weeks were like? For me it was the worst part! It was very difficult! There were those weekly twenty minutes that I said *ouch* here we go again! It gets in your head, obviously, that feeling that they're putting something inside you that you didn't ask for, that you do not want, that feeling that something could happen to us, that we could be disfigured, and then, my God, we wouldn't be a woman anymore! [...] Basically, something is happening against your will, even though you know it is necessary or good for your health... I don't know what is good! And it was not good. It has many side effects, so many that... it (vagina) got a little shorter because of the surgical intervention and tighter because of radiation. I was lucky it didn't get dry. [...] And as for my intimacy, I still feel like a woman!" (LUA, 2019)

Those three weeks had a bad start, twenty minutes of unwanted exposure and mechanical penetration that left more than 'psychological marks' or 'hard memories', using Lua's words. Aggravating the consequences of her surgery, those repeated twenty minutes shortened and tightened her vagina, changing not only her body but also her husband's relation and reaction to her. At a sexual level, Lua says 'it was never the same', even now, twelve years later, gradually diminishing his closeness, his desire and the regularity of sexual intercourse, increasing only two things, her 'sadness and sorrow'. Regarding intimacy, Lua says she did not felt that change in herself, never understanding the motives for his 'reluctance and growing distance'. "The difference was on the other side, not mine!" Lua's words indicate, ironically, that surgery and brachytherapy had stronger collateral effects on her husband, on his sexual drive and behaviour. Those three Mondays and 60 minutes, one hour of treatment, created undesirable changes across the years, 'disfiguring' the couple's relationship, altering their emotional and physical bonds. Nevertheless, illness and treatment had different effects on other family members, motivating reinforced ties of care and affection between Lua and her mother.

#### 5. FAMILY ISSUES: WHEN HER ILLNESS BECAME THEIRS

My mother went to the hospital every single day! [...] She's not the hugging type, but at the right moment, I know I can to count on her. [...] She has to do it her way! Even now, every once in a while, we clash! She thinks she's still talking to a 10-year-old girl. During that time, we stayed at her house. She said, 'you're not going home, you'll stay here, in your old room!' She made lunch, dinner, anything that could help me to recover as soon as possible. [...] At a certain point, I was getting better and I wanted to have my intimacy back, my own space again, doing things my way, with my family. [...] Going back to my life was very important to me as a woman. I needed to be myself again as a person... my identity! But this wasn't done in a very peaceful way...



because of her personality. I noticed that the day I was packing up my stuff to go home again, she wasn't thrilled about it." (LUA, 2019)

When Lua became ill, being hospitalized and treated for cancer, Lua's mother reclaimed and reaffirmed her own motherhood. Her constant presence and help, providing care and shelter, assisting Lua and her family during convalescence, convey a deep sense of responsibility toward her 36 year-old daughter. 'Treating her like a ten-year old child', she prepared the meals and the old room, demonstrating she was still a mother with parental functions, keeping Lua under her roof. In that house, Lua was no longer a mother, but a daughter bringing a grandson. Lua's mother saw her again as a dependent 'fragile being', needing the assistance and the attention of others. There was no umbilical cord between the two for over 36 years, but Lua's mother still provided the nutrients and comfort she needed, extending the nurturing bond to her family. Breaking this tight bond for the second time is always a violent process that entails some degree of distress. By leaving that house and going back to her home, where she was a woman, a mother and a wife, Lua repossessed her adulthood, diminishing her mother's ascendancy. She was ready to reassume her normal life, and that process required leaving not only the hospital and its routines but also her old room in her parents' household.

Every Wednesday, I had blood tests to see how things were. But the day of my greatest happiness eventually arrived... The best moment ever was when the doctor told me - and she used the word I wanted to hear - you are cured! She really said that! You are discharged from the IPO! We feel relieved! And I asked her... are you really sure everything is all right? And she said... it is! [...] These were the best news I've ever had! [...] This I remember, 13th of March, 2008! What a joy! It was like I had won a contest! (laughs) I made it, I survived, I resisted... a survivor! That day... oh gosh, I went home, I held on to my son, I grabbed him... I don't know for how long! My heart was so light! I thought okay, this time I have won, well I hope so! In fact, until now this hasn't troubled me anymore. [...] At that moment... it is obviously a huge happiness! I was myself again! (LUA, 2019)

Lua understood her remission as liberation from medical spaces and procedures. The absence of disease meant having 'no more treatments, brachytherapy, hospitalizations and surgeries', in her words going back to her 'peace, books and music, to her own things, to the ones she belonged to.' But Lua soon found this was a 'momentary joy', since her illness and treatment triggered additional health issues and complications. Her adnexectomy, the removal



of her fallopian tubes and ovaries, resulted in an early menopause, whose consequences and impact, in Lua's words, were 'pow, sudden, radical', not giving her body enough time to adapt. She was also diagnosed with hypothyroidism and hypertension, high blood pressure, in a cause-effect relationship. She was informed that she would start to feel the effects of her surgical menopause, a set of health issues that not only increased her anxiety but also her medication prescriptions. Finally, what began as a personal experience of endometrial cancer became a family issue, forcing her family members to seek medical guidance and subject themselves to a specific set of laboratory analysis.

Endometrial cancer affects women mostly after 50. [...] By having this type of cancer at 36, I had to undergo a genetic evaluation to know if I had any gene mutations. I have something called the Lynch Syndrome, which gives me a much greater chance of developing an intestinal problem. [...] I have the report here... the molecular study was performed by amplification detecting the mutation c.2152C>T. [...] They say here that Lynch Syndrome is a genetically inherited cancer predisposition. The mutation is transmitted with a 50% probability to the descendants of the gene carrier individual. The tumours that most often occur in this disease are colon cancer... an 80% risk. I have this 80%... it's something absolutely... that I could have felt as a devastating thing... but no! They advised me to have regular medical exams, colonoscopies. My father and brother also had to go to the Genetics Centre to find out! My father had something, less than me, but there was something. My brother was lucky, he had absolutely no problem. But I have the Lynch Syndrome, which in fact is another load that I have to carry! [...] My son will also have to check if he has the gene mutation when he reaches 18. (LUA, 2019)

When Lua assumed her illness and treatment were coming to an end, a genetic test determined she would have to maintain her links to hospitals, doctors and medical analysis for the rest of her life. Lynch Syndrome, also designated as hereditary nonpolyposis colorectal cancer, explained her early endometrial cancer at the age of 36, also giving her an increased risk of developing colon, stomach or small intestine cancer, among other malignancies. Her endometrial cancer, far from being a disease confined to her body and to the temporality of the years 2007 and 2008, when she was diagnosed and treated, became 'part of the family', an inherited predisposition to cancer, linking past, present and future, placing under that same pressure the carriers of the gene mutation, her father and possibly her son. The child who grew in her womb, providing, at the age of three, the resilience she needed to face cancer, was now a probable carrier of the same syndrome. By the time I interviewed Lua, her son was 14



years old and in four years time he will know if he shares this possibility with his mother. Lua cannot tell if she, her father or her son will have to experience any unwanted health challenges, but they will be kept under surveillance, preventing mistakes, delays and misdiagnosis.

## 6. THE END AND OTHER BEGINNINGS: PAST, PRESENT AND FUTURE

They didn't detect endometrial cancer in my pap smears... we have to be attentive to these signs, the bleeding, the repetitive things... not ignoring recurring complaints from the patients. [...] The inattention of doctors... they should realize that they have to stop thinking that, for example, diseases like this only happen after 50! There must be a way for doctors to realize that not everything they have learned in college has to be *ipsis verbis*! Usually... the word says it all, usually doesn't mean necessarily! These are two completely different things! [...] At 36 this is not normal... maybe, if at the very beginning of my complaints, the doctors had been more attentive, maybe they could have realized, oh wait, this can cause more complicated things... and maybe they could have avoided this outcome. If I didn't have the gene mutation... maybe I had to go through this whole thing, but hey, we never know! [...] I think the doctors were sloppy. They only get worried when things are already very aggravated and then sometimes... there's no more time!" (LUA, 2019)

In Lua's words we can understand the urgency of recognizing not only the visible symptoms but also the visceral and embodied understandings brought by patients into the diagnostic process. To improve diagnosis, doctors cannot depend exclusively on biomedical theories and protocols. More than looking at bodies, organs and samples, they have to hear the person, to acknowledge the patient as a carrier of valid information. As a woman, Lua knew her bleeding was not normal, that her tiredness and lack of energy were related to her blood loss and that her blood clots were too large, frequent and dramatic to be left unseen. She did not have access to specific diagnostic procedures for her symptoms, only the routine tests of a healthy woman, although she voiced her complaints for over two years. She was not scheduled for hospitalization, she took herself to the hospital already at risk, with an extremely low haemoglobin count. Her blood clots were not the subject of medical interest or examination. She pulled the doctor by the arm and compelled him to observe them. That night at the hospital, Lua was losing time and blood, but her assertiveness alerted the doctors to the seriousness of her medical condition, saving her life. But a cancer experience and its corresponding treatment entail losses and changes that time and sutures cannot fully mend.



It obviously leaves marks, it does... this intestinal issue, the fact of having this area of the belly... I have abdominal adhesions. I used to have a very flat belly and after the second surgery I gained this scarred little piece of fat... and at the muscular level they are... torn. I've been told that this area in the abdomen... the muscles... it will be hard to strengthen them. The radiotherapy was aimed here, so it's not very easy. [...] I'm different now! Before there were no scars! But I quickly found a way to deal with this scar of mine. This is the scar that saved me from dying! So, for me this scar means life. That's how I learned to deal with it. It's true that the first time I looked at it I thought, oh gosh, they could have done it better. They could have tried to fix it! (laughs) It is already so hard going through this whole process that we should come out of it more or less like the way we were before. It would help our self-esteem. My self-esteem took a blow and I had many doubts! But, above all, it left marks that I want to see as positive as possible! (LUA, 2019)

Lua concentrates her attention on her abdomen to speak about her past transformations, present condition and future uncertainties. The flat expandable belly where she carried her growing son for nine months is now emptied of her uterus, ovaries and fallopian tubes, but it gained a scarred and wrinkled line of stitches and fat, recalling her disease and oncology treatment. Her abdominal adhesions and torn muscles are also a visceral reminder of her cancer story, the irreversible consequences of two surgeries and twenty-five sessions of radiotherapy. Beneath skin, fat and muscles, the movement of her intestines, stomach and other smaller organs carry the oversized weight of a mutation and syndrome that might result in a new malignancy, without a defined calendar or a clear location. Lua does not like the appearance of the scarred line on her body, but she appreciates the story it tells us. That line joins the dots and draws the story of a woman who bled for two years, ravaged by endometrial cancer and anaemia, who endured the emotional and physical toil of surgical procedures, radiation sessions and brachytherapy applicators, and nevertheless prevailed. Her body image might be secondary when compared to her self-preservation, but Lua found a way to integrate scars, fat, adhesions, radiation tattoos and weak muscles in her reconstructed identity and self-esteem, adding a new layer of meaning to these marks, celebrating their presence and manifestation as signs of resistance, survival and life.

I really want this story of mine... I hope... to have a happy ending forever! I hope, with all the strengths in my body to have a happy ending forever... that the 'cured' word will exist forever... that's it! When you asked me, does cancer ever end? Wow... you know? There is ALWAYS... it's like have something over our heads... everyone has... the thing is, the others aren't aware. [...] Cured, the word cured...! Later on we don't know, but nobody knows! Everyone lives under this uncertainty, so how do you



know? But now, until further notice, you have to enjoy life, to live, live! The word 'living' was one of the words I said most often at that time... what do you want now? Do you have any...? Yes, I want to live! I WANT TO LIVE! With very large capital letters, LIVE! (LUA, 2019)

A woman with a genetic predisposition to cancer is never free from illness or from the unwanted news of another diagnosis. Even in remission, healed or 'cured', using the words of her doctor and the word she wanted to hear, Lua knows there is always a menace written in her genes and obscuring her future. "On the other hand, I have this side of me that says okay, move forward, we cannot stop, let's move on!" Lua has an optimistic 'side', a character that drives her to expect the best, to focus on the present moment, living life at the fullest, appreciating every single day, year and opportunity. She sees that the beauty of life is in its fragilities and uncertainties, a condition of precariousness we all share and carry throughout our lives. Knowing the impossibility of predicting the future, she refuses to live in an illogical fear, hoping to have a 'happy ending' to her experience and story. The word 'living' amassed a growing performative strength as Lua uttered and repeated its sound, one, two, three, four, five and six times. She said the word with a smile on her lips, resonating with happiness, as a statement of victory. Lua 'wants to live' and with these words she created 'The End' to her story.

# 7. ILLUSTRATIONS: METAPHORS AND IMAGES OF ENDOMETRIAL CANCER

Using its dictionary definition, 'illustrating is the act of making clear and distinct, making a comparison or example intended to make something apprehensible, removing obscurity'. An image painted or drawn to enhance or elucidate an academic work is a visual form of illustration. But it is also a form of experiencing, knowing and doing, a way of creating empathy with the experience of another person, using creativity and imagination to reach another form of understanding, using paper to do different things, amplifying the action of social science beyond the exercise of writing. As a combination of embodied knowledge, oral narrative, anthropological and creative reasoning, blending text and image, I could not explain this article's illustrations or title without referring to the name my co-creator has chosen to maintain her anonymity. After my conversation with Lua, her words and metaphors



immediately pointed to her son and to the idea of the vagina as a way to reach her uterus and consequently her endometrial cancer story. Nevertheless, I had no clear image or format for the drawings and paintings. However, before and during our conversation, she expressed her desire to be kept anonymous, although not knowing which name she would chose to substitute her own. Lua (Moon) was a name she mentioned while the interview was coming to an end, saying it represented her mysterious side. 'Lua' was indeed perfect for a cryptic representation of this woman who wanted to remain unidentified, since it uses the name of an astronomical body, without any connection any other real or fictional female character or person. She decided to use it, indicating her decision by written message. "The Moon (Lua) has a special meaning for me because of its poetic side, its enchanting light, its 'mood swings', its phases... the eclipses. I think Lua will probably maintain my anonymity more easily. Lua it is!" (LUA, 2019)

The name she chose revealed itself as the most heuristic metaphor for the creation of her story's illustrations, providing me with the perfect form of a circle. As a spherical reality, the Moon (Lua) was ideal for a stylized uterus, an abdomen or pregnant belly, a vaginal canal and the tip of a cylindrical brachytherapy applicator. The lunar month has 28 days or four weeks, equivalent to the duration of a woman's menstrual cycle. This analogy was also appropriate for Lua's story, since she lost her uterus, Fallopian tubes, ovaries and menstrual blood, discontinuing the cycle, entering an unexpected surgical menopause. Regarding the notion of anonymity, it also represents her wish. There is one visible and illuminated side she allows us to read and see, her story, but the readers and viewers will not know her name, her identity, her dark far side. Finally, it was central to the title of this article – Radiant – pointing not only to the fact that the Moon reflects the light of another astronomical body, the Sun, but also to the notion that Lua's identity is a reflection of her son, defining her completeness and accomplishment as a woman only through his existence, performing the work of a mother. Radiant, however, is a word that by its etymology also conveys the idea of radiation, of brachytherapy, the violent energy that changed her vagina in shape and size. However, using another definition of this word, 'marked by or expressive of love', she was capable of resisting the violence of illness and treatment with the love for her son, using that attachment



as her healing ontological 'cord'. In spite of all her past losses and the impending menaces of her Lynch syndrome mutations, she persists, surviving with the happiness of being the radiant mother of a bright little boy.

The illustrations created for her story, motivated by her words, knowledge and experience, intend to convey and portray these fundamental realities, processes and events. Her son, her uterus and her adenocarcinoma were similarly removed through an incision in her abdomen. There, in her belly, her radiation tattoos, the scars of her laparotomies and caesarean section tell the opposite stories of illness and resistance, of affliction and love. Deciding to use these dichotomies, I created two diptychs, one concerning illness and resistance, her cancer and her child, and the second representing treatment, its instruments and *locus* of invasive action. The first drawing (Fig. 1) represents her son, calmly growing in her womb, the making of her resistance against cancer, within the same organ where her adenocarcinoma began to develop not long after his birth, diagnosed three years later.

The opposing image (Fig. 2) represents a cancer cell, replicating the characteristic protrusions and protuberances depicted in medical illustrations and micrographs. Although circular or globular, its shape inverts the craters and indentations of the Moon's (Lua) textured surface, emphasizing its disruptive nature, the reverse side of health. The curvilinear overlaid threads that give texture to the images represent Lua's curly strands of hair, one of her most characteristic physical traits. Enfolding and feeding the foetus and covering the cancerous cell, they point to the physical resemblance and indivisible link between mother and son, but also to Lua's mutation, a constitutive part of her genes, inscribed in every inch of her body. Juxtaposing a growing child and a growing malignancy, resistance versus illness, required the use of contrasting chromatics. The foetus, her son, is depicted in a lively red background, a luminous fiery colour that conveys the fluidity of blood, the warmth of flesh and the orderly reproduction of life. The cancerous cell is painted in black, devoid of colour, as an evolving form of degenerate life. They stand in opposite ontological planes, the intentional labour of love and creation of life and the unwanted inner breeding and unruly multiplication of decay and death. The adenocarcinoma may have torn apart Lua's womb, but her son gained



supremacy over any form of cancer or mutation, reoccupying his mother's lap, igniting her strength, redefining the purpose of her life.

Regarding her treatment, I used inverted geometrical forms, the concave entrance of her vulva into the tubular cavity of her irradiated vagina and the convex tip of the brachytherapy applicator, the warm hollowed malleability of the red pink flesh and the cold inflexible metal of the white cylindrical radiation instrument. Starting and prolonging a two-year 'monologue' (ENSLER, 1998) about blood, Lua's vagina was an opening providing liquid information about her deteriorating condition. But it was also an access entry for radiation, being sequentially a channel for the manifestation of illness and for the application of treatment. In these paintings and drawings (Figs. 3 and 4), both these processes are portrayed as matters of shared observation, bringing to attention realities that normally remain hidden beneath our clothes, between the legs and behind hospital doors. Vaginas do communicate, and Lua was saved by one, by blood clots that fell like words of warning through its 'big mouth', affirming what no one wanted to see, when no one wanted to look. Why did I draw the tip of a cylindrical brachytherapy applicator pointing towards us? Because a medical instrument can also violate a woman's intimacy if she is not prepared to face it, informed about the procedure, knowing that a vaginal brachytherapy applicator is a 'penis shaped material', using Lua's words, inserted through the vagina to irradiate an internal and delimited area of flesh. Its oversized outline, covering an A4 sheet of paper, replicates the magnitude of brachytherapy's invasiveness and violence, intensely entrenched in Lua's flesh, memories and story, overshadowing its healing function. The distance between a vulva and a uterus or endometrium is relatively short, but the gap between ignorance and knowledge about women's bodies and needs, when facing an experience such as a gynaecological cancer, is still unacceptably large. Against the notion of an unconditional submission to medical procedures, lying down and opening the legs, confronted with the shape of the brachytherapy applicator, we can stand up for the right of every woman to access and acquire information, demanding humane principles of treatment and care.



### **CONCLUDING NOTES**

Social openness on this subject is very subjective. If we try to be politically correct, it seems easy to say that such openness exists. But honestly, in practice, I don't think so, because it is still a taboo. Those who suffer are not comfortable to go into great detail about all its consequences. Intimacy is very private thing and, as far as I am concerned, I wanted to be as low profile as possible. [...] Whenever I described my experience, I never spoke about intimate details! [...] The question of anonymity... it's perhaps a matter of shame. I can even speak about endometrial cancer in general, what it is about... but I do not like to address the intimacy issues related to this disease. I don't think I could share my feelings about the whole process of illness and recovery with strangers. [...] You had to earn my trust so that I could tell you my story. But it was simpler than I thought. Your professionalism, the simplicity of your speech made me trust your intentions regarding your research, and your affection won me over." (LUA, 2019)

Do bodies and cancers have a south? Can a woman's experience and story point to another direction? My line of research is strongly embedded in the Epistemologies of the South (SANTOS, 2018, 2018b), assembling forms of knowledge excluded from hegemonic and monolithic readings of cancer, aiming to promote broader concepts and inclusive actions in matters of health and illness. My interlocutors are women, female cancer patients, gathering the stories and knowledge that emerge from their experiences, forms of resistance and creative agency, their concepts and representations of wellbeing, health, healing, and treatment. For this article, the South is clearly not a geographical space or place, but rather a metaphor for the realities, experiences and knowledge emerging from a body repeatedly invisibilized and ignored by biomedical ways of reasoning and acting. The South is also a metaphor for the organs, body parts, fluids and processes marginalized from public collective discourse, such as cancerous endometria, vaginal blood clots or irradiated vaginas. What does the embodied knowledge of Lua teach us? Can her experience and story redefine our concepts of illness and resistance? What kind of understandings can we create from the combination of embodied, narrative, anthropological and creative forms of knowing and doing?

Lua's words point to a distinction between treatment and resistance, from diagnosis to remission. In her story, biomedicine and oncology emerge as tentative and impaired readings, inattentive even to visible and quantifiable signs and symptoms that supposedly constitute the core of their focus. During the two years of her growing complaints and vaginal haemorrhage, her doctors were not prepared to acknowledge the information being given by her body and



speech, expelled by her vagina and expressed by her words. Medical examinations and routine pap smears resulted in misdiagnosis, evidencing the inability of biomedicine to give a meaningful use to embodied facts and knowledge *falling* outside the frame of its theories, protocols and procedures. Whatever falls inside toilets, sanitary pads and bed sheets, outside syringes, blood collection tubes and microscope slides, cannot be acknowledged as a valid symptom. As ineffective procedures, cervical screenings and vaginal ultrasounds could not find the signs of any malignant condition, only uterine fibroids. Analogously, the intravenous administration of iron and the subsequent blood transfusion did not eliminate the causes of her abnormal bleeding. But Lua was not silenced or restrained by the biomedical ascendancy over her seemingly 'benign' condition. It was her own body, voice, and agency that 'saved' her, not inadequate medical tests, uninformed doctors or delayed surgeries.

Regarding diagnosis and treatment, Lua's vagina, externalizing the flow that caused her anaemia and asthenia, was her channel of information, releasing the blood clots that proved the urgency of her condition. Lua's assertiveness, voicing and showing her coagulated haemorrhage spreading inside the toilet bowl, forced the doctors to act. The first surgical procedure was performed without a clear definition or understanding of her condition, serving also as an exploratory excision for a subsequent histopathology analysis and report supported by the results of a CAT scan. The endometrial adenocarcinoma diagnosis was followed by a laparoscopic adnexectomy, twenty-five sessions of radiation and three sessions of vaginal brachytherapy. The medical staff did not provide the information Lua needed to be prepared for what was to come, sixty-minutes with the invasive cylinder-shaped brachytherapy applicator between her legs, across her vulva and inside her vagina, on an uncomfortable and seemingly insecure table. Again, her vagina served as channel to reach the emptied space previously occupied by her uterus and endometrium. It allowed a bidirectional movement of fluids and energies, the ejection of blood and the localized delivery of radiation, a physical pathway for diagnosis and treatment.

Lua's uterus, her son and her family can be understood as undivided realities, merging the aetiology of illness with the origins of resistance. Lua's experience and story of endometrial cancer, the diseased inner layer or lining of her uterus, is also a story about a



pregnancy, her nurturing womb, and her three-year-old child. Paradoxically, against the structuring order of time, Lua was able to generate and materialize her resistance and healing strategy against cancer three years before her diagnosis. Her cancerous organ was previously a creative vessel for her son's gestation and birth, 'that person' that became the fundamental reason for her survival, using Lua's words. Resistance and illness were thus created in the same organ with opposite form and substance, that of a 'little boy' and of an 'adenocarcinoma'. This relationship of affection and care grew during three years, strengthening her bond with the child and her inner resilience to face any unfortunate event, underlining the ascendancy of her parental responsibilities over any personal fragilities. While going through the physical, emotional and psychological hardships of her illness and treatment, Lua focused her attention not on her body and life but on her son's, enduring every medical course of action in order to survive and participate on his growth, education and future. Motherhood became the ontological matrix of what she could be, have and accomplish, the antithesis of illness and cancer, that is, of all she could lose. Throughout her surgeries, radiotherapy and brachytherapy sessions, emptied of her internal sexual organs, uterus, ovaries and Fallopian tubes, and feeling her vagina being shortened and tightened by radiation, Lua also redefined her womanhood through motherhood. Instead of understanding these subtractions as a diminished corporeity, indelicately substituted by scarred abdominal fat and weak muscles, she reinforces the relevance and meaning of being a mother as her most defining female asset and characteristic.

However, Lua's cancer experience changed the relational subtleties of her whole family. It engendered proximity, giving her mother the opportunity to reassert her own motherhood during Lua's passage through illness and convalescence. It had long-term collateral effects in her husband, diminishing his sexual drive and the couple's intimacy, creating distance between them. It also reconnected every member of her family within a new reading of their genetic lineage, redefining their bodies as involuntary carriers and inheritors of gene mutations attached to a long list of malignant possibilities. Lynch syndrome, or hereditary nonpolyposis colorectal cancer, shared by Lua, her father, and possibly her son, explaining her endometrial cancer and giving them an increased risk of developing several possible



future malignancies, changed her understandings not only of her body and health but also of her family's past, present and future. They will carry the probability of cancer in their DNA during their entire lives, threatening her survival, her father's progression into old age and her son's transition from childhood into adulthood. Her endometrial cancer was reformulated as a family's propensity to cancer disease, adding an unexpected layer of risk to the meaning of motherhood, a legacy she does not want to share with her young son.

When our conversation ended, I told Lua that her story would be retold in the format of an article written for an academic journal, aiming to demonstrate how her experience and knowledge conveyed a different conception of resistance and an ontological redefinition of apparently distinct bodies as undivided realities, since her well-being is not separable from her son's existence and influence. The audio recording was untouched for almost half a year until the on-line journal Ñanduty issued a call on feminist epistemologies and South/South solidarities, providing a suitable context to present our shared reflections and findings. Bodies do have a south, and women's anatomy and physiology entail processes and materialities largely misunderstood, invisibilized and silenced by hegemonic forms of knowledge and mainstream relational, discursive, political, social and cultural dynamics. We can only 'learn from the south' if we hear and see everything women's bodies experience, say, think and feel, from their most diseased organs to all the liquid and solid things forming and falling in and from its internal parts, surfaces and openings, from malignant tumours to blood clots.

Recognizing the validity of multiple forms of experiencing, knowing and doing, we are impelled to look for everything that remains hidden in the margins and between the lines, reducing the 'absences and wasted experiences' (SANTOS, 2003, 2007). Using the idea that we can resist and 'talk back' from the margin (HOOKS, 1995, 1995b), my work dialogues with women's narratives, with what their bodies and words can teach us, understanding what matters to them, their needs and claims. By gathering their standpoints and situated knowledge (HARAWAY, 2004 & HARDING, 2004), we can encompass a larger portion of reality, creating an opportunity to rethink illness and resistance, spreading these lessons not only in academia but also in our communities. As a female researcher, accepting the incompleteness of scientific and anthropological knowledge (HARAWAY, 2004; HARDING,



2004 & SANTOS, 2004), in my most recent analyses I decided to integrate art, imagination and affection in my theoretical and methodological approach, aiming to contribute to a form of knowledge that can be read, seen and felt, bringing my relatives, friends and acquaintances into the conversation (NORONHA, 2019). Lua is a friend, and our relationship of care, trust and affection, beyond the ethical rules of emotionally detached and impartial science, allowed us to speak about her son, her cancerous endometrium and her bleeding and irradiated vagina, giving a new form and meaning to the idea of resistance on the sheets of drawing paper and on the central pages of an academic article.

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