Shared pain between a mother and her son: Unsettling clinical encounters through the entanglement of bodies, affects, and pain in Fibromyalgia treatment

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Abstract:

This article is an autoethnography of the entangled mother-son experiences with Fibromyalgia (FMS), analysing how gender and sexuality intertwined with our biomedical narratives. Considering that 80 to 90% of FMS patients are women, in this article I examine the affective entanglement between health practitioner and FMS patient. I address this affective relationship as an illustration of how biomedical and cultural approaches are co-constituted and feed on 'biocultural' theories in order to make sense of pain. Through an analysis of the gendered aspects of FMS, I argue that affective entanglements between the patient, family, and health practitioner are materially productive and have healing agency when recognizing her/his/their singularities not as deviants from a normative status of healthiness, but as a result of biocultural constellations of oppressions.

Keywords: Fibromyalgia; autoethnography; affect; feminist science studies; medical humanities

In September 1965, Ivone was born in a small village in Minas Gerais, one of the biggest states in Brazil. The youngest daughter in a family of seven children, Ivone was always home, trying to help her mother with the domestic chores. During her upbringing and childhood years, which was at the time of the Brazilian dictatorship (until March of 1985), Ivone faced the weight of being a woman in a country that has its roots in patriarchal structures. During her childhood, she was forbidden to attend school, because her father did not believe that women should educate themselves. When her father passed away when she was eight, her mother decided to take her and her younger brother to the brand-new capital of Brazil, Brasília. They looked for better life conditions for the family, and Ivone started going to school. In the mornings she went to school, and in the afternoons, she worked as a maid for families in their neighbourhood: cleaning dishes, scrubbing the floor, washing clothes, and babysitting vounger children. Growing up, there was always the weight of working and studying. As the years passed, she became responsible for her mother and for maintaining the household. The next turning point in her life happened many years later when she was accepted in the public examination to be a police officer. This would be her first job with a fair salary, one that helped her to leave her mother's home, and start a new life.

After becoming a police officer, Ivone got married and, in 1992, she had her first son. A year and a half later, I would be born. As she always repeats, her life 'started again after becoming a mother.' During our conversations that led me to start thinking about this work, she would constantly mention that 'being a mom is to give up on the self in the name of her sons.' That is exactly how I feel about my upbringing. I saw my mother give up on her dream to go to university, because she needed to work to be able to provide us, me and my brother, with the opportunity of pursuing a higher education degree. Looking back at her life, she now sees how she was always

dedicating her time and attention to others, leaving her with very little energy to focus on herself.

Following my mother's biomedical story and considering that attention is an important form of affective energy (Brennan 2004), I conduct this article as an evocative autoethnography (Bochner and Ellis 2016) that tells her story through my perspective, as her son, and questions how different her story would be if it was not for the pressure and gendered expectations that structurally limited her opportunities in life. More specifically, I want to inquire about the relation between the gendered aspects of my mother's life narrative and her current health state after the beginning of the 2000s, when she was diagnosed with Fibromyalgia (FMS), a chronic condition that is associated with severe musculoskeletal pain (Brennan 2004; Pryma 2017; Wolfe at al. 2018).

The objective of this article is to question how affect influences the outcomes of clinical encounters. Considering the cultural and social aspects that permeate the diagnosis process, I inquire how patient, medical practitioner, and family can influence the lives and the healing process of those living with FMS. Through this autoethnographic account, that does not aim at having value as proof or nor will be used for this purpose, I want to investigate how we can rethink clinical encounters not through exceedingly medical and technical perspectives, but through intersectional and gendered lenses. Since this is an anthropological research, I am particularly interested in investigating how culture shapes the biomedical framework and vocabulary to address pain - attributing meaning, offering explanations, and inscribing legitimacy to it. I argue that normative gendered expectations regarding women's role as primary care givers and mothers is a structural way of shaping the forms in which female pain is managed and interpreted.

Following Mara Buchbinder's approach to understanding chronic pain, I see meaning of pain as

... a critical component of biomedical explanations insofar as explanations encode moral judgments about the source of suffering and the patient's deservingness of certain treatments (...). This underscores that explanatory meaning is not only symbolic, but is also embedded in underlying relations of power and structures of inequality (Buchbinder 2015, 9).

Thus, I perceive through gendered inequalities how power structures are in play when it comes to accepting minorities as reliable narrators of their own pain. Via the works of affect theory, focusing on how affective interactions circulate and are transmitted in clinical encounters, I offer the 'affective attuning' as a way to unsettle normative gendered readings of pain, seeing the healing process as connected to daily life activities – escaping the private realm and occupying the public sphere.

Constructed as an interwoven narrative of my mother's biomedical story and mine, in this article I will use our conversations about pain and gender as a way to rethink the biomedical discourses on FMS. First, I engage with the matters of truth, trust, and visibility in the process of diagnosis, considering the impacts of the unbalanced power relations in the process of communicating and having pain acknowledged. In this section, I address how gender, class, and race can influence the difficulties of having a chronic pain diagnosis. In the following section, I turn to the works on affect theory (Ahmed 2004; Brennan 2004) to rethink how a clinical encounter is composed by social and cultural aspects that are hardly recognized within biomedical discourses. Through highlighting the cultural aspects of meaning-making and communication during the clinical encounter, I suggest affect as a way to rethink the relationship between medical practitioner, patient, and family. Finally, in the last two sections, I develop the idea of 'unsettling clinical encounters' having the gendered gap in FMS diagnosis as the focus. In this part, I offer a close reading of current debates on FMS diagnosis that clearly rely on the body/mind binary to explain why more women are prone to experiencing FMS during their lifespan. Tying back to the discussions of the previous sections, I suggest that the current debate on 'biased' diagnosis is in fact related to the normative gendered expectations placed upon women's bodies.

Encountering Fibromyalgia

Before FMS became part my mother's life, another biomedical story took centre stage. During my childhood, I would often complain to my mom about constant headaches and severe pain in my legs. My mother took me to several medical practitioners and all of them came up with a similar explanation: children sometimes use pain to get attention. Although I was young, I already felt the discomfort of having my pain being dismissed by someone else. I would cry to my mom and tell her that I was not lying, constantly trying to reaffirm to her that I was telling the truth. Family members that would witness these moments had comments on how I should 'man up' and act like a 'proper boy'. Without any visual hints on my body that would serve to prove my pain, this one-sided dynamic regarding my bodily experience would last for some years, until a medical practitioner listened to my complaints more carefully and discovered that I had an 'aortic coarctation' – a heart defect that consists of a "narrowing of the major artery (the aorta) that carries blood to the body" (American Heart Association n.d.). As my mother shared with me during our conversations, this long-lasting search for a result has put a lot of pressure on her. She had to deal with the anxiety caused by people who reaffirmed that all I was doing was just a performance for attention while also trying to listen to me and give me the benefit of the doubt.

After years looking for answers, she succumbed into pain as well. After my heart surgery, my mother started complaining about her musculoskeletal pain. Like in my case, visual symptoms were hardly found. The lack of 'visual evidence' of our pain got new meanings

for us during our conversations. When revisiting these moments of pain, we started considering how gender and sexuality were constantly used as forms of dismissing our experiences as something that was 'not real' or 'highly performative'. As suggested by Buchbinder, regarding the visuality of pain:

Because it is invisible, chronic pain is not accountable to the same types of evidentiary truths as the pain of a wound or a broken limb. It therefore renders its subjects morally suspect, calling the authenticity of their suffering into question. Chronic pain thus raises additional challenges to language and belief that people in pain can begin to overcome only when sustaining intimate relationships with others (2015, 4).

Although narrated as specific to chronic pain, Buchbinder's analysis can also be extended to other invisible pains in which the subject in pain does not abide to the descriptions of a reliable narrator. As in my mother's story and mine, our subjectivities were used as way to explain our pain – I needed to 'man up' and my mother needed to stop being so sensitive.

During the period in which we were trying to discover the source of her pains, I witnessed in every clinical encounter how gender would play a role on how the medical practitioner would explain the possible diagnosis and how motherhood, domestic work, and care giving would come up as a naturalized source of pressure that could also be negatively impacting her health. At every clinical encounter, we would observe the narrative repeat itself: the oftentimes male medical practitioner would ask her general questions about her medical past without properly addressing her pain. Most of the times, the medical practitioner would either deny her pain, questioning whether it was not just normal pain that is part of life, or part of the pressure that women, as mother and/or wife, face in their daily life.

After years trying to get a diagnosis for what she was experiencing, my mother finally got a name for her pain: it was FMS.

As she shared with me when during our conversations about her pain, at that moment, receiving a medical 'validation' did not change the way she felt. Naming the pain was not sufficient to make her and us, her immediate family, know what were the implications of such a rheumatic condition – one that has no visual appearance or organic cause. After getting an in-depth explanation and doing some independent research, we came to understand that FMS is a rheumatic condition characterized by musculoskeletal and muscular pain accompanied by stiffness and tenderness in the body and that approximately 80 to 90% of the patients diagnosed with FMS are women (Wolfe at al. 2018). After being diagnosed, Ivone was informed that no cure was available and that research on this topic was at a very early stage. My mother and I have more access to information now, fifteen years later, but much of her problems and pains are still the same – especially the difficulties of handling the structural and institutional prejudices when it comes to communicating her pain and having them acknowledged.

After going through all these years trying to find an explanation for our pain, made us become closer, we shared pains and trust in each other's stories. Unlike mine, her pain is still lasting and, based on her previous experiences trying to communicate it, she agrees with Buchbinder's considerations about how "living with chronic pain is a thoroughly social phenomenon, and that managing pain is always deeply rooted in ongoing social life and family care" (2015 4). In fact, differently from Elaine Scarry (1985), a famous philosopher that argues in her book *The Body in Pain* that pain resists language and symbolization, we see in our shared narrative that language and culture constitute an important tool to bring pain out of the private realm — understanding and responding to pain is a relational business that relies on trust and sensibility towards the other (Buchbinder 2015; Pryma 2017). Our subjectivities

intermingled with the ways of communicating our bodily experiences, and due to a structural aversion to femininity, we had our narrative invalided by normative biomedical discourses.

Gender, affect, labour, and pain

Teresa Brennan describes FMS as one of the 'new maladies of the soul' (2004, 45). Her notion of affect, as the material and physiological form of emotions that can be transmitted, is a thought-provoking theoretical perspective to analyse FMS and the clinical encounter. According to the Brennan, "the transmission of energy and affect is at the partial root of – and perhaps the whole explanation for – the new diagnostic disorders" like FMS (Brennan 2004, 45). She understands FMS as a disorder of attentive energy, and explains that there is an excess of it. Similarly, Lilleaas and von der Fehr (2011), in their study regarding the gendered aspect of chronic pain, explain this bodily phenomenon as a 'bodily state of preparedness for others' reinforcing how this excessive attention with the outside shadows the individual's own necessities.

As discussed above, throughout her whole life, my mother's attention would always be directed outwards instead of inwards. However, as we came to understand during our conversations on pain, her urge to care and be attentive towards others, does not solely come from a place of compassion and altruism. The constant state of availability to others is part of a larger framework in which gendered expectations of what it is to be a woman, a wife, and a mother (Lileaas and von der Fehr 2011) are forms of limiting women's access to their own bodies. In fact, when I was receiving my mother's unconditional attention, I was also, even though unconsciously, draining her energy. As described by Brennan, "if I receive another's love, I receive their living attention; and this attention, logically, is a biological force in itself, as palpable an energy as adenosine triphosphate (ATP), the bioenergetic basis of life and consciousness" (Brennan 2004, 34).

As discussed in many studies regarding chronic pain disorders, which in general affect more women than men, women just feel constantly denied of having their pain acknowledged, feeling like being thrown back and forth to different medical institutions (Werner and Malterud 2003). Women, within the current modus operandi of the social and economic system, are expected to fulfil the roles of caregivers and family supporters as they maintain the household and also work to be able to financially contribute to the family budget, while setting their own needs aside (Lileaas and von de Fehr 2011). This double burden that Brennan (2004) describes as excessive attention was already addressed in the past by radical and Marxist feminists when tackling the issue of labour rights by highlighting how patriarchal structures enable negative psychic and material effects to women (Hartmann 1981, 13). According to second wave feminism, compulsory motherhood and marriage are a form of women's unpaid work, leading to their segregation and isolation from the public sphere. At the same time, "the operations of the entire society depend on the regular performance of this work" Young 2005,10). As shown by Maria Dalla Costa and other Marxist feminists, women's responsibilities at home reinforce their lower position in the labour market and jeopardize their possibilities of economic freedom (1971, 13).

Therefore, following these critical theories regarding the gendered division of society (in terms of opportunities and responsibilities), the female body is constantly registered as a 'body for others' (Lileaas and von der Fehr 2014) that is highly influenced and demarked by social and cultural dynamics. The female positionality within the family and the public sphere pressures them with works of attention – which demands excessive energy to care for the other whilst forgetting the necessity of caring for the self. Thus, the relationship between gendered oppressive structures, chronic pain, and culture are way more complex than what is roughly acknowledged by medical discourses. In order to properly address

the issue of chronic pain, it is necessary to see medicine as "a system of symbolic meanings anchored in particular arrangements of social institutions and patterns of social interaction" (Kleinman 1980, 110). The language of pain is culturally constructed and, therefore, the social environment is an important variable in shaping the opportunities and forms of enjoying health based on the intersections of other social categories such as gender, sexuality, race, and class.

Unsettling the clinical encounter

The fact that the body is simultaneously material and cultural is another evidence of the existence of the 'transmission of affect.' As discussed by Brennan,

The transmission of the affect means that we are not self-contained in terms of our energies. There is no secure distinction between the individual and the environment. But the transmission does not mean that a person's particular emotional experience is irrelevant. We may influence the registration of the transmitted affect in a variety of ways; affects are not received or registered in a vacuum (2004, 6).

Following Brennan, I argue that it is important to consider how the transmission of affect also takes place in a clinical encounter. I see in the affective transmission a way of fleshing out how the relationship between medical practitioner and FMS patient needs to be culturally assessed in order to rethink the modes of diagnosing and treating rheumatic and chronic pain.

The entry point to analyse a clinical encounter is to consider how bodies are read and how symptoms are pondered by those involved in it. During a clinical encounter, cultural and social parameters are constantly being deployed in the communication between patient and medical practitioner (Lileaus and von der Fehr 2011; Buchbinder 2015). Gender, race, sexuality, and class are indeed important

categories when it comes to how, when, and why someone gets diagnosed with FMS (Pryma 2017). However, these social and cultural aspects of the process of diagnosis are often dismissed by medical research that solely focus on biological aspects of the considered illness.

For example, in current research on FMS, medical practitioners accredit the female endocrinal specificities as the leading cause for the discrepant difference between genders in the diagnosis of FMS (Wolfe at al. 2018). On the other hand, if we challenge this affirmation with the previously mentioned cultural and social standpoint that revolves the life of women, this biologically deterministic argument is undermined — especially by feminist accounts of the body and embodiment that are critical of the scientific discourse that snubs culture in the name of pure and objective science (Frost 2011; Wilson 2015). In fact, what frequently comes up in feminist debates on medical humanities is how, according to cultural aspects that are under the influence of patriarchal structures and the neoliberal system, women are considered to have less endurance to pain and are more likely to cope with it through emotionally centred tactics (Lilleaas and von der Fehr 2014).

According to the official medical procedure to diagnose FMS, the symptoms need to persist for at least three months and frequently are deemed as mere results of psychological unbalances such as depression, fear, and anxiety, or even from specific traumas during the early stages of development (Walker et al. 1997). Therefore, during the clinical encounter between health practitioner and patient, not only medicine is part of the diagnosis, but also the cultural aspects that are supporting the process of unravelling the aspects of the rheumatic condition. There is an interaction in which language is communicating the affects and pain that outlines the existence of FMS – as in my case and my mother's case, the body in pain is constantly seeking its recognition from medical institution in order

to release itself from the burden of constantly asking oneself: 'Am I crazy? Is it just in my head?'

Hence, the affective entanglement between health practitioner and the FMS patient is an illustration of how biocultural approaches are important to address pain. The analysis of the gendered aspects of FMS fleshes out how these affective entanglements between patient and health practitioner are materially productive and have a healing agency when the patient's singularities are recognized not as deviants from a normative status of healthiness, but as a result of biocultural constellations that led to the ill health status. In this sense, what I mean by 'unsettling clinical encounters' is to acknowledge it as an affective event in which every layer of the social world plays a part in reshaping healing as a vibrant experience.

Unsettling the gendered gap in Fibromyalgia diagnosis

In September of 2018, a group of four scholars from the United States published a paper challenging the already mentioned discrepant rates of FMS diagnosis regarding the patient's gender. They claimed that the 9:1 ratio and other high gaps between men and women diagnosed with FMS are all a reflex of biased diagnosis. For them, if the diagnosis is done correctly, the difference between incidences among men and women will drop considerably reaching levels such as 60% of women and 40% of men in FMS diagnosis (Wolfe at al. 2018). Part of their discussion of the issue is that there are two types of FMS - the Criteria Based Fibromyalgia and the Clinical Fibromyalgia. According to them, the first one is the one based on the validated and published criteria of assessment of pain developed by the American College of Rheumatology in 2016 (ibid.). According to this criteria, one has the 'real' Fibromyalgia, the criteria based one, if they have a) a widespread pain of seven on a scale of zero to ten; b) generalized pain in at least four of five regions of the body – which cannot include jaw, chest, and abdominal pain; c) symptoms that persist for at least three months; and d) a symptom severity of a minimum of nine on a scale of zero to twelve. On the other hand, the Clinical Fibromyalgia, which the authors name as 'the face of Fibromyalgia' due to its popularity, is the other strand of this embodied phenomenon that relies more on the medical professional to give the diagnosis of FMS (ibid.). According to them, this type of FMS is less reliant on scientific and mechanic forms of assessment of the pain and, as the authors imply, this is the cause for more cases of misdiagnosis and bias.

However, my aim is not to necessarily to inquire whether the authors are right or wrong regarding their conclusion. Rather, I would like to use their findings to investigate how in both described cases, FMS diagnosis is permeated by a circulation of affects that take place in the clinical encounter – where pain has to be something measured and assessed, even though it is such a subjective and embodied phenomenon that can hardly be explained or put into words (Pryma 2017). Moreover, I think that it is important to highlight that in both the criteria-based and clinical strands of FMS, the rates of women are higher than men. This reinforces the bio-socio-cultural understanding of the phenomenon in a perspective that defies the normative division between mind and body, nature and culture – highlighting the gendered aspect of the occurrence of this rheumatic pain.

When contrasting the modes of assessing pain in both types of FMS, the authors put science on top of humanness, and give the medical practitioners and their tools the power of reading (or, in many cases, misreading) the pain of the other through touch (Wolfe at al. 2018). According to them, the 9:1 ratio is not veritable because most of the cases are in fact misdiagnosis that is given based on a preestablished visions of women's capacity of dealing with pain and emotional strength (ibid.). Still, is it actually bias, what the authors are calling bias? Isn't it more of a prejudice towards women and a misreading of what experiencing pain means? Being biased, in this case, can be also understood as a clear expression of the cultural

readings of biological differences – an understanding that has more consequences for female bodies and some male bodies that do not subscribe to the normative vision of what gender is and what it entails.

In this sense, according to their reading of the clinical encounter, pain does not circulate all over the women's body as the FMS patients may describe. Pain is defined by the biomedical discourse through their gender. Feeling the pain and sharing insecurities is part of what womanhood is under the eyes, bodies, structures, institutions, and expectations of the patriarchal system. Here, in complement to Brennan's conceptualization of the 'transmission of affect' (which is attentive to the energies involved in human interactions), I want to also explore Sara Ahmed's idea of 'affective economies' as a way of explaining how, within the clinical encounter, body, pain, and affect circulate and entangle with each other (Ahmed 2004).

According to Ahmed, affect plays a crucial role in the 'surfacing' of individual and collective bodies through how it circulates between bodies and signs. Like Brennan (2004), Ahmed's argument challenges any assumption that affect is a private matter, that they simply belong to individuals, or even that they emerge from within and necessarily move outward toward others. For her, affect suggests that feelings are not simply 'within' or 'without.' They flesh out the surfaces or permeable boundaries of bodies and worlds. Based on Marx's notion of capital, she suggests an economy where affect circulates between signifiers in relationships of difference and displacement. In such affective economies, emotions do things, and they align individuals with communities through the very intensity of their treatment. Rather than seeing emotions as psychological dispositions, she suggests considering how they work, in concrete and particular ways, to mediate the relationship between the psychic and the social, and between the individual and the collective. In particular, she shows how affect works by sticking figures together – which she calls adherence. In affective economies, the adherence between two entities (e.g. the pain and the female body) creates the very effect of a collective, which she calls coherence. Ahmed suggests that while feelings do not positively reside in a subject or figure, they still work to bind subjects together since affect does not reside in an object or sign but is an effect of the circulation between them. Some signs increase in affective value as an effect of the movement between them: the more they circulate, the more affective they become, and the more they appear to 'contain' affect.

Translating this body of work to the analysis of the clinical encounter, we can then rethink what happens within that moment when patient and medical practitioner intermingle their senses and emotions in the quest for answers. Flashing back to my initial narrative of my mother's experience with FMS, it is possible to illustrate what Ahmed suggests regarding the circulation of affect, and also tackle the already mentioned position that a large amount of FMS diagnosis is a result of bias. During a clinical encounter, the bodies that participate in the relationship are already covered by affective expectations: the medical practitioner is expected to give answers, the woman comes with a heavy load of information that shapes their experiences based on the preconceived notion of womanhood, and pain circulates as the currency that will determine whether the patients experience is really 'organic' or if it is only part of her depressive and anxious mind. Prejudice adheres to the female body and now the woman is in coherence with other female bodies that have their experiences of pain snubbed and devalued.

This accumulative affect surrounds women's bodies and makes them more vulnerable to contexts of pain management (Enrico et al. 2017). A great deal of these unbalances and biases against women are a reflection of the current situation in which women are under a double burden: while being expected to contribute to the household income, they still are expected to carry the burden of domestic work (Young 2005). Here, it is also important to highlight that race and class are also circulating within the clinical encounter. Being non-

white and poor can surely make the situation more delicate for those who want their pain acknowledged and treated. For example, Pryma's research on black women who suffered from FMS shows how an intersectional approach to health research can reveal not only how racialized institutions shape illness experience and medical care, but also how these institutions make some individuals visible while rendering others invisible (2017). Similar to Ahmed's 'affective economies' (2014) and Brennan's 'transmission of affect' (2004), Pryma sheds a light on how bodies are embedded in a complex social context. Minorities face even more difficulties getting their pain diagnosed and treated than others. Women are perceived as more prone to pain disorders than men, but because pain is interpreted through a gendered lens, women are also much more likely than men to have their symptoms attributed to neuroticism, hypochondria, or emotional distress. Racism and misogyny are endemic to healthcare systems where patients in order to get treatment must submit themselves to misunderstandings about race and biological difference (Pryma 2017). Strategies that individuals use to negotiate pain and disability may vary depending on their social position (ibid.). Focusing on affect enables us to highlight how culture is an extremely important aspect during the diagnosis and the healing process. It is not possible to treat someone if we don't understand how culture is also part of medical methods.

Conclusion

This article argued that it is necessary to 'unsettle the clinical encounter', by acknowledging it as an affective event in which every layer of the social world plays a part in reshaping healing as a vibrant experience. However, within this short definition, it is not clear who are the ones responsible to unsettle the clinical encounter, and all the other encounters that are permeated by prejudices and inequalities. So, as a concluding remark, I invite people to start rethinking these encounters and try to balance privileges in a way that will raise

equality and make care something less of a burden and more of an act of shared responsibilities, love, and empathy. Looking back at my mother's experience with FMS, I can see that too many times I was blind regarding her situation, but now I hope that this research and this article will represent the first step towards promoting change and repairing the past. Pain has the power of bridging concepts and closing gaps, turning something that commonly is seen as private into a public urge to the acknowledgment of how health is shaped by oppressive structures that exceeds the traditional grammar to communicate with and about the body in pain.

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