

Diagnosis or stigma? Problematizing disease from a duoethnographic approach

¿Diagnóstico o estigma? Problematizar la enfermedad desde un acercamiento duoetnográfico

Diagnóstico ou estigma? Problematizar a doença a partir de uma abordagem duoetnográfica

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Abstract: Objective: The purpose of this paper is to talk about the sociocultural constructions around the disease. The main interest is to contribute to dismantle from our experiences as researchers and diagnosed women, the stigma that permeates the daily lives of people like us: obese or with HPV (Human Papilloma Virus). Methodology: Through the methodology known as duoethnography, in which two individuals narrate shared experiences to study in detail a sociocultural phenomenon, we present a series of thoughts that question the place in which we are placed when we are valued as sick. Results: We found, from our simultaneous reflections, three epiphanies that relate first to biomedical stigma, then to personal stigma and then to sociocultural stigma. A fourth epiphany expounds joint learning considerations during the authors' academic shared experience. Conclusion: We are interested, above all, in leaving an invitation to critically consider stigma, we are concerned with talking about care and pointing out discriminatory practices rather than denying our diagnoses.

Keywords: disease, stigma, collaborative autoethnography, HPV and fatness.

Resumen: Objetivo: El propósito de este escrito es hablar sobre las construcciones socioculturales alrededor de la enfermedad. La principal preocupación es contribuir a desmontar desde nuestras vivencias como investigadoras y mujeres diagnosticadas, el estigma que impregna la vida cotidiana de las personas como nosotras: obesas o con VPH (virus del papiloma humano). Metodología: Mediante la metodología conocida como duoetnografía, en la que dos individuos narran experiencias compartidas para profundizar sobre un fenómeno sociocultural, presentamos una serie de cavilaciones que cuestionan el lugar social en el que se nos coloca al ser valuadas como enfermas. Resultados: Encontramos, a partir de nuestras reflexiones simultáneas, tres epifanías que se relacionan, primero, con el

estigma biomédico, luego, con el estigma personal y, después, con el estigma sociocultural. Una cuarta epifanía expone las consideraciones de aprendizaje conjunto durante el proceso de convivencia académica de las autoras. Conclusión: Nos interesa, sobre todo, dejar una invitación a considerar críticamente el estigma, nos preocupa hablar de cuidado y apuntar las prácticas discriminatorias más que negar nuestros diagnósticos.

Palabras clave: enfermedad; estigma; autoetnografía colaborativa; VPH y gordura.

Resumo: Objetivo: O objetivo deste trabalho é falar sobre as construções socioculturais que envolvem a doença. A principal preocupação é contribuir para desmontar, desde nossas experiências como pesquisadoras e mulheres diagnosticadas, o estigma que permeia a vida diária de pessoas como nós: obesas ou com HPV (Human Papilloma Virus). Metodologia: Por meio da metodologia conhecida como duoetnografia, na qual dois indivíduos narram experiências compartilhadas a fim de aprofundar um fenômeno sociocultural, apresentamos uma série de reflexões que questionam o lugar social em que somos colocados quando somos categorizadas como doentes. Resultados: Encontramos, a partir de nossas reflexões simultâneas, três epifanias que se relacionam primeiro com o estigma biomédico, depois com o estigma pessoal e depois com o estigma sociocultural. Uma quarta epifania expõe as considerações de aprendizagem conjunta durante o processo de convivência acadêmica das autoras. Conclusão: Estamos interessados, acima de tudo, em deixar um convite para considerar criticamente o estigma, estamos preocupadas em falar de cuidados e apontar práticas discriminatórias em vez de negar nossos diagnósticos.

Palavras-chave: doença; estigma; autoetnografia colaborativa; HPV e gordura.

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Introduction

The disease is the stigma. In the duoethnography we present next, our main interest is talking about sociocultural constructions around the disease, not to discuss considerations of the disease itself. Our main concern is to contribute to dismantling from our experiences as researchers and diagnosed women the stigma that impregnates the daily life of women like us: obese or diagnosed with HPV (Human Papillomavirus).

We are interested in the discussion on the rigid dichotomy: disease versus health. We have a series of certainties about the pathologizing experiences of having been signaled as carriers of said diseases, that disqualify us from taking power over the ailments of our corporalities. We are not sick. We are not interested in denying or refuting our clinical analyses, but rather in all the effects of truth that work around it, to infantilize, blame and shame, discrediting all those vital experiences that fall outside the health norm. ⁽¹⁾

Diagnosis is not destiny. We believe that deeply questioning the absolute truths for vital existence that the medical system imposes on us is fundamental because our knowledge makes us experts on our own bodies. Thus, taking agency over them, we can face the fear of exclusion and death to which we are confined when diagnosed. When we say that we are not sick, we mean that, regardless of our diagnoses or clinical analysis, we do not legitimize that truth given by the medical system, perpetrated by doctors and health personnel. We are not sick because our experiences show that there are alternative vital forms to those that the medical system inevitably refers us.

Agustin Lejarraga states that “illness is constructed through a doctor-patient relationship in which roles and expectations of mutual fulfillment are generated. Medicine is a cultural response to legitimize the condition of being sick in someone who can no longer fulfill their usual roles”.⁽²⁾

Drawing on the discourses from the anti-capacitist activism of Johanna Hedva and Leonor Silvestri, we believe we should think carefully how the social structure legitimates discourses about what is healthy or unhealthy. It is essential to reflect on how our bodies are sensitive and react to regimes of oppression.⁽³⁾

The effort to connect our diagnoses with the experience of stigma is rooted first, in the experiential recognition that stigma put us in place in which we were negatively signaled. These intuitions led us to the theoretical search works that would help us deepen the understanding of the phenomenon we noticed. We came across academic works that addressed both HPV and obesity. Writings such as *Fat & Proud: The Politics of Size* by Charlotte Cooper;⁽⁴⁾ *Cuerpos sin patronos* by Laura Contreras and Nicolás Cuello;⁽⁵⁾ *10 gritos contra la gordofobia* by Magda Piñeyro;⁽⁶⁾ *Infección por virus de papiloma humano y prevención de cáncer cervical* by Georgina Sánchez Ramírez and Mónica Luna Blanco;⁽⁷⁾ articles like “Sobrevivendo ao estigma da gordura: um estudo socioantropológico sobre obesidade” by Rafael da Silva Mattos and Madel Therezinha Luz;⁽⁸⁾ “Working toward eradicating weight stigma by combating pathologization” by Rachel Fox, Kelly Park, Rowan Hildebrand-Chupp and Anne T. Vo.;⁽⁹⁾ “The harm inflicted by polite concern: language, fat and stigma” by Cindi SturtzSreetharan, Sarah Trainer and Alexandra Brewis;⁽¹⁰⁾ “Diagnosis and the practices of patienthood: How diagnostic journeys shape illness experiences” by Melanie Jeske, Jennifer James and Kelly Joyce;⁽¹¹⁾ ““Me sentí enfermar”: percepciones y comprensión de las mujeres del resultado positivo de un test de virus del papiloma humano en Jujuy, Argentina” by Lucila Szwarc, Victoria Sánchez Antelo, Melisa Paolino and Silvina Arrossi;⁽¹²⁾ “The Stigma of Sexually Transmitted Infections” by Amy S.D. and Shamera L.;⁽¹³⁾ in addition to “La obesidad en México. Estado de la política pública y recomendaciones para su prevención y control” by Juan Rivera Dommarco et al.⁽¹⁴⁾

Studies on these topics have proliferated, but not so much with methodologies that allow a qualitative understanding of the phenomenon which leaves a knowledge gap that translates into epistemic injustice. We believe it is possible to bring justice to paying attention to injustice, as there are social spaces where injustice is the norm.⁽¹⁵⁾ Injustice is concomitant with stigma. We believe that there is still a lack of theoretical, cultural, ethnographic, and collective resources to interpret the phenomenon we address here, this text is an attempt to contribute to filling that gap.

Methodology

What we intend to do is, through the methodology known as duoethnography, present a series of reflections that question the social position in which we are placed when diagnosed as ill. This will allow us to share this quest through qualitative approaches and approximations that are uncommon in the academic context. Our interest is more focused on contributing to the understanding of the formation and internalization of stigma than on proving its existence. For this, we find it fundamental to incorporate into our health professional job training, that one of us has, the theoretical perspective we share from a feminist theory and socioanthropology.

Duoethnography was developed by Sawyer and Norris and it is a methodology in which “two or more individuals give similar and different meanings to a common phenomenon experienced in their lives”.⁽¹⁶⁾ In other words, duoethnography “renegotiates meaning and reality through storytelling, revising, and comprehension of memories of an experience with another person”.⁽¹⁷⁾

Duoethnography is a qualitative research method that, similar to autoethnography, aims to connect the personal with the sociocultural and political.⁽¹⁸⁾ What characterizes duoethnography are the conditions of dialogue and conversation, which encourage the exchange of individual life experiences that, when combined, generate innovative social meanings, but above all, enhance the understanding of shared experiences.⁽¹⁹⁾ When engaging in deep conversations, we are able to reexamine what we believe, that is how the possibility of reconceptualizing our thoughts, practices, and agencies is created.

We present this document based on our collective reflections on three epiphanies that are related, first to biomedical stigma, then to personal stigma, and finally to sociocultural stigma. Said epiphanies did not occur in a linear or sequential manner, we have been discussing them, in order to provide theoretical explanations and put aside the sense of victimization and pathologization imposed by the very nature of stigma. Here, we present them consecutively to systematize and allow exposition to the phenomenon.

The fourth epiphany, on the other hand, exposes the considerations of collaborative learning during this process of academic coexistence. It has been incredibly interesting to witness the various ways in which what we have experienced and shared among ourselves has added consistency to our own research. All of this, both on a personal and intellectual level, has been the turning point that undoubtedly stimulated feminism.

Discussion

Previous notes

The first time we saw each other was when we were starting the admission process for the doctoral program in sociocultural studies, during the seminar where we presented our research project proposals to the academic core of the postgraduate program.

Since both of us were accepted and throughout our years of training, we have shared this life project and coincided in our concerns regarding the study of illness from disciplinary fields that may seem opposed. Coming from sociology and nursing backgrounds has allowed us to discuss the topic from these two perspectives.

I, Mariely, before entering the doctoral program, studied a nursery undergraduate degree and a master's degree in nursing sciences. Since long ago, I have been excited about reflecting on unconventional research approaches and studying the health/illness/care

process through qualitative research, sociology, anthropology, body studies, and gender studies. I am a full-time researcher-professor, specialized in nursing subjects focused on public health or primary care (prevention, health education, timely detection, and treatment). I identify myself as a sociologist nurse, researcher, professor, woman, mother, daughter, friend, and person diagnosed with HPV. From all these identities, I have directly observed and experienced how women with a positive HPV diagnosis are stigmatized. They are labeled as promiscuous, dirty, careless about their sexual health, and responsible for having the virus. ⁽²⁰⁻²⁴⁾ I have witnessed how healthcare personnel outrage and infringe women by morally judging them based only on their diagnosis: they provide care with bias, guided by precepts, feelings, and taboos. Once, while developing fieldwork, I asked a sixty-year-old woman to perform a self-vaginal swab. She told me that she would usually do it herself because she hadn't been tested in thirty years, she said that the reason was that the last time she had a Papanicolaou done the nurses who attended her left her exposed with her legs wide open while whispering and mocking about her genitals. On another occasion, I witnessed a doctor scoldingly asking a young woman diagnosed with HPV how many men she had slept with, since that was the reason for her infection. That is how a difficult illness-care process begins, a perverse consequence of this is that by not openly discussing the situation, we avoid confronting the effect of stigma, which is discrimination.

I, Magda, am a sociologist, and since my major studies, I have been interested in cultural topics, gender, and vulnerable groups. I identify myself as a professor, feminist, and politically active fat woman. During a long part of my lifetime, I have felt dissatisfied with the social treatment I receive due to the size and shape of my body. It seems to me that my fat body becomes a public matter, defined by the medical system as pathological. Us, people whose bodies stand out from normative standards of size and health at first glance, are treated as if we are sick. I am interested in making visible the practices that normalize mistreatment towards fat individuals and perpetuate oppression. In addition to teaching socioanthropology of the body and feminism, I do in fat-feminist academic activism, as I consider, like bell hooks in her text *Enseñar a transgredir* that “the classroom remains the most radical space of possibility in the universities”. ⁽²⁵⁾ In schools, and in classrooms particularly, I have been able to corroborate how oppressive hierarchies such as sexism, classism, or fatphobia affect the way of teaching and learning, in the way that these perpetuate differences that are vital to eradicate because they hinder the integral development of any person and society. It is essential to address, point out, and problematize them so they can be discussed. And classrooms are an ideal place to encourage critical thinking and agency.

Both of us, as we took the curricular subjects and delved into the theoretical discussions of our doctoral program, began to realize that our stances on various socioanthropological phenomena were very similar. We also coincided ethically on certain issues of social justice. We are both feminists, we are interested in bringing up issues related to corporeality and are happily wanting to do sociocultural analyses using qualitative methodologies, particularly through autoethnography. We adhere to the postulates that champion the idea that the analysis of our biological bodies, which are also conscious, interpret and act, experience, in other words, our bodies are embodied agents. ⁽²⁶⁾ This is fundamental for the comprehension of the phenomenon we are investigating.

In socioanthropological studies of the body, the English term embodiment is used to discuss on the theoretical breakthrough that suggests that the social is not inscribed onto the body but that the body itself is the genuine site of culture, the corporeal as the “material process of social interaction”. ⁽²⁷⁾

We need to return to the body without neglecting all its processes, an embodied body that expresses the political, cultural, and social context it inhabits by itself. We believe that duoethnography allows us to engage in conversations about the sociocultural construction of the illness with which they have assigned our bodies.

We came across duoethnography through the course Methodological strategies to transcend the natural sciences paradigm, where we thoroughly examined epistemological and methodological matters of autoethnography. Among the readings in the course was a recently published text edited by Phiona Stanley and Greg Vass, titled Questions of Culture in Autoethnography, ⁽²⁸⁾ which contains sixteen articles, but our attention was particularly drawn to Ulrike Najar and Julie Choi's piece titled "How do 'we' know what 'they' need? Learning together through duoethnography and English language teaching to immigrant and refugee women", due to its dual-voice construction about the pedagogical, ethical, and privilege-related challenges they encountered as volunteer English teachers for refugee women seeking asylum in Australia.

We had already talked about writing something together about the discriminatory events we had experienced through our bodies and within the medical system, so the duoethnographic article only confirmed that this was the ideal methodology to undertake this journey.

First epiphany. Eureka! we are not sick

In the Sociocultural Theories class, Mariely was presenting on the book *Estigma* by Erving Goffman. She mentioned how society categorizes individuals who deviate from "normality" in a way that discredits them. Goffman refers to it as stigma, it is a "special class of relationship between attribute and stereotype". ⁽²⁹⁾ Furthermore, according to Arellano & Castro, stigma is formed through perceptions and attitudes towards an attribute evaluated as negative, which leads towards discriminatory behaviors. ⁽²⁰⁾ In this regard, going back to Goffman, there are three types of stigmata: abominations of the body, character defects of the individual (for example, mental disturbances), and tribal stigmas (such as race and religion). The book also analyzes the support relationships that may exist between the same stigmatized people, those who share their stigma. ⁽²⁹⁾

After the presentation, the following conversation took place:

Mariely: Are you going to use the terms obesity or overweight from a health perspective?

With a frown at the question, with the distrust that characterizes her, Magda responds:

Magda: No. I am not obese, because that term pathologizes me. I am not interested in addressing the topic of fatness from a health perspective. I am not sick; I am not an illness. There are many ways to explain why a body is fat.

Slightly disgruntled, considering her background as a nurse, distrustful Mariely continues:

Mariely: Really? I was taught that if you don't have a normal body mass index, you are obese and therefore sick. So why don't you approach the concept of obesity from a biomedical point of view? What does it mean that it pathologizes you?

Magda: Well, the body mass index is a standardization, and nobody is the same. Bodies vary, bone structures do it too, so do phenotypes, and dietary practices worldwide. How can they continue to rely on a single indicator without accounting

for bodily differences? Besides, I know people who are fat for very different reasons. That index is anachronistic and should no longer be used. And if only with a single number, I am labeled as sick, without knowing anything else about me, then, I believe it is problematic. It is not my “fault” that I am fat, it is not because I want to be sick or that I lack self-esteem. I have always been fat. I went on diets for years and would lose weight, but I always gained it back.

Mariely: I had never thought about that, Magda. Do you mean that there are prejudices that the biomedical system itself reproduces and that that discriminates against people, seeing them as objects or bodies rather than as individuals who are socioculturally constructed?

Magda: Exactly. I know people who are fat because they eat unhealthy food, because they are anxious or have emotional problems, because they have experienced sexual abuse, because they have specific dietary habits, because they have genetic predispositions, because they can only consume certain foods, or because their body structure is naturally like that. Because of that, we can't assume that the reasons for being fat are the same for everyone. Maybe that's why weight loss treatments fail 95 % of the time. There are many fat people whose clinical tests fall within the parameters of health. Not all fat people have diseases; therefore, they shouldn't assume we are sick by just looking at us. Doctors infer, as soon as they see me, that I am sick. Recently, I went to the healthcare system in which I am affiliated, just to pick up my allergy medication, and as soon as the doctor saw me get in, she said: Aren't you afraid of dying from a heart attack? Look at yourself. She diagnosed me by just looking at me. That is something to be upset about, that is what makes me feel sick. It made me feel terrible that I looked like I was dying, not even worth a greeting. That is not caring for my health, that is making how I feel about my body worsen. That treatment is what made me feel sick, not being fat. It doesn't make me want to go back to the doctor's office. That does affect my mental health, which can translate into specific physical ailments.

Mariely: I can relate to what you're saying, in my experience as a woman who was diagnosed as HPV positive, I have faced discrimination from medical personnel who only by seeing my diagnosis label me as promiscuous, nasty, lacking sexual education, and lacking self-care, but it has been scientifically proven that many women have been infected by their monogamous partners, not by a sexual slip. ^(12, 21, 30, 31) As if all women were saying “infect me, I want to have a sexually transmitted disease!”. You're right, I only feel sick when I go to the doctor's office or when someone finds out about my condition because I know what assumptions are made about HPV. What I'm interested in investigating with my research are the experiences of women diagnosed with HPV and how they experience it because, because in my own experience as a patient I felt bad, discredited, and now I realize that I'm not the only one who has faced discrimination because of it. It's the way the diagnosis is treated that makes me feel sick.

Magda: Exactly! That is what makes me sick, people seeing illness in my body without knowing anything else about it. I go through life perfectly fine, until someone reminds me that my body is not “normal and therefore I deserve to be stigmatized”.

We look at each other smiling, we just found a vein of gold. We didn't identify ourselves as sick! A sense of complicit pride overwhelmed us. To challenge the biomedical stigma, we agreed with Esteban that:

The biological determinism is the denial that, in the hierarchy of things, the cultural or the psychological affects the biological. It is the illusion of the independence of the biological from any social and historical context, which is expressed in two directions: an autonomy of biological processes with respect to psychology and social relationships, and a dependency of these two orders on the natural substrate. ⁽³²⁾

We turned to his approach from anthropology, which:

proposes that illness should be understood as a multidimensional phenomenon in contrast to the analytical unidimensionality solely focused on biology that has articulated the biomedical model in recent times. ⁽³²⁾

Second epiphany. Coming out of the closet of the stigma of the disease

In July 2019, took place a seminar called *From our bodies: gender, health, and autoethnography*, in which we participated. Excited about the proposal, we traveled to that city, unaware that it would be highly significant for our ongoing research. Far away from home, for the first time, we found ourselves in a safe academic space, you could feel a sense of feminist solidarity, which facilitated open discussions about the personal motivations behind our inquiries. We read Ibero-American literature and coincided with other women interested in doing studies from social sciences and feminism, breaking away from orthodox research methodologies.

From the planning stage of the program, Mariely was invited to present her ongoing research protocol. When the day arrived, she shattered the veil of shame that until then she hadn't known how to name. With a simple yet transgressive statement, "My name is Mariely, and I am HPV positive", she left no one indifferent.

When we were alone together, we revisited the emotions unleashed in both of us after such a powerful declaration.

Magda: How beautiful! Congratulations! You're so brave! You said it in front of everyone. It's the first time I've heard you embrace being HPV positive.

Mariely: I didn't plan it; those words came out of my mouth without thinking. I stepped out of that imaginary space I was in. I immediately felt different after saying that phrase, as if something was lifted off my shoulders. It's very difficult to talk about our own illnesses, but I never imagined I would feel relieved by saying it. It was as if naming it made it real, and I felt that I could say it without caring about what others would think. It released the knot in my throat that I had carried for so long. I wish I could say it to everyone without being judged. Living with a sexually transmitted disease and not knowing if what I'm doing for my health is enough to prevent it from developing into cancer is very challenging, but adding the fact that people judge me makes it even more complicated.

Magda: Mariely, you have come out of the closet of stigma! I think you've shown a lot of courage in doing so. I can understand what it feels like to publicly embrace who you are, it is difficult to do it in front of everyone when you know that what you affirm is not pleasing to them or is seen as wrong. I came out of the closet of

fatphobia when I posted a cartoon on social media that aimed to criticize the beauty standards imposed on fat bodies. I remember feeling nervous and dizzy, doubting whether I should publish it or not. That cartoon was my public declaration of my fatness. I thought people would mock me, that I was putting myself on a silver platter for criticism. But the opposite happened; the post received positive reactions and comments. No disaster occurred, and it felt incredibly good.

When Nicolás Cuello talks about the identity of fat bodies, he talks about the configuration of a relational stigma that “potentially affects all bodily experiences, through all forms of cultural stigmatization”.⁽³³⁾ That night, while we read and discussed the articles for the next seminar session, we uncorked a red wine bottle and toasted to our coming out of the closet. Finally, we could celebrate together for disobeying the mandate of loneliness and shame that was imposed (like that, in past tense) to us by our medical diagnoses.

Third epiphany. Resist the norm

There are structural conditions sustained within a biomedical context that society reproduces. The recognition of the pernicious conditions surrounding the experience of any stigma is a long process. “Sometimes, the emotional impact suffered from such a diagnosis could be more harmful than the clinical symptoms caused by the virus”.⁽³⁴⁾ Socially, these conditions are often reproduced without us realizing it. To address the stigmatizing sociocultural elements related to our diagnoses; it has taken time, discomfort, reflection, and decision-making about the violence that we have experienced.

On one occasion, while sharing with a group of colleagues, we were discussing embracing our identities as fat and HPV positive. One of them made an observation:

Colleague: Mariely, don't introduce yourself like that. Being HPV positive doesn't define you or describe you as a person.

Both of us felt upset and exchanged glances because we had perceived a hint of discrimination in the comment. Mariely then responded:

Why are you saying that to me? Do you believe we can't discuss these topics in public spaces? In my experience as a patient and a researcher, I have witnessed how many women are unable to express or make their conditions visible due to fear of discrimination, fear of discreditation, and negative social judgment. For me, it is not a bad thing to be known as a woman who is HPV positive. On the contrary, I would like, by acknowledging it, to create a space where many women can approach and find support and empathetic listening.

Magda intervened:

That sounds like you believe that being HPV positive is something horrible. And that's what is truly sickening, more than the condition itself. As a fat person, I constantly hear that I shouldn't label myself with that word, that it's considered ugly, or people try to correct me by saying: “You're not ugly”. In other words, they associate fatness with something negative or with ugliness, and to me, that is the terrible part. When people assume those things about fat bodies, they also assume them about me and that's discriminatory, oppressive.

And she continued addressing the colleague while the others in the room remained attentive to the discussion:

Do you have any idea how it feels to constantly be told that you're sick, that you're ugly, that you're nasty, that you lack willpower? As if women who are fat or who have HPV choose to be that way because they don't love themselves, because they have low self-esteem, because they don't eat properly, because they don't have monogamous partners, and so on. How can't you see how harmful those assumptions about other people's bodies are?

There was an uncomfortable silence. According to the National Survey on Discrimination (ENADIS by its acronym in Spanish) 2017, stigma is:

the devaluation or discrediting of people from certain population groups based on an attribute, quality, or identity that is considered inferior, abnormal, or different within a specific social and cultural context, as it does not fit what is socially established. ⁽³⁵⁾

Socioculturally, many beliefs with stigmatizing biases are assumed to be normal. While people generally don't necessarily act with malice, but rather respond based on the way they were socialized with those specific ideas, it should not be overlooked that these beliefs and ideas come with discriminatory practices. The innocent correction from our colleague is a clear example of the devaluation or discrediting experienced by individuals who are not considered normal (not healthy) within what is socially established as such.

On the other hand, those of us who do not fit within these norms of normality (non-sick/healthy) experience episodes of discrimination. Once again, following the ENADIS glossary, we understand discrimination as

a set of processes or patterns of inferiorizing treatment based on negative prejudices or stigmas, as well as a set of culturally rooted beliefs directed against a social group due to some prohibited motive of discrimination, which lead to a reduction or denial of access to or enjoyment of their fundamental rights and freedoms. ⁽³⁵⁾

The discriminatory beliefs and practices that label women with HPV as promiscuous, unfaithful, or deceived, guilty of contagion; and those that fat women burden such as that they have a low self-esteem, are non-attractive, experience a lack of willpower, and are guilty for having larger bodies, are oppressive.

We use the term oppression because the exercise of such practices is systematic and persistent. While there are differences in frequency and consequences between weight-related oppression and the experiences of women with HPV, they function in similar ways and end up undermining bodily freedoms for both groups.

One of the persistent beliefs about obesity is that overweight individuals are addicted to food, as the approach focuses on quantity of calorie intake. Another tenacious belief regarding HPV carriers is that they have had multiple sexual partners, a perspective that simplifies the issues faced by many women and that deprives them of appropriate medical care.

We want to acknowledge the oppression manifested in discriminatory practices fostered by stigma, as it seeps into even the most private actions, such as how we nourish ourselves and our sexuality. Even though these aspects are highly personal, they are still influenced by the prejudice associated with the diagnoses. Many overweight women can attest to the perpetual dieting they endure, while many HPV carriers are aware of the impact the diagnosis has on their sexual lives.

Fourth epiphany. Learning together

This duoethnography is a segment of our joint learning process, a means that “allows us to use our differences to enrich our vision and our common struggles”.⁽³⁶⁾ It serves as evidence of joyful, supportive, and non-violent didactics, free from competition or power struggles. We have recognized our individualities as women, and that is what unites us.

The first time we discussed the knowledge we had internalized from each other was when we witnessed the great response from women diagnosed with HPV who wanted to participate in one of our research projects. We discovered that a considerable number of women we knew and were close friends with were living with this condition, yet they never spoke about it. Some of them even wanted to share their stories but requested anonymity. The surprising aspect was the secrecy with which they managed their diagnosis, even though there were many who desired to discuss the topic. We realized the oppressive power of stigma when it is internalized, as Arellano & Castro say that once it is “accepted, it becomes susceptible to discrimination”.⁽²⁰⁾ Not discussing the issue is a protective measure against potential displays of exclusion and social punishment.

The second time, one of us was conducting online adult nursing practice and administration classes for sixth-semester nursing students due to the COVID contingency, and a debate arose on whether to continue providing health education to patients with obesity or not. One student was upset, arguing that there was no point in giving such talks to people who didn't care because if they had that problem, it was their choice. Then, as the professor, I countered arguing that diseases are multifactorial, society itself plays a role by setting beauty standards that cause women to reject their bodies and experience depression or anxiety, leading to eating disorders. Another factor is the food industry, which increasingly produces harmful processed foods marketed as healthy or low-fat, without mentioning their excessive sugar content, which leads to fat accumulation in our bodies. So, are we truly free to decide about our illness? Is the patient truly to blame for his/her condition? Or is he/she influenced by social expectations? Healthcare professionals must always consider these sociocultural constructs to provide holistic care.

Our shared experiences have allowed us to delve deeper into our knowledge, enabling us to discuss our research not only as a storytelling exchange but as a critical and emotional learning experience, transcending academia.

In both episodes, we were together, speaking with two voices. The reflections on HPV were a blend of our knowledge, a broader and more intimate understanding of what we were researching. The reflections on obesity, it was the result of deeply ingrained experiences of discrimination, being considered in the education of nursing students.

After spending so much time together, conducting research, delving into our own experiences, and sharing our episodes of discrimination and distress from being stigmatized as sick, we want to make it clear that our main goal is to invite critical reflection on biomedical, cultural, and social stigma. We are more concerned with discussing care and addressing discriminatory practices rather than denying our diagnoses.

Conclusions

As a corollary, we present a decalogue to disobey stigmatizing norms:

1. While you are getting your diagnosis, do not accept violence, do not accept the hierarchy that says that the doctor knows more about your body than you do. We question that the

- doctor knows more about our own body than we do. If the relationship you have with your doctor or health professional is not good, look for another option.
2. Stop being patient and empower yourself to make decisions about your body. Question, don't be silent. Change that being a passive "patient" for being an empowered person, responsible for your own health, a critical person, questioning, demanding information from health professionals. Invite to question and choose about your body, about your own health, disease, care, treatment, rehabilitation, etcetera. Choose whether or not you want them to perform the following activities: touch you, intervene, prick, scrutinize, check, explore, assess, diagnose, ask. Always question and choose yes or no, be a different, abnormal and irreverent patient. ⁽³⁷⁾
 3. Do not feel ashamed of being diagnosed as sick. Being sick is not a "sin" and should not be a stigma.
 4. If you have been diagnosed, talk about it! Don't go through that process alone. Discuss it publicly. The personal is political, and you are not the only person going through it. This gives you the opportunity to feel supported, find allies to challenge the legitimacy of the illness. It is possible to live with a diagnosis that is not a path of exclusion and death.
 5. Distrust the biological, cultural, and social definition of illness. Regarding the biological definition (disease), no scientific knowledge is absolute and forever. What is now considered "good treatment, healthy" may not be the same in a few years. Diseases and their treatments depend on ongoing research and advancements, as well as sociocultural needs. "We believe in medicine, but there must be critical reflection from the doctor, the healthcare professional, to meet the needs of 'the patient'". ⁽³⁸⁾ Distrust the cultural definition of illness because culture is also a creation that stems from a set of internalized dispositions, perceptions, emotions, and actions of individuals within their immediate social group and the institutions they navigate. Distrust the social definition of sickness because various contexts of socioeconomic class, ideology, religion, and politics influence how the diagnosis is experienced. ⁽³²⁾
 6. Don't forget that we experience all three stigmas (biomedical, sociocultural, and personal).
 7. Be skeptical of the social responsibility imposed on you because your body doesn't function according to the norms dictated by the biomedical system.
 8. Each body experiences illness in a unique way and should be treated accordingly. Avoid generalizations; we have the right for all sociocultural factors that interfere with our health-disease process to be considered.
 9. Remember that the term illness is not synonymous with being dirty, abnormal, or lacking self-love.
 10. Engaging in self-care practices does not guarantee overall health as it depends on multiple factors. Pay attention to all of them.

Ethical aspects

The use of duoethnographic method does not exempt us from ethical responsibility. We believe, in fact, that us being both informants and researchers, this responsibility can be even more intricate. In order to conduct this research, we have clearly established ethical duties, including careful consideration of our own specific experiences with diagnosis and lived stigma. We have also been attentive to the contributions of individuals who have facilitated our theoretical elaborations and led us to epiphanies that are presented throughout the text. ⁽³⁹⁾

There were those who acted as interlocutors, supporting us in the process of discussion and providing us with relevant literature and theoretical-methodological approaches to support our initial investigative intuitions.

Throughout this process, we have adhered to ethical guidelines such as: do not cause harm to ourselves or others, respect for consent and autonomy, review of interpretations by individuals involved in the dialogues presented, consideration of our potential audience, and protection of identity and confidentiality. ⁽³⁹⁾

According to the classification in the General Health Law in Mexico, this research does not pose any risk. Article 17 states that studies such as the one we present are not considered dangerous if they employ documentary retrospective research techniques or do not involve intentional intervention or modification of the physiological, psychological, and social variables of the individuals participating in the study. Likewise, we have also considered the criteria established by the Declaration of Helsinki on ethical principles for research involving human subjects. ⁽⁴⁰⁾ Additionally, we have taken into account the General Health Law (articles 2, 3, 17, 68 section IV, Title V Research for Health, articles 96, 97, 99, 100 section IV informed consent, 101, and 102 section IV research protocol): and the regulations of the General Health Law regarding health research. ⁽⁴¹⁾

Investigative backroom

We believe that this article itself is part of the behind-the-scenes research of our doctoral theses. It presents a series of epiphanies that shaped, in an alternating and nonlinear manner the consistency of our certainties, leading us to the realization that it was important to expose the oppressive sociocultural constructions surrounding our medical diagnoses.

Although during the doctoral process we observed ethical, theoretical, and experiential coincidences and discussed them, not only between the two of us but also persistently with the members of our advisory committees, we decided to write this article after coming across a duoethnographic article. Encountering this methodology prompted us to finally sit down and articulate this text. We believed we had found a way to systematize our experience and openly present our sociocultural analyses based on our lived experiences.

As researchers, we knew that we had to trust our informants, so we made the decision to bring our stigmatizing experiences into conversation. We had our diagnoses, experiences, conceptual knowledge, and now the methodology to carry out this inquiry.

We had the critical and unconditional support of our mentors, whose guidance was both academic and personal. The decisions we made were always consensus-based, and we did not have disagreements but rather a genuine interest in sharing what we were learning. We firmly believe that in this duoethnography, our dialogue is rhizomatic.

Ontological position of the researchers

Mariely: Bachelor of Nursing, Master of Nursing Sciences with a focus on primary healthcare, and Doctor of Sociocultural Studies. Researcher, professor, student, woman,

mother, daughter, friend, and carrier of HPV. Full-time Professor-Researcher in the Nursing department for 15 years in higher education. I have participated in articles such as “Lived experience of informal primary caregivers of individuals with mental distress”, “Experience with Papanicolaou smear test among university students”, “Women's perception of self-collected vaginal swabs and self-concept”, among others. In my doctoral journey, I worked with qualitative methodology, gender and health studies, support networks in healthcare, body studies, sociocultural studies, and Grounded Theory. My doctoral thesis is titled *Construcciones socioculturales frente al diagnóstico de VPH en mujeres*.

Magda: Bachelor of Sociology, Master of Social and Humanistic Research, and Doctor of Sociocultural Studies. I am a professor, feminist, working-class fat woman. I have collaborated with various civil society organizations and government institutes, conducting research and giving workshops and lectures. I have completed courses endorsed by national and international institutions on Human Rights. Since 2006, I have established myself as a teacher in secondary and higher education. I engage in political activism from an academic feminist perspective. In recent years, I have presented papers at various national and international conferences. I have written articles such as “Lonjas. Meneo autoetnográfico”, “Devenir gorda. Proceso de identificaciones y afectaciones deseantes” and “Un cuerpo propio”. I also write poetry. During my doctoral process, I specialized in autoethnographic methodology and fat studies. My doctoral thesis is titled *Hacerse gorda. Una autoetnografía feminista*.

Together, we have presented talks, workshops, radio programs, seminars, and conferences on topics such as: “Stereotypes, stigmas, and discrimination”; “Differences between quantitative and qualitative research protocols”; “Weaving sisterhood”; “Introduction to qualitative research methods”; “Female support networks in a doctoral investigation”, among others.

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