

Vulnerability Studies: An Introduction

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Illness Storytelling and Embodiment

This is Meenakshi Srihari and in this session we are going to look at how we may read the sick body's vulnerability. Now there are many ways for us to think about the relationship between sick bodies and vulnerability. In this session titled "Illness, Storytelling and Embodiment". we will try to respond to the three questions that I am listing now. How is the sick body rendered vulnerable? How does the sick body narrate its vulnerability in various literary and social contexts? And how does the sick body construct itself as a vulnerable subject in various social and cultural contexts? Now at the bottom or the heart of these questions lies storytelling. The sick body or the vulnerable body needs storytelling not just to convey the fact of its illness to somebody who might reach out like medical personnel or like relatives or friends but it also needs storytelling to reclaim its individual narrative from a rather homogenizing medical narrative. Now what do I mean by this? Medical institutions and their narratives are often derived from a sense of medical proceduralism.

Now by medical proceduralism I mean the bureaucratic processes that drive the logic of diagnosis or the logic of treatment options and that may tend to universalize the individual sick person's vulnerability. Now it is necessary that the sick body produce its own story and narrate its own story in order to reclaim its narrative from this sort of effacing and universalizing medical narrative. Now one particular example where we see this kind of context playing out where the medical narrative tries to overshadow what's happening with the sick body or in the sick person's life is in literary examples of the conversation between the patient and the physician. An example is up on your slide now from the Pulitzer winning play *Wit* written by Margaret Edson where you see a conversation playing out between the physician, Kelekian and the protagonist Vivian Bearing.

Now it is to be remembered that in this particular context Vivian Bearing is an academic who is very scholarly and who teaches John Donne and who is very overwhelmed by this sudden disease that has overcome her. So, in the situation and in the conversation, we see how Kelekian is trying to give her a diagnosis. I am quoting from one of the passages

over here. Kelekian says “Now it is an insidious adenocarcinoma which has spread from the primary adnexal mass”. You see how Vivian contradicts this or rather interrupts him and says “insidious” and she tries to interpret “insidious” in her own manner.

However you see as the conversation goes on that Kelekian starts using more and more medical jargon and Vivian for all her scholarliness is reduced to an obedient and docile patient. Kelekian also tells her that the only way to actually cure her cancer is to use a very aggressive form of treatment and Vivian cannot question him about this because he presents it as an invocation to her scholarliness when he says that the treatment will not just help in curing her or in attempting to cure her but will also help in medical research itself. Now this is an appeal to Vivian's scholarly and it is also a manner of saying that the treatment chosen is not just the best treatment option for the patient but it's also a manner of bettering medical research itself. So overwhelmed by her disease and by the language of the medical diagnosis that is meted out to her Vivian agrees with this treatment option. Now diagnosis can be overwhelming and can render the body vulnerable.

However there is also another manner or another side to diagnosis that can render the body vulnerable and this is found in the form of diagnosis not being adequate or not having reached a diagnosis at all. An example for this would be difficult to diagnose diseases like chronic fatigue syndrome or Lyme disease. Lyme disease, for example which is notoriously difficult to pin down and is more prevalent among women is a disease that has become symbolic of a larger patriarchal medical culture beliefs that women have the propensity to subconsciously feel sick all the time. A narrative such as Poro-chista Khakpour's *Sick* for example talks about how the Iranian-born writer was diagnosed hundreds of times with various diseases including psychosomatic diseases such as PTSD before she was finally pinned down with Lyme disease. Now in such a case we find that society or the medical institution often tends to regard these patients as unreliable witnesses to their own body stories.

Poro-chista Khakpour's story specifically also inverts the narrative temporality that we are used to. The diagnosis is generally the first part of the narrative that begins an ill person's fitness narrative or illness narrative but, in these cases, we see that the diagnosis becomes the end. End in terms of both the objective of the narrative itself and end in terms of temporal sequence. Now another way in which the diagnosis turns the patient vulnerable is the lack of it or the lack of adequate information about it. In a graphic narrative like David Small's *Stitches* for instance we see how the story revolves around a young Small who was treated with hundreds of x-rays by his physician father because of his sinus issues. Now these x-rays ultimately lead to Small getting oral cancer because of which or following which he has a surgery that makes him lose his voice itself.

Now accidentally and later in the narrative Small does discover that he has had cancer and gradually his father lets him know that he might have been the person who has caused these because of his improper treatments. Now over here we see a condition in which the patient loses his voice not just because he has no agency or say in the matter but also because of an actual misuse of medical treatment. Now according to the *Horrorisms* author Adriana Cavarero, infants are already susceptible to more vulnerability than the others which renders them helpless as well. Here, David Small is both vulnerable and helpless because of the mistreatment meted out to him by his parents. Now, with focus on patient autonomy being lost because of medical mistreatment and the focus of stitches as well on how some treatments can lead to the patient becoming more vulnerable or can lead to the patient being more harmed results or brings us to this notion of embodied paranoia.

Now this phrase “embodied paranoia” was coined by the sociologist Arthur Frank to describe this state of patients where patients fear the very institutions that are designed to help them. Now at the very heart of embodied paranoia lies the notion that patients are both scared of the institutions that help them though they are aware and guilty of this fear as well because they know that these institutions might actually end up helping them without harming them as well. Now an example of this would be chemotherapy where the torturous side effects of chemo often leave the patient scared to take up the treatment but they have no option because this is often the treatment that is prescribed to them. Now if the patient thinks and feels “I do not want to die on a machine” then this thought encapsulates the feeling of embodied paranoia perfectly. Now we've looked at a couple of slides from *Stitches* where this feeling of embodied paranoia is perfectly embodied or is exemplified.

Now in slide one we will look at how David Small as an infant is mistreated by his father with hundreds of x-rays and correspondingly, we will see that in the next slide Small is reduced to the site of his body because of his illness. Now the contrast between these two slides the first being that David Small is completely helpless in the face of the violence meted out to him by his father in the form of a medical treatment nevertheless and in the second slide his subjective rendering of how he feels when he does not have a voice both literally and figuratively he does not have a voice he does not have a say in how his disease should be managed can be seen in both of these slides. Now this example shows us that corporeality lies at the heart of an illness narrative. Corporeality or embodiment of the body, embodiment is the manner in which a physical representation a representation of the physical body is made in order to represent the innermost sense of self that the patient is going through. So representing your physical body can be a way also of showing what you're going through affectively or what you're feeling emotionally and we see that one technique over here that Small for instance is using in his memoir is that

of showing how the patient feels reduced to the ground zero of illness which is the body itself.

Now another way of showing the vulnerable othering of the body is by playing around with conceptions of border crossings and conceptions of imagined spaces. Now the ill person finds themselves a stranger in their own body when they discover parts of the body that ache or parts of the body that are breaking down during an illness that were perfectly fine before. Now this feeling of homelessness or unhomeliness or uncanniness is also exacerbated when foreign materials enter the body. Now what do I mean by foreign materials? These could be in the form of germs that enter the body it could be in the form of pills or medicines that enter the body it could also be in the form of medical instruments and tools such as cannulas or such as incubation tubes that are made to enter the body through orifices. Now this entering of foreign invaders into the body also adds to the feeling of uncanniness and represents what we are going to call the abject for the body.

Now the abject is that feeling when the body feels outside of itself. Now as Elizabeth Grosz has a very beautifully put about the abject and I quote the “abject is the impossible object still part of the subject an object the subject strives to expel but which is ineliminable. In ingesting objects into itself, or expelling objects from itself, the subject can never be distinct from these objects. The ingested or expelled objects are neither part of the body nor separate from it”. Now several writers have praised this analogy between the ill body and the abject. In cancer narratives specifically the tumor forms a part of this notion of the abject because the tumor is both a foreign body and a very monstrous body at that an alien body at that which enters the body or which grows in the body however it is also composed by the composed of or produced by the rapid proliferation of one's own cells so it one finds that the tumor becomes a part of the self and at the same time the tumor is something you want to eject from your body hence the tumor becomes a part of the abject. Now Susan Gubar in her memoir *Memoir of a Debulked Woman* where she talks about her experiences with ovarian cancer also talks about how her body slowly becomes alien to her.

Now Gubar talks about her tumor thus and I quote “Cancer is paranoia's dream come true: there is something in there that I cannot see or feel or imagine, trying to murder me. What was inside me, requiring gutting, that I could neither see nor feel but might attempt to imagine?” and later she continues lamenting how it is “Impossible to know the cancer cells is stealthy forays, disorienting to picture the masses of growth they seem to have laid down, unbeknownst to me at the center of my being.” Here Gubar is talking about not just how malignant the tumor has become but also how the tumor occupies the center of her being right now she can no longer distinguish between the subject and the object of

her suffering. Now Gubar's narrative also talks about the slow dehumanization of the sick person to a sick object. Gubar talks about the cultural history of gynecological and specifically ovarian cancer and how the medical and social perception of these cancers has also led to the dehumanization of women. She talks about how, for example, in the 19th century gynecological cancer was perceived as a product of a libido in excess of desire. In the 20th century she talks about how cancers most cancers of women were seen as a product of repressed desires. In the 21st century she talks about how the prevalence of a difficult surgery like hysterectomy shows the patriarchal mindset of doctors who believe that women's bodies and specifically women's reproductive organs are diseased and abnormal. So this dehumanization that women like Gubar feel is not just because of the marginalization they face as women but also because of the corporeal impeachment that happens because of medical treatment. Now one other major tool of embodiment that one finds especially in graphic narratives or in comics of diseases is the hand.

Now by hand I am referring to the hand-drawn quality of these comics as such we find that this hand-drawn quality of the comics is a stark reminder of the materiality of the comic itself and helps in situating the artist's body or the sick body in this context within the comic. Now in comics we see that the verbal medium and the visual medium come together however since as both the visual and the verbal medium are hand-drawn the reader gets to bear witness to both of the embodiment both in the visual and the verbal form. Now this was first laid out by Hillary Chute when she spoke about embodiment in women's graphic narratives but it is something that we might adopt for the sick body in graphic narratives as well. Now as an example of this up on your slide I have a panel from Marisa Acocella's graphic memoir *Cancer Vixen* where you will see that in this panel the red background the stark red background which has the word cancer jostling against each other are the parts of the panel that really reach out to you and Marissa herself and her fiance who are out on a date in this particular panel are as small as the small talk she talks about. We see how cancer over here has taken over not just her life but also has taken over the room and all the air that she can breathe in.

So this over here is an example of the embodiment of the artist and what is going on in the artist's mind itself. Now in the same text we also see how Marisa is frightened of how the illness might not just lead to a possible death but disrupt what she regards her as her everyday. Now this is also represented using the metaphor of the hand. So, in this particular example up on your slide next you'll see how the entire in the entire page Marisa's hand takes center stage. Now this is the sequence of panels where Marisa is talking about how she is frightened that if the doctors use her drawing hand to for the chemotherapy tubes then she will not be able to assert her voice as an artist anymore.

This is a classic example of how Marissa does not want the extreme or cancer in this case

to impinge upon or to disturb or disrupt her every day because her every day is how she exerts agency over her cancer in the first place. Now while some theorists like Talcott Parsons who has spoken about the sick role have spoken about how the sick need not carry out their usual obligations while they are ill, people like Marisa and several other sick bodies who have narrative their illness tend to try and live their lives despite their illness. Now, this exertion of agency has also happened over here because of the symbolism and because of the use of the figure of the hand. Now, in our last segment in today's session I would like to bring forth the idea of witnessing. Now the sick body is not just witness to the deterioration or breakdown of your own body during your sickness but is also witness to a whole culture and a whole societal perception of your sickness itself.

Now in the case of say memoirs that are written by caregivers or pieces of writing about sick bodies written by journalists the kind of witnessing that happens is different. In doctor memoirs especially and as an aside I should mention that doctor memoirs will include renderings of vulnerability by doctors who talk about their own experiences treating people. This would include say an example such as Ian Williams's *The Bad Doctor*. This piece may also include memoirs where the physician turns into a patient and becomes a vulnerable body. So, this would include an example such as Paul Kalanithi's *When Breath Becomes Air*. But over here in this segment of witnessing I want to talk about memoirs written by doctors where doctors try and observe the patient's story beyond the medical history itself. Now Arthur Kleinman calls this kind of witnessing empathetic witnessing and he says that this process for doctors involves quite a bit of unlearning where they choose to and they learn how to observe a person's illness not just as something that might appear in a medical textbook but something that might include the social and cultural context that the person is engrossed or enmeshed in. Now this is, of course, based on the assumption you know the whole idea of witnessing in an ill person's narrative is based on the assumption that the ill person writes not just for himself or herself but for a whole class of people who have also suffered from the same illness or who are also looking for some support in the form of somebody else's narrative.

Now Thomas Couser pretends the same vein of thought when he talks about the disability narrative. He calls these books "somebody memoirs" and "some body memoirs" and he talks about how in these memoirs the marginalized or the stigmatized also get a voice because the person writing represents this whole group of people who are perhaps too frightened or ashamed to write about their disabilities or to write about their sicknesses. So, an example for a singular voice standing for a collective is now up on your next slide. Now this is an example from Marisa Marchetto's book *Cancer Vixen* again and you see that this is a panel that extends for the whole page. There are no frames in this panel and time extends beyond the regular borders of a comic.

This is known in comics terminology as a bleed and Scott McCloud would explain it thus. He would say that “time is no longer contained by the familiar lines of the closed panel but instead hemorrhages and escapes into timeless space”. Now in this particular panel we can see how Marchetto has her back to us. She is sitting behind her artist's table her pen poised and she's looking at a range of people from across the globe talking about how they might have gotten their cancers. There are some who talk about environmental carcinogens. There are some who talk about jet fuel being dumped. Some who talk about benzene and Marchetto is witness to all of these stories. Now an interesting thing about this panel is that by being positioned behind Marchetto the reader also shares Marchetto's vantage point and hence we turn witness not just to Marchetto's story but also to the stories of all the people she is witnessing. So, this makes us witnesses as well. This is coined rather beautifully by Kelly Oliver in her book *Beyond Witnessing* where she coins the word “response-ability” to talk about how we should be vigilant to open our minds to be able to respond to people's narratives.

Now Oliver talks about two kinds of witnessing over here. She talks about witnessing as an eyewitness which is a first-hand witness and she talks about bearing witness which is witnessing something that can be recognized but that is beyond just being seen. As readers of a graphic narrative, we find that we are in a position to do both. We both see the deterioration of the body as it is drawn by these embodied artists in very material terms and we also bear witness since we're able to read beyond the lines of the verbal narratives given there. Now in this session we have seen through various examples of narratives to see how the ill bodies position themselves in different literary social and cultural contexts.

We have also seen them give larger meanings to their sicknesses and stand up and question the social and cultural contexts and dominant cultures that usually describe them. We have seen how vulnerable bodies need a voice and need storytelling in order to be able to reclaim their narratives from homogenizing narratives that are extended not just by medical institutions and the society but also by cultural perceptions and historical notions as well. We have seen thus that the vulnerable sick body is a subject of the human rights discourse.