Portfolio Medical Anthropology Autumn 2020

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BZG984

23 966 keystrokes

Piece 1

When people fall ill their lives are disrupted to varying degrees depending on their life and medical conditions.

To fall "ill" emphasizes on the personal perception and experience of the patient. Cecil G. Helman explains this distinction in Medical Anthropology between a "disease" and an "illness". In opposition the word disease brings the biomedical symptoms of a condition and is linked to the history of the disease but does not question the perception of the individual. (Helman, 1978)

Indeed, falling ill is a very individual experience. But in the meantime, the signification/explication, and the treatment of this illness is shaped differently regarding the culture and society you live in. This is explained with the ethnographic work of Rivers in Melanesia. He shows how one condition, stomach-ache, and constipation, is cured by a massage with two very different explications between the western medicine and the local medicine he studies. (Rivers, 1926). We see that in illnesses, the treatment is also focused on the feeling of the patient. Even if the two ways to cure it are different, they have the same purpose: cope with the illness. There is a need to "cope with" because the lives of people are "disrupted".

"Disrupted" lives is here understood as a rupture of the equilibrium in one-person life. But more importantly the disruption is a rupture in the understanding of one person's life. How is it possible to understand the bad luck happening to us in that moment?

We can describe this situation with the word "misfortune". This question of misfortune is underpinned in the ethnographic work of E. E. Evans-Pritchard on the Zande population. The Zande community explains this notion of misfortune by the theory of witches and witchcraft. Evans-Pritchard shows that magic and witchcraft play a role there we cannot compare with our societies and that has its own logic: "The Zande notion of witchcraft is incompatible with our ways of thought." (Evans-Pritchard, 1937). We can keep from this example of witchcraft that human beings have to make sense out of such bad events. By making sense, cultural beliefs arrive in the interpretation of the patient.

This is how misfortune creates a big disruption in the understanding of humans. When a bad event happens, as a cancer diagnosis for example, we do not understand "why" and "how" this happened. There is a difference between what we feel, and what we just learned. There we have a disruption.

There is the role of beliefs and cultural models. They help us to understand and make sense out of the medical treatment. Helman shows how "in an ordinary English suburban community on the outskirts of London" (Helman, 1978) the folk's beliefs are fostered by the local doctors. Indeed, they don't try to struggle against the belief of the "hot" and "cold" diseases because it helps the patient to accept the treatment, he/she needs.

Nonetheless, the disruption is not only a question of understanding. The life of the patients is disrupted by the disability, the pain, the family relations ... These degrees depend on two criteria in the sentence we discuss. The first one is the "life" of the person. Of course, we are not all equals in front of illnesses. The access to the medical aid is not equal. The obligations we have among the society are not the same. The disruption is then more or less intense in the life of the patient. The family models impact on the adherence of the patient to the treatment has been studied by a group of middle east scholars on the case of cancer TDM (Treatment-Decision Making). They show that the eastern family by its solidarity makes a difference in the way the cancerous patient responds to the treatment (Abdulrahim Al-Bahri, Mansour Al-Moundhri, Mohammed Al-Azri, 2017).

The disruption depends also on the medical conditions. A medical condition is the damage caused by the disease to the patient. And for the same disease the conditions can be very different. Then the disruption is unequally severe regarding the pain and disability occurred by the illness. There is also a distinction in the timeline of the illness and its conditions. Some diseases are temporaries, like a flue, but some have chronic conditions, like diabetes. This question of the conditions brings us to the "living with" of illnesses. A lot of the life-threatening diseases are treated nowadays, and we live longer and longer with their conditions. The illness as then to be taken in a long-term perspective. The question is also how families live with the ill person. We previously said that families play a role in the treatment of the patient, we add now that families "live with" the disease when the patient "have" the disease.

During my portfolio I want to use the example of cancer and more specially breast cancer to develop my reflexion. The breast cancer follows what has been said in this introduction: with the development of technology, we now live longer with breast cancer, making the "living with" more intense for the patient and the family. Also, cancer is surrounded by beliefs. Susan Sontag takes this example in her book *Illness as metaphor* (Sontag, 1978). As reported in a more recent article: "In her *Illness as metaphor* (1978), she focused on the recurrent use of military metaphors (among others) in relation to cancer, not only in describing the nature of the "killer disease" itself as "invasive", as "setting up outposts" that "colonise" the body, but in

referring to available treatments as "bombardment" and "chemical warfare" and as "weapons" to be used against the "demonic enemy" in the "crusade against cancer."" (M Hanne, S J Hawken, 2007). But with the risk detection and the actual treatments, a lot of women go through a breast cancer, even if it is a metaphor of death. How do they feel about this terrible time?

The other interesting aspect of this disease for my portfolio is the fact that only women are threatened by breast cancer, and we can see a communitarian narrative around this disease. Breast cancer affects the femininity and has a common history with feminism. This idea is developed in the chapter of the book *Mammographies* (Mary K. DeShazer, 2013) entitled "Breast Cancer Narratives as Feminist Theory". Based on the case Audre Lorde, who was both a black lesbian activist and a victim of breast cancer, this chapter shows how the breast cancer has a particular effect on the patients by touching their femininity.

With this example I wish to show that Medical Anthropology brings elements on how to deal with breast cancer that the traditional discourse of medicine may avoid. In the context of the introductory course, I will try to bring insights on the question of living with an illness, even a life threatening one, through my readings and the class lectures.

In a nuteshell, we have to focus on the way patient understand and feel their illnesses. In this understanding, the role of society and beliefs is fundamental. They help to bring answers to the unexplainable "misfortune" and the disruption in their lives. A disruption that is different regarding the life conditions of the patient. Between many elements, we brought the question of the family in the treatment. Finally, we said how different an illness was regarding the medical conditions of the patient. And we concluded by the example of breast cancer that help us understand the theory exposed.

Piece 2

"How can the concept of 'symbolic efficacy' help us understand how people make sense of/address their health and illness?"

Write a section that builds on the previous introductory section that answers this sub-question. Use the course texts that discuss symbolic efficacy, and you may continue to use the example that you introduced in portfolio 1.

"The medical system forms an indissoluble and hierarchical whole in which healing acts are closely linked with ideas about disease causation and models for classifying disease. The whole is oriented toward the problem of effectively dealing with illness. From this viewpoint, healing is not the outcome of diagnostic acts, but the healing function is active from the outset in the way illness is perceived and the experience of illness organized." Kleinman, A.K. (2010)

Even if illnesses are different from one another, the way we treat those illnesses should have nothing to do with beliefs? Even if breast cancer is lived at a very personal level, science is universal, and we know how to eradicate crazy cells.

It is pure logic someone falls ill, and scientists use medicine to treat this patient. However, there is a reason we use the word « patient » to talk about suffering people: they are waiting for something.

If we come back to the first piece of this portfolio the lives of patients are disrupted. And we defined this disruption as a physical pain and a disability but also as the loss of equilibrium in the mental and emotional life. Patients have lost the equilibrium in their life. And treatment is not enough to bring it back. In fact, breast cancer patients do not suffer from their disease at first but from the treatment (chemotherapy, X ray ...). So, for now we can say patients are not only waiting for a treatment after the loss of their equilibrium.

If the biomedical treatment brings back balance in one-person life, we say it is an "efficient" treatment. But "efficacy" is not only a biomedical question. Do people with breast-cancer face only a cellular issue? What is making the healing system answer "efficient"?

The first question we have to bring is what else do you loose when you lose your health condition? One first element is to say that you lose the understanding of your entire life. You now suffer from a disease you barely know and are sentenced to a medical condition you will discover. The understanding is lost because the diagnosis does have any sense: why now, why

me, where are we going with it? Also, it does not have a meaning in the life of the patient. For example, a young woman who never experience medical conditions may not imagine herself with breast cancer ever. This question of sense making, and meaning is paramount to understand how to make a treatment efficient.

The understanding of the patient and the acceptance to be treated is indeed what separate medicine from torture. We can use X rays to torture one individual and to cure one patient, with the difference that the patient is there on purpose and that the X Ray are a part of balanced solution.

The very precise moment this loose of understanding begins is the diagnosis. We always learn about the illness for the first time when a healer tells you the word for your symptoms. In the case of breast cancer that is very important because the patient normally don't feel intense pain before the diagnosis. Breast cancer diagnosis Often in western countries women are diagnosed after a normal check-up. Suddenly those women learn they are going to die soon if they do not suffer now. Does a life where you know the end is approaching has any sense. Acknowledging life is short brings a strong philosophical challenge to make sense out of this very new health condition. The treatment is also not very easy to put in a big picture: why would we accept to go through chemotherapy and X rays if we will die anyway?

The reason that we go through the treatment is partly because we trust our healer. We use the word healer because it may not be a medical doctor. Anthropology largely studied some other type of healer to understand the mechanisms underneath the healing process. In the field work of Turner (1967) where she studied a tribal healer called Muchona, we approach the position of the healer in the one society. Muchona is living apart from the village and have been through a knowledge transmission process that makes him a respectable interpret of plant healing for example. Here we see that the position of the medical doctor is not far from Muchona. We trust him/her without knowing ourselves and he interprets signs, radio for example. But radio analyses may not be efficient in the society of Muchona and plants solution may not convince in Denmark, what is important is that they speak the same language as the patient.

Since the patient has to give sense and a meaning to the diagnosis, it is crucial that the healer use a reasoning and symbols that are common with the patient to be sure the patient is included in the conclusion. Then the word « interpret » is very interesting, we can see the medical doctor as the link between the common logic the patient and the illness. If the explanation is using

elements from the common knowledge and culture, there is more probability that the illness finds a sense in the mind of the patient.

However, a good explanation would not be enough to convince to go through a chemotherapy. That is why we talked also about meaning making. There the question is no more about understanding the disease but how can this illness relate with my past experiences. Here again the role of the healer is huge. The healer helps to find a narrative to this illness. This role is studied by Levi-Strauss (1963) with a comparison of shamanism and psychoanalyse work. The broader idea of Levi-Strauss is about the structure, and here the narrative is like a structure that helps the patient to find the meaning needed. For example, the narrative of hope and happy endings may be used in the case of breast cancer diagnosis. The patient accepts the narrative and now going through the treatment process is not going in contradiction in her life.

In the two mechanisms of sense making and meaning making we see that the healer has to use in two different ways the world of symbols and cultural structures. And the emotional balance found after this work of meaning and sense making is said as symbolic efficient. Symbolic efficacy is what completes the efficiency of the biomedical treatment.

This is called symbolic efficacy: When a doctor examinates a patient, he/she uses words that have a symbolic. In our example of Breast Cancer in western societies, the model is biomedical medicine. The words used invocate the explanatory models in that culture. Why is that efficient, because it with these words that the disease is understood and can treated. Kleinman, A.K. (2010). But what makes symbolic efficacy is not that the cancer is treated (biochemically) but that the patient is brought back to a cultural world that we do understand. What Kleinman shows is that medicine has one role, in every culture, to manage and control hazard and disease, then western rationality is not more efficient than witchcraft idioms.

But Kleinman also brings a very interesting point: in our societies we try to remove the human aspects of healing. And when we talk about a very physical disease as cancer, I feel like we forget the patients do not stop feeling, thinking, stressing, depressing... during the treatment. There I want to use the testimonies of ill women that I found www.sharecancersupport.org to support my point. The first testimony is about the "med" of the woman and we can see her and the "med" friendly posing. The third post is about relationship during breast cancer, what is for sure a major problematic. Another post is introduced this way: "This is my story, the one God gave me to share, but it wouldn't be complete without first telling you ourstory." There is the point of Kleinman, healing is collective, and illnesses is also "ourstory".

Now we understand how symbolic efficacy gives the opportunity for the patient to understand, give a meaning to what is happening. But symbolic efficacy is not only happening at the beginning of the illness, as we saw with the testimonies the finding of the meaning of an illness is a process that patients talk about years after. In the same way Levi-Strauss talk about the power of myths, we will see that patients not only understand but narrate their illness to address it.

Piece 3

"How can the concept of 'illness narratives' help us understand how people make sense of/address their health and illness?"

We now move forward on the timeline of illnesses. We have seen that people lose the comprehension of their life after being diagnosed. Then we have seen how symbols bring an efficient answer to the illness disruption. However, through this healing process involving interactions, medicines, surgery, what can the patient do? The statement of this portfolio last piece is that patients make sense of their illness by putting the events it represents into a story or in anthropological terms, a narrative. After we go through an experience, we transform a list of events into an order that gives a plot, a beginning and an end, the result of this process is called: a narrative. The process itself has been studied by many scholars and we can call it "emplotment" like Paul Ricoeur does. Now we have the definitions, we can ask how "narratives" and "addressing illnesses" are related? Do creating stories help to get healed? We have already seen in the work of Levi-Strauss (1963) that the storytelling has a therapeutical effect with the example of shamanism, but it seemed that this therapeutical effect came from the knowledge of the symbols coming from the shaman. In this example the narrative came from the practitioner, but we can easily imagine that patients voice their feelings and tell it out loud. In fact, we are talking about the "illness narratives" and they are plural. People share their experiences, with their friends, online etc. These experiences shape different patterns of how people make sense of their illness. Arthur W. Frank (1997) distinguish the main patterns of the illness narratives. The restitution, chaos and quest narratives describe how people give a sense to their illness. Restitution is about going through the illness and find the previous quality of life. The Chaos scenario is telling that nothing is possible to stop the disease and the quality of life is lost. Finally, the Quest narratives tell that the illness is teaching the patient how to live. Different from the pattern, the narratives are also different from the illness they address. The disease we chose (breast cancer) is particular for the fact that this disease only threatens women. By touching to a part of the body that is a symbol of femininity, breast cancer narratives describe a way to live with cancer, but also a wounded femininity.

As we saw it in Levi-Strauss, healers are also storytellers. The difference between a narrative and a story is that narratives serve "a greater whole", a plot. C. Mattingly (2010) defines the concept of "therapeutic emplotment". It is a co-construction that enable the patient to restore

an idea of beginning and end to the treatment process. By doing an ethnography of an occupational therapist, she writes: "One of the most interesting features of therapeutic emplotment is that while it can be guided by the therapist, it cannot be dictated.". The patient is, by acting and interacting, building a narrative and this narrative gives the patient a goal to move from one step of the treatment to the next one. We asked this question in the previous piece of this porstfolio: "Do people with breast cancer face only a cellular issue?". We saw that healers and symbolic efficacy bring an alternative to biomedical treatment to the way to bring back balance after diagnosis. The "therapeutic emplotment" is in the same terms, helping to make sense and directly address the illness by reordering the events in a plot. Women who have been diagnosed with breast cancer need to go through a lot, building an objective via a narrative is a way to cope with this illness and the treatment. These women by voicing their feelings and interacting with the practitioner create a new narrative that can be called "Going through breast cancer treatment". For example this website that is giving information to primary breast cancer diagnosed women is constructing and ideal-type path through breast cancer: https://breastcancernow.org/information-support/facing-breast-cancer/going-through-breastcancer-treatment).

In the case of this website and the previous one about breast cancer survivors, we see that narratives are built socially. Steffen V. (1997) deals with this question through the observation of Alcoholic Anonymous meetings. She explains that these groups are based on personal experiences, but they are designed in a way that give tenets to their members. This underlines the fact that illness narratives are talking about shared experiences. Breast cancer is an experience that has been shared by many women. When we check these websites, we see a vocabulary, colors (rose) and scarfs that define the experience diagnosed women go through. In the life of sharing experiences, it is no more scientists talking but patients talking to patients. Illness narratives give the possibility to patients to share their experiences and great a group. This collective experience can somehow bring back balance in the life of an individual. And we find groups designed on the same basis as AA in Steffen V. (1997) for Breast Cancer. On this website you find Support the Groups for **Breast** https://www.breastcancer.org/treatment/comp_med/types/group. In the presentation we see the notion of "closed" and "open" membership and breast cancer survivor talks in the same way as AA organization.

The support groups for illnesses, and specially for breast cancer, is a way to share the experience of being ill. Patients share something very special together and sharing their life experience is

a way to address illness. By telling their testimony, patients create a narrative of the illness, a way to look at it so it becomes acceptable. For sure, in the case of breast cancer, the fact that the illness touches to femininity is a big part of the shared experience. Bonnie Annis, a survivor shares her feelings on this website: https://www.curetoday.com/view/warrior-or-wounded-life-after-breast-cancer. We see in her story the notion of wounded femininity. Breast cancer is a new way to feel the body and to embrace femininity. This very particular experience would be more difficult if none support groups or other institutions would not exist. By sharing their pain breast cancer patient create a sense of sorority. The support groups and the sensibilization campaign gather women around a common threat, a disease that only target themselves. The common interest and the group effect help scientists to raise funds for research and develop the treatment solution and living with technologies. Movement like "Octobre rose" in France to promote the research for breast cancer is the consequence of the narrative developed by sharing patients' experience.

We have already mentioned the case of Audre Lorde earlier in this portfolio. She is used as example in the book of Arthur W. Franck, *The Wounded storyteller* (1995). She embodies this theme of wounded femininity in breast cancer. Breast cancer treatment is dehumanizing. By sharing a narrative around the question of being a woman with cancer Audre Lorde and Support Groups create an identity in which going through biochemical treatments become acceptable.

To conclude this Portfolio, we can say that illnesses reshape our lives by disrupting them but also by forcing us find a new balance. In the case of Breast Cancer, we can see that this illness sometimes synonym of instant death, is surrounded by testimonies of living with it, or in more exact terms: to survive breast cancer. Becoming a "survivor" is the objective that keeps patients invested in the treatment. To continue this portfolio, we could discuss how the question of "life in risk" is related to our case. All the initiatives around breast cancer treatment helped to develop a prevention process. This prevention process is changing the way see breast cancer from a deadly misfortune to a managed risk.

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