

There is neither a first nor a last word and there are no limits to the dialogic context.
Mikhail Bakhtin

THE SOCIAL DIMENSIONS OF ILLNESS: PATIENTS' AGENCY IN CANCER TREATMENT

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Tine Tjørnhøj-Thomsen, University of Southern Denmark & Mette Terp Høybye, Silkeborg Regional Hospital, Denmark

Interview by Ana Fonseca

Ana Fonseca:

Thanks for listening to Radio Heteroglossia, I'm Ana Fonseca and our guests today are Drs. Mette Terp Høybye and Tine Tjørnhøj-Thomsen. Dr. [Mette Terp Høybye](#) is an anthropologist and a senior researcher in the Elective Surgery Centre at the [Silkeborg Regional Hospital](#) in Denmark. Dr. [Tine Tjørnhøj-Thomsen](#) is also an anthropologist and a professor at the National Institute of Public Health at the [University of Southern Denmark](#). Today we will be discussing the article written by these two scholars entitled, "Encounters in Cancer Treatment: Intersubjective Configurations of a Need for Rehabilitation" published in 2014 in the academic journal *Medical Anthropology Quarterly*, which examines the stories of cancer patients after treatment to get insights into the ways patients exercise their agency and how the doctor/patient encounter during treatment furthers the need for rehabilitation. Drs. Høybye and Tjørnhøj-Thomsen welcome and thank you for talking to us today.

Mette Terp Høybye:

Thank you very much for having us.

Tine Tjørnhøj-Thomsen:

Thank you very much.

Ana Fonseca: In your article, you provide three contrasting examples of women's experiences of breast cancer treatment with their physicians. We learn about Susan who received attentiveness and care from her doctor; while Lisa experienced the fragmentation and objectification of patients by doctors and nurses while being seen only through her illness; and Cathrin who developed a sense of mistrust and felt that she was dehumanized by her physician. Of course, these are not the real names of the patients, their actual names remain anonymous, I just want to clarify this to our listeners.

Tine Tjørnhøj-Thomsen: Yeah.

Mette Terp Høybye: Correct.

Ana Fonseca: I wonder if you can talk more about their particular experiences and tell us how you think we can account for the different kinds of doctor/patient encounters that Susan, Lisa and Cathrin went through.

Mette Terp Høybye: What came out really strongly across the material where we pulled through forth these three exemplary cases was that the patient, the nature of the relation to the physician has a very high impact on the experience of cancer treatment. So we see that if the physician is experienced by the patient as being very attentive to her situation, explaining again and again and making him or herself available for the patient's questions and concerns, the physician is experienced as recognizing the individual needs of the patient. Whereas physicians who did not perceive the same attentiveness and recognition, that kind of relation seemed to impact the experience of cancer treatment in a more negative way as experienced by the patient.

Tine Tjørnhøj-Thomsen: Yes, in our research we discussed this a lot because of course these are individual stories but each of them exemplifies a pattern in our ethnographic material. Each story is an example of this relationship with physicians as experienced by the patients. The story of Cathrin, we didn't see this kind of story that much in our material, but they were there. And the point is that even though Cathrin is really doing an effort to be a good patient to involve and engage herself in her treatment, she is not recognized by the physician. This is really what leaves her with the sense of mistrust and misrecognition.

Ana Fonseca: Yeah, those two elements, trust and recognition, are also quite central to your article. You mention how, in the case of Cathrin, she lost that trust on her doctor. First because she was misdiagnosed initially, and secondly because the physician sort of downplayed her knowledge about her disease. I wonder if you can talk more about the idea of trust and recognition that is so important in that encounter between patient and doctor.

Tine Tjørnhøj-Thomsen: Yes, in the end of the day it is about recognition. It is about the physician recognizing the patient's life situation and that this life situation and the stories are more than only treatment. In Cathrin's case, it is made very explicit that this is what it is about. And trust is a key word in the encounter as it's also recognition. The point is that in Denmark there is a lot of attention to the fact that the patient need to actually be active, they have to do something themselves, they have to be involved in their treatment and take responsibility. That is an overall discourse, not all patients are able to do that. But actually Cathrin, she makes a huge effort to do this, but she is not recognized by doing it and this is what leaves her really frustrated and angry. The interesting point here is that even though we meet her a long time after this encounter, it still seems to be having a great impact on her life. So that is why we think that this is really crucial to investigate, how this encounter impacts and shapes peoples' lives off the cancer 5:43. The point is that physicians and other health care professionals recognize that people are impacted and that listening to their stories it's really important also. Of course this is difficult for them because in Denmark, as in other countries, there is not that much time to involve yourself with the patients and there is a lot of both structural and institutional factors that make this difficult. But nevertheless, we really think that this is a very important point.

Mette Terp Høybye: It really touches on a core discussion that we had throughout our work with this paper that cancer is often displayed, and it is of course potentially a terminal disease, but it seems very prominent in our material that it's not the cancer really that makes people sick. It's the treatment. What we find in our material is that a lot of people told us that they didn't have a clue that they had cancer; they didn't have any notifications of this from their body. But then they went into treatment and they became really sick. A parallel to this is that what constitutes patients' need for rehabilitation afterwards is not only prominently the physical scars that they may be left with, but

also the social relations to significant persons during their treatment such as the physician. But as Tine Tjørnhøj-Thomsen said earlier on, this is often a result of the lack of time and different structural and institutional problems that they're all facing in their practices.

Ana Fonseca:

Yes, and as Dr. Tjørnhøj-Thomsen pointed out earlier, this is a situation that is not unique to Denmark. Doctors in many parts of the world face similar time constraints with patients so it would be very interesting to know how they feel about the system within which they have to work.

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Mette Terp Høybye:

Yeah.

Ana Fonseca:

You also note in your article how, in the context of an illness such as cancer, patients are in a vulnerable and marginal position not only because of their physical and emotional distress, but also because of their relative lack of knowledge about the illness and the kind of care they may receive. As a result, patients' stories of their experiences with breast cancer become the main focus of your article. Along these lines, you argue that, put on quotes, "the agency elicited in a story is fundamental to empowering the patient." I wonder if you can talk more about this, how does the act of storytelling or expressing their experiences with the illness allow cancer patients to be empowered and have some agency?

Mette Terp Høybye:

The ability to reflect and give your own version on what happened, what did you encounter? How did it affect you? And how did you react to it? We hear in the article from more than one of the women how they portray themselves in particular ways and present this as a reason for how they dealt with the encounter. They represent themselves as persons, as women, as agents of their own lives and stories. So the story and the act of storytelling provide a way of presenting oneself as someone who acts. Susan, for instance, says that, "I'm a strong person and this is why I never thought I would die from it" – this is not the exact quote but from how I recall it. - So in this sense the story and the act of storytelling provide her a way to take on agency again even though she may have lost some of the control to the illness. She can be empowered by her own story in this way.

Tine Tjørnhøj-Thomsen: There are several levels in this, I think. On the one hand, the stories we are told, they are also ethnographic windows into the experiences of cancer treatment. This is one level. On another level, it is also a matter of how people generally get agency by telling stories. The idea that telling a story is a form of agency is actually theoretically informed, we have gone through a lot of research literature about narrative and narrativity. Through the fact that you can tell a story you are the one who select and configure what you are telling and this is actually the agency that you have in telling a story. You have the power to present yourself the way in which you want to be portrayed and you also have a kind of power on what you actually tell. So this is what we mean by storytelling as agency. It is also a way of controlling things. If you don't have anything left, you always have a story to tell. During cancer treatment you experience a lot of loss of control, but in telling stories you can somehow regain control over your life. It is therefore important to bring this up in healthcare generally to recognize and acknowledge these stories.

Ana Fonseca: As a concluding point I would like to ask you, how does anthropology as a social science help us understand illness and in particular cancer?

Mette Terp Høybye: What anthropology and more broadly Social Sciences can contribute is through the unique methodologies that we also use here, the ethnographic practice, we get an opportunity to really study the social relations and contexts of an illness like cancer or other phenomena that are not open to us through reading about them or through encountering them as mere physical phenomena. So what we are trying to stress very strongly in this paper is how the social relation is configuring the experience of illness in very unique ways.

Tine Tjørnhøj-Thomsen: Yes, one of the crucial things in anthropology is the attention to context and the interaction between the individual and social communities. We are also, of course, very inspired by, for instance, medical anthropology and the way that medical anthropology has paid attention to narrativity, to the importance illness stories and to the way that people perceive their illness. Also, in medical anthropology there's been a lot of research into the encounters between physicians and patients. Therefore, we are also really inspired by both theories and the methods that are offered by our discipline.

Ana Fonseca: Drs. Høybye and Tjørnhøj-Thomsen thank you for your time and for sharing with us your knowledge and perspectives about these issues.

Mette Terp Høybye: Thank you.

Tine Tjørnhøj-Thomsen: Thank you very much.

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