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## AJANKOHTAISTA

# WRITTEN CANCER NARRATIVES AN ETHNOMEDICAL STUDY OF CANCER PATIENTS' THOUGHTS, EMOTIONS AND EXPERIENCES

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Until today this has been an untold story. It is about to become my personal experience narrative that is a construct of various experiences, thoughts and feelings. This story – untold so far – has been my experience that I will interpret, here and now, to this particular audience, from my point of view. To begin with, I would like to discuss three questions: *how*, *why* and *what*. In my opinion, these are the central questions that should be taken into consideration when dealing with textual units such as written narratives (Hanks 1996). Therefore, in my thesis *Written Cancer Narratives. An Ethnomedical Study of Cancer Patients' Thoughts, Emotions and Experiences*, these questions are also posed in the following order: What have Finnish cancer patients written, how they have done it, and why?

However, in today's story I am about to tell you: How did I reach the subject of cancer; why is it important to study personal illness experiences from the ethnomedical point of view; and what are the main aspects that influence the writing about personal illness experience. In this manner I hope to unveil some aspects of the work I have done during the past years.

Like most other personal experience stories, this story must also return to the past to explain how it all began. I believe it was in 1996 when, for the first time in my life, I entered the Estonian Folklore Archive in Tartu. A year later, my long-term mentor

Mare Kõiva asked me to pick a research topic. There I was – standing and facing brown shelves labelled with bizarre names, such as *kratt* (wealth-carrier), *katk* (plague), *lendva* (stroke), *tuulispask* (whirlwind), etc. signifying various (mostly long-forgotten) mythological beings in Estonian folklore. Rather spontaneously, I chose something called *halltõbi* – an illness called ague in English. I believe this was the moment when narratives about illnesses, and illnesses in cultural, and particularly ethnomedical context, became my long-term passion.

## CHOOSING CANCER AS A FOLKLORE RESEARCH TOPIC

As I also mention in my thesis, the available archive texts – ethnomedical records from the past – could not satisfy my curiosity towards the meaning of illness: its meaning in the particular cultural context, and furthermore, its' meaning for the people suffering from an illness. Thus, in order to get a better access to interpreting the cultural meaning of illness, I started to look for a topic that could be reflected in the modern cultural context and societal setting. As a consequence of several concurrences, cancer became the topic since, in my opinion, cancer, at least in the ethnomedical sense, clearly represents a modern mythological illness. By calling cancer a modern mythological illness, I refer to the fact that people do not have enough information about cancer's aetiology, and although diagnostic techniques for cancer are very advanced, the outcome of available treatment methods often or still is rather uncertain. Thus, despite medical advantages, cancer represents a true threat to human lives, and because of its historical roots, it is still associated with death in people's minds.

Choosing cancer for my research topic appeared to be a truly fortunate decision as I found out that the Finnish Folklore Archive and Finnish Cancer Society had already organized a writing competition for cancer patients in 1994. This writing competition had resulted in magnificent 672 answers with more than 6000 pages of writings from cancer patients and their close ones. As a result, in November 2006, I set myself the goal to work through the available materials. I understood that the resources were plentiful for answers I was looking for. However, I still had to find the best way for interpreting the materials. As a folklorist strongly influenced by linguistic anthropology, I came to a conclusion that one part of my work has to concentrate on the quality of written narratives, but at the same time, I had to implement the ethnomedical approach containing the popular images of illness from the past to present, its popular aetiology, as well as coping strategies and treatments in use, as to analyse the course of illness.

The thesis became organised as a series of case studies dealing with the representations of cancer experience and their significance in the particular context. Above all, the thesis follows the general course of illness – from the moment of diagnosis until the final solution of the individual cancer experience. Some scholars believe that each diagnosed cancer is unique, which means that cancer narratives can be also considered to be unique in many ways. However, the fact that all of them more or less follow the course of the illness highlights the main difference between the experiences gained and those presented in the writing – in cancer narratives the illness

experience supplies the narrative structure with temporal and spatial meeting points and structural segments that make the narrative comprehensible and meaningful while expressing the author's intentions (Bakhtin 1981; Hanks 1989).

## **ILLNESS MODELS COMBINE INDIVIDUAL AND CULTURAL UNDERSTANDING**

Now, let me approach my second question, the why -question. Why is the study of cultural and personal meanings of illness significant? We know from our school biology classes that cancer is an error in cell or tissue level – a mutant cell – that can appear in different body parts, bones, and blood. Equipped with such rational explanation, physicians working in the field of evidence-based medicine, aim to stop the mutant cell from spreading within the diseased body. Whereas the questions posed in my thesis concern the human side of illness, namely, what happens to human being as he or she is declared of being ill. At this point, personal illness narratives become significant, as without the possibility for self-expression, we cannot know what is going on. Approaching the question from an ethnomedical perspective, we can ask questions that are also central to many cancer patients. As they construct their personal explanatory models of illness they often ask the following questions: Why did it happen? Why did it happen to me? Why now? What would happen to me if nothing was done about it? What are its likely effects on other people? What should I do about it? (Helman 1981, 549.) Looking answers to similar questions, the ethnomedical study of cancer patients' thoughts, emotions, and experiences concentrates on patients' 'voicings', which are important in order to make the cancer experience understandable and open in the current cultural and societal setting.

Furthermore, particularly in the written narratives, the natural world and the glimpses of tradition become bound together with one general aim – to tackle the illness and mediate its meanings. Such reasoning takes place in the linguistically and culturally pre-set discourse, and like any set of popular beliefs, the ideas about cancer are also heterogeneous and even contradictory. Every patient creates for her- or himself a suitable illness model that helps to explain and cope even if no medical aid is provided. Therefore, I suggest that for researchers, in order to offer help and create better conditions for those in need or suffering, knowing the personal explanatory models or the patients' point of view is significant. Otherwise we will be totally in the dark without any particular hope of satisfactory outcome.

Let me exemplify how the writers operate between individual and cultural understanding. The cancer narratives analysed in my thesis contain various theories about the reasons for falling ill with cancer. The studied materials indicate that as long as cancer concerns 'other people', and not 'us' or 'me', the rational explanation is fine but when cancer becomes an individual problem it immediately becomes interpreted as a particular illness with a particular significance in the person's life. Cancer patients' narratives indicate that this meaningful illness needs an explanation that encompasses the person and his or her personal history, as well as the external

and internal factors responsible for cancer. Although today people have lost contact with the mythological worldview, the underlying idea about illness as some kind of independent being approaching people from outside is captured in language and in basic models of thinking. Accordingly, cancer is imagined entering the human body in order to destroy it, whereas the human task would be to understand its origin in order to implement a cure.

According to the official suggestion of the Finnish Cancer Association, cancer may be caused by inner problems, environmental influences, or individual lifestyle. Accordingly, among the preventative suggestions we find advice that one should take care of one's health by doing exercise, avoiding the sun, eating healthy food, minimising alcohol intake, and checking one's physical condition regularly. The personal explanatory models are marshalled in response to a particular illness episode and are not identical to the general societal beliefs about particular illness. Indeed, in their writings, cancer patients do use culturally accepted knowledge and interpret it to suit the circumstances of their personal cancer experience. The main problem is that individual experiences, in many ways different from culturally agreed expectations, have impact only on the reasoning of a particular person. Consequently, as cancer suddenly becomes an individual challenge, people find it difficult to accept that, despite all individual efforts, they have still fallen ill.

With regard to the course of a person's life, the meaning of cancer can change several times. After falling ill and during the illness patients constantly experience new aspects of cancer. During this process many culturally accepted ideas prove to be wrong compared to individual experience and thus, people negotiate their own illness model based on their own life stories. However, culturally accepted ideas are less flexible and therefore, popular cancer discourse stays unchanged. As a result, people still tend to believe that cancer can be contagious or is an outcome of some kind of norm-breaking.

This kind of stability is characteristic to any set of popular beliefs and is connected with the process of communication. When individual experience (personal voice) is in opposition to popular reasoning, communicative acts, such as composing a narrative, force people to maintain the culturally pre-set beliefs framing the discourse. Thus, when debating the origin of illness, or other illness-related beliefs, respondents in fact repeat culturally accepted beliefs and therefore, reproduce them in their narratives. Consequently, even if marshalling individual explanations towards culturally approved explanations all respondents actually select an aetiology that is appropriate and acceptable within their own life from among the existing explanations. And there we have it – folklore – or more accurately the substance a tradition is made of – an excellent material for a folkloristic study (Honko 1988, 9).

## **BREAKING THE SILENCE BY WRITING ABOUT CANCER**

Now I have already reached the what -question and shed light on some of the results I found out during my research. I must say that it has been really fascinating to see how some themes or structural segments have rather accidentally gained their place

## Piret Paal: Written Cancer Narratives

in this study. While examining the cancer patients' written narratives I concentrated on the themes people discuss in their writings repeatedly. I used thematic approach and discovered issues that cancer patients are often confronted with, which include problems at work, the loss of identity in the hospital surrounding, the somewhat insufficient patient-physician relationships, and worries about the treatments and their outcome. Thus, narrative representation offers an insight into the important issues in cancer patients' lives but as I already mentioned, the thematic approach also revealed unexpected structural segments, such as dreams or certain metaphors. However, more importantly the stories revealed a lot about significant silence surrounding cancer.

The significant silence in culture-bound cancer discourse is connected to cancer patients' fears of being labelled or judged by society. By throwing light on areas of the past, I have established a context that can help us to understand why it is difficult to talk about cancer and of the most significant myths surrounding this illness among cancer patients. Analysing the popular images of cancer in the cultural context has also given an answer to the question "Why do people write about their illness?" Based on the cancer narratives, various culture-bound restrictions surrounding the subject become apparent that explains the need for written self-expression among cancer patients. The opportunity to write about cancer and share personal thoughts, feelings, and experiences has been accepted as an excellent way of expressing ideas suppressed in everyday communication. Without doubt, written self-expression offers a good possibility to share one's suppressed thoughts that might not be in accordance with traditional way of thinking without being judged or labelled by others. This also explains the great interest towards the archival request regarding the collecting of cancer experiences.

I wish to point out that the archive's request offered an additional path by which to express ideas that run against the culturally or socially agreed ideologies. For example, the lethal image of cancer is challenged by examples based on individual experience, which is also understandable considering the number of patients who are eventually cured. People claim that having cancer helped them understand how human life unfolds and that even if illness occurs, that does not stop other things happening: people fall in love, graduate school, babies are born, new hobbies are discovered or old ones regained. Thus, the image of cancer may have a relative significance in human life particularly when compared to other threats that put people's lives in danger.

And now it is time for me to conclude my little story. The close examination of cancer narratives highlighted three important issues that should be noted when dealing with materials collected via archival request. Firstly, narratives are interpretations of experience, which means that the writing, although containing truthful events, follow certain narrative tendencies and authorial intentions that make the described events different from actual life events. The representations or reconstructions of illness experiences include respondents' individual negotiations and interpretations that evaluate the meaning of cancer in their lives and therefore, the events described need to be pre-selected in order to become meaningful within a narrative. Secondly, cancer narratives are thematic and, in general, follow the culturally agreed structure of the pathological drama or illness course. The ways the stories are structured or

put together are dependent on the writers' competence and skills of self-expression; however, the narratives also have a responsive character in order to meet the expectations of the organisers of the writing competition. The writers' intentions are to be understood, which means their stories must fit within certain frameworks, which to a certain extent, are in accordance with culture-bound ideas and socioculturally defined cancer discourse. Thirdly, interpreting the written narratives of the writing competition as wholes is a complicated task because of their idiosyncratic nature. Nevertheless, the large text corpus they provide, creates an excellent context within which comparison can highlight similarities and differences and to identify units that are useful for analytical study. In my opinion, such intertextual comparison based on a large text corpus allow the creation of sufficient arguments, as well as results, and as a result hopefully generates ideas for further discussion.

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